

## Stress or anxiety

Many people are shocked when they first hear about their HIV status. They might feel scared, lonely and stressed. This is a normal reaction, not an illness. It is not depression. Time, counselling and joining a support group will help you overcome these feelings. Here is a whole set of normal responses you might go through when facing your HIV status:



Shock Denial Anger Bargaining Loneliness Fear Feel watched Sad Acceptance Hope

## Depression

Depression is common in people living with HIV. However, it is often missed by the nurse or doctor. Tell your nurse or doctor if you think you have depression.

Depression usually develops over a few weeks. It is a general feeling of a depressed mood linked with physical symptoms. Depression is caused by an imbalance of certain chemicals in the brain. Depression often comes with chronic disease, loss of your job, problems with a relationship, loss of a family member and damage to your self-esteem. Many HIV patients go through all of these experiences. Some women also get depression after having a baby.

## Check list

If you suspect depression check for these symptoms:

- Do you feel down most of the time?
- Do you lack enjoyment with fun-things like music, soccer or chocolate?
- Do you try to find peace by overeating? Do you lack appetite and lose weight?
- Do you sleep badly at night? Do you struggle to get up in the mornings?
- Do you feel angry and agitated quickly? Do you feel very passive?
- Do you lack energy every day?
- Do you struggle to concentrate? Is it difficult to decide about simple matters?
- Do you feel guilty? Do you feel worthless sometimes?
- Do you think of death a lot? Do you think of killing yourself?

If your answer to many of these questions is yes, you have some degree of depression. Depression can be treated with Amitriptyline or Fluoxetine and psychological support.



## **Dementia**

With dementia your thinking gets affected so that you are later unable to communicate, you struggle to pay attention and you become forgetful. You also lose your function of movement. You become clumsy, lose your sense of balance or even become paralysed. Your personality can change in that you can become apathetic and zombie-like.

Dementia is a general slowing down of brain function caused by the HIV virus actually penetrating the brain.

## **Making the diagnosis**

Before a nurse/doctor can make a diagnosis of dementia, other brain illnesses like depression or meningitis must be excluded. For example, forgetfulness and reduced concentration are often caused by depression. Depressed mood, however is uncommon in dementia patients. Patients are usually unaware of their deteriorating state.

## **Staging of HIV**

HIV dementia is classified as stage four, thus often called AIDS dementia.

## **Treatment**

AIDS dementia is treated with AZT, best given with full antiretroviral regimen.



## You cannot get infected with HIV by looking after a loved one



Many families are scared to look after their loved ones who are sick. They do not know what to do and they fear getting infected with HIV. However, you cannot get HIV by sharing a household and looking after a family member with HIV. Some people think cuts on the skin of the sick person might transmit the virus. However, healthy skin is very good protection against transmission of HIV. Doctors and nurses who touch many people with HIV and open sores do not get infected. If you have hospital gloves, use them. If you don't, wash your hands after handling

your loved one. Linen full of blood, or panties full of menstruation can be washed after soaking them in a bucket of cold water with a teaspoon of jik. If you have no jik you can also use vinegar or lemon juice.

## Treat your loved one the way you would like to be treated

Very sick people need to feel cared for. Talk to them openly. Do not hide bad news from them. Spend a lot of time with them. If you do not know what to talk about, read a story, listen to a radio program or sing a song. Even if the sick one does not speak, s/he can still hear your voice. Let the person know you are there for them. Family members should take turns to care for the sick person. Make sure the sick one does not have pain. Get treatments for pain or sleeping problems or other medical problems from the clinic regularly.



## Bedsore

Bedsore are open sores of the skin that appear on people who are so ill they cannot roll over in bed. This happens more to very thin and weak patients. The sores are formed where the bed presses against the bony parts of the body, most often on the buttocks, the back and the feet.



## Bedsores can be prevented

- A chronically sick person should get out of bed and sit in a soft chair as much as possible.
- Sick people should not lie in the same position for too long. Turn the sick person every two hours. They can lie on their back, on their right side, on their left side or on their tummy. A family member should turn the ill person during the night.
- Bath the ill person every day. Rub the skin gently with baby oil.
- Use soft bed sheets on a mattress. Straighten the sheet often. Wrinkled sheets can injure the skin. Wash the sheet daily or if it gets dirty with urine, toilet, vomit or food.
- Get some linen-savers from the clinic. A linen-saver is like a nappy that you can put under the sick person.
- Put cushions under the person so that the bony parts rub less.
- Feed the sick person as well as possible. Many small meals are necessary.
- Vitamin tablets and food supplements help.
- Take the person to a clinic as soon as you get worried about the person's condition. Should you have no transport for the sick person, still speak to the nurse – perhaps she can advise you.



## Bedsores are difficult to treat, but here are a few tips

Dissolve a spoon of salt in a bucket of clean water and wash the sores. The clinic should give you sterile bandages to put over the bedsore.

Get help from the clinic again if the bedsore has pus (yellow or greenish fluid), is smelly or if the skin around the bedsore is red and painful. Some antibiotic tablets and pain tablets will probably be necessary.



## Pain can be treated

Pain can be treated. You should not feel any pain. Doctors do not always understand your pain. If you have a painful eye, they might only give you a cream to heal the eye. They sometimes forget to give you treatments for pain while the eye heals. Many people have pain with TB. If the nurses give you TB medicines only you must ask for pain tablets as well.



Sometimes you will only get pain tablets for three days from the clinic. Yet you know your pain lasts for the full month. Tell the doctor or nurse about this problem. They are used to treat pain in patients with cancer. They freely prescribe expensive medicines for months. Remind them of this when your pain is not successfully treated.

## Treat the cause of the pain

A doctor or nurse should examine you and find the cause of the pain. Different causes of pain need special treatments. Peripheral neuropathy needs Amitriptyline. Shingles needs Acyclovir. Cryptococcal meningitis needs Fluconazole. Abdominal cramps need Hyoscine Butylbromide. Heartburn (sometimes called ulcers) needs antacids.

## Get emotional support

Sometimes you fear HIV, because it is a dangerous illness. Your fear makes the pain worse. If the nurse or doctor can tell you your neck pain is caused by stress, this often already helps. Perhaps a session with the counsellor will help more than stronger pain tablets.



Pain is often worse at night. Bad sleep can make pain worse. These two problems have to be solved together. Some Amitriptyline tablets may help you sleep better.



Loneliness can also make pain worse. Share your feelings with your family. Tell the people who care about you about the HIV. Tell them about your pain. Ask them to sit with you for some time. Perhaps they can massage your body softly. If there is no one there, listen to some music. Join a support group.

### **How pain should be treated – control the pain?**

If you have a long lasting pain, take pain tablets regularly. Do not wait for the pain before taking the medicines. Take the medicines regularly. Take them three or four or five times per day as prescribed. It often helps to take a double dose at night to keep you without pain during the night. If you wake up with pain take the medicines again.

If you need more medicines than prescribed go back to the nurse or doctor. You might have to take a stronger medicine or you might need to take two different medicines for pain at the same time.

### **Here is a list of pain medicines listed from good to strongest**

- Paracetamol (Panado, Dolorol, Painamol, Painstop) is good and safe. Do not take more than 10 tablets per day.
- Aspirin (Disprin) is also good. Watch out for side effects like ulcers, asthma or kidney problems.
- Indomethacin (Indocid, Arthrexin), Diclofenac (Voltaren, Panamor) or Ibuprofen (Brufen, Inza) are all good for muscle and joint pain. They should be taken with food. They can cause ulcers.
- Paracetamol & Codeine are stronger than Paracetamol alone. This combination helps against cough and diarrhoea.
- Dextropropoxyphene (Doloxene) is a strong pain medicine. It is not generally available at clinics.
- Codeine Phosphate is very strong. Only doctors can prescribe this. It can cause drowsiness or constipation.
- Tilidine (Valoron) is the strongest pain medicine for children.
- Morphine is the strongest pain medicine. It can be taken five times a day. It should be taken with a laxative to prevent constipation.



## Traditional medicines and clinic medicines

People living with HIV go through a daily routine of taking medicines. On the one hand there are traditional medicines – customs like slaughtering a goat, or “mutis” from an African traditional healer. “Immune boosters” like Moducare, Hypo-Plus, Spirulina, Sutherlandia and others have not been tested scientifically. Clinic medicines have all been tested scientifically for use against a specific illness. The Medicines Control Council (MCC) strictly controls their quality. Here are some guidelines that will help you understand how clinic medicines work.

## Medicines can help, but they can be dangerous



REMEMBER: MEDICINES CAN KILL

Clinic medicines have been tested to be effective and safe. However, they can have side effects – they can make you feel unwell in some way. Let us take the injection for family planning. It is

effective for all women, because they do not get pregnant as long as they use it. Its side effects are that the injection is painful and that the menstruation might stay away while using the injection. Other medicines can cause side effects such as nausea or itching. Some medicines can have serious side effects and can even cause death if not attended to.

If you take too much of a medicine it can be dangerous. Some people swallow a handful of medicines when they are frustrated. This is called an overdose. Always get help from a clinic if this happens.

## Traditional medicines do have side effects

Some people think traditional medicines do not have side effects. However, natural traditional medicines have side effects too. Many people believe that laxatives or enemas that wash out the intestines help to clean the bad things out of the body. This is usually of no help and can even be harmful. People living with HIV often lose weight. If you often use laxatives this makes you lose even more useful nutrition from your intestines.

## How do medicines get tested?

Before a medicine can be registered with the MCC the pharmaceutical company must prove it is effective and safe. First a new product is tested in the laboratory. Then a few healthy volunteers take the medicine to see if it does not have unacceptable side effects. Then clinical trials are done.



Clinical trials are studies that test medicines in a large group of sick people. Half the people will get the new product and the other half will get medication that is already well known. After some time doctors can measure scientifically whether the patients who are using the new product are recovering faster from the illness than the patients who are not using it. Such trials can only be done after a patient has been fully informed and has given written consent to participate in the study.

## Dishonest advertising

We see many dieting products advertised on TV, where people claim to have lost a lot of weight. This might sound convincing, but it could be that the person also started doing exercises at the same time. Perhaps s/he lost weight because of the exercises and not the dieting product. Also, we are not told how many people used the dieting product without losing weight. Many traditional medicines, herbal remedies and immune boosters, get advertised in the same dishonest way.

## How do medicines work for a specific illness?

Medicines do not work in a magical way. They are chemicals that interact with chemicals of your body. Scientists analyse the chemicals active in your body. Some illnesses are caused by an imbalance of these chemicals. Some medicines correct these imbalances. Other illnesses caused by germs are called infections. Different medicines are produced to stop specific germs. One person might have diarrhoea caused by bacteria. Antibiotic medicine will help. Not all illnesses need medicines. For instance, most cases of diarrhoea stop on their own after a few days. Drinking a lot of water and eating lots of food is sometimes sufficient.



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## Some medicines cure, some prevent illnesses and some treat symptoms

Some medicines can cure illnesses. For instance, a full six months of TB treatment usually kills all TB germs in the body. Another example is antibiotics. They can cure bacterial infections like pneumonia. It is important to finish all the antibiotic tablets you receive from the clinic. As with TB, even if you feel better, the germs might not all be dead until you finish all the tablets.

