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U.S. President's Emergency Plan for AIDS Relief

TEEN TALK

A GUIDE FOR POSITIVE LIVING

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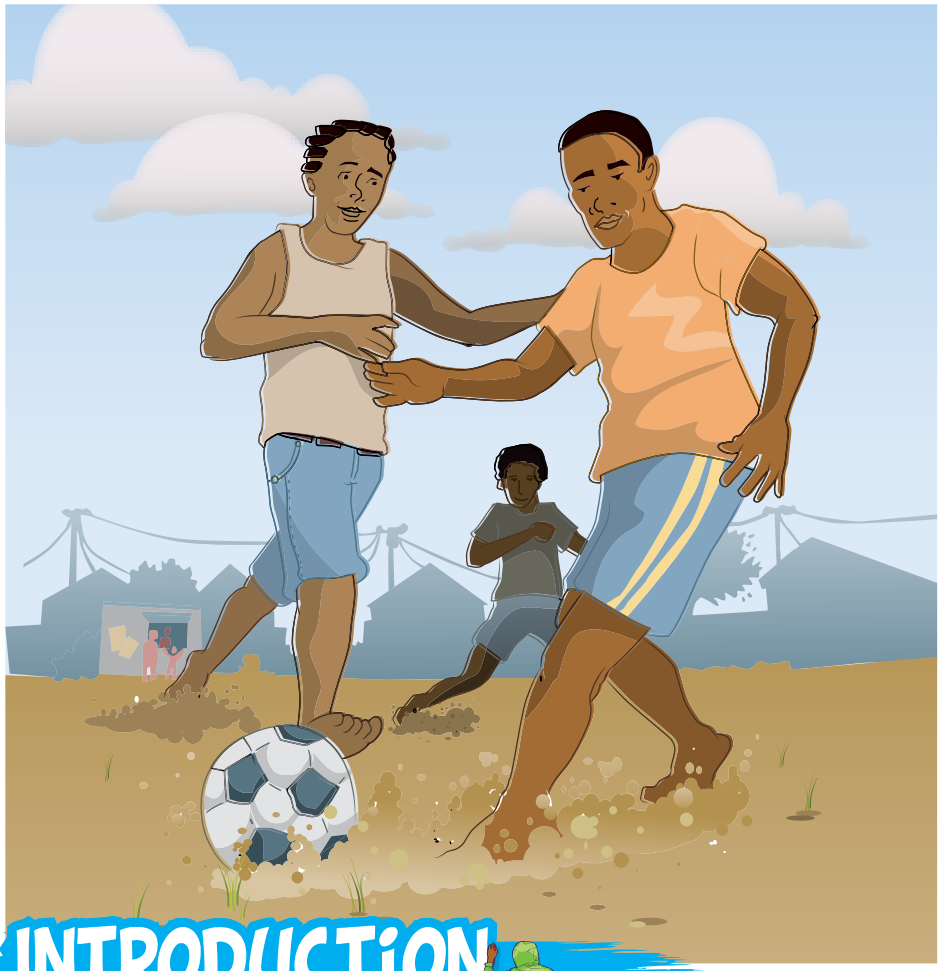
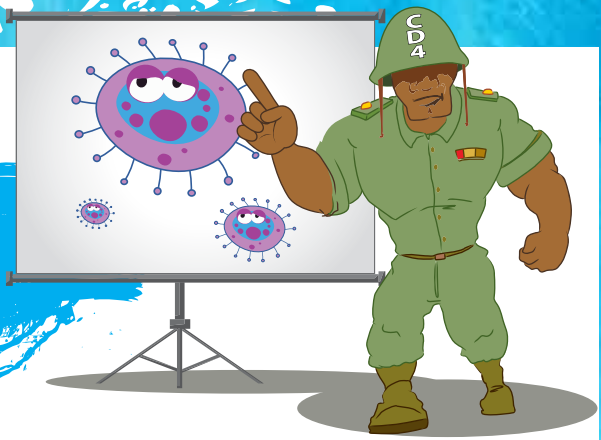


INTRODUCTION

Being a teenager can be difficult but it can also be very exciting since there are more opportunities, choices, and free time. You don't always have someone telling you what to do. You can make your own decisions. You can choose to do things that feel right to you, like where to go, who to spend time with, what to do after secondary school, or even if and when you want to start having sex.

All of this may be overwhelming because there are many choices to make and a lot of pressure to do things that you may not feel ready to do. This is especially true for teens with HIV because they have all of the concerns that non-infected teenagers have AND those that relate to having HIV. That is why we created this book just for you. We hope that it will help you to make good decisions and that it will also give you ideas about who to talk to for more information.

LET'S TALK ABOUT HIV



1. What is HIV?

HIV stands for Human Immunodeficiency Virus. It is a virus that attacks the body's immune system (the system that helps to keep us healthy), making it easier for someone to develop severe infections like pneumonia and tuberculosis. HIV is also the virus that causes AIDS (Acquired Immune Deficiency Syndrome) and can be diagnosed when someone develops certain kinds of severe infections and is also HIV-positive. It is important to know that HIV and AIDS are not the same. Someone may live for a very long time with HIV infection and never develop AIDS.

Once HIV enters the body, it attacks the "soldiers" (CD4 cells) that help the body to stay healthy. The virus makes copies of itself and begins to take over the body's immune system, making it too weak to fight off infection. While there is no cure for HIV, scientists from all over the world have created medications that stop the virus from making copies of itself and help the body to heal its immune system.

2. How is HIV transmitted?

It is very important to know the ways in which HIV can be transmitted and the ways in which it cannot. Understanding this will help you to know how to prevent others from becoming infected.

HIV may be transmitted in the following different ways:

- From mother-to-child during birth
- Through breastfeeding
- Through unprotected sex
- Through sharing needles or razors
- Through blood transfusions with infected blood

You cannot become infected with or transmit HIV by:

- Sharing drinking glasses or utensils with an HIV-positive person
- Using the same toilet as an HIV-positive person
- Hugging or shaking hands
- Kissing
- Mosquito bites
- Dog bites

3. Can I live a long and healthy life if I am HIV-positive?

Yes, by living positively! And you might be surprised to know that YOU and the choices that you make will influence whether or not living a long and healthy life is possible…more than the virus does! In order to stay healthy and live positively:

- Take your medications every day and make sure to see your doctor for frequent visits.
  - Try to eat fruits and vegetables every day. These foods help to support and build your immune system.
- Make good choices. By staying away from drugs, alcohol, and tobacco you are allowing your body to remain strong against HIV.
- Sleep. Your body needs its rest, especially when it is undergoing so many changes during your teenage years. Sleep helps to refresh your body and keep your mind sharp and alert.
- Make friends. Finding a friend or family member to talk to when you are unhappy or sad can make a big difference in your health. Having someone to rely on will ease your mind and help you to realize that you are not alone.
- Find a favourite activity…and do it often! Whether it is football, reading a good book, listening to music, or spending time with friends, do things that make you feel happy.
- Study hard! You have your whole life ahead of you and that means that when secondary school is completed, you will need to continue on to university or look for a job. Good marks are very important for a secure future so study hard and set goals for yourself.
- Pray. While religion is a very personal matter for most people, whatever your beliefs may be, turning to God may improve your outlook on life and help you through troubled times!

LET'S TALK ABOUT ARVS

4. What is an ARV?

ARV stands for antiretroviral. This term is used to describe the type of medication that is used to stop HIV from making copies of itself and then making your immune system very weak. There are a lot of different kinds of ARV medications and your doctor will choose the ones that he/she feels will work best for you. You will usually take between two to three pills twice daily and your doctor will have you come for appointments every one to three months to examine you and draw your blood to make sure that the virus is responding to the medication.

In addition to your ARV medications, your doctor may also choose to give you a couple of other tablets like Co-trimoxazole and/or a multivitamin. Co-trimoxazole is given to you for a period of time when the number of CD4 ("soldier") cells in the body is low and you are more likely to develop a severe infection. This medicine is an antibiotic and helps to keep your body's immune system strong. A multivitamin is often given to teenagers to help keep the levels of certain nutrients like Iron, Calcium, and Zinc high in the body's tissues. These vitamins are especially important for maintaining your body's overall health and function. Just like your ARVs, it is important to remember to take these medications every single day.

5. What side effects can I expect from ARV therapy?

Sometimes the medications may give you a rash, an upset stomach, diarrhoea, or strange sensations in your arms and legs. It is important to report these things to your doctor or other health-care provider because there may be a different medication that he/she could give you instead of the one causing the problems. It is also important to ask your doctor if your medicines can be taken with food. This will sometimes help make it easier to take the medications by preventing you from getting an upset stomach.

6. Is ARV therapy a cure for HIV?

ARV therapy is not a cure for HIV. It does not kill the virus. It only stops itself from reproducing in your body. If you take your ARV medications as your doctor tells you, you will start to feel better because the amount of the virus in your body will decrease. However, there will always be some virus in your body.

7. What happens when you take your medications at different times from those agreed with your doctor?

The main reason for taking your ARVs at the same time every day is to make sure that the drug levels in your body remain high enough to suppress the virus all of the time. When you skip a dose or take your pills outside the set times, the drug levels in your bloodstream become very low and the drug does not work effectively.

8. I have heard about pill breaks and that this may be an option if I am having too many side-effects and am tired of taking my pills. Is this wise?

Pill-breaks are not to be taken unless the doctor specifically recommends this. If you are having trouble with side effects it is important to keep seeking medical guidance. A 'pill break' may lead to drug resistance and it will be very difficult to get your system back on the right track.

9. I have been taking ARV therapy for a year and I feel good, why do I have to continue to take it?

ARV therapy is a commitment for life; it does not get rid of HIV in your body. Even when your immune system is functioning well and your viral load is undetectable in your blood, the virus is still there, and will begin to multiply rapidly if you stop taking your ARVs. Stopping your ARV therapy will lead to your immune system weakening-your health will deteriorate significantly.

LET'S TALK ABOUT ADHERENCE

10. What does the word "adherence" mean?

Adherence means taking your medication as prescribed, every day for the rest of your life. The first step towards adhering to your ARV therapy is understanding why and how you have to take your medications. ARV therapy will only work if you adhere to your treatment all of the time. If not, the virus will no longer be suppressed and may become resistant to the medications, meaning that the medications will no longer work. Remember, you must contact your doctor immediately if you experience any problems with your medications.

11. What is drug resistance?

If the tablets are not taken every day, you will give the virus a chance to develop something doctors refer to as resistance. Resistance occurs when the HIV inside of your body becomes smart. If it goes many days without seeing the medications in your body, the HIV will start to ignore them once it begins to see the medications again. In no time at all, the HIV will begin multiplying and taking over your body, leaving you very weak and ill. Even if you start taking your medications regularly, they will not work properly and it will be as if you are not taking any tablets at all. Your doctor will be able to tell that you are not taking your medicines when he/she tests your blood and discovers a large amount of HIV in the body and a very low number of "soldiers" or CD4 cells. You may also develop fevers, weight loss, poor appetite, a skin rash or pneumonia. Your doctor may be able to change the type of medications that you take; however, there are a limited number to choose from because HIV is a very difficult virus to fight. If you keep forgetting to take your tablets, or if you simply refuse to take them, you will develop a type of HIV that is resistant to all available types of ARVs, leaving you unable to be treated.

12. What happens if I miss just one day? Does the virus become resistant?

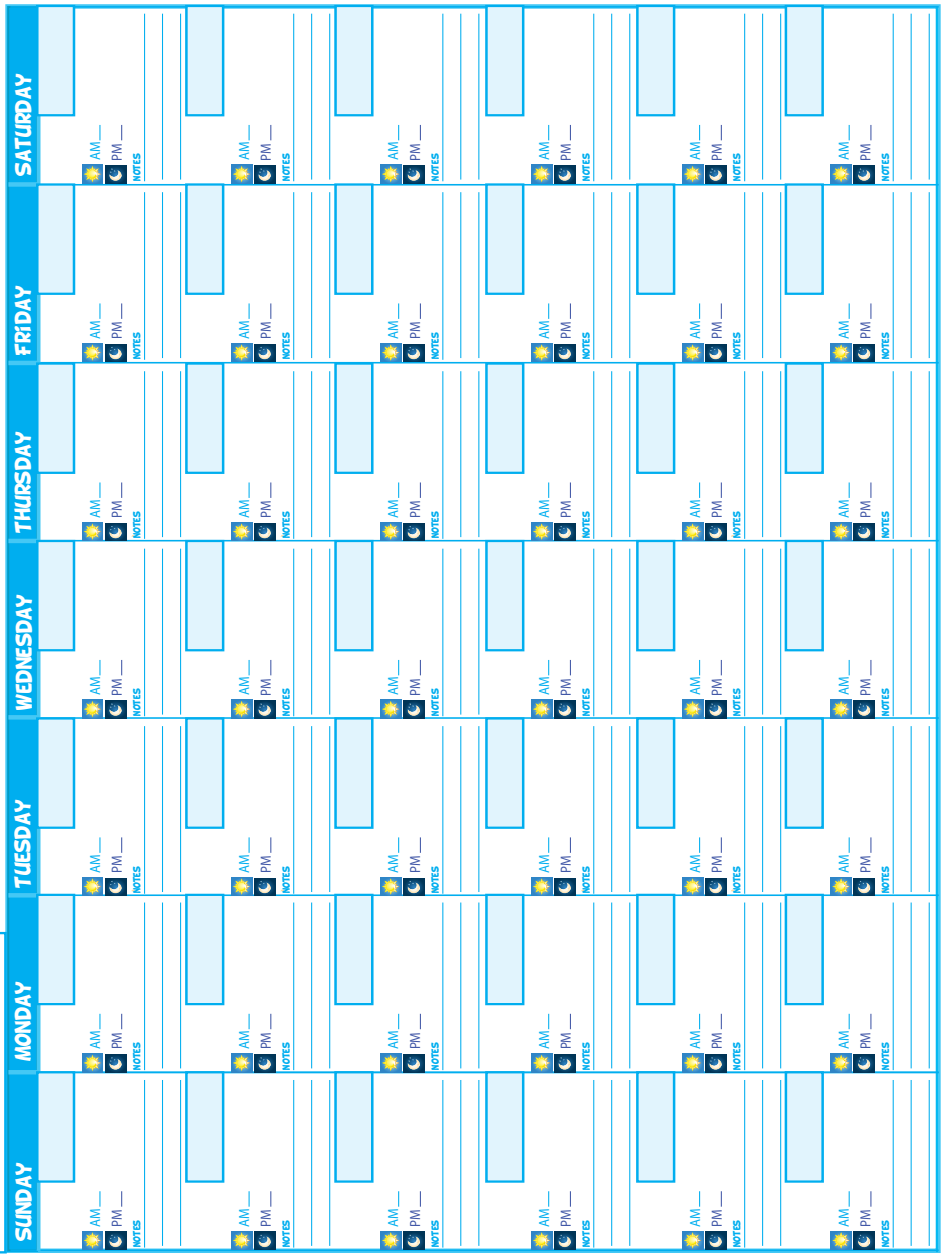
Yes, the virus could become resistant. You must ensure that you do not miss any doses and that you always have one or two scheduled doses with you all of the time.

13. It is difficult to adhere to ARV therapy for the rest of your life. Are there any other options?

Unfortunately there are no other options, but to adhere to treatment. Although adherence to treatment is difficult, the benefits of adherence — living a long and productive life — far outweigh the burden of taking the drugs. Like anything else in life, once you form a habit, it becomes easier.

FIGURE 1: PILL CALENDAR

If you don't already have a calendar, you may copy this one by hand or make photocopies for use as your own pill calendar. Write the month and year where indicated and then write the days of the month in the top right corner of each cell. Each day when you take your medication, tick the line next to "AM" for your morning pills and "PM" for your evening pills. Depending on your regimen, you may take your medication either once or twice a day.

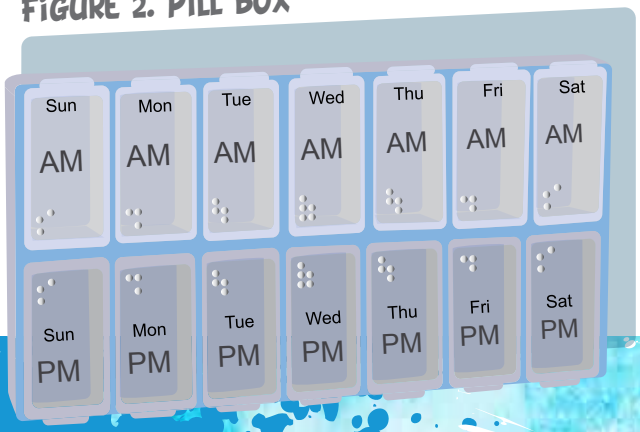


Here are some ways that teens can remember to take tablets each and every day. Do the one that works best for you!

- Pill calendar- You can make a pill calendar to help you keep track of when to take your meds (see Figure 1). There are usually two spaces for each day of the calendar, one to write your morning medicines in and one to write your evening medicines in. You can cross off each day after you have taken the pills until you finish the month and are ready to begin again. You can decorate your pill calendar with colours, stickers, pictures…whatever makes you remember to look at it and take your tablets. When you reach the end of your calendar, reward yourself with a special treat if you have taken all of your pills!
- Buddy system- Is there someone else who takes medications at your home? If so, you should try to remind each other to take the tablets…or better yet, you could do it together! It may help you remember to take them if there is someone else who is doing it along with you as well.
- Traveling and/or Social Activities- Just because you take medicines twice-a-day does not mean that you cannot spend time with your friends, travel to visit family members, or take a holiday. You must prepare ahead of time and be sure to carry your tablets with you if you know that you will not be home to take them. Take advantage of pill boxes (see Figure 2) if they are available at your clinic or pharmacy – or make your own! Pill boxes can be stored in a purse or backpack and are easy to travel with.
- Alarm Clock- If you have an alarm clock at home or an alarm that can be set on your wristwatch or cellphone, set it! Having an alarm go off will remind you to take your medicines even if you are busy and are likely to forget.
- Personal Responsibility- A lot of teens will blame their parents, grandparents, aunties, uncles, sisters, brothers, etc., for not being around to give them their tablets. As a teen, you are starting to learn a lot about personal responsibility and need to be accountable for yourself. You should know the dosages as well as the name of your medications. DO NOT depend on anyone else to remind you to take your tablets. Your health is your responsibility and it will show others around you that you want to take care of yourself!

One last important thing to remember is to NEVER stop your medications without your doctor's approval. This is very dangerous because you could develop severe infections and become very sick. If you are having difficulty remembering to take your pills or if you don't like the way the tablets make you feel, please talk to your doctor before stopping the medication. They will be able to discuss these problems with you and offer you solutions. Remember that they have your best interests in mind!

FIGURE 2. PILL BOX



LET'S TALK ABOUT FRIENDS AND BEING SOCIAL

When you are a teenager, you begin to develop a need to have private thoughts and you might want to keep some parts of your life all to yourself. For example, you might decide to tell only certain friends about things that are happening to your family or about how you are doing in school. HIV is another issue that is very personal and you must decide who you want and who you don't want to share this information with.

14. What should I do if I am offered alcohol or drugs? How will this affect me differently than other teens because of my infection?

Using alcohol and drugs can have many negative effects, and it can cause problems related to HIV. First of all, using drugs and alcohol may cause major problems with your health by interfering with your medication's ability to work properly. You should talk to your doctor about the medicines that you are taking and how alcohol and drugs can affect your body. Also, drinking alcohol and using drugs can affect your judgment and make you more likely to have unprotected sex. Once again, unprotected sex can be very dangerous for your health and the person that you are having sex with. If you use drugs that are injected with needles, you are at risk for becoming infected with other diseases and for spreading HIV by sharing needles. Blood gets into the needles and when another person uses a contaminated needle, it carries a high risk of spreading diseases because infected blood can be injected directly into the bloodstream. Remember, sharing a needle or syringe for any reason can be a major health risk. Alcohol and drugs can affect a person's life by making it less stable. This lifestyle may also make it difficult to attend medical appointments and properly take your medicines. Not taking proper care of your health puts you at major risk of getting very sick.

15. How does smoking affect my health? How can I quit if I am currently a smoker?

You have the choice to smoke or not to smoke. Nicotine is the ingredient that makes tobacco an addictive (but not illegal) drug. It is what gives smokers pleasure but also makes it very difficult to quit. If you choose to smoke, you need to be aware of the major health risks involved as well as the discomfort it may cause for those around you who are non-smokers. You might have heard that smoking may result in lung cancer. This is because cigarettes and other tobacco products contain

"carcinogens," or cancer-causing agents, that damage the lungs. In addition to causing cancer, if you are HIV-positive, smoking can cause further damage to your lungs leading to irreversible and incurable lung disease. Not only does smoking cause lung disease, it can cause heart disease and if someone who is smoking also happens to be pregnant, it can have devastating effects on the unborn baby by restricting the flow of oxygen to the womb.

Here are some tips if you are a smoker and want to quit. Remember NEVER QUIT QUITTING!

- Remind yourself, DAILY, of the risks to your health that smoking confers upon you.
- Choose a time to quit that is best for you! Do not quit during a time that is stressful for you because it may lead you back to smoking as an unhealthy way to relieve tension. On the other hand, do not keep putting it off because of multiple stressful events occurring in a short period of time. If you don't set a date or time to quit, you might never follow through.
- Keep a smoking diary to figure out what triggers you to smoke. This will help you to identify times that are particularly dangerous and then you will better understand what your urge to smoke truly is — a habit.
- If your friends smoke, tell them that you have quit and ask them not to offer you cigarettes.
- For a period of time you may find yourself tempted to give in and "smoke just once." During this time, refrain from going to places where a lot of people are smoking. This craving, or need to have a cigarette, will eventually pass but don't make it harder on yourself in the meantime!
- You will be surprised, once you quit smoking, just how much extra money you will have. Reward yourself with some sweets or some new shoes because you deserve it!

16. If I want to get tattoos or a piercing, how can I do that without infecting others?

Everyone needs to think seriously before deciding to get a tattoo or piercing. Ask yourself whether this is something you want to have on your body forever. Tattooing and body piercing can also cause general infections if the equipment is not properly cleaned or if the person doing the tattooing/piercing is not careful about washing his or her hands, using gloves, and disinfecting the equipment. Also, if you don't care for your tattoo or piercing properly, it can get infected. A risk of HIV transmission and the transmission of Hepatitis B and C does exist if the instruments are not disinfected correctly. Instruments used for skin piercing should only be used once and then thrown away OR properly cleaned and sterilized. Other infections and blood problems can result from tattooing and piercing and include a severe wound infection, skin diseases, and allergic reaction to the jewellery or the ink used for the tattoo.

17. How do I react if a partner tries to hurt me physically?

No one has the right to hurt you in any way. No one has the right to hit you or even touch you in a way that makes you uncomfortable. And no one has the right to force you to have sex or to do anything you don't want to do. Remember, your life is precious. If someone is hurting you, you need to get help and get away from that person. That person needs help too. Without it, the violence will get worse. There is no specific type of person that becomes violent. However, someone may do things that will make you think that they could become violent. Here are some things that people who are more likely than others to become violent may do:

- Be very jealous and possessive
- Try to keep you from your friends and family
- Try to control you
- Use alcohol or other drugs; the more drunk a person is, the more likely it is for serious injuries and violence to occur during dating
- Get angry often
- Have experienced abuse in the past or have witnessed abuse of family members in the past
- Engage in frequent physical fighting
- Damage other's property, steal
- Join a "gang" or a group of people who harm others or threaten to harm others.

Don't spend time alone with people who are violent or are likely to become violent. If you are in a bad situation, try to remove yourself first. If that is not an option, try to remove the person from the situation that started these behaviours without putting yourself in more danger. You can ask for help and protection. Ending a violent relationship can be difficult and dangerous. It is not something that you should go through alone. Tell someone you trust and respect and ask for help. This could be a family member, friend, teacher, social worker, pastor or health-care provider. The police can also help.

18. How can I deal with feeling different than other teenagers?

Having HIV means that you are dealing with something much more difficult than what most other teens have to deal with. It may feel frustrating because their lives seem so much easier than yours. You may wish your problems were as simple as theirs. It is important to try to realize that everyone's life is different, and there may be things that you don't know about that your friends are having a difficult time with too. You have a lot in common with other teens: friends, dating, and deciding what you want your life to be like in the future. A lot of things in your life are similar to things in other teens' lives, so you are probably a lot more alike than you may feel sometimes.

LET'S TALK ABOUT NUTRITION

When you are a teen, your body undergoes a lot of changes. You grow taller and develop into young men and women. This cannot happen properly unless your body is given the vitamins and nutrients it needs every day. Being HIV-positive means that you are at greater risk of becoming "malnourished" than someone who is not infected. Infection changes the way your body breaks down sugar, fat, protein, vitamins and minerals, increasing your body's need for these nutrients. Malnutrition along with HIV can worsen your body's immune system and lead you to develop more severe infections. You may stop growing and lose weight. You may feel tired and have difficulty concentrating at school. It is very important that your doctor or health-care provider follow your height and weight at every visit and refer you to a dietician or nutritionist if there are any concerns.

19. What kinds of foods do I need to eat in order to gain weight or maintain a healthy weight?

If your doctor or health-care provider tells you that you need to gain weight, you need to eat foods that are high in calories (energy). You can get most of this energy from the starch group by eating things like:

- Bread
- Pap (also known as nshima, phaletshe, ugali, posho, sadza and fufu)
- Porridge
- Maizemeal/Cornmeal
- Sorghum
- Rice
- Potatoes (sweet or regular)
- Millet
- Pasta

20. What kinds of foods do I need to eat in order to keep my muscles healthy?

If your doctor or health-care provider tells you that you need to build your muscle mass, you need to eat foods that are high in protein. Examples of such foods are:

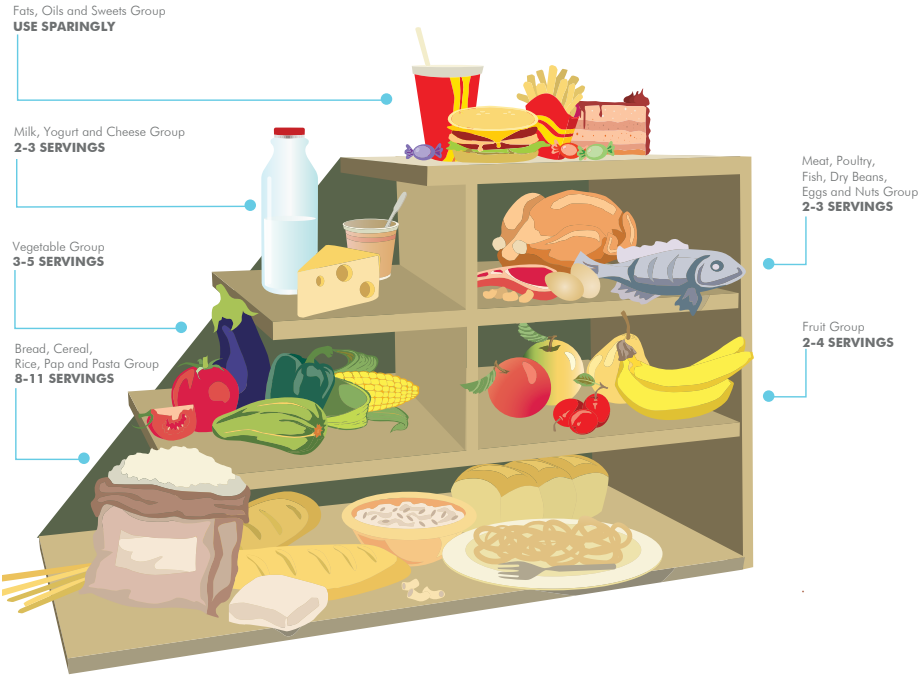
- Meat
- Fish
- Eggs
- Milk
- Dairy products (e.g. yogurt and cheese)
- Peanut butter
- Beans, peas, nuts, seeds

21. What about sweets and snack foods?

As a teen it is very popular to eat at fast food restaurants when you are with your friends. You must remember that it is okay to have this kind of food every once in a while, but that it is not good to eat it every day. These foods are high in fat and sugar and do not offer much nutrition to your body. Small amounts of these foods will provide you with extra calories, which may be of benefit to you depending on your nutritional goals.

22. Are there any vitamins or minerals that are especially important?

Yes! It is easy for people living with HIV to lose important vitamins and minerals because of infection and the improper way in which the body uses these nutrients. Vitamins A, B, C, and E are important to help your immune system function correctly. Vitamins A and C are also important for wound healing and Vitamin A is important for good vision. The B Vitamins (e.g. B12, B6) are important for energy production and growth. Vitamin E is good for helping the production of red blood cells that help carry oxygen to different parts of the body. Minerals such as zinc, iron, potassium, and copper are also important.



- What is the best way to get these vitamins and nutrients into my body?

  - A daily multivitamin is a great way to make sure that your body gets the nutrients and energy it needs. You should know, however, that this is not a replacement for eating the vitamins and minerals. In fact, taking your multivitamin with food may prevent you from becoming nauseous.
  - Fruits and vegetables contain a lot of these vitamins and nutrients, so it is a good idea to eat these each and every day.

23. What can I do when I am not feeling well?

It is very easy for people infected with HIV to lose weight. If there is loss of appetite, fever, vomiting, diarrhoea, or sores in the mouth, then weight loss typically results. At this point, you need to eat more in order to regain weight and adding extra fats to food can help increase energy intake. Here are some general suggestions for days when you are not feeling well:

Loss of appetite

- Make meals as appealing as possible.
- Eat smaller meals and eat more frequently throughout the day.
- Eat with your family and/or friends.
- Add sauces or gravies to dry foods to make them taste better.
- Eat foods that need little chewing.
- Try not to drink liquid with meals as they will fill you up, instead, drink juices and milk between meals.

Nausea and Vomiting

- Eat light meals and beverages and try to eat these smaller meals more frequently during the day.
- Cold foods may be easier to eat than hot foods because they are less likely to have strong smells that may make you feel sick.
- To calm your stomach, cut a lemon in half, rub it between your hands and inhale its scent.
- If possible, stay out of the kitchen when food is being cooked because the smells may make you feel worse.
- Avoid spicy (chilli), greasy, and fatty foods and focus on eating foods that are either salty or bland such as toast or dry cereal.
- Ginger beer, root ginger, or ginger biscuits may help nausea.
- Your doctor may have medicines to help with nausea and vomiting, if necessary.

Constipation

- Eat foods that are high in fibre such as brown bread, oats, maize (corn) on the cob, whole grain wheat breakfast cereal (e.g. Weetabix), brown rice, and fresh fruits and vegetables.
- Drink **PLENTY** of liquids. Warm liquids, especially in the morning are effective.
- Exercise helps too if you are feeling up to it.

Diarrhoea

- Drink plenty of fluids to avoid dehydration. You can have diluted fruit juices, ORS (oral rehydration solution), salty soups, and/or rice water.
- Decrease the amount of milk and dairy products that you consume. This may worsen your diarrhoea.
- Reduce foods that are high in fibre since these encourage your bowels to move more frequently.
- Eat maize (corn) meal, bananas, and rice.
- Avoid caffeine (soda, coffee, tea).
- Eat small and frequent meals.
- Eat foods that are lower in fat.

Painful or Difficult Swallowing (sore mouth)

- Eat soft, chopped foods that require minimal chewing (i.e. soft porridge, mashed potatoes, pumpkins, mashed vegetables and fruits, scrambled eggs, and minced meat).
- Suck on an ice cube before you eat your meal.
- If your mouth is dry, avoid foods that stick to the top of your mouth like peanut butter.
- Avoid hot and spicy foods as well as foods that are high in acid like oranges, pineapples, and lemons.
- Eat your foods warm rather than hot as they will be easier to eat.

24. Where can I get more information on good nutrition?

There are plenty of people available to help you make good decisions about what you should eat. Visiting your local clinic or doctor is a good way to find out if the choices you are making about what you eat are correct or if you could be directed to do something else that could improve your nutrition. In many areas there are dieticians who are individuals that are specially trained in nutrition. Many times, your doctor will know of a dietician in the area and he/she could refer you there so you can receive counselling on nutrition.

LET'S TALK ABOUT EXERCISE

25. Why is "fitness" so important and what does it mean?

You have probably heard the phrase, "I want to get fit" on TV, in the movies, or from one of your friends. Being physically "fit" or "in shape" refers to the ability to live an active lifestyle without becoming too tired or sick. Because everyone has different lifestyles, fitness is not the same for every individual and it depends on someone's interests, favourite hobbies, and how much time their job or school requires each day. Things like your age and whether you are male or female also affect one's fitness level. As we age, we become less fit because our muscles get weaker and our bones become lighter. Men, because they have more muscles and heavier bones, can usually generate more power and move faster than women.

26. What does it mean to exercise? What are different types of exercise?

In order to stay healthy, everyone must pay close attention to fitness or in other words, they must **EXERCISE.** Here are some different types of exercises that exist. It is good to do a combination of these as this will lead to better overall body fitness.

- Cardiovascular: This is what you may have heard referred to as "aerobic" activity, which means that as you exercise your heart rate increases and pumps blood to all of your organs while delivering oxygen to your muscles at the same time. Doing cardiovascular exercise (e.g. dancing, running, swimming, biking, etc.) most days of the week will protect you from developing future problems like diabetes and heart disease.
- Muscular endurance/strength: This refers to the ability of your muscles to withstand long periods of use AND also to how much weight a person can lift at once. You can increase your muscle strength by lifting weights but this is not recommended for adolescents under the age of 16.
- Flexibility: This term refers to how far your body parts (e.g. arms, legs) can move. Good flexibility will help to prevent injury to your muscles and tendons during physical activity. It can be accomplished and/or improved by stretching both before AND after exercising and also by doing activities that promote flexibility like yoga.

27. What will exercise help to do for me physically?

There are many physical benefits of exercise including:

- Helping you to feel good
- Helping you to "burn" fat, improving your physical shape AND your overall health through weight control
- Helping to improve your posture through the shaping and building of your muscles which will, in turn, help to maintain the strength of your bones
- Helping to keep your body's joints (e.g. elbows, knees, hips, shoulders) flexible and injury-free
- Helping you to build stamina and endurance which means making your heart pump blood loaded with oxygen to your organs more efficiently and thereby, preventing disease.

28. Can exercise help me mentally and emotionally?

In addition to physical benefits, you might be surprised to learn that there are mental and emotional benefits from exercise and physical fitness as well. These include:

- Providing a way for you to interact with your current friends as well as to meet new people that may become good sources of support for you
- Providing a lot of FUN for you and a way to release stress and tension or overcome boredom
- Allowing you to build your self-confidence by overcoming fears, facing new challenges, and developing new skills
- Developing an appreciation for cooperation, responsibility, respect, and self-discipline.

29. How can I get started with my own exercise routine?

The most important thing to consider when designing your own exercise/fitness routine is to choose the activities you feel most comfortable doing and that will provide you with the most enjoyment. Here are a few tips that may help you in deciding on a final plan:

- Make a list. Write down your goals for your fitness routine. Why do you want to get fit?
- Ask someone for advice that has experience with physical fitness. This could be your doctor, a friend, a personal trainer, or someone who has been trained in physical education such as an athletic trainer at a college or university.
- Do not attempt to do too much at one time. Start out with 1 or 2 activities a couple of times a week and gradually increase the amount of time you devote to physical fitness. Working yourself too hard initially may prevent you from accomplishing the goals that you set out to achieve by introducing unwanted overuse injuries.
- **Do NOT** mimic the training schedules of elite footballers or netball players. It takes years and years of training and practice to perform at the level of elite athletes and this could lead to serious injury if attempted.
- Go **EASY** on yourself. Changes will not happen overnight. It takes weeks to months of dedication to achieve the results you want but it is definitely worth the wait!

LET'S TALK ABOUT SEX

Part of growing up is deciding if, when, and who you want to have sex with. Every teenager must make these decisions, but because you have HIV, your decision has many more implications for your own health and critical implications for the person you are involved with. The first decision that all teenagers must consider is whether they are emotionally ready to have sex. To do this, one must think about the risk of pregnancy and HIV and other sexually transmitted infections (STIs) while making the decision. The following section will answer questions that many teens with HIV are likely to ask.

30. How do I cope when someone no longer wants to be my boyfriend/girlfriend?

- You must come to terms with the fact that the relationship did not work out. It is important to learn why it did not work so that your next relationship will be better.
- It is okay to feel sad or lonely after a break-up but do not feel sorry for yourself. Realize that you are a good person and that you deserve to be happy.
- Begin a new hobby or do something that you enjoy to help you stop thinking about the break-up.
- Talk to people that you trust about the feelings that you are experiencing. You may find that they have been through a break-up too and can help you!
- Instead of focusing on the negatives of being single, focus on the positives.
- Respect the other person and do not spread untrue rumours or lies about them because you are feeling hurt.
- No matter what happens, never harass or threaten the person you were dating. This could end up getting you into serious trouble with the law.

31. When is it okay to kiss someone?

When you feel close to someone, a normal feeling is to want to kiss the person. Kissing on the cheek is very safe. Skin is a great barrier. No one has spread HIV through ordinary social contact like dry kisses, hugs, and handshakes. Open-mouth kissing is a little bit different. It is possible to transmit HIV if you have visible cuts or sores in your mouth, where HIV could enter.

32. How do I know if I have cuts or sores in my mouth?

If you know for sure that you have cuts or sores in your mouth, try to avoid kissing until they are healed. If you're not sure, take a look. Inspect your mouth or drink some orange juice - if you see a mark or feel burning when you drink the juice, there is a good chance that you have cuts or sores in your mouth.

33. How can I prevent myself from getting other diseases?

It is normal and healthy to worry about giving your disease to someone else, but protecting your body also has to be a priority. If you choose to have sex you need to protect yourself for many reasons. You are at risk for contracting (or "getting") other diseases that are passed through sex. There are other infections that can make you very sick. These include chlamydia, gonorrhoea, hepatitis B and C, herpes, syphilis, trichomoniasis, genital warts, and other problems caused by the Human Papilloma Virus (HPV). Some of these infections have no cure and can be passed through semen (sperm), blood, vaginal fluids, or skin contact with genital warts or sores.

If you are infected with a sexually-transmitted infection (in addition to HIV), you are three to five times more likely than other HIV-infected people to transmit HIV through sex. That means that if you get an STI from having sex with someone who does not have HIV, you become more likely to give him or her HIV. You can get very sick so remember to protect yourself.

You should go to a clinic if you have any of the following symptoms:

- Pain during urination
- Sores, ulcers, or blisters on or around your penis or vagina
- Itching or irritation on your penis or vagina
- Discharge that is yellow, greenish, thick or foul smelling
- Pain during sexual intercourse
- Abdominal pain.

Some or all of these symptoms can be related to STIs. If you are experiencing any of these symptoms, it is important to treat yourself and your partner with medicine. In the meantime, it is crucial to abstain from sexual intercourse.

34. How do I protect myself and others during sexual intercourse?

Condoms are the best method for preventing sexually transmitted infections (STIs), including HIV. Condoms are 88% to 97% effective as a method of birth control when used properly. However, there is a risk of the condom breaking or slipping off during intercourse.

35. How do I use a male condom correctly?

Remember, there is no way that is 100% effective in preventing the transmission of HIV or other STIs during sex. Not having sex is always the safest choice you can make. If you choose to have sex, be sure to use a latex condom every time. The other important thing that you need to know is that for condoms to work, they must be used properly. Here is how to do it.

- Check the expiration date and don't use outdated condoms.
- Use a new latex condom each time you have sex.
- Be careful when opening the package. Make sure you don't tear the condom.
- Put the condom on as soon as the penis is hard.
- Pinch the tip of the condom. Squeeze out any air, and make sure it is completely unrolled down to the base of the penis.
- If you are not circumcised, to avoid breaking the condom, push your foreskin back before you put the condom on your penis.
- If you want to use a lubricant, spread it on the outside after the condom is on your penis. Use only water-based lubricants with latex condoms, not oil-based ones, since oil, Vaseline or lotion will make latex fall apart.
- Check the condom during sex to make sure it is still in place and unbroken.
- At the end of sex, the male ejaculates semen, which is something referred to as "coming". Hold the rim of the condom and pull out slowly right after coming. Pull the condom-covered penis out while it's still hard. Be sure to hold on to the rim at the base. Don't let it spill or slip off!
- Take the condom off. Throw it away in a rubbish bin or pit latrine. Wash your hands.
- You can find latex condoms and water-based lubricants at pharmacies, food stores, and local shops.
- In most places, you do not need to be a certain age to buy condoms. Free condoms are available at many local organizations and clinics.

36. What do I do if I love my boyfriend and he refuses to use a condom?

Speak to your partner and find out why he doesn't want to use a condom. Explain to your partner that using condoms is more hygienic and prevents the spread of HIV and other STIs, and that with condoms you can relax and feel safe and enjoy sex. As a woman, you have the option of wearing a female condom. If your partner refuses for you to wear a female condom, explain to him that you cannot have sex, because you are both at risk of either being infected or re-infected with HIV. This will be difficult, but you have to protect yourself.

37. What if the condom breaks?

If the condom breaks during sex or if you accidentally expose your HIV-negative partner to your bodily fluids, do not panic. Exposure to bodily fluids does not automatically mean your partner has become infected, although you must take every precaution to prevent transmitting HIV. Some hospitals and clinics might offer post-exposure prophylaxis (PEP), a special antiretroviral drug treatment that is started immediately after someone is exposed to HIV which allows a person's immune system a chance to provide protection against the virus and prevent it from becoming established in someone's body. PEP must be started as soon as possible after unsafe sex or a condom breaking, ideally within 24 hours and no later than 72 hours (three days). PEP usually consists of a month-long course of two or three different types of the antiretroviral drugs that are also prescribed as treatment for people living with HIV.

After accidental exposure, with or without PEP, one should get a rapid test immediately to determine their current status (also called a "baseline"), and again in three to four months. Waiting three to four months is necessary; otherwise, the test may say the person is negative, when in fact they are positive. This is called the "window period", a period of time — typically up to twelve weeks after infection — when an HIV-positive person will test negative for HIV because their immune system has not begun to produce antibodies to fight the virus. Antibodies are like a flagging system that tag outside organisms like bacteria and viruses to be attacked by other cells (soldiers) of the body's immune system. The HIV tests most commonly used in Africa are antibody tests, which check for these antibodies in the blood.

38. Can I use two condoms at the same time for extra protection?

YOU MUST NEVER USE TWO CONDOMS AT THE SAME TIME.

Using two condoms, male or female, will cause friction resulting in either or both condoms tearing. Two condoms will **NOT** give you more protection.

39. What if I transmit HIV to someone else?

Knowing that you have transmitted HIV to someone else can be very difficult to deal with. You should do everything you can to prevent this from happening. If this does happen, it can be very difficult. You may feel a sense of guilt, which is normal in this situation. The best thing to do is to seek help from a social worker or doctor who can help you and your partner deal with your feelings and take steps to find appropriate medical care.

40. What other forms of birth control are there?

The only 100% effective and totally safe method of preventing pregnancy or transmission of STIs, including HIV, is abstinence. Abstinence means not having intercourse, so there is no chance of pregnancy or contracting a sexually transmitted infection. If someone pressures you for sex, remember that it is your body and you have the right to say no. You should talk to your doctor or other health-care provider about what method of protection is best for you. The following methods listed below are less effective than condoms in preventing the spread of HIV and other STIs. These methods may be considered in addition to using a condom for extra birth control protection. Other types of birth control include:

- Birth Control Pills: Birth control pills provide no protection against STIs or HIV/AIDS. Birth control pills help prevent pregnancy with artificial versions of female hormones. They work

by preventing the release of eggs from the ovaries every month, a process called "ovulation". The pills come in different types and brands and are taken in 21 or 28 day cycles. Pills often require a doctor's prescription, and must be taken on a strict schedule (check first with your local health-care provider). When taken every day, they are 97% to 99% effective in preventing pregnancy. Birth control pills can have certain side effects (e.g. weight gain, tender breasts, spotting, nausea, headache, high blood pressure, and abnormal blood clotting) but these side effects will not happen to every person. If you are interested in birth control pills, it is important that you speak with your doctor because there may be some bad interactions between certain HIV medications and birth control.

- Depo-Provera: Depo-Provera offers no protection against HIV/AIDS or other STIs. It is an injectable form of contraception, and protects against pregnancy for a full three months. While Depo-Provera offers the benefit of not having to take a pill every day, there are risks and side effects (weak bones, weight gain, hair loss) that a woman should discuss with a doctor before deciding on this method.

- Intrauterine devices (IUDs): IUDs do not prevent transmission of sexually transmitted diseases. IUDs work well and provide safe, long term contraception. An IUD is a small, flexible T shaped device that is inserted by a trained health care provider into a woman's uterus through her vagina and cervix. IUDs are either made of copper or secrete progestin and work by preventing sperm from fertilizing eggs. Some women who use IUDs for contraception experience irregular menstrual bleeding and heavier menstrual bleeding and cramping.

41. How do I protect myself during oral sex?

It is possible to spread STIs through performing and receiving oral sex. If you are RECEIVING oral sex from someone else, you are only being exposed to saliva. The concentrations of HIV in saliva are so low that nobody has ever been infected with HIV from saliva. Remember, however, that you can get other sexually transmitted diseases (e.g. herpes) by receiving oral sex. It is still very important to be careful, however, because blood, semen, and vaginal fluid may all contain the virus. The risk for contracting HIV increases:

- If you or your partner have cuts or sores around or in your mouth
- If your partner ejaculates in your mouth
- If your partner has another STI.

If you choose to have oral sex, and you or your partner is male, use a latex condom on the penis. Research has shown that using a latex condom on the penis is effective in preventing the transmission of HIV. Condoms are not risk free, but they greatly reduce the risk of transmitting HIV to your partner. If you or your partner is female, use a latex barrier (such as a cut-open non-lubricated condom that makes a square) between your mouth and the vagina. The barrier reduces the risk of blood or vaginal fluids entering the mouth.

42. Can I spread HIV through anal sex?

It is possible for either sex partner to become infected with HIV during anal sex, whether they are male or female. In fact, anal sex carries the highest risk for transmission of HIV and other STIs because of the small tears that can occur in the lining of the anus. HIV can be found in the blood, semen, or vaginal fluid of a person infected with the virus. Having unprotected (i.e. without a condom) anal sex is extremely risky behaviour. If people choose to have anal sex, they should use a latex condom. Most of the time, condoms work well. However, condoms are more likely to break during anal sex than during vaginal sex. Thus, even with a condom, anal sex can be risky. A person should use a water-based lubricant (not petroleum jelly) in addition to the condom to reduce the chances of the condom breaking.

43. If I choose not to have sex, how do I deal with "hormones"?

If you are not ready for sex or feel that it is too much of a risk, there are things you can do. If you are with someone that you are attracted to, just holding and touching them can be exciting. People like different things. Some people can spend hours touching each other's hands or faces, or massaging each other's backs. Other people like to have their boyfriends or girlfriends kiss their neck or hug them. Other people like to just lie next to each other. There are many things you can do together besides sex that can feel good. And, it gives you an opportunity to get to know your partner better before you decide to have sex.

44. If I have sex with another HIV-infected person, do I still need to use protection?

Yes. You definitely need to protect yourself with condoms if you have sex with another person who is already infected with HIV. Your partner may have different strains of the disease than you do, and if you transmit new strains to each other, you may make each other sicker. Your partner might have resistance to certain ARVs (antiretrovirals) and pass on his/her resistance to you even if you have excellent pill adherence. Repeated infection with new or different strains of HIV can make the illness progress further. You need to keep your health and your partner's health in mind even if you are both infected.

45. Do I still need to worry about infecting others if my viral load is undetectable?

We know that lower HIV viral loads are associated with a lower risk of transmitting HIV. The problem is that we have no way of knowing how low the risk is for any individual. Another problem is that viral loads in semen and vaginal secretions are different and often higher than viral levels measured in the blood. Aside from not having sex at all, using protection every time is the only way to ensure the lowest risk of transmission.

46. For women, is it okay to have sex during my periods?

HIV is transmitted during sex by semen or vaginal secretions. Since HIV is also transmitted through blood, having sex during your period may increase the risk for transmitting HIV but no one really knows how much greater the risk is. Because of this, many women are reluctant to expose their partner to any type

of increased risk and so they avoid having sex during their periods.

47. When do I need to start going to a gynaecologist?

Changes in cells of the cervix (i.e. bottom part of the female uterus) are common in HIV-infected females. Often the changes occur without any signs or symptoms. These changes could be an early and treatable form of cervical cancer. In fact, gynaecological (gynae) problems are some of the most common complications experienced by women living with HIV. Therefore, seeing a gynaecologist at least once a year is very important. Gynaecological problems range from irregular periods to vaginal infections that do not resolve.

Changes in periods are common in all women, but they may be especially common in women with HIV. These changes may include irregular, heavier, lighter, or painful periods. It may also end menstrual bleeding altogether. Tracking the dates of your period from month-to-month on a calendar is always a good idea. This way you can let your doctor know if you have any changes in your periods. It's important to determine why your period has changed. Many gynaecological problems can remain undetected. Left untreated, they can weaken the immune system even more. Yearly physical examinations to detect problems are very important, even when you're feeling well and you don't have symptoms. Early detection and treatment are critical steps to prevent a gynaecological condition from getting worse. A Pap smear is a test where something that looks like a long cotton swab or brush is inserted into the vagina. Cells from the cervix are taken and tested for pre-cancer or cancer of the cervix. The Pap smear can be uncomfortable, but generally it shouldn't hurt unless you have inflammation or an infection. A Pap smear every six to twelve months is recommended. If any abnormalities are found, your gynaecologist may recommend more frequent visits and further testing.

You should see a gynaecologist on a regular basis especially if you are having sex or have an unusual or odorous vaginal discharge, cramping, irregular periods, genital warts, pain and itching around the vagina, painful lesions or sores, or burning or pain when urinating.

48. What are some of the consequences of teenage pregnancy?

Unplanned pregnancies pose difficult decisions for teenagers, especially those who are HIV-positive. To begin with, unprotected sex places you, your partner and your unborn child at risk of HIV infection or re-infection. Also, teenage parents often fail to achieve the qualifications they deserve as they may need to leave their schooling to take care of their children. Children of teenage parents are more likely to be born premature, have poor health outcomes and a higher infant mortality (death) rate than those born to older parents, as teens are not fully developed themselves (physically, mentally, and emotionally) and may also find it difficult to access antenatal care and support. The social disadvantages faced by their families also mean that children of teenage parents generally achieve less educationally than children of older parents and are at a higher risk of unemployment themselves. Teenage pregnancy, therefore, has far-reaching consequences for the young people involved and subsequent generations. You and your partner should think carefully about these consequences when deciding whether to have a child or not.

LET'S TALK ABOUT POSITIVE PREVENTION

49. Who will benefit from positive prevention?

All PLHIV (People Living with HIV/AIDS) and their partners benefit from positive prevention, also known as "positive health, dignity and prevention". Applying positive prevention measures will help increase your self-esteem, confidence, and ability to protect your own health and avoid passing the infection to others. If you are on ART and living positively, you will feel healthy and have the same desires and needs as HIV-negative people, including the desire for sex and the desire to reproduce.

50. What is the importance of positive prevention?

Positive prevention involves:

- Recognizing your rights while living with HIV, including choosing whether or not to have sex, and planning whether to have children.
- Seeking the information and support you need to help you disclose your HIV status to your sexual partner, ensuring that you both can chose to have sex that is safer for both of you and that you can access the support you need to prevent the transmission of HIV to your children, should you plan to have any.

Your Rights and Responsibilities:

You have a right to live a long, healthy and fulfilling life, whatever your HIV status. However, if you are living with HIV, you also have the responsibility to prevent further transmission of HIV to others.

51. Why positive prevention?

Positive prevention practices can support you to:

- Improve your health by protecting yourself from re-infection with HIV
- Protect others from HIV infection
- Access HIV testing and counselling services to enable you to make informed decisions with regards to your health and well-being
- Access information about when to start taking ARV medicines and which ARV medicine to take in order to improve your status
- Increase your chance of adhering to therapy. Once you have started taking ARVs, it is very important to take them every day, at the right times and in the right way.

52. How do I cope with positive prevention?

Incorporating prevention methods into one's life can be difficult, whether you are HIV-positive or not. However, PLHIV may experience unique challenges when trying to practice positive prevention. These include:

- Stigma and discrimination: You may feel embarrassed or uncomfortable about disclosing your HIV-positive status to your sexual partner, thus compromising your decision to introduce safer sex practices into a relationship. The fear of abandonment or rejection may hinder you from practicing positive prevention. Many PLHIV suffer from self-stigma. Self-stigma is often characterized by a fear of how people will relate to you due to your HIV status and can cause people living with HIV to see themselves as shameful or worthless. If you suffer from self-stigma, you may avoid being around other people or sharing your HIV status. You can fight self-stigma by going for counselling or finding people you can trust with whom to share your feelings.

- Lack of accurate information: Knowledge levels around positive prevention methods are often low, since prevention for PLHIV is a newer concept than prevention for those who are HIV-negative. By sharing information about positive prevention as widely as possible with other PLHIV and their caregivers, you can help to ensure that more PLHIV are aware of how practicing positive prevention will benefit them.

- Lack of access to prevention services: In some countries prevention methods and tools are often hard to access. PLHIV must make all efforts to access prevention, care, and treatment services. Join advocacy efforts and activities in your community to fight for greater access to these services.

53. What are the steps towards effective positive prevention?

Know your status

Positive prevention begins when you receive an HIV-positive test result. Having already gone for an HIV test, you have begun the "prevention" process already, as it shows that you are taking responsibility for your own life and lives of your loved ones.

Deal with self-stigma

When you first find out you are HIV-positive, you may begin to have several mixed and negative feelings. These could include feelings of shame, guilt, or reduced desire to have sex. This could be part of self-stigma, so seek adequate counselling to overcome it.

Disclose your HIV status

Once you accept your HIV status, it is then important to consider disclosing to others, so as to get the necessary support.

Seek services: prevention, treatment, care, and support

If you choose to seek and access effective treatment, care, and support that is available to you, you will feel better over time and may regain your desire for sex, for relationships and possibly for having children. Positive prevention plays a key role in helping you to do all these things.

Living a healthy lifestyle

This is important to the process of practicing positive living. As you access counselling and other services, you can begin to adopt a lifestyle that will keep your body and soul healthy.

The future

As you accept your status and begin to access relevant services, you can easily plan your future in terms of:

- When to start treatment and how to stay on treatment
- How to build a support network for yourself
- Engaging in succession planning (planning for the future) with your family and openly discussing their security and comfort if you should become ill or your condition worsens
- Realizing your goals and dreams in life, whether they are professional, educational or social.

Serving the community

Your role as a PLHIV is very important in the community. You can support others to seek HIV testing and counselling services; support them to accept their HIV-positive status; become a treatment buddy for those on treatment; advocate for improved access and availability of services and rights of PLHIV in your community; and promote positive prevention practices.

Through your active involvement in community affairs (e.g. work, social, and family) you will also reflect how PLHIV can continue to be valuable members of society irrespective of their HIV status.

Positive prevention strategies involve interventions at the three main levels:

- Individual level
- Community level
- Policy level

Individual level interventions involve PLHIV adopting risk reduction behaviours to ensure the well-being of their own health and that of others, while community level interventions involve providing a supportive environment for PLHIV to practice positive living and subsequently positive prevention. Policy level interventions involve influencing policies and laws to be transformative and supportive of the rights of PLHIV in adhering to their responsibilities and enjoying availability, accessibility and affordability of services to support PLHIV to practice positive living.

54. What can be done at the individual level?

HIV testing and counselling is an important part of positive prevention as it helps people to find out about their status and take positive action to stay healthy and protect the health of their loved ones and sexual partners. If you already know that you are HIV-positive, you are encouraged to access HIV testing and counselling (HTC) and other health care services.

HIV counselling and testing:

- Helps you to know your status. By knowing your status, you can make informed decisions about your health.
- Acts as an entry point to prevention, treatment, care and other services.
- Is confidential. This means that no one will know your result unless you share it with them.
- Can be accessed at local clinics and hospitals or other testing centres and mobile units.

Everyone who is sexually active and who does not know his or her HIV status should go for HIV testing and counselling.

Safer sex counselling

It is important to seek and access safer sex counselling. Post-test counselling provides the first opportunity after your HIV diagnosis to discuss emotions, health issues, safer sex, prevention, treatment, care and support options.

Some issues, which can be discussed during safer-sex counselling, are:

- Factors that increase the risk of HIV transmission through unprotected sex such as untreated sexually transmitted infections (STI) in you or your partner, rough or forced sex; the use of herbs to make the vagina dry; and high viral load of someone who has recently become infected with HIV and its risk implications.
- Knowing more about safer sex to minimize the risk of HIV transmission while still enjoying the right to having sex. Knowing how to protect yourself and your partner from further HIV transmission will build your self-esteem and confidence, and help you to negotiate for safer sex in the future.
- There are many different safer sex activities that you can engage in to continue enjoying a satisfying sex life. Some of these include having non-penetrative sex and having protective penetrative sex with a male or female condom, even during oral sex.
- Communicating effectively is important when discussing and negotiating safer sex options with your partner. A safer sex counsellor can give you advice on useful communication tips and suggestions.

ABC as a preventative strategy for PLHIV

The ABC approach can offer a number of options for practicing safer sex.

- Abstaining or delaying sex until marriage: you may decide that abstinence is the best prevention method for you, though it is important to keep in mind that abstinence only works if you stick to it. If your situation changes, you need to be aware of other prevention options.

Delaying sex until marriage will reduce the number of sexual contacts you have and will help you make informed choices when you do begin to have sex.

- Being faithful works if both you and your partner are faithful and if your partner is supportive and accepting of your HIV-positive status. If you and/or your partner are living with HIV and want to have sex, then you need to practice other prevention methods – such as non-penetrative sex or condom use in your relationship.

The practice of having multiple concurrent partnerships (MCPs), which means engaging in two or more sexual relationships that overlap in time, has been shown to be one of the major drivers of the HIV epidemic in sub-Saharan Africa. Many people in the region engage in this practice, unintentionally creating sexual networks. This greatly increases the risk of HIV transmission because, if one person in the network has unprotected sex and gets infected with HIV, he or she places other members of the sexual network at risk of HIV infection.

- Correct and consistent condom usage is also important. Both male and female condoms can significantly reduce the risk of HIV transmission if used correctly and consistently every time you have sex. It is up to you and your partner to decide which condoms suit your relationship best. Some people feel that condoms reduce the intimacy of sex, but there are various ways to enjoy condom use and maintain relationship intimacy. Female condoms also allow women to be in greater control of prevention.

Accessing treatment and care alongside positive prevention

It is important to access available and quality treatment and care for PLHIV, as they are closely linked to the successful practice of positive prevention. Positive prevention is about improving overall quality of life and wellbeing and providing a holistic approach to wellbeing, which includes all aspects of your life: mind, body, and soul.

- MIND: By living positively and practicing positive prevention (also known as "positive health, dignity and prevention") you will be able to play an active role in your community and continue to stimulate your mind. This will make you feel better about yourself and help you to fulfil your purpose as you work towards achieving your dreams and ambitions.

- BODY: Learning to live positively includes preventing HIV re-infection; treating any opportunistic infections (OIs); keeping to a nutritious diet; exercising and getting adequate rest; maintaining good personal hygiene; avoiding alcohol, illegal drugs and smoking; and taking your medicines correctly. All these things will improve your health and give you a more positive outlook on life.

- SOUL: By finding ways to reduce stress; believing in yourself and exercising your rights; disclosing to someone you love and trust-and receiving their support and having meaningful relationships, you will become emotionally at ease. Positive prevention is about helping to ensure that you feel confident, happy and healthy. Having the "will to live" is one of the strongest medicines for people living with HIV. If you have the will to live then you will feel less stressed and more positive about life and your body will respond in very good ways. Many people find that being HIV-positive increases their appreciation of spirituality, whatever their spiritual orientation may be.

55. What can be done at the community level?

Community mobilization and support

- As part of a wider community you influence that community and are influenced by it. You need the support of your community in order to effectively practice positive prevention behaviours.
- Peer support groups are an effective strategy in community mobilization interventions. They are a platform where you can share experiences and challenges and provide mutual support amongst PLHIV.
- Home-based caregivers (HBC) provide care and support for PLHIV and are important in promoting safer sex and referring PLHIV for STI and OI diagnosis and treatment. This can reduce the stigma and discrimination associated with HIV and encourage community acceptance of PLHIV.
- While it is very important for communities to be aware of the vital role they have to play in supporting PLHIV to practice positive prevention, it is important to be mindful that you have a responsibility in encouraging the support of your community. You can do this by organizing and participating in campaigns and PLHIV groups to increase the visibility of PLHIV within your community, enhance education around HIV and reduce HIV stigma and discrimination. By 'giving a face to the HIV epidemic' and acting as a role model, you can help reduce the stigma and fears associated with HIV.
- Organizations (e.g. non-governmental organizations [NGOs] and other civil society organizations (CSOs) in your community can support you with necessary training and support to engage in campaigns and other community activities, and give you the confidence needed, as well as help you with stress-coping strategies.

LET'S TALK ABOUT MULTIPLE CONCURRENT PARTNERSHIPS (MCPs)

56. What are Multiple Concurrent Partnerships (MCPs)?

MCPs refer to the practice whereby men and/or women have more than one sexual relationship at the same time. These relationships can be long or short-term. They vary in nature and meaning, ranging from one night stands with a sex worker, a stranger or even a friend; to long-term relationships. This greatly increases the risk of HIV transmission because, if one person in the network has unprotected sex and gets infected with HIV, he or she places other members of the sexual network at risk of HIV infection.

Reasons for engaging in MCPs vary. Some people do it for simple pleasure and fun; others do it for money or material gain. Yet, others do it as a form of revenge on cheating partners or perhaps just because of loneliness.

International organizations such as UNAIDS and regional bodies such as the Southern African Development Community (SADC) recognize that MCPs are a key contributor to the spread of HIV in southern Africa. The practice is widespread throughout the region and it has been cited as one of the reasons HIV prevalence is higher in southern Africa than in any other part of the continent.

57. Why do MCPs carry such a high risk of HIV transmission?

When people engage in unprotected sex with multiple concurrent partners, they increase their chances of becoming HIV-infected. Long-term associations often offer challenges to the continued use of condoms during sex. Unequal power relationships in such liaisons add to the difficulty of negotiating and sustaining condom use. After some time, the parties concerned tend to think they now know each other and trust each other and condom use falls by the wayside. "But I love you" becomes a reason to stop using condoms. This is an extremely risky thing to do.

Unprotected sex is always a risk and the more you have it, the greater your risk of contracting HIV becomes. Each partner in a sexual network may have their own additional partners with whom they are having unprotected sex. All it takes is for HIV to enter the network through one individual for everybody to be at risk of infection.

When somebody is first infected with HIV, their viral load is very high, making it very easy for them to transmit the virus to their partner. So take the example of Joseph, who has a wife but also a girlfriend. The girlfriend becomes infected with HIV after she has sex with another man because Joseph is with his wife. The girlfriend is very likely to pass HIV on to Joseph during unprotected sex as her viral load will be very high at this time. Joseph, with a very high viral load (having been recently infected), will then pass the virus on to his wife if they have unprotected sex. In the end all three people involved – Joseph, his girlfriend, and his wife – end up getting infected with HIV. If they continue to have multiple concurrent partnerships, HIV will continue to spread throughout their sexual network, until someone breaks the chain by practicing abstinence, faithfulness (i.e. mutual monogamy), or safer sex (e.g. using condoms).

LET'S TALK ABOUT SAFE MALE CIRCUMSCION

58. What does "circumcision" mean?

You may have heard the word "circumcision" from your friends, on TV, or in advertisements on the local mini-buses. What does this mean? Circumcision is the surgical process of removing the foreskin from the male penis. The foreskin protects the sensitivity of the glans (i.e. head of the penis) from irritation, infection, and injury. This may be done directly after birth or on a special date and time according to culture and religion. It can be done on babies, young children, or even adults. Doctors and surgeons are the ones who perform the circumcision. In many parts of the world, people choose not to have their boys circumcised after birth for a number of reasons and, likewise, many adult males never decide to become circumcised. It is a very personal decision on the part of the parents or on the part of the person who would be undergoing the procedure.

59. Will circumcision prevent me from getting HIV or transmitting HIV to others?

Yes. Circumcision helps prevent people from getting HIV through sex. The World Health Organization and UNAIDS have found that men who are circumcised are much less likely to become infected with HIV, or to infect another person. Male circumcision however is not 100% effective at preventing HIV, so even men who are circumcised should continue to practice safer sex by using condoms, having fewer sexual partners, being faithful to one uninfected partner or even abstaining from sex.

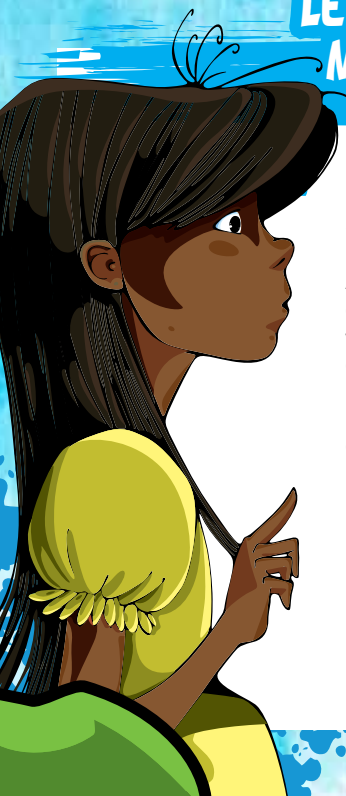
60. What does "Safe Male Circumcision" mean?

Safe Male Circumcision is circumcision that is performed by a trained health care provider such as a doctor or nurse as opposed to circumcision that is performed by a traditional circumciser. It is also called voluntary medical male circumcision. Safe Male Circumcision is always voluntary.
Because circumcision is a minor surgery, there is some risk but when circumcision is performed by a well-trained health care provider, the risks are few. Any problems can be easily managed by the trained providers so it is highly unlikely that there will be complications.

61. Where can I go for more information?

Many hospitals, clinics and private doctors now offer voluntary medical male circumcision.
Talk to your doctor, nurse or community health worker for more information.

LET'S TALK ABOUT PREVENTION OF MOTHER-TO-CHILD TRANSMISSION (PMTCT) (A.K.A. PREVENTION OF VERTICAL TRANSMISSION)



62. Will I ever be able to have children?

Although there is always a risk of transmitting HIV to your partner and child, new methods are being developed to decrease the risk for adults with HIV who want to become parents. Making the decision to have a child is a very important decision and one that takes a lot of thought and planning. It is something you need to discuss with your doctor and partner before you make the decision to have a child. The following are some options and facts to consider if you choose to try to have a child:

- There are no guarantees that the child will be HIV-negative. Most transmission of HIV from mother to baby happens near or during the delivery, but it can also happen during breastfeeding.
- The risk of passing the virus to the baby during pregnancy and birth is higher if the mother has increased levels of HIV in her bloodstream (viral load) and fewer numbers of the

"soldiers" or CD4 cells. That is one of the reasons why it is important to know your CD4 count whether or not you are on ARVs. Typically, the lower your CD4 count, the higher the amount of virus you have in your blood.

- HIV-positive women who take one or more antiretroviral medications during and after pregnancy can lower the risk of passing the virus to their babies during birth and breastfeeding. Because of this, HIV-positive women all over the world are making the choice to take antiretrovirals (ARVs) during and after pregnancy and fewer babies are contracting the virus. Your doctor will know which ARV or combination of ARVs is standard for HIV-positive women in your country.

- Some women may be taking HIV medicines for their own health and then become pregnant. If this happens, they should talk with their doctor to discuss the risks and benefits of the drugs to the baby and whether the medicines need to be changed.

- Countries in sub-Saharan Africa vary in terms of safe infant feeding recommendations. Most recommend exclusive breastfeeding in the first six months of life for infants with HIV-positive mothers, while others recommend formula feeding. Your health-care providers will know the standard recommendation from the Ministry of Health in your country. Pregnant women should discuss feeding plans with their health-care provider prior to delivery so that they can agree upon and prepare for the best feeding method. In areas where water quality and other health indicators are generally poor, exclusive breastfeeding for the first six months while on ARVs has been shown to be the safest way to prevent HIV transmission and other infant illnesses like diarrhoea and respiratory infections. Ask your healthcare provider if you are not sure if the water is safe where you are. It is also important to remember that switching from breastfeeding to bottle-feeding and then back to breastfeeding, something called "mixed feeding," increases the risk that the baby will become infected with HIV. When we talk about "mixed feeding," we also include giving any liquids (including water), or any complementary foods when breastfeeding. It is recommended that mothers never mix feed their infants in the first six months of life as this practice increases the risk of the baby getting infected. After the age of six months, a baby's body is now more mature and s/he needs more food to keep growing. So, if a mother decides to continue breastfeeding her infant after six months of age, mixed feeding (adding complementary foods and liquids) is fine—it is much less risky (the baby's body is more mature) and it is needed to keep the baby growing. In general, we recommend that mothers who are HIV-positive breastfeed their babies until they are twelve months old, exclusively for the first six months, and then adding complementary foods after that.

- A Caesarean section may reduce the chance of passing on the virus to the baby, but there may also be more health risks involved for the mother. Many villages are very far from hospitals that can perform Caesarean sections. This option should be discussed with a doctor or other health-care provider.

- An alternative to having your own child is to adopt one. Many adults that wish to have children consider adoption, regardless of their HIV status. Contact the appropriate social welfare authorities to find out the rules and regulations regarding adoption in your country.

63. What if I have an unplanned pregnancy?

If you should become pregnant, it is very important to take good care of yourself as this will affect your unborn child's health as well. As soon as the pregnancy is confirmed, it is important to begin receiving prenatal care from an OB/Gynaecology clinic for necessary testing and vitamins. Since you are HIV-positive, your medical doctor can give you advice as to how to keep you from transmitting the virus to the baby, something referred to as Prevention of Mother-to-Child Transmission (PMTCT). If the pregnancy was truly unplanned, there are a number of options available to you. Pregnancy during your teenage years can be scary but there are people that can help you with making some very important decisions regarding your options, including your doctor. You may decide to give the child up for adoption or allow the child to stay with a relative as the legal guardian until you are at a place in your life when you can take care of the child on your own. When deciding about whether or not you are able to raise a child, take into consideration the issues of money, education, where you are going to live, and who will help you take care of the child. Talk to people around you that you trust for guidance and advice.

64. What are some common facts and myths about PMTCT?

MYTH: A man should have sexually transmitted infections as many times as possible to be seen as a "real man."

FACT: Sexually transmitted infections (STIs) increase your chances of contracting HIV and repeated STIs can lead to infertility and/or sterility. It is therefore not necessary for men to expose themselves to STIs to prove their manhood as it is dangerous to their health and the health of their sexual partner(s).

Bottom Line: Men should always practice safe sex and know their HIV status.

MYTH: If the viral load of a person on ARVs is undetectable, he/she is free from HIV/AIDS and cannot transmit HIV.

FACT: The person can still transmit HIV even if his/her viral load is undetectable. The viral load test is used to detect the amount of the HIV virus in your body. You will always have some amount of virus circulating because there is no cure for HIV/AIDS.

MYTH: My partner's HIV status is obviously my status; therefore, if my partner enrols in the PMTCT program it means that I am also HIV-positive.

FACT: It is possible to find partners having different HIV status. It is very important for both partners to go for testing because you would never know if you have different statuses or not.

Bottom Line: Your partner's HIV status is **NOT** obviously yours **GET TESTED!**

MYTH: AZT cures pregnant women who are HIV-positive.

FACT: AZT and other antiretroviral medications reduce the risk of the virus being transmitted from mother to child during pregnancy, labour, delivery, and breastfeeding. It does NOT cure HIV/AIDS.

Bottom Line: There is still no cure for HIV/AIDS.

MYTH: It is OK to give my baby formula when there is clean water available to mix it with and then breastfeed my baby when there is no clean water.

FACT: Switching from breastfeeding to bottle-feeding and then back to breastfeeding, something called "mixed feeding," increases the risk that the baby will become infected with HIV in the first six months of life. After six months, when the babies' intestines are more mature, and a baby needs the extra calories, mixed feeding is less risky and is important for growth. So, if an infant is breastfeeding, mixed feeding once he/she is older than six months is beneficial for proper growth.

MYTH: PMTCT is a program for women and children only.

FACT: PMTCT is a program for the whole family. Women, partners, and children need family support in order to utilize the PMTCT services accordingly.

Bottom Line: Let us share the responsibility.

MYTH: Sexual and reproductive health services are for women because they provide family planning.

FACT: These services are for both men AND women. Men should also access such services as they are good for their health, their partners', and their children's health.

Bottom Line: PMTCT is for the whole family.

MYTH: My baby can't get HIV if I am on ARVs.

FACT: PMTCT does NOT prevent transmission of HIV from an infected mother to the baby 100% of the time; it simply reduces the likelihood that transmission will occur. HIV-positive parents should be provided with adequate information before making decisions regarding getting pregnant.

MYTH: If you are not sick it means that you do not have HIV.

FACT: The only way to know whether you have HIV or not is by having a test.

Bottom Line: Know your status—go for an HIV test.

LET'S TALK ABOUT EMOTIONS

65. Where can I look for emotional support?

The best people to look to for support are people you trust who understand and accept both you and your HIV status. Sometimes it is easiest to talk to family members, people you live with, teachers, or friends who know you are living with HIV. You can also always talk to a social worker, doctor, psychologist or other health-care providers. They usually know a lot about HIV and can give you good advice. If you are religious, you may find comfort in your place of worship.

66. Where can I go to talk with or be around other teens with HIV?

A lot of teens with HIV find it very helpful to be around others who also have HIV. When a group of people with a common illness or condition come together to support each other, it is called a peer support group. Some peer support groups exist specifically for HIV-positive teens. If you choose to participate in a peer support group, you will be able to meet other teens who have similar thoughts and feelings as you, possibly building a lot of friendships. If you are interested in joining a peer support group or if you would like to find out more information about other places that you may be able to go, talk to your social worker, nurse or other health-care provider about finding such opportunities where you live.

67. What changes can I expect in how I am treated now that I am a teenager infected with HIV?

If you have had HIV for most of your life, things may change as you get older. You may find that people ask you more questions about HIV. For example, when you are a child at school and you go to the medical clinic, the other kids might not ask questions. You have to be prepared to answer questions that classmates and friends might ask about HIV, or about any changes to your body that may have happened because of your medications. Being ready for such questions is the best thing that you can do to handle them. Be as honest as you feel comfortable being, and remember that your body is your business. You may find that you want to tell people that you are HIV-positive less often than you did when you were younger. However, you may also find that you need support outside of your family and medical providers. Choose whom you want to tell carefully, and be prepared to deal with their reactions.

68. What should I do when I feel sad or unhappy?

Sometimes it is okay to let yourself feel sad or to cry. These emotions are inside of you and you are going to feel them every now and then. It is important to remember that strong emotions are a normal part of being a teen. Every teen has moments of anger, sadness, frustration, and fear. Hormones can affect your mood, especially when you are a teenager, because your body begins to make more of them. For young women, feeling sad or angry is normal, especially during the days before your monthly period starts. Just like it is important and useful to know your body, it is also good to learn ways to deal with sad emotions. Here are some things that might help you feel better:

- Listen to your favourite music.
- Write about how you are feeling. Writing a poem or a song about your feelings can also help. Writing letters to a friend, a parent or family member, God, someone who has died, or someone you haven't talked to in a while, may help you to feel better.

- Read a book to take your mind off of your problems.
- Watch your favourite movie or TV show.
- Draw, paint, or create artwork to help you express yourself. Even if you don't think you are a great artist, as long as what you create is coming from you and your feelings, it can be helpful.
- Exercise.
- Meditate or pray.
- Talk to someone you feel close with about what you are feeling. This can help you understand your feelings and help you realize that you are not alone.

69. What does "depression" mean?

You may have heard the word "depression". There are many different definitions and ideas about what this means. It is important for you to know that certain things like the death of a family member, a failing mark in school, or having poor health can make people feel "depressed" or sad for a period of time. This is very normal and many people find that the depression goes away with time. It is also important to know that for some people, depression can be a serious illness. Just like HIV, depression is also a medical condition. It results when the chemicals in the brain do not work properly. Serious depression is able to be treated with counselling and medication. If nothing that you do to try and ease your sadness seems to be working, you may be depressed and need help. Here are some symptoms of depression:

- Feeling sad and unhappy most of the time
- Not feeling like doing the things you usually enjoy
- Not having energy or motivation, or feeling agitated
- Feeling guilty and hopeless about the future
- Feeling angry
- Worrying a lot
- Having difficulty making decisions
- Crying a lot, sometimes for no reason
- Spending lots of time alone and avoiding your friends
- Eating too much or too little, losing or gaining weight
- Sleeping all of the time or not sleeping at all
- Feeling irritable
- Thinking of not wanting to be alive or having suicidal thoughts.

If you think that any of these things describes how you feel, you may be depressed and need some help. Talking to a social worker, psychologist, or other counsellor can often help. You can also go to your local clinic or doctor and they will be able to give you information about where to go for treatment. Along with counselling, there are medications that have been shown to help depression, but they must be taken with instructions from your doctor. It is important that the doctor knows what other medicines you are taking so there are no bad side-effects from taking them together.

Depression is common and can be cured. However, if it is not treated, it is much more likely to get worse and to come back in the future. Untreated depression may make you turn to alcohol and drugs, and other things that make people feel worse. It can also lead to considering thoughts about killing yourself, something called "suicide".

70. What should I do if I start thinking about suicide?

If you are feeling suicidal, you should talk to someone right away. Do not feel ashamed or that people will think you are strange. This is an emergency and you need to make sure that someone you trust is aware of your feelings. Call your clinic or medical doctor right away. They can put you in touch with a social worker or psychologist that can evaluate you immediately and attempt to help you in any way possible. You can talk to someone that you trust, such as a friend, a teacher or school counsellor, or a parent or relative. Remember that you are not alone and that there are people who can help. Suicidal thoughts can be treated. Don't give up on yourself or your life. If a friend tells you that he/she is thinking about suicide, it is very important to confide in an adult or someone that can help you immediately. Never assume that your friend is not being serious.

71. How can I cope with missing my parents or siblings who have died from AIDS?

When a parent or sibling dies, it changes your life forever. It is important to express your feelings about death and try to keep memories of your loved ones alive. You can perform rituals to remember your loved ones in a way that makes you feel close to them. You can write letters, telling your loved ones things that you wanted them to know before they died or things that you want them to know about your life and what you are doing. You can talk about your memories and experiences with your loved ones. You can make a book of photographs of your memories with them. It is important that you realize that you are still alive and you have to go on with your life. This may take time to understand. Realize that these people will always be with you through your memories of them.

72. How can I cope with missing friends who have died from AIDS?

It is important to decide how you will remember your friends, whether by writing something about them, thinking of special memories, or collecting photographs. Sometimes it helps to send a card to the family of your friend describing memories of the times you spent together or just your thoughts about your friend. This will be good for both you and your friend's family. Try to think of how your friend influenced your life and the lives of other people and the things that made them happy. If you think about your friend's happiest times, it will help you to remember how their lives were.

73. How can I value myself and my life?

It is very important to set "long-term" goals for yourself, or goals that you wish to achieve in months or years. Think about things that you want for your education, social relationships, career, romance, or whatever is important to you. The next step is to figure out ways that you can meet these goals. You should also set "short-term goals for yourself", or goals that you can accomplish today, tomorrow, or next week which can be as simple as saying something nice to your siblings or as complicated as quitting the use of alcohol or drugs. Reward yourself when you achieve a goal, whether it's a long-term or short-term one, or if you do something or make a change that makes you feel proud. It is also important to live in the moment and to feel as much joy as possible in your life. This may help you realize that your life has incredible value and that you should enjoy it as much as possible.

74. How can I set goals for myself?

If you remember the acronym, "SMART", it will be easy for you to remember what your goals should reflect.

Specific: Make sure that goals are simple and focus on what you would like to happen in your life. An example might be that you would like to have a family by the time you are 30 years old.

Measurable: If you have an idea as to how and when you might be able to achieve your goals, it will allow you to figure out what steps you will need to take to accomplish them. For example, if your goal is to graduate from university, you will know you are making progress towards accomplishing your goal when you complete secondary school.

Attainable: Make sure that your goals are realistic. Do not set yourself up for disappointment by making your goals ones that are impractical.

Realistic: Make a plan as to how you are going to achieve your goals that is easy for you to follow. This will make it much more enjoyable for you to reach them.

Time-oriented: Set a target date/time for your goals to help you stay on track.

75. What do I do if my brothers and sisters are angry or jealous about the attention I receive?

Your siblings, whether they are infected with HIV or not, are going to be emotionally affected by the fact that you are HIV-positive. They may be worried about what will happen to you and what will happen to them in the future. Like you, your siblings need to feel a sense of hope and trust in the future. Talk to your brothers and sisters about HIV and about your life. If your siblings feel like they aren't getting enough attention, it might help to spend extra time with them and give them a chance to do things they are good at or like to do. Communicating with them as much as possible is the best way to help the relationship.

76. How can I stop my parents/caregivers from disrespecting my privacy?

You may feel that your parents or caregivers are overprotective and treat you differently. It is important for you to realize that they care about you and worry about your health and that is why they are very involved in your life. Instead of getting angry or frustrated with them when you feel they are

disrespecting your privacy, try to have a conversation with them. Explain that you understand that they are concerned about your health, but that you need some privacy, such as a journal or private conversations with friends. This may help them understand that you are mature enough to have some parts of your life to yourself.

77. What if my parents/caregivers do not want me to disclose my status to anyone?

Some families and caregivers make the decision to keep HIV a secret. You may not agree with this decision, but there are reasons why that decision is made. They might be worried about others treating you differently or rejecting you. They may be scared to lose the support of other family members or friends. They may worry about losing jobs or experiencing social rejection. However, it can be stressful and lonely to keep this secret, especially as you get older. The best thing you can do is to try to communicate with your family about what you want. If there is a certain person you want to tell, like a friend or teacher, explain to them that you believe this person will keep your secret and why you would feel better if they knew about your HIV status. If they still do not want you to reveal the secret, then it is still important to have open and honest discussions within the family. This can help you deal with keeping HIV a secret from other people, and ensure that you have someone to talk to about your feelings concerning your HIV status.

LET'S TALK ABOUT DISCLOSURE

78. Why should you disclose?

Disclosing your HIV status is not easy and can be frightening, but it can also be quite empowering. Before disclosing, it is important to consider carefully whom to disclose to, how and when to do this, and think about how the person you choose to disclose to may react. It is important that your disclosure is a positive experience; therefore it needs to be given a lot of thought.

There are several benefits to disclosing your HIV status:

- Those who love and care about you will be able to support you and it makes it easier for you to ask for help if you need it. Supportive loved ones will be able to encourage you through hard times and congratulate you when you overcome difficult periods.
- If you are keeping something secret it can be a burden on the mind and places additional strain on the body. This stress can be lowered as you share your HIV status with others.
- As you disclose your status to people you trust and who love you, you can all work together to help you live a long, healthy and fulfilling life.
- When you disclose your HIV-positive status within your community you are helping to reduce secrecy, stigma and discrimination surrounding HIV, and opening doors for greater community support for people living with HIV (PLHIV) and among PLHIV themselves.
- When you share your HIV status openly, other PLHIV in your community are more likely to follow suit and share their HIV status too.

79. Who should you disclose your status to?

You may decide to disclose your status to a variety of people and for a number of reasons. These could include:

- Family and friends: so you can receive support and assistance.
- Sexual partner: to enable you to discuss prevention strategies together and go for voluntary counselling and testing (VCT) together.
- Service providers: to access prevention, treatment, support, and care services, and timely information on HIV and prevention issues.
- PLHIV support groups: to share experiences, successes and challenges and provide support for one another.
- Employers and workmates: to access workplace support and medical benefits that may be available in the work place.

Remember that even if you and your partner are both HIV-positive, it is important to practice safer sex and to avoid re-infection with a different strain of HIV.

80. How do I tell a boyfriend or girlfriend that I am HIV-positive?

Telling someone you care about that you are infected with HIV is not easy. Still, it is important that someone you are involved with physically and romantically knows of your diagnosis. It's the right thing to do. You might be scared that he or she won't want to be with you anymore or will be angry that you have kept it a secret. It is hard to know how a person will react.

If you trust the person enough to be with him or her, then you have to trust the person with the truth. If the person reacts negatively, then at least you have protected your own health and theirs by being honest. Having to lie to someone you are close with can be depressing and exhausting. If the person does accept your diagnosis and wants to continue the relationship, you will probably feel relieved and closer to the person. Also, sharing the responsibility for protecting yourselves can make it a lot easier.

Working up the nerve to talk about your diagnosis can be the hardest part. If you think it will help you, you may ask a social worker or other health-care provider to be present during the discussion. Think about what you want to say and how you want to say it. Tell your partner that you need to talk to him or her about a subject that isn't easy for you. Explain how important it is for you to be honest with him or her. You may want to consider saying something like:

"This is very hard for me to do but before our relationship goes any further, there's something about me that I think you should know. I am HIV-positive and I am working hard to stay healthy. I am telling you because I want you to stay healthy too."

The person may react with a lot of questions about how you got the disease, medical information, and who else you may have told. You should answer these questions to the extent that you feel comfortable. You don't have to tell any more than you want to. A good idea would be to give information about how you can and cannot pass on the virus. Your partner may have very little information about what having HIV means. The person may need some time to think about it. Encourage your partner to try to find out information on his or her own. Be willing to give your partner space and be open to more communication. It is not good to say,

"I have HIV. Now you know, and I don't want to talk about it anymore."

But always remember that your relationship does not have to be completely serious and only focused on HIV. HIV is important, but it is not the only thing about you. You still have interests and ideas. Remind the person that you are still the same person you were before you told him or her about your diagnosis. Let the person into your life as much as both of you feel comfortable with. Talk about your feelings and how difficult it was for you to share this information. Let the person try to understand what you are going through. You may also want to ask the person not to tell anyone else about your diagnosis. Remind the person that you trusted him or her with this information.

If your partner is at risk for having HIV, you should encourage him or her to get tested. If you begin or continue to have sex with your partner, protection needs to be discussed completely. It may feel strange to plan out having sex and it may be embarrassing to discuss using condoms, but remember that you are protecting your health and your partner's. You may fear that your partner will react violently to your telling him or her about your HIV status. If he or she has been violent in the past, you should have someone else present who can protect you or at least tell the person in a public place. Telling the person over the phone may be another option. You should also take steps to get out of a violent relationship and these are discussed later in this book. If you choose to tell the person alone and the person reacts violently, get away as quickly as possible and call for help.

81. When should I disclose?

It is easier to disclose and share your HIV-positive status with others when you yourself have accepted your status and overcome any negative emotions such as fear, guilt, anger, or denial – which many people may feel when they first find out that they are HIV-positive.

The difficulties you face in accepting your status may result in self-stigma, whereby you stigmatize your own infection because of negative perceptions you have about HIV. Self-stigma prevents PLHIV from seeking the treatment, care, and support they need and can lead to unnecessary illness and, at times, early death.

To be able to practice positive living and positive prevention, you must first accept your status, and know that HIV is a manageable disease. With this acceptance, you are on the way to a healthier and longer life, and it will be harder for others to stigmatize you.

Try the following steps to help you get to this positive state of hope and acceptance:

- Get as much accurate information about HIV as you can.
- Look for a health-care provider that you like and trust and go for regular check-ups.
- If you have not needed to start taking ARVs yet, prepare yourself mentally for when that time occurs.
- Join a PLHIV peer support group for teens living with HIV and share with and learn from your peers.
- Try to talk with a counsellor about any problems or anxieties you have, about your health, your future and the future of your loved ones.

82. How do I disclose my status?

Begin by learning all you can about HIV, positive living and related issues. Once empowered with the right knowledge, you are better able to manage any misconception, stigma and discrimination you may face during disclosure.

Discuss your disclosure plans with a counsellor or health-care provider, and as you make your choices, keep the following in mind:

- Think carefully before you disclose your status publicly as you cannot take the information back once it is out there.
- Once you are sure you are ready to disclose, think about who to disclose to because the first time you disclose to someone may be the most difficult. You need to be sure that the person you disclose to will be understanding and supportive.
- You may find it easier to ask someone to accompany you when you decide to disclose, so that they can provide support. This could be a counsellor, a member of your support group, a friend or family member.
- When going to disclose to a person of your choice, it may be useful to take HIV material with you. This will assist in explaining facts and answering any questions they might have.
- Disclosing your HIV status is your decision and you have the right to choose to whom, how, and when to disclose your status.

83. How can I find out about ways that I can help other HIV-positive teens with similar questions?

Some teens with HIV find that teaching and supporting others with HIV is very rewarding. You may think about becoming a "mentor" for other teens living with HIV who feel afraid and alone. Before you choose to get involved in this, you have to be sure that you are ready to let people, most of whom you will not know, know that you are living with HIV. Some teens enjoy the opportunity to help others and to teach them about how to live a healthy lifestyle. It may help them to feel that they are doing something positive with their disease. Ask your doctor or other health-care provider whether or not he or she is aware of any opportunities to get involved in teen leadership or mentoring youth with HIV.

LET'S TALK ABOUT TRANSITION OF CARE

84. What is transition of care?

Transition of care is the active process of preparing for and making the move from paediatric, or child-based, care to adult-based care. In some settings this will require changing health providers and health facilities, in other settings you will remain with the same provider in the same facility. Regardless of the setting, successful transition of care requires that your various needs are met appropriately, be they medical (health-related), academic (school-related), or vocational (job-related). A smooth health care transition can also make other transitions to adulthood, such as those related to work, school, and family, easier to handle. Though not all young people will have access to specialized paediatric or adolescent care, many of the principles in this section will still help you make the transition towards self-management of your HIV, and allow you to go from taking antiretroviral therapy as a child to taking it as an adult.

85. Why do I need to transition to adult-based care?

As a child, your medical needs are usually best met by a paediatrician (children's doctor) or a paediatric clinic where the providers are used to being very responsible for the care of their patients. As you get older, however, your medical needs change and usually require attention by an internist or other adult-care doctor, who will expect you to be more responsible for your own care. This means that you will need to be able to independently ask questions about your health and advocate for your needs, while following the advice of your doctor or other health-care provider. Many people eventually leave their paediatrician or paediatric clinic to find an adult doctor. When this happens, the patient has been "transferred" (switched from one doctor to another) and transition has occurred.

86. What if I don't want to transition?

It is normal to feel anxious or worried about transitions in life, whether it's the transition from adolescence to adulthood, from secondary school to university, from living at home to living on one's own, or from paediatric (child) medical care to adult medical care. You, like many other young people, may have seen a certain doctor or group of health care providers during your childhood and adolescence, and you may be hesitant or experience emotions of sadness, anger, or confusion about leaving the people who have cared for you in your early years. You may also have concerns about what awaits you on the other side of transition. It is important that you share your thoughts and feelings about transition with your health care providers so that they can help you work through any anxieties or worries you might have. The earlier you start to have these conversations with your providers and other people who support you, the better prepared you will be when the time comes for transition, whether it's a physical transition from one clinic to another, a health care transition from one provider to another, or a mental and developmental transition from childhood to adulthood or dependence (e.g. relying on others for your care) to independence (e.g. managing your own care). You should work closely with your providers to develop an individualized timeline and plan for transition that will prepare you for the challenges and opportunities that lie ahead. You may also find it helpful to speak to other young adults who have already transitioned and get their advice on how to best prepare for and manage your own transition.

87. When will I need to transition to an adult doctor?

Most people, including adolescents living with HIV, will leave their paediatrician or paediatric clinic somewhere between their teens to mid-twenties. The exact age at which someone transfers from paediatric to adult-based care depends on a number of factors, including their readiness (how ready they are to make the move, medically or emotionally), their level of maturity, their medical needs (those with special or complicated medical needs may need to transfer later), their life situation (whether they are in the process of moving from home for school or work), their insurance situation (some private or public insurance plans have age cut-offs for paediatric care, etc.), and other reasons. Over time, you will need to learn to take the lead in meeting your various needs, medical and otherwise. As an adult patient, you will be expected to take responsibility and ownership for your health and wellbeing.

88. What knowledge or skills will I need in order to have a successful transition?

There are many things you can learn and skills you can develop to prepare yourself for transition. You should first meet with your doctor to discuss the skills you will need and make a plan for how and when you will develop them. This list of knowledge and skills "milestones" and the timeline for when you will accomplish them will become your personalized transition plan. You should start working on this plan as soon as possible, beginning as young as age ten, when you can start planning future goals with your

doctor, or at least three years before your transition is planned. But starting your plan late is better than nothing! Below are some general knowledge and skills questions that you should address in your plan:

- Do you understand your HIV/AIDS diagnosis?
- Do you understand other health conditions that you have?
- Do you know what to do to keep healthy?
- Do you know what to do to keep safe (i.e. avoid unsafe behaviours, activities and situations)?
- Do you know how to communicate well with your doctor and other health-care providers?
- Are you comfortable asking your doctor and other health-care providers questions about your health?
- Do you know how to use community services?
- Do you practice responsible sexual behaviour (i.e. prevent the spread of HIV and keep yourself safe from getting other diseases or strains of HIV)?
- Do you seek information and counselling when needed?
- Do you keep track of your health records?
- Do you understand your health insurance status and related issues?
- Do you remember to take your medications on your own?
- Do you make and attend health appointments on your own?
- Do you know how to arrange your own transportation and use it safely?

89. How can I be a better advocate for my own health needs?

The first thing you can do to better advocate for your own health needs is to learn about your HIV/AIDS diagnosis and other health conditions. You should understand any changes or symptoms caused by your medical condition(s) and any side effects caused by your ARVs or other medications. As you get older, you should take more and more responsibility for taking your own meds without having to be reminded by someone else when and how to take them. You should also understand any tests you need to take (blood, x-ray, etc.) and what the results mean – your doctor can help you to learn more about your tests. Being your own health care advocate also means knowing the warning signs for when you need emergency help and who to call in case of an emergency. You should carry your emergency contact info with you, along with your insurance card (if you have one) and any other important health care information. You should learn how to make your own doctors' appointments and write down any questions you have for the doctor prior to your visit. During your doctor's visit, you should speak up and ask any questions that you might have. If you don't understand the answer, you should ask again. You should also talk to your doctor and other health-care providers about difficult or sensitive topics like relationships, drugs, and family planning. Be sure to ask for copies of medical tests and reports and ask for clarification if you don't understand something.

90. How can I take charge of my health care information?

To take charge of your health care information, you should first understand the medications you are taking, including their names and when you need to take them, as well as any medications you used to take and why your doctor changed them (e.g. side effects, resistance, etc.). You should also know how to call your pharmacy and how to refill your meds. If you have health insurance, you should understand how it works and which expenses you are responsible for (and have a plan for paying any of these expenses). Be sure to keep a list of addresses and contact information for all of your health-care providers as well as other community resources. You should also keep a notebook or journal of your

medications, medical history, and medical test results. You can also ask your doctor or other health-care provider to give you a short written summary of your health condition – sometimes this is called a "portable medical summary" because you can carry it with you, especially if you need to switch doctors. You should also be able to give a brief history of your condition verbally – you can practice doing this in front of a mirror!

LET'S TALK ABOUT THE FUTURE

91. Will I ever be able to get a job or go on to university?

Absolutely! Follow your dreams. It is very important for you to set goals for yourself and do what you dream of doing with your life. If it is your personal goal to get a job or attend university, then there is no reason not to. As long as you are in a place where you can receive quality, ongoing medical care, there should be no problem. You should plan a meaningful future for yourself.

92. How should I face the day ahead?

- Laugh every day.
- Try and do one thing each day that you have not done before. If you can't, think of two things you can do the next day.
- Treat yourself to one nice thing every day. It can be calling a friend, reading a good book, eating your favourite food…anything that makes you feel good!
- Do something nice for someone else every day. Tell someone you love them, come home on time, or tell a friend something you like about them.
- Keep living and learning.

- Never lose hope.

Where can I go for more information?

For more information you can visit your local:

- Public hospital or clinic
- Social welfare office
- School clinic
- Youth-serving organization
- Voluntary counselling and testing centre
- PLHIV support group or other peer support group.

Here are some international organizations that you might find helpful:

Adolescent AIDS Program
Children's Hospital at Montefiore Medical Center
+1 718-882-0232
www.AdolescentAIDS.org

Advocates for Youth
+1 202-347-5700
www.advocatesforyouth.org and www.youthhiv.org

AIDS Alliance for Children, Youth and Families
+1 202-785-3564
www.aids-alliance.org

Baylor International Pediatric AIDS Inititaive (BIPAI)
+1 832-822-1038
www.bipai.org

Elizabeth Glaser Pediatric AIDS Foundation
+1 202-296-9185
www.pedaids.org

Global Network of People Living with HIV/AIDS
+31-20-423 4114
www.gnpplus.net

Global Youth Coalition on HIV/AIDS
+1 917-677-9827
gyca.tigweb.org

Other Helpful Websites:

www.thebody.com
www.k4health.org/toolkits/alhiv
www.aidstar-one.com

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