

Chapter Three

Living positively with AIDS

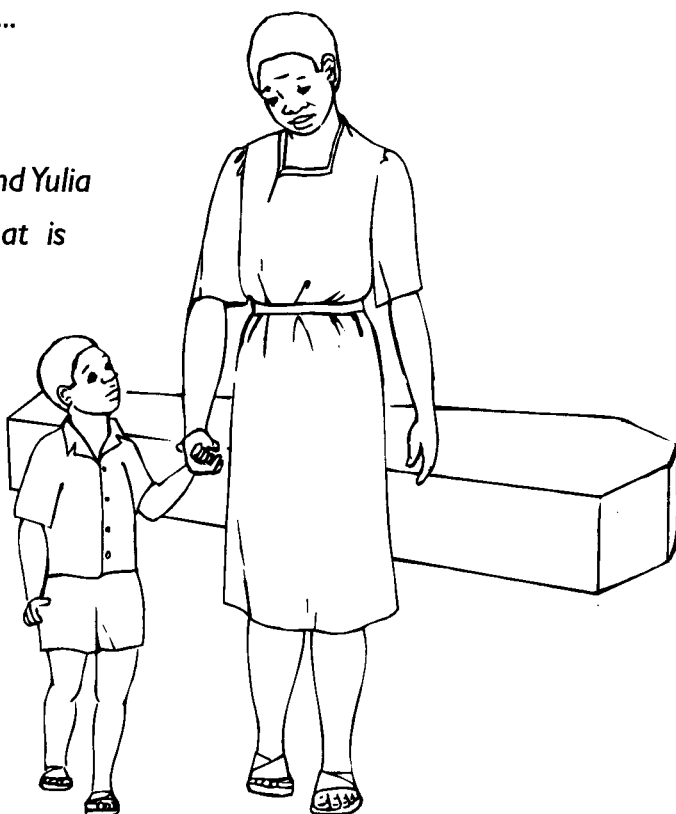
This chapter tells the second part of the story about AIDS, which is again followed by teaching notes providing detailed information. The story continues below from where it left off in Chapter Two and again is presented in a way that you can use directly when teaching.

Yulia and Yokaana

Now let us join Yulia and her family again, where we left off before. It is...

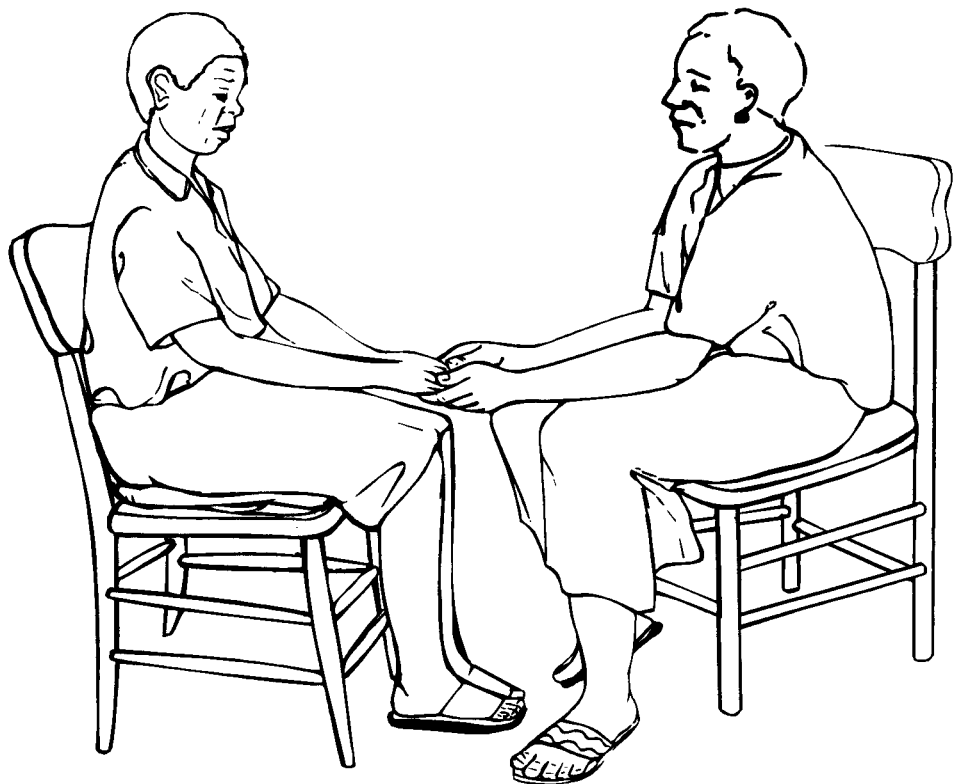
1991

Her husband has just died and Yulia decides she must know what is happening to her family.



Shortly after Mukasa's death Yulia goes to a clinic and asks for a blood test for HIV. The people in the clinic talk with her a long time about her life and what the test means. Her blood is taken and she is told to return to the clinic in two weeks.

Yulia returns to the clinic and meets a woman who tells her that the test is positive, that she is infected with the virus.



They talk for a long time. The woman is very kind and tells Yulia she must fight this virus and live as long as she can for Yokaana's sake. The woman says there are many things she can do, and that there are many people who will help her.

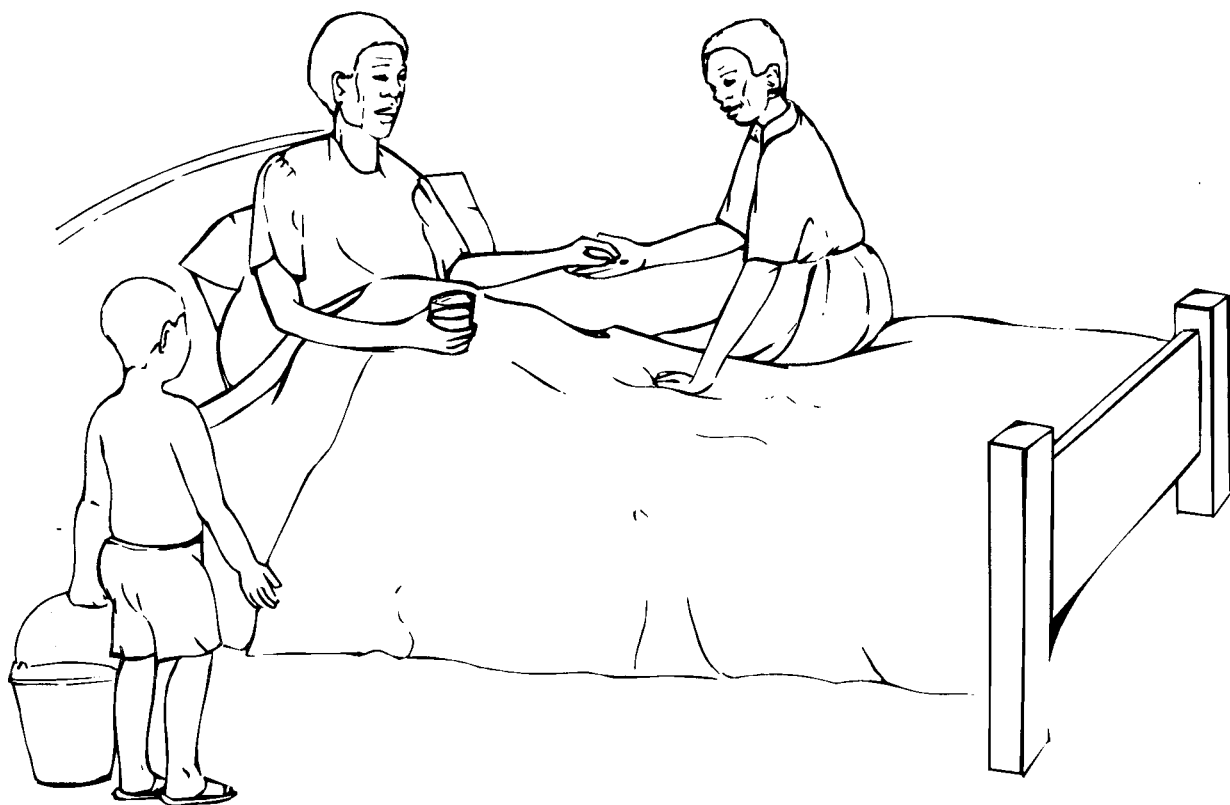
1992

Sometimes Yulia does not feel well and she goes to the clinic for treatment.

She has been able to keep working in the shop. Recently she took a training course offered by an AIDS organization from the capital city and now she has been trained to provide help to people who are sick – especially those with AIDS. She learned about coping with the problems of AIDS and how to help people with AIDS and their families manage.

NOW

This is Yulia, she still lives near here. Yulia visits people in their homes. She takes her son with her and he helps with simple chores for these other families. She talks in the community about AIDS and about health. She gives both her knowledge and her hope. She says she can live with AIDS and that when she dies the virus in her will die too.



Teaching notes about living positively with AIDS

Again, take your audience back through the story and look in detail at how Yulia coped after the death of Mukasa. As in Chapter Two, the information is presented below in a way you can use directly when teaching.

◆ **What has happened to the family?**

1. The reaction Yulia had to learning that her child had AIDS was normal. When somebody experiences a shock or a loss they have emotions or feelings called "loss reactions". These are feelings which come any time new and serious problems like HIV and AIDS are confronted. It is normal to have strong feelings about them. Most people are frightened of HIV and AIDS.
2. People who find out that they have HIV infection or AIDS, or learn that someone important to them has HIV or AIDS, may experience many different feelings, such as anger, fear and sadness. Sometimes people may **deny** having the disease at all. Remember Yulia's first visit to the doctor when she refused to believe that AIDS was the cause of her child's problems? This is denial. Feelings like these can cause family communication to break down. Whether because of denial or fear of his reaction, Yulia did not tell Mukasa what the doctor told her, and she did not go back to find out the result of her first blood test.
3. Yulia's denial was, unfortunately, very common. It was only after the death of Mukasa that something in Yulia would no longer allow her to push this information away or deny it, and this is when she began to take positive action.

◆ **What might cause Yulia's denial?**

Yulia was probably afraid that her family and friends would no longer love and accept her.

Other concerns that come with AIDS are about what will happen to the children in a family. There will also be worries about jobs, like "Will I be allowed to work?" or "Will I be able to work and support my family?" and also about housing.

Think about ways to increase support and acceptance in your own community.

◆ **How did Yulia feel when she understood that she had HIV infection and possibly AIDS?**

Think about how you would feel if you were infected.

Shown on the next pages are some of the feelings people might experience when they find out they have HIV or AIDS.

Responses to AIDS

Each of these feelings or reactions is part of a normal response to a situation of great stress. A person might move from one response to the next in a progression leading finally to acceptance of their situation, or more commonly **their feelings will keep changing**. One day they might feel rejected and lonely – the next day hopeful and energetic. One day depressed, another day angry. Let us look at each of these reactions separately and think about how these make someone feel, and how a person feeling like this might be helped.



SHOCK

No matter how much someone prepares, it is a shock to learn that one has HIV infection or AIDS. A person might feel confused and not know what to do. It is good for people to be with someone they trust at this time.



DENIAL

At first they might not be able to believe that they really have HIV or AIDS. They might think, just as Yulia did, "The doctor must be wrong" or "It can't be true – I feel so strong".

Not wanting to believe is a strong force that people may use subconsciously to protect themselves from the threat posed by AIDS. If you are trying to help such people, don't be angry or impatient with them if it seems that they are not facing facts. Try to remember that as a health care worker you can help them to understand what having HIV or AIDS means and that this is the best way to help overcome denial.



ANGER

People might become very angry when they learn that they have HIV or AIDS. This is a common feeling and can come when they blame themselves or the person they think gave them HIV. Some may even blame God.

Anger is normal but it may not be helpful since it can focus on blaming others (being angry with them) or themselves (feeling guilty), rather than taking positive actions. Talking to someone can help a person overcome feelings of anger and help them accept their situation.

If you are trying to help someone with HIV or AIDS, anger is a difficult reaction to cope with, especially when it is directed at you. It is important for you to try to understand and not take the anger personally. It is difficult, of course, to receive anger without responding.



BARGAINING

A person with AIDS might try to bargain, thinking, "God will cure me if I stop having sex" or "The ancestors will make me better if I slaughter a goat" or "I will be good and it (AIDS) will go away". People with HIV or AIDS need to be helped to get through the feeling of bargaining.



FEAR

People with HIV or AIDS fear many things, for example:

- pain
- losing their job
- other people knowing that they are infected
- rejection
- leaving their children
- death.

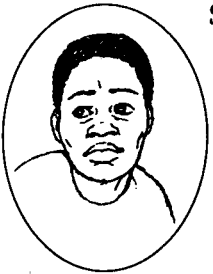
These fears become less when they talk to someone who understands. Someone with AIDS might also find that they are worried about things that they do not need to fear. For example, they may find that when other people learn they have HIV, they show great love and kindness rather than the feared rejection.



LONELINESS

A person with AIDS might often feel lonely. This feeling may come and go for a long time and depends on the support given by family and friends. Anyone who has AIDS must be helped to remember that they are not alone; that they are surrounded by family, friends and a community that cares about them. Many other people have HIV or AIDS.

Help families and communities to understand that people with HIV and AIDS need companionship. Infected people can often find others with HIV and AIDS and provide companionship and support for one another.



SELF-CONSCIOUSNESS

When a person has HIV or AIDS they might think everyone is looking at them or talking about them. This may make them want to hide. Sometimes a person with AIDS may feel unworthy of friendship.

You can help them not to hide or feel discouraged by encouraging them to stay active in the community. This can increase the acceptance of people with HIV/AIDS by showing the world that people with HIV and AIDS are valuable members of society, just like everyone else.

Help them to think well of themselves and to be proud. They are still important.



DEPRESSION

If a person finds out that they have HIV or AIDS they may feel there is no good reason for living. They may feel useless, and want to stay at home, not eat, and not talk to anyone.

Depression can make someone weak both in mind and body. It is important to try and help them overcome this depression and not give up. Encourage them to put on nice clothes, visit friends, keep busy with things that matter, do something that helps others, and to think about their children and friends who still need them.



ACCEPTANCE

After some time, a person with HIV or AIDS will usually begin to accept their situation. This will help the person to feel better. Such a person will feel more peaceful in their mind, and will begin to think about the best ways to live.

They might think:

- “What can I do to make the best of the rest of my life?”
- “What foods should I eat to help me stay healthy?”
- “What plans should I make so that my children are provided for in the future?”
- “Let me be grateful for every single day. Let me appreciate my family and friends and show them how much I care for them.”

HOPE



You can help someone with HIV or AIDS have hope about many things. For example:

- hope that they will live a long time
- hope that their baby will be healthy
- hope that each sickness will be treated as it comes
- hope because they are loved and accepted for who they are
- hope that scientists will find a cure
- hope because of belief in a life after death.

It is important to have hope. Hope lifts spirits and gives strength to face each situation. Hope can help each person to fight HIV and AIDS – to live positively and to live longer.

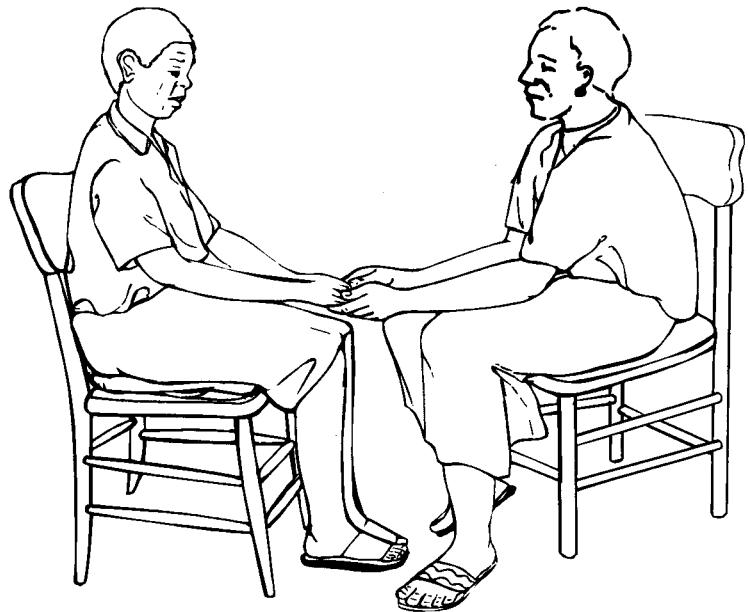
Remember, even if a person has hope today, it is possible to feel angry or depressed tomorrow. This is normal. Even people without HIV or AIDS go up and down emotionally every day. The important thing is to try to instill the feelings of hope again and again.

People who have AIDS, or people who are in contact with someone with AIDS, are often afraid that the negative feelings described above will become too strong. **These feelings cannot, and should not, be avoided. They are normal reactions to a crisis.** Family, friends, neighbours, health care workers – anyone who cares – can help another person cope with these feelings by listening, and talking to the person about their feelings.

What is counselling?

Counsellors are people who are trained to help others to understand their problems, identify and develop solutions, and make their own decisions about what to do. Counselling involves being with them, listening to them talk about their problems and fears, helping them to increase their own self-esteem, and when necessary giving **correct** and **useful** information based on what they need to know at that point in time.

When Yulia went back to the clinic she was counselled.



Many of the skills needed for counselling are similar to those needed for teaching (see Chapter One), because they are skills of **effective communication**.

In the last section you saw the reactions people might have on learning they have HIV / AIDS. Go back and look at all the faces showing those reactions. No matter how much you care for people you cannot change their feelings. Only they can do that. But by offering your time and just listening, you are telling them that you care and that their feelings are normal and accepted. By allowing them to talk about their feelings, you give them the opportunity to understand and overcome their negative feelings. This helps them begin to make choices and act on decisions. A feeling of empowerment or hope, of having a choice and being able to act, is strong therapy for someone who is feeling helpless and unworthy.

Counselling is a skill that requires effective training to develop. There may be times, if you are working with people with AIDS and their families, when you believe more skilled counselling is needed to deal with serious psychological issues. At these times you may want to refer the sick person for help elsewhere, from people who are experienced in providing such support, perhaps in government or voluntary services or in religious or spiritual organizations.

However, there are skills used by counsellors which **all of us** can use to help each other during the times we are talking together. Many health care workers and people like Yulia are being trained to improve their communication skills, particularly in relation to AIDS. Those who are in contact with someone with AIDS, or with anyone who is experiencing emotional pain, can do a lot to help them and make them feel better by using simple counselling techniques.

- ◆ **Think of a time when you felt badly about something and how, after talking with someone else – a friend, a family member, a health care worker, a pastor – you felt better. What did that other person do that “helped” you?**

Often the answer is:

“Nothing, he just listened and sat with me while I told him everything”.

Or maybe:

“She was just kind and didn’t judge anything I said. She helped me to understand what was really bothering me and what I could do”.

These answers tell us what some of these **effective communication skills** are:

- listening actively
- trying to understand what the person is feeling
- asking good questions
- respecting people and their feelings, and not telling them to change
- being non-judgemental
- providing correct information.

All of these things tell a person, “You are not alone – I am with you”. This is so important to someone who is afraid of being rejected and who might feel like a failure.

The most common mistake you can make when trying to “help” people who are experiencing emotional pain is to try to change their feelings. You don’t want them to be hurt and perhaps the issues they are confronting scare you too.

To distance yourself from this pain you may:

- deny their emotions, for example by saying, "You shouldn't feel that way"
- give advice, such as "All you need to do is... and things will be better".

These types of messages are a "mistake" because they tell people:

- that they are not respected or capable – that they cannot manage their own problems
- that you are not interested
- that you are uncomfortable with the pain they are experiencing.

Because you want people to feel better or to be "cured" of the difficult feelings they are experiencing, you may try to convince them to feel differently. But by doing this you are telling them that what they are feeling is unacceptable and that they are failing you somehow unless they change. This only adds to their feelings of self-rejection and isolation.

Listening is one of the most important parts of good communication. This means you have to be silent sometimes. Let the conversation move at the other person's speed rather than at yours.

Asking good questions comes from good listening and is part of helping someone see another point of view. The questions you ask should always come from your listening. When you listen you are not just hearing words, you are hearing the feelings behind the words and the person's own view of their situation. The questions you ask can help both of you gain a better understanding of the situation.

Another important way you can help is by being able to give consistent and accurate information. The ability to say you do not know an answer but will try to find one is **always** better than making an answer up (see Chapter One). Telling the truth establishes the trust and the respect needed to build a helpful relationship.

The trust you earn means you must guard the privacy of the information shared. **Never** gossip or break this trust. Breaking trust tells a person:

- they are not worthy of respect
- it was a mistake to seek help or share their feelings.

Because of this, they may not seek the help they need in the future.

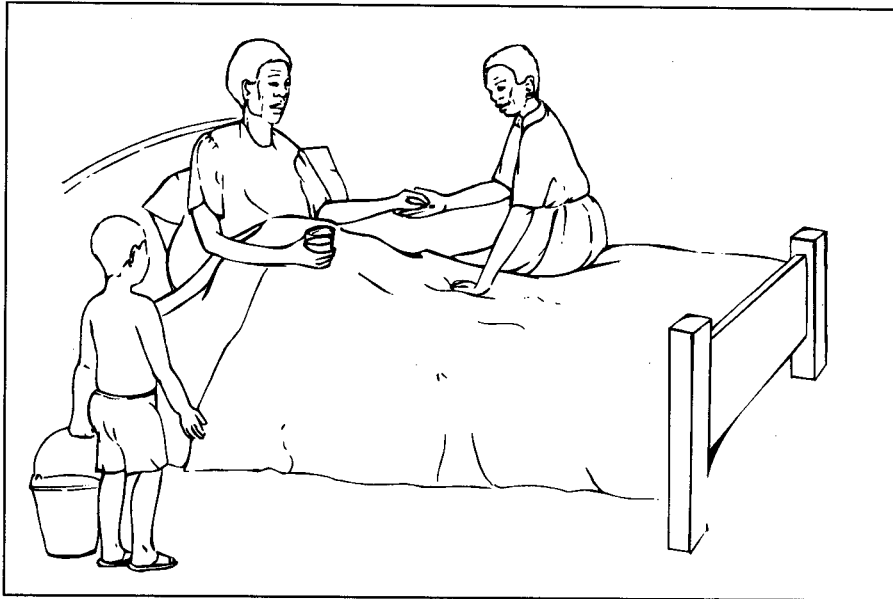
There are no easy answers to the difficult questions that are asked by those with AIDS. You cannot always have the "right" answer. Using truth and your ability to care are the only things you can be certain are "right". Your own discomfort and fears will be part of your attempts to help. Sometimes you will need to pay attention to these feelings and get help for yourself. Perhaps this comment from a woman who described the counselling she received says it all equally well:

"He looked me in the eye and said 'I don't know what I would do in your situation, except I would be scared'. I felt, suddenly, so much better. I was scared but I wasn't alone somehow."

When you are caring for someone you must watch your own reactions to the person you are trying to help. If you find yourself becoming **impatient** or **angry** these are signs that you are having trouble dealing with your own emotions and are less likely to be helpful to the person. You may be thinking, "He just doesn't seem to be able to face facts" or "She won't do anything to help herself". Your needs as a care-provider cannot be ignored but they should not be a burden to the person who is experiencing the grief of his or her own condition. You may need some special time to address your own concerns in private with counsellors, pastors or other health care workers. You may need help in understanding the sick person's needs and fears.

As AIDS worsens and a person becomes more and more ill, very often worries about physical health are outweighed by practical and emotional worries about money, housing, disability, change in lifestyle, family and other relationships, and the approach of death. You can help by offering practical help in planning for the future and by giving spiritual support, for example by helping someone strengthen or re-establish their religious affiliation (see Chapter Seven).

Yulia and her child going into the homes of other people with AIDS gave a very important message in the community.



Often the help needed in caring for someone with AIDS and for those who love them is very simple. Offering to help with chores, bringing favourite foods, watching over children and playing with them, telling stories, singing songs, sharing prayers – these are simple acts with strong messages of hope and belonging.

Everyone needs the love and help of those around them. Isolation from other people is frightening and it hurts very deeply when it seems the love of others has gone and you are rejected. A clear understanding between those with AIDS and everyone around them can do a great deal to help people face this disease compassionately and rationally.

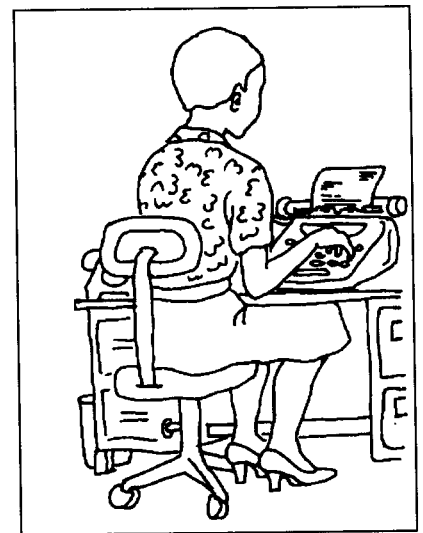


◆ **What did Yulia learn in her training to help her care for herself and for others with AIDS?**

First she was told that it is currently believed that all people with HIV infection will go on to develop AIDS. Modern medicine and traditional healers do not yet have a cure for AIDS. But many of the infections that come with AIDS can be treated and many symptoms can be dealt with using simple medicines and proper care. Most importantly, Yulia was taught about how to live positively with AIDS.

She learned that if you have HIV or AIDS, you should try to keep strong. This means you should:

- eat a good diet whenever possible, including food that is rich in proteins, vitamins and carbohydrates
- stay as active as possible; exercise helps prevent depression and anxiety
- rest when you are tired and get enough sleep
- continue to work, if possible
- stay occupied with meaningful or at least distracting activities
- give both physical and emotional affection
- meet as often as you can with your friends and family
- talk to someone about the diagnosis and the illness
- seek medical attention for health problems and follow the advice you are given – this includes taking steps to prevent other infections.



If you are caring for children or infants with HIV / AIDS you should make sure they receive immunizations for other diseases.

And you should avoid:

- other infections – including further exposures to HIV; each infection you get weakens the immune system further making you susceptible to subsequent infections, which makes your immune system weaker still, and so on

- using unprescribed medicines – certain medicines can have side-effects that may be particularly harmful if you have AIDS
- isolation – your friends can do a lot to help you keep active and feeling positive; do not shut them out of your life.



Yulia was taught about caring for people with AIDS at home.

She learned that there are two issues that are of great concern to people with AIDS and their families. The first is how to prevent HIV transmission from the person with AIDS to anyone else in the home or the community. The second is how to maintain a safe environment that does not expose the person with AIDS to unnecessary infections.

Preventing HIV transmission in the home

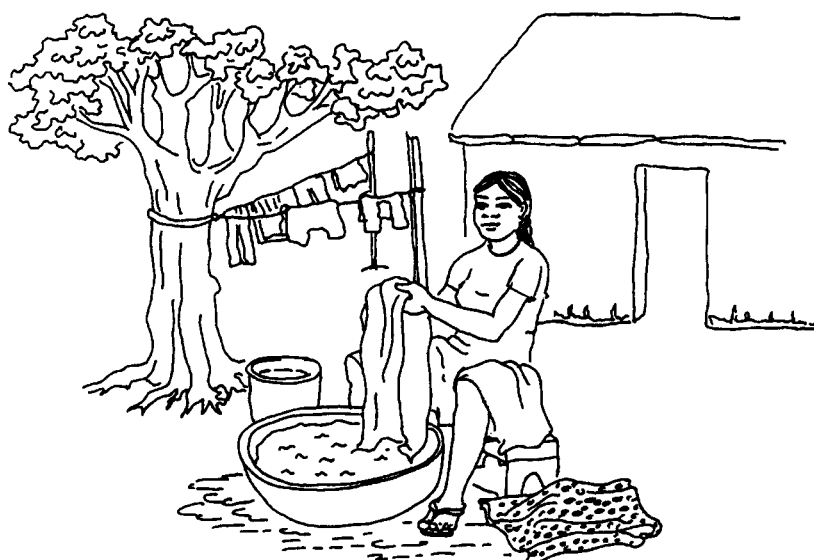
As you learned from the first part of the story, HIV can be transmitted from one person to another. However, unlike some other infectious organisms, HIV is not easily transmitted except by unprotected sexual intercourse or close blood-to-blood contact. The virus dies quickly outside the human body.

There is no risk of acquiring HIV from people infected with HIV (or people with AIDS) in the home care situation provided you follow certain simple rules.

Because AIDS is known to be fatal, people are concerned about whether it is safe to care for an infected person. Those providing home care should be taught to follow these rules:

- Wash your hands with soap and water after changing soiled bed sheets and clothing, and after having contact with body fluids.
- Keep wounds covered. Both caregivers and people with AIDS should cover any open wounds they may have on their hands or other places likely to have contact with other people, their bedding or clothing. Cover open wounds with a bandage or cloth. Use a piece of plastic or paper, gloves or a big leaf to handle soiled items.
- Keep bedding and clothing clean. This will help keep sick people comfortable and prevent skin problems. If you follow the first two rules the risk of transmission through contact with soiled clothing or linens is extremely low. To clean clothing or sheets stained with blood, diarrhoea or other body fluids:
 1. keep separate from other household laundry
 2. holding an unstained part, rinse off any blood or diarrhoea with water – be particularly careful if there are large amounts of blood, such as after childbirth
 3. wash in soapy water, hang to dry and fold or iron as you would normally.

Any action you want to take beyond this, such as the use of bleach or boiling water, will also be effective but is not necessary.



- Don't share sharp skin-piercing instruments. Don't share toothbrushes, razors, needles, or anything else that can cut or come into contact with blood. If it is necessary to share these types of objects, boil them in water prior to use.

It is important to emphasize that HIV is not spread during normal social contact. People should not worry about getting other sexually transmitted diseases (STDs), like syphilis or gonorrhoea, from this type of contact with people, and they should have no greater worry regarding HIV/AIDS. However, it is important to avoid other common infections that are spread by normal social contact, such as diarrhoea and respiratory infections.

Avoiding other infections

Yulia also told people other things that are simply good health practices.

Yulia learned that if you have AIDS you have a weak immune system and can get infections more easily. Each infection you get weakens your immune system further. But there is a lot you can do to ensure that you are protected from infections of all types. Good hygiene (cleanliness) in the home is an important part of protecting against diseases such as diarrhoea and respiratory infections. But many organisms that cause opportunistic infections already live in your body, and will cause disease if your immune system becomes too weak to stop them. Therefore, avoiding contact with healthy people is not necessary.

The following is what Yulia taught other people to do in their homes so that everyone in the family (including the person with AIDS) was safe from common infections.

The best way to prevent these common infections from spreading from person to person is to wash your hands frequently with soap and water and then dry them well.



Good Hygiene

Always wash your hands before:

- cooking
- eating
- feeding another person
- giving medicine.

Always wash your hands after:

- using a toilet or changing nappies.

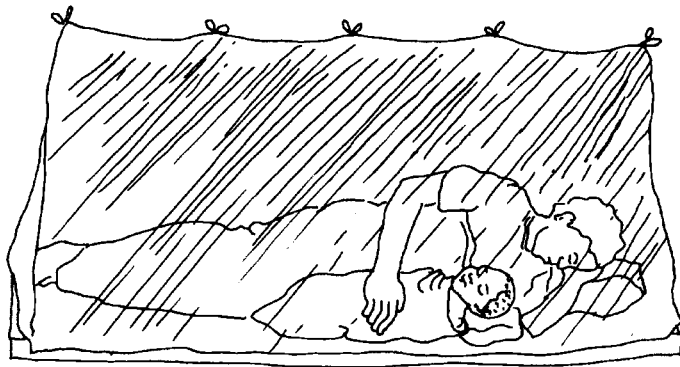
Other practices that ensure good hygiene:

- Use clean water whenever possible and boil drinking water, especially for young children.
- Wash bed linen, towels and clothes with soap and water.
- Store food properly to prevent it from spoiling and causing infection.
- When someone in the family is sick, wash drinking cups before you share them.
- Cover your mouth when sneezing or coughing.
- Avoid spitting or always spit into a container, not on the ground.
- Kiss babies on the top of their heads rather than on the lips.
- Wash eating utensils, including items for babies, with soap and water.
- Carefully wash all raw fruits and vegetables with clean water.
- Wash objects that a child or infant frequently puts in its mouth with soap and clean water.
- Dispose of waste properly.
- Put dirty things like nappies, used tissues, handkerchiefs, and other soiled objects out of the reach of children until they can be removed from the home. Put them in a container that is hard to open until you can clean or dispose of them properly.
- Proper waste disposal may include using a pit latrine, or burning or burying objects.

Avoiding malaria

In many parts of the world malaria is a very common illness caused by an infection passed by the bite of a mosquito. There are many things you can do to prevent this infection and therefore prevent the further weakening of the body, including the following:

- Use bed nets (mosquito nets preferably treated with insecticide) or a sheet to protect the family when they sleep – cover the baby's cradle or bed with a mosquito net or thin cloth.



- Use insecticide sprays and repellents to protect your home or body from any mosquitos in the area.
- Drain any standing water which may be a mosquito breeding ground in your community.

Special issues concerning children with AIDS

There is another issue that Yulia knew was a great worry to the people in her community – the children. The fact that a mother cannot know for sure, even with a test, whether her baby is infected with HIV is very distressing. Remember, both of Yulia's children would have tested positive at birth for HIV antibodies. Yulia knew many mothers whose feelings were mixed – if a child has HIV and might die soon then perhaps it is best not to get too attached, yet if the child is not infected it will need every help to grow and thrive.



There is no easy answer to this problem. Even if a child is infected there can be years of life and things that can be done to make those years as healthy and full as possible.

Mothers and fathers need information to help them understand the facts and then they need support to help them cope during this time of uncertainty by focusing on their child's life and health rather than on the fear of illness.

General rules on caring for a child with HIV infection or AIDS

Yulia learned the following rules.

1. Feed the child well



For a child less than four to six months old the best food is breast milk. Breast milk is important because it gives an infant protection against many types of infections. Also, since breast milk is clean, the infant is not at risk of getting diarrhoea as with milk of other types.

However, the fact that HIV can be passed through breast milk makes it more difficult to decide what is best for the child. In many areas of the world the risk of transmission of HIV by breast-feeding is low compared with the risk of the infant dying of other infectious diseases if not breast-fed.

As the health care worker, you will have to help the HIV-infected mother weigh the possible risks to the infant of breast-feeding versus not breast-feeding, taking into account such things as:

- whether many of the children in the area are at risk of, or die from, infections and poor nutrition

- whether there is a good alternative to breast-feeding available that is clean, safe, nutritious and affordable.

It is recommended that if the HIV-infected mother lives in a place where many children die at a young age from infectious diseases (like respiratory infections or diarrhoea), or if the child is likely to be malnourished, she should breast-feed her infant, even if she is infected with HIV or has AIDS.

However, if she has the possibility of giving a clean, safe and nutritious substitute for breast milk that is affordable for the entire period it is required, it would be a good choice. If she decides to feed her baby using breast-milk substitutes rather than breast milk, she must use clean water, which has been boiled and then cooled, and clean equipment (teats and bottles, cups and spoons). Remind her to follow the directions carefully and not to add more water in an effort to save money – this can lead to malnutrition in her child. If she cannot follow all of the above requirements all of the time, advise her to breast-feed her baby.

An infant who is breast-fed should receive only breast milk until it is four to six months old. Once a child is four to six months old it should be given some solid foods along with the breast milk. Healthy foods that are warm and either soft or mashed can be given with a spoon or your fingers. (Don't forget hands must be washed first!) Milk alone is not enough for a child after six months, but it is very important that breast-feeding or a nutritious substitute be continued along with other foods.

As the child grows give more and larger quantities of adult foods. The section on nutrition problems in Chapter Five gives information on healthy foods.

2. Have the child immunized

You may be asked whether an infant with HIV/AIDS should be given vaccines against the common childhood illnesses. All infants, **including those with HIV infection and AIDS**, should be given the standard vaccines against diphtheria, pertussis (whooping cough) and tetanus (DPT vaccine), and against poliomyelitis (polio) and measles. This should be done as early as possible in accordance with the immunization schedules of your



country. In many countries, the BCG vaccine is given to all infants at birth to prevent tuberculosis. The only exception is that if an infant has clinical symptoms of AIDS, such as failure to thrive and frequent infections, it **should not** receive BCG, but should receive **all** other vaccines mentioned above.

3. Make sure the child gets early treatment for infections

The advice given earlier in this chapter on avoiding common infections is important. As children become older they will need to learn these things for themselves, for example about washing their hands after going to the toilet or latrine, and about the importance of washing their hands before eating. Protecting children with AIDS from other infections is more difficult than protecting adults because children tend to put things in their mouths and they are exposed to more illnesses that are new to them.

It is much better for a family to go to the same health care setting where the child's health history is known rather than keep changing or "shopping around".

Note: Chapter Five of this handbook describes the common symptoms of AIDS and how to treat them. Many of the symptoms children show are the same as those experienced by adults and the advice for their care is also very similar in most cases. Where the treatment of children is different, this is explained.

4. Treat the child as normal

Many of the infants who are infected with HIV will have months or years of life without symptoms. Every effort should be made to help them lead as normal a life as possible. This includes letting them spend time playing with other children.

A child with HIV infection should go to school as usual, except when there is an outbreak of an infection in the school which could make the child ill.



Chapter Four

Care of the dying

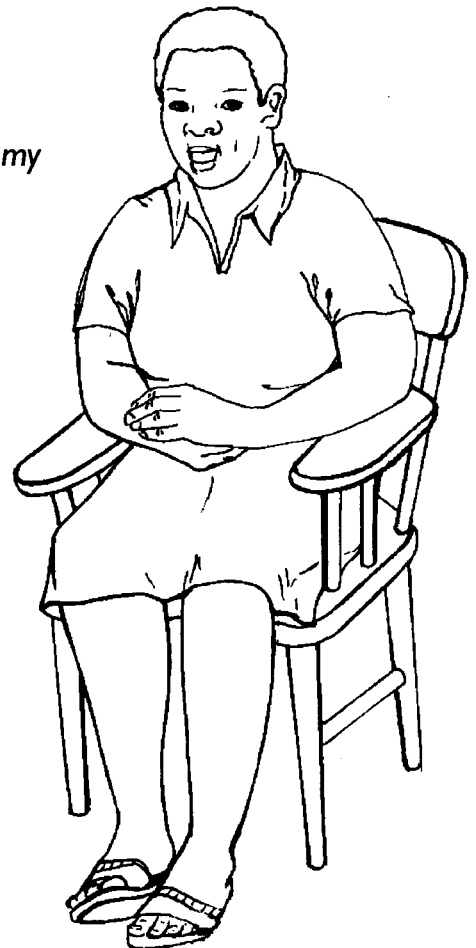
This chapter begins with the final part of the story about the family you first met in Chapter Two. Yulia is dead now and her sister Anna tells how she died and how her community reacted.

The rest of the chapter provides information you need to give to family members who are caring for someone who is dying from AIDS. The information is presented in a way that you can use when speaking directly to the family.

Yulia's legacy

Yulia died last night. I am Anna and she was my sister. I will miss her.

Our family and community have lost another. But we all must die in our time and it was her time. She went as one should, proud and in peace. She taught us in her death much about our lives. Let me tell you of her dying – it was good and perhaps we shall all live and die so well.





She was carrying this infection, who knows how long.

It seems to come from nowhere, or maybe everywhere. But it is in so many of us and takes us one by one until I think there are thousands who are gone.

She lost her husband three years back and a child before that. Then she faced it, told us it was called AIDS and learned that there was just a bit more time before she too would go. So, she began to fight, for herself and for her little one who was left – Yokaana is his name. She was so proud of him and so sure that it was up to us to teach and keep our little ones free of this illness until they could learn to keep themselves free.

Long before her death Yulia said it was important to plan to die. We began to sit together, many of us. At first it was just the women – women who were sick or widowed, had lost their children or were worried. In her work Yulia came across many women whose lives were so similar to hers – they too had lost their husbands but for them everything seemed lost. We began, slowly, to meet together and talk of these things.



We had seen people die alone, people die with all their wishes for those they loved ignored, people die rejected, people die without names or a family to remember them. We had seen families divide and become warring parties. It was too much sorrow for all the world to bear. "Not us, not me", we each said.

For most of us the only place we have learnt or thought of death has been in our religion. We don't talk of it anywhere else in our lives. Making money, raising children, carrying water, chopping wood, building the future are what we know best. How strange death seems when we look it in the face – how little related to our "lives" and how difficult to talk about. Yulia had great courage to speak of this.

Yulia said that each person needed to make a plan for "living and dying proud" as she called it, so that even when death seemed very far away we could be sure we would be ready when it was our time to die. We talked about what each of us wanted at the end that would make death not so bitter. We decided that if a person can do things to have a "good life" then they can also do things to have a "good death". These are the things we decided we must be sure of in order to meet and accept death:

- *that, if possible, we should know what it is that is killing us*
- *that there is nothing more that can be done by doctors and healers and that it is our time to die*
- *that those we care about will be taken care of and will try to accept our leaving them*
- *that we are not alone in our fear and are loved here and now*
- *that we accept what we have done to others and what others have done to us*
- *that our wishes will be respected, so that as far as possible we shall be given full choice over our lives and what will happen to us until the end*
- *that we should not be forgotten, or perhaps that our life has a meaning larger than we can know.*

We began by looking at each of these things and thinking about what it would take to make them possible. Some of these are things that can happen only if all of us encourage and help each other.

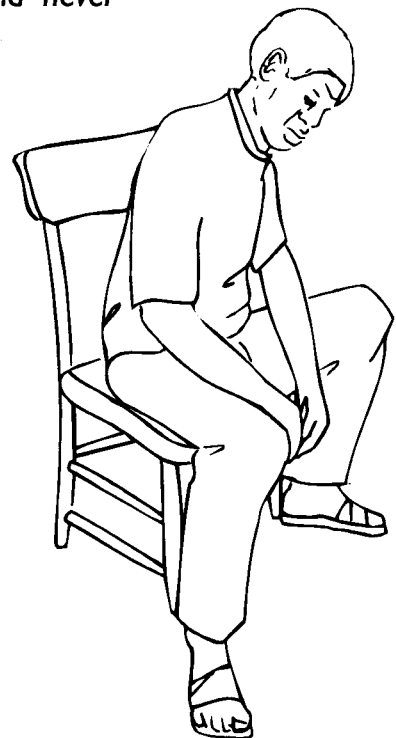
We began, together, to decide what things we could do and what help we needed from outside to strengthen our ability to face up to this disease and fight it. Our actions really began by asking some questions:

- *What do I need to do to keep myself and my family safe?*
- *What could we do to make our community stronger to face the challenge of this disease?*
- *What help can we get from outside our community (from the Government or other agencies) to protect and support our people?*

Within each of us the first thing we had to find was acceptance. It is in acceptance that caring can grow.

Yulia always said she was sorry that when her husband died they had not known that it was because of AIDS. She is sure that he would have accepted death more easily had he known that and had a chance to prepare.

He was caught by surprise in some ways and never understood what it was that got him. She was sorry because she knows she kept this knowledge from him by her denial, and she did not tell him what the doctor had said when she took the baby to the clinic. Maybe things would have been different if she had listened to the doctor then and told Mukasa. And, she knows he never meant to pass this illness to her. But, she said through not blaming anybody – not blaming herself for perhaps taking from Mukasa the chance to live longer and to die in knowledge, and not



blaming him for bringing this illness into their little family, because of which she lost her second child – comes acceptance.

From this acceptance, she said, her heart could look outwards to give more and to ask more of the community.

We talked together of our own sorrows and anger. Soon our little group of women was joined by some of the men and after a while we asked the village elder, the headman, to join us and hear our ideas.

We were not sure how to plan. Yulia said that the people who had given her training would be willing to come to us if we asked. In some communities there is help for people with AIDS; practical and spiritual help. Help with ways to make money, keep jobs, find food and medicines, make wills and ensure that last wishes are respected. Yulia told us of a community near the capital which was being helped in these ways.

So, Yulia and some of the men went and told these people about us and they agreed to come.

And it was then, together with these people, that we made a community plan.



Together some of us women started to collect money, small amounts left over from what we had, and to set it aside for our children. Over time and with the help of those people from the AIDS organization, we found ways to raise some money for those too sick to work or care for their families. The AIDS organization also gave us materials or loans to help. Some people raised chickens to sell the meat and eggs and others worked with their hands making pieces to sell on the road. The money we earn is first for the children, second to help with the costs of transporting people to health centres and back to the village, and last for funerals and burials.

The face of our community changed. It became a friendlier place in which to live and die. This Yulia offered to us all and to herself.

Last night was her time and she died as she lived – an example for us all. Let me tell you what she did in those last days.

Yokaana is seven years old now. Yulia had him tested at the clinic to show us and herself that caring for each other, staying together and being a family, carried no risk – Yokaana has no HIV. She turned the illness into the enemy, not those with the illness. Maybe now we know this enemy a little better and how to keep it away. She turned her anger at the illness into a force in all our lives.

But one day, it seemed, she knew that death was near and that it could no longer be kept away. She changed. She became quieter. I argued with her then saying “Fight, fight more, it doesn’t have to win now”. But she said “Yes, sister, the time is short. Just as we have a time to fight and to live, so we have a time to die and mine is near – be with me”. Over these two weeks we came to be with her as she had done for so many others.

She made it clear how Yokaana was to be brought from a child to a man and with whom he would live. The money and possessions that they had were taken into account and agreements were made on how they should



be passed to others, and within her family. We did this as a community to be sure that all would honour her wishes and protect her son. She had seen too many others lose even this last peace.

She asked to be part of our lives even to the end. We put her bed outside with us. My sisters and I took turns cooking, telling stories, remembering the past, praying and doing what needs to be done.

She had pain – it made her feel better to have her skin rubbed with Vaseline. She said it eased the aching. And the doctor had given some medicine for her pain which she would ask for sometimes, but she would also say, “Sister, tell me a story or sing me a song”.



She would move about a bit with our help, sometimes to a bench in the shade and sometimes to lie in the breeze near the door. She kept saying how beautiful it was – this life, this earth. It was something that shone from her – what can I call it? Yokaana would tell her of his day and they would talk together quietly sometimes. It is hard for a boy so young who loved his mother.

I did what she had done for so many others – reminded people of the good things they had done and helped them forget their sorrow or pain. I'd ask her, "What did you do here on this earth that made one person smile and feel better? Tell me a story of one of those times".

In these last years her trust in God was more and more a part of her life, and in these last weeks she seemed to belong as much with God as with us. It was a great comfort to her when friends visited to share the spirit with her.

I have lost much but I know she died in grace knowing she was loved. I hope to die so well.



Teaching notes on care of the dying

At some point in the disease process of AIDS, there is nothing more that can be done to treat the opportunistic infections, or the symptoms that they cause. The infections or illnesses have progressed beyond what medicines can cure. At this point, the goal of **all** care (medical, nursing, pastoral and psychological) is to keep the person as comfortable as possible and to maintain their dignity. In some places this is called palliative care.

◆ When does this begin?

It is often difficult to decide when the focus on medical treatment should stop and care for the dying should begin. The change in care may begin, for example:

- when medical treatment is not available or is no longer effective
- when the person says he or she is ready to die and really does appear to be very sick – this is clearly different from someone who is depressed for a time and who must be encouraged not to give up
- when the body's vital organs begin to fail.

◆ Where can you provide care for someone who is dying?

Care for the dying can be provided in a hospital or in the home. Most people prefer, or are forced by circumstances, to remain at home. However, some people may not want to actually die in the home. They may want to stay at home until the last moment but either because of their own or the family's wishes they may want to go to the hospital to die. If this is the case, a plan for transporting them will need to be thought out.

◆ What are the goals of caring for someone who is dying?

- keeping them comfortable and protecting them from problems that can make them feel worse
- helping them to be as independent as possible
- assisting them in grieving for, and coping with, the continuing losses they experience
- helping them and their families prepare for death – this may include making a will, tending to relationships in the family or the community, and arranging for the transfer of responsibilities

- keeping them within the community and family groups for as long as possible – family members can bring them into this part of their lives even when it seems they are too ill to enjoy or understand what is going on.

◆ **What can you do to meet these goals?**

Give comfort

- If the person is in constant pain, make sure that the pain medication is available in regular doses. It should not be taken just when the pain is really bad.
- Use relaxation techniques such as encouraging deep breathing, or giving back rubs or body massages.
- Continue basic physical care to keep the person clean and dry and to prevent skin problems, and stiffness or locking of joints.
- Encourage communication within the family and community. People with AIDS and those they love need to feel that they are not outside the love and life of their community. Help them use this time as a chance to heal old wounds and to make peace with each other. This will help to increase the comfort and acceptance of the whole family.
- Provide physical contact by touching, holding hands and hugging.
- Provide or arrange for counselling if desired, for example from religious representatives. They can be very helpful for spiritual counselling.

Allow the sick person independence

- Accept the person's own decisions such as a refusal to eat or get up, or even a demand to get up when you think that resting would be better for them.
- Respect requests, for example regarding visitors.
- Ask them what they are feeling. Listen and allow the person to talk about how they feel.
- Accept the person's feelings of anger, fear, grief and other emotions.

Prepare for death

- Talk about death if the person wishes to. Many people feel that it is not good to talk about the fact that someone is going to die, as if mentioning death is a wish for death. But by discussing death openly, those around are helping the dying person to feel that their concerns are heard, that their wishes will be followed and that they are not alone. **To avoid talking about death is a form of denial.**

- One of the most common worries is for the future of the children in a family. People may fear that their children will be hungry or lack money for school fees after they have died. Begin planning with relatives, friends or orphan programmes for the future of the children. It will ease such worries if the person knows that suitable arrangements have already been made.
- The person may be worried about being in pain as they near death. The fear can be lessened by knowing what it will be like. If the person asks, describe what might happen, such as difficulty in breathing, or passing in and out of consciousness. If pain medications are available, reassure the person that they will be used in order to prevent unnecessary pain.
- The person may be worried about what will happen after they die. The anxiety can be lessened by helping them to write a will, by planning details such as funeral arrangements and discussing spiritual beliefs, perhaps with a representative of the person's religion.

◆ **What precautions do you or the family need to take with the body of someone who has died of AIDS?**

Immediately after death, you need to follow the same rules in dealing with the body as you did when helping the person through their illness. Hands should be protected when cleaning and laying out the body, particularly if there are body fluids such as diarrhoea or blood, and then washed with soap and water afterwards. Wounds on hands or arms should be covered with a plaster or bandage.

Shortly after the person has died the virus will also die. HIV can only live and reproduce inside a living person. Therefore you do not need to worry about special precautions during the funeral itself.

◆ **How can you help the family after the death?**

Immediately after a person has died, the family may need help to grieve or to arrange practical matters. You can offer this by listening to them. You can also assist them with the funeral arrangements in accordance with the customs and regulations of the area in which you live.

The death may continue to cause practical difficulties for the family. This is particularly true if planning for the death was not done properly. Also, the family and loved ones will continue to grieve for many months. Any care or practical help you can give during this time can be useful. Setting aside time to visit and asking how they are doing will help them to think of life beyond this painful time.

