

Module 9

People Living with HIV/AIDS



FLOW CHART

Content Flow at A Glance

Module 9: People Living With HIV/AIDS

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Module 9

People Living With HIV/AIDS

“ Life may not be the party we hoped for, but while we are here we should dance”

Unknown

I Introduction

Globally, at the end of 2002, there were 42 million people living with HIV/AIDS (PLWHAs), 19 million of them women and more than 3 million of them children under 15 years of age. Currently, about 5 million people are acquiring HIV each year. Prevalence rates have risen sharply in virtually every region of the world in the past decade. Projections for 126 low and middle-income countries showed that an additional 45 million people would become infected between 2002 and 2010 in the absence of concerted and robust prevention efforts. Asia and the Pacific now accounts for one in every five new HIV infections worldwide. In all, over 8 million people were living with the virus in the region at the end of 2002; 2.6 million of who were young people aged 15 to 24.

II Living healthy and productive lives

People living with HIV/AIDS can live healthy and productive lives when they have access to information, treatment, care and support.

Information includes knowing what your rights are in terms of employment, welfare, education and family life, and having clear information about treatment and how to get treatment. It also means knowing about property rights, personal laws related to divorce, alimony and custody of children. Personal laws gain importance in the context of women, as they are likely to face more discrimination and harassment on being diagnosed with HIV/AIDS.

Support means acceptance, affection, respect and love from friends and family and from the community. It also means supportive laws to protect against discrimination and stigmatization.

Care includes moral support and access to necessary medical treatments, a healthy diet, clean water and accommodation.

Although key human rights, such as the right to information, the right to life and the right to health create entitlement to care and support, most young people (especially young women) living with HIV/AIDS do not have full access to these services. The situation is worse for young people belonging to marginalized groups, such as sex workers, homosexuals and injecting drug users.

The realization of human rights and other constitutional rights is not simply a matter of state action to develop laws and policies that protect against discrimination and stigma. Advocacy for public policies and legal action is also very important. However, this is not enough to transform the reality at the grassroots. When it comes

to improving the daily lives of people living with HIV/AIDS the community, family and friends have to play an important and dynamic role.

III Peers and PLWHAs

Assuming the responsibility to provide information, care and support to their peers living with HIV/AIDS is a task in which youth can make a very big difference. Offering friendship, providing access to information on care, setting up home visiting programmes for those who are sick and organizing support services are some of the possible actions they can take.

A good place to start showing your solidarity may be within your group or family or with colleagues and relatives.

Don't fear or falter!

- If you know that someone in your group has HIV or AIDS, make sure that friends who are already aware of his/her condition know that it is safe to touch, hug, share food and be together socially.
- If your HIV/AIDS infected friends want you to maintain confidentiality, respect their wishes.
- Don't forget to show your concern, affection and love.
- If the person is sick, help out with cooking, shopping, getting medication, cleaning or simply talking about his/her feelings.
- To address stigmatization and discrimination at the work place, create awareness about rights in the work place of people living with HIV/AIDS.
- Advocate for behaviour and conduct that are supportive of people living with HIV/AIDS.

A good starting point is to listen to experiences of people living with HIV/AIDS. Listen carefully and list the ways in which they think they could have been helped. Add any others that you can think of and discuss it together.

- Say hello
- Invite him/her to lunch or dinner, a movie or a walk
- Just listen
- Hold his/her hand
- Discuss the future
- Celebrate special days and anniversaries
- Ask how you can help
- Run errands and pick up medication
- Give a hug
- Clean the house
- Give a small token of affection and care
- Invite others to spend time together

IV Information

Some people call information the “cheapest form of therapy”. Developing youth friendly HIV/AIDS information/resource services focused on the needs of people living with HIV/AIDS is not difficult. A simple information leaflet, a discussion in a peer group, a list of important phone numbers and people who can help can make a big difference.

People living with HIV/AIDS and those living with them or caring for them need up-to-date information on a range of issues. For example, caretakers need information to help them understand the progression of HIV and to know what advice to give; people with HIV need information to be able to seek early treatment for common illnesses.

Counselling can be very useful for anyone in a difficult and stressful situation. This includes anyone going for an HIV test, anyone diagnosed HIV positive and caregivers looking after someone who is ill.

If young people wish to work with PLWHAs they can get training in counselling skills and develop networks that provide support.

V Practical Tips for Care Givers

- Treat people living with HIV/AIDS with dignity and respect
- Listen
- Respect their need for confidentiality and privacy
- Let them know that it is okay to talk about their feelings or to show anger.
- Ask to visit or do things together, do not ignore them and stay away.
- Share your concerns and feelings; do not pretend that everything is normal.
- If a person is sick, offer to shop/cook/clean. Do not wait to be asked.
- Help them take their medication and seek treatment on time.
- Do not allow them to become isolated. Tell them about support groups and other services that may be available in the community.

VI Care and Support for People Living With HIV/AIDS (PLWHAs)

Care and support are based on an active concern for the well being of others and ourselves. People directly affected by HIV/AIDS need care. People with HIV/AIDS, families and communities are involved in care and support. They all need support to face the challenges of illness. The aim of HIV/AIDS care and support is to improve the quality of life of people living with HIV/AIDS, their families and communities. Care and support are also important because they assist efforts to prevent the spread of HIV/AIDS.

Comprehensive care meets the needs of the PLWHAs, their families and communities. This "holistic" care method requires a variety of information, resources and services to address a range of needs – not just medical needs.

Components of Comprehensive Care

- Diagnosis
- Treatment
- Referral and follow up
- Nursing care
- Counselling
- Support to meet psychological, spiritual, economic, social and legal needs.

Depending on the stage of illness and circumstances each person living with HIV/AIDS has different needs. For example, a person with HIV/AIDS who is not ill will have different needs and require different care and support than a person with HIV/AIDS who is very ill and bed ridden most of the time.

Comprehensive care for a person with HIV/AIDS should happen along a continuum of care. This means responding to the range of care and support needs in different places such as hospital, clinic, community and home. Over the course of the persons illness, responding to these needs also requires a coordinated response from people with a variety of complimentary skills for example, counsellors, nurses, doctors, community health workers, people with HIV/AIDS, pharmacists, family and friends. It is vital that people and places involved in care and support work together to have an efficient flow of information, resources and services between them to ensure a continuum of quality care and support.

Session 9.1

Needs of a Person Living with HIV/AIDS

Expected Outcomes

Participants will become aware of the special needs of a person living with HIV/AIDS.

Participants will be able to appropriately respond to the needs of a person living with HIV/AIDS.

Learning From Mr. X

Objective To sensitize the participants to the needs of a person living with HIV/AIDS.

To enable participants to see that treatment, care and support can be provided through linkages with various agencies, individuals, resources and services.

Materials Case study, flip charts, markers.

Time 1 hour 30 minutes.

Process Ask the participants to divide into groups of 5 to 6.

Explain that people living with HIV/AIDS need care and support. This care and support comes from different people at different times. The exercise will enable the participants to understand this and think of ways in which they can support and care for their friends, family and relatives.

Hand out the case study to each group, and ask them to discuss it.

They should answer the questions at the end of the case study, and prepare a presentation.

Give them 30 minutes to do the exercise.

Invite the groups to make their presentations. Encourage the observers to ask questions and discuss.

Reassemble in the large group and facilitate a discussion using the following questions:

- *What did you learn from this exercise?*
- *The case study mentions some of the needs and solutions for a person living with HIV/AIDS, can you think of other needs/requirements of a person living with HIV/AIDS?*

In your opinion would the needs and requirements of a man and woman be similar? Why and why not?

- *List some of the needs/requirements that would be different for a man and woman.*
- *Can you think of ways in which you can help a person living with HIV/AIDS? How?*

Note for the Facilitator

This exercise is useful in encouraging the participants to think about the range of needs that PLWHAs may have. During the discussion in the large group, encourage the participants to think creatively while brainstorming on the needs and requirements of the PLWHAs given the socio-cultural, economic and gender dimensions of HIV/AIDS.

Case study that may be used for this exercise:

Mr. X lives in a town in Zambia. He went to a hospital for an HIV/AIDS test because he was losing weight and coughing. Due to his cough the doctor also checked him for Tuberculosis (TB). The results of both tests were positive. The doctor started Mr. X on TB treatment while he was in the hospital, but when Mr. X was coughing less he was sent home and referred to the home-based care team of a local church. The team came to Mr. X's house to ensure that he took his medication. He shouted at them and told them not to come back. The team persuaded Mr. X to see the medical officer who listened carefully and realized that Mr. X was afraid that his neighbours would see the team visiting him. As a result, the people would realize that he has TB and reject him. So, the team helped Mr. X to talk to a trust worthy relative. The relative learnt to help Mr. X take his drugs every day and go for check ups at the hospital. Mr. X's TB was controlled and he started to feel much happier.

- *Where did Mr. X go for his HIV/AIDS test and TB treatment? What support did he receive from the hospital staff?*
- *Who did the doctor refer him to for home-based care?*
- *What support did Mr. X receive from the home based care team?*
- *Why does Mr. X feel happy and healthy?*

At a skills building workshop in Zambia, participants came up with the following elements in a comprehensive care exercise:

- Personal and family hygiene
- Spiritual support
- Environmental hygiene
- Education on diet, food
- Income generating activities
- Employment
- Sharing experiences
- Transport
- Counselling
- Nursing care

- Clothing, blankets
- Relief of symptoms, treatment, medication
- School needs
- Singing

Afterwards, the facilitator led a group discussion about what had been learnt from the activity. For example, the participants agreed that effective care and support should involve responding to a variety of physical, spiritual, psychosocial and material needs.

Session 9.2

Consequences of Living with HIV/AIDS

Expected Outcomes

Participants will know the issues a person living with HIV/AIDS faces.

Participants will be able to identify the types of support needed by a person living with HIV/AIDS.

Participants will be able to provide a network of support services required by a person living with HIV/AIDS.

Of Course It Has Effects!

Objectives Understand the personal and social repercussions of infection faced by a person infected with HIV/AIDS.
 Develop sensitivity towards persons infected with HIV/AIDS.
 Identify the support systems needed for persons infected with HIV/AIDS.

Materials Paper, markers, flip charts.

Time 1 hour.

Process Ask the participants to break into four groups, and pick up some flip charts and markers for the group exercise.

Tell them to imagine that a person they know has tested positive for HIV/AIDS.

Ask them to work in their respective groups and draw up two lists of consequences they think would follow this news (one social and one personal).

Ask group 1 to discuss and make a list of the consequences for the individual who has tested positive – personal and social.

Ask group 2 to make a list of the consequences for the individual's partner – personal and social.

Ask group 3 to make a list of the consequences for the individual's school- aged child – personal and social.

Ask group 4 to make a list of the consequences for the individual's teenage sister and brother – personal and social.

Give the groups at least 20 minutes to do this exercise.

Invite the participants to display their flipcharts on the walls marked PERSONAL and SOCIAL (this can be done while the groups are working).

It is possible that the participants will create more categories such economic or cultural, so be prepared to include them in the presentation.

Once the groups have put up their lists, ask them to stand around the wall bearing PERSONAL charts. Encourage them to read it and facilitate a discussion on the emerging issues.

Next, turn to the SOCIAL wall and repeat the process of reading and encouraging discussion.

Use the following questions for discussion:

- *How did you feel when you were told that a person you know has tested positive?*
- *How did you feel when you were asked to discuss and list the consequences?*
- *Why did you feel the way you felt?*
- *Why do you think there are such wide spread consequences for the person who has tested positive and for those associated with him?*
- *Do you think some of the consequences discussed can be avoided? How?*

Note for the Facilitator

You can widen the scope of the discussion by relating the participants' responses to the responses that an HIV infected person might face in relation to the culture, norms, laws and rights within a particular country or society. Participants may bring up the issue of the rights of an HIV infected person, so be prepared to deal with this eventuality. Find out if there are any discriminatory laws in your country or society, such as laws barring an HIV infected person from seeking employment or getting married. Clarify any myths or misinformation that may arise during the course of the discussion. Allow the participants to discuss the issue of discrimination and stigmatization attached to HIV/AIDS. Do not force the participants to accept any one point of view, but encourage them to explore their personal responses and reactions.

Session 9.3

PLWHAs Face Discrimination

Expected Outcomes

Participants will become sensitive to the types of discrimination faced by PLWHAs. Participants will take steps to reduce the discrimination faced by their peers who are living with HIV/AIDS.

Aren't I Human?

Objectives Become aware of discrimination against HIV infected individuals. Understand the different ways in which discrimination towards a person infected with HIV/AIDS is expressed. Decide whether the discrimination is appropriate or inappropriate. Think of ways to reduce the discrimination.

Materials Chalk, previously prepared statements, flip charts, markers.

Time 1 hour.

Process Invite the participants to sit in a circle on the floor.

Ask them to pick up one piece of chalk each. Explain that this exercise will enable them to explore “discrimination” through their responses to the statements you will read.

Invite the participants to devise signs for “agree” and “disagree”.

Each participant should use chalk to make their signs and put them on the floor. Observe the signs made by the participants and after each statement, encourage them to discuss the reasons for their responses. Clarify any myths and misinformation.

The participants may want to know the meaning of the term “discrimination”. Explain the term with examples before starting the exercise.

You may want to use the following questions to generate discussion:

- *Why do people discriminate against some people?*
- *How can you reduce discrimination?*
- *What can you do to reduce or stop discrimination?*
- *Have you ever felt discriminated against? Would you like to share the experience?*
- *What would you do if you discovered that a person infected with HIV had been asked to leave his/her job in your community?*

Note for the Facilitator

Discrimination is a sensitive issue and requires gentle handling. It is usually related to long held beliefs and practices. People need time to deal it. Help participants explore their feelings and understand their reasons and responses to the statements you read.

The statements that you might like to use for this exercise are as follows (next to each is a note you can use for discussion):

Rekha's parents died because of AIDS. Her school authorities found out and asked her to leave the school.	This is discriminatory because the child, whose parents have HIV/AIDS, has the same right to be educated as anyone else. Additionally HIV/AIDS can only be transmitted through sexual contact, transfer of blood and blood products and from mother to child.
The village council decided to bar any person infected with HIV/AIDS from living in the village.	People infected with HIV have the right to a normal life. A ban of this type is no protection against HIV/AIDS. The council would have to spend large amounts on enforcing such a ban. HIV/AIDS cannot be transmitted through the air, by sharing of clothes or by living next to the infected persons.
Li is infected with HIV. His employer has asked him to stop coming for work.	People infected with HIV/AIDS have the right to work and gainful employment. Perhaps the employer is afraid that if the clients find out about Li they will stop coming to his firm.
Karim's test results have just come in. He doesn't want his parents to know that he has tested positive for HIV, but the clinic staff has sent a letter to his parents.	The right to confidentiality has been violated. The doctor-patient relationship is based on trust and integrity. Karim has a right to inform, or not inform, his parents in his own time and space.
John is an employee in a transport company. The new rules of the company state that every employee will be tested for HIV/AIDS and that in future, no person will be employed without a test for HIV/AIDS.	This is discriminatory because it bars people with HIV/AIDS from access to equal opportunities. The test will have to be repeated over and over again, as the person being tested may be in the "window" period. To be tested, or not, is a personal decision and cannot be forced. It requires personal preparedness and counselling.
Sheela went for a medical test because she was suffering from TB. The hospital did a test for HIV without her knowledge and then refused to treat her.	Testing without the consent and knowledge of the person is a violation of the person's rights and trust. Refusal to treat a person with HIV is also discriminatory. In many countries hospitals and health care personnel have been sued for such violations of a persons right to treatment and care.
The waiter in the hotel refuses to serve Pari	This is discriminatory. HIV cannot be transmitted through touch or proximity or through sharing of

because she is HIV positive.	utensils.
Huan has been admitted to a care centre even though he is healthy and capable of living a normal life.	This is discriminatory. A person with HIV/AIDS has the right to a healthy and normal life. He has a right to work and be happy. People with HIV/AIDS need love and care and can be looked after at home or in their community.

In the context of HIV/AIDS, discrimination seems to be caused mainly by:

- A presumption that those who are infected lack morality.
- Racism, homophobia, class differences and sexism.
- Laws and social norms that reflect prejudice, fears and biases.
- Misguided fears of catching the virus through social contact.

Session 9.4

Removing discrimination against people living with HIV/AIDS

Expected Outcomes

Participants will be familiar with specific methods that minimize discrimination against PLWHAs.

Participants will develop appropriate behaviour for dealing with peers who are living with HIV/AIDS.

I'd Like To Help

Objectives Learn specific ways to minimize discrimination against persons infected with HIV/AIDS.
Learn specific ways to promote a positive attitude within the family and community towards PLWHAs.

Materials Flip charts, markers, paper, scissors, tape, coloured markers.

Time 1 hour.

Process Ask the participants to divide into four groups.

Explain that they will be doing some exercises pertaining to the objectives specified above in the small group.

Ask group 1 to prepare a small role-play showing how they would take care of a friend who has been infected with HIV.

Ask group 2 to prepare an article for the local newspaper emphasizing the need to stop discrimination against people living with HIV/AIDS.

Ask group 3 and 4 to prepare posters with positive messages for raising awareness about the needs and requirements of people living with HIV/AIDS. They may prepare posters for the community, peer groups or government.

Give the groups 30 minutes to do these exercises. Then ask them to convene in the training room.

Invite group 3 and 4 to display their posters in the room. Invite group 2 to share their article. Group 1 should be invited towards the end to stage their role-play.

Discuss the issues raised in the exercises after the of each group presents

Encourage the participants to ask questions and discuss the subject. If the participants have any misconceptions about HIV/AIDS please address them.

Take the opportunity to emphasize the right to equality and the charter of human rights.

Close the session with a recap of the major learnings from the exercise. These can be summed up in the following three broad headings – dealing with discrimination, care for people living with HIV/AIDS and communication about the needs of PLWHAs.

Note for the facilitator

This is an interesting mix of exercises that allows the participants to be creative and learn from one another. As a facilitator, you should be prepared with some interesting posters and articles to share with the participants. Also, it may be useful to make a small presentation on Human Rights and HIV/AIDS (this charter is given in Module III). Alternatively, you could give a home task to the participants, for example, a rapid survey among their peer group on prevalent attitudes about PLWHAs. They could also do this survey in their community or with their family members.

Helpline for the peer educator

This material can also be used for making handouts.

To start a public awareness campaign in your community you could begin by exploring the following:

- Are there beliefs, norms and behaviours in your community that generate and promote negative attitudes towards specific groups of people; thus increasing their vulnerability to HIV/AIDS?
- What are people's beliefs and knowledge about HIV/AIDS?

Tips for a public awareness campaign

- Present positive images; people living with HIV/AIDS have the right to live a healthy and normal life.
- Involve the target groups (those who will receive the messages) in preparing and planning the campaign.
- Involve the people living with HIV/AIDS to help in the design and planning and delivery of the campaign.
- Make the messages short, direct and appropriate to the life style of the target audience.
- Aim to motivate, not advise or lecture.
- Test the images and messages by showing them to a group of target audiences and asking their reactions. For example, you could ask them what they feel about the pictures and words used in the posters?
- Refrain from annoying people; your aim is to educate and inform.
- Do not use words that reinforce negative attitudes and behaviours.

Session 9.5 Helping PLWHAs

Expected Outcomes

Participants will know some ways to help PLWHAs.

Participants will help and support PLWHAs.

Who, Where, How?

Objective Think of concrete and practical ways to help Person Living with HIV/AIDS.

Materials Blackboard, chalk, scenarios (given at the end of the exercise).

Time 45 minutes

Process Ask the participants to divide into 4 groups.

Explain that you will be handing out a sheet with a scenario written on it.

Each group will receive a different scenario and will have to come up with at least two of ways of helping the people in the scenario.

They must think of things that they themselves can do.

Give the groups 20 minutes to do this exercise and then invite them to give presentations.

Encourage the participants to discuss the pros and cons of each presentation and whether the ways suggested by the presenters are practical, or not. How can the participants improve on the suggestions?

Note for the Facilitator

To be a caregiver for someone who has HIV/AIDS means giving extra amounts of warmth and gentleness. Most people with HIV/AIDS are young adults who are alert, full of energy and excited about life. For many, life has become full of fear, anger and fatigue. Many have lost hope, support from their community, friends, and family, and they need others to care for them. A caregiver may need to be nurse, cook, messenger, cleaner or listener. Overall care giving is about being a friend and companion. Every small gesture contributes in making the person feel wanted and cared for. You could also invite a person living with HIV/AIDS to come and share his/her experience with the participants or show a video on the life of a person living with HIV/AIDS (it is useful to choose a film that is based in a socio-cultural environment similar to that of the participants).

The following scenarios can be used for this exercise:

Scenario 1

Radha is 23 years old and she has HIV/AIDS. She is pregnant and fears that the baby may also have HIV/AIDS. Radha's husband died of HIV/AIDS. Her in-laws live nearby but do not talk to her. They blame her for giving the virus to their son. Her parents do not see her. They feel that their responsibilities ended when she got married. Moreover, they are poor and do not have the time and resources to help her. Her neighbours do not talk to her. They fear that they may also get HIV/AIDS. Radha is not educated and has no skills. People in the village do not allow her to work because of the fear that they may get HIV/AIDS. Radha was all right at first, but now she is tired, can't work and has very little money to buy food. She stays at home, simply waiting to die.

Scenario 2

Ibrahim is 19 years old. He works in a factory in a city. Last year, Ibrahim went in for a blood test, as he suspected that he might be infected with HIV. The result came out positive and his worst fears came true. His employers discovered his HIV positive status and terminated his contract. Ibrahim is unable to find another job and scared of returning to his family in the village. He wants to share his problem with his friends but is unable to do so due to the fear of losing their support. He is depressed, lonely, afraid and worried about the future. He would very much like to have a friend to talk to.

Scenario 3

Sue is 16 years old. She is studying in a college and loves to party. She has many friends and a boy friend. She went for an HIV test because she has been feeling unwell, and the doctor advised her to take the test. Her result was positive and she was devastated. She is unable to accept the result and is scared of its impact on her life. Her parents are unable to understand her withdrawn and dull behaviour. Sue is contemplating suicide.

Scenario 4

Y is 20 years old. He is working in a bank and planning to get married. Y has led a life of excitement and experimentation (partying, girlfriends and drugs). He knew about the possibilities of HIV/AIDS but never believed it could happen to him. He has plans for the future and wants to achieve great success in his career. His girlfriend is also working as a secretary in a multi-national company. Y was advised to take an HIV test because he was suffering from a STI. The test results were positive. He has been going for counselling but is unable to come to terms with the result. He is scared but unable to share the trauma with his girlfriend or friends. He is losing control and has once again resumed taking drugs.

Note: These scenarios are just suggestions, you may want to change them to suit the socio-cultural realities of the group with whom you conduct the session. You can write more scenarios based on newspaper items, case studies and experience.

Session 9.6

Understanding Care and Treatment for PLWHAs

Expected Outcomes

Participants will develop a common understanding on what is meant by treatment for PLWHAs.

Participants will be able to identify sources of care and support for PLWHAs.

Do We Understand?

Objective To develop a common understanding of what is meant by treatment/care for PLWHAs

Materials Flip charts, markers, scenario sheets, transparencies or charts showing the definition of “treatment.”

Time 2 hours.

Process Invite the participants to sit in a circle. Explain that they will be doing an exercise to gain an understanding of the needs of people living with HIV/AIDS. Explain that these needs determine treatment and care possibilities for PLWHAs.

Ask the participants to divide into 6 groups.

Give each group a scenario of a person living with HIV/AIDS and ask them to work out answers to the questions given at the end of the scenario.

Ask the groups to read the scenarios, brainstorm and prepare their presentations. Allow 20 to 25 minutes for the exercise.

Starting with group 1 invite each group to put up their presentation on the wall. Encourage discussion and questions at the end of each presentation.

Invite the participants to return to the circle, and facilitate a discussion using the following questions:

- *What did you learn from this exercise?*
- *Who is responsible for the care and support of people living with HIV/AIDS? Why?*
- *Do women living with HIV/AIDS require different types of care and support? Why and why not?*
- *What is the difference between the needs/requirements of women and men living with HIV/AIDS?*
- *Can you think of ways in which you can help people living with HIV/AIDS? How can you help?*

Note for the facilitator

This is a comprehensive exercise for sensitizing participants to the varied needs of people living with HIV/AIDS. Focus on the multiple issues of care and support through this exercise and encourage the participants to think about the socio-economic, cultural, gender, religious, medical, psychological dimensions of the subject. Participants may come up with general solutions, but ask them to be specific and detailed. As a peer educator, be prepared with a list of contact numbers and addresses of people and places that provide care for PLWHAs and give it to the participants.

Helpline for the peer educator

This material can also be used for making handouts.

Treatment is a key element of care and support for PLWHAs. Any action that improves a person's quality and length of life is a form of treatment. Treatment can happen without medication. For example, personal and social or psychosocial support is also a treatment because it can provide relief and improve a person's well being.

For medication to be effective, other forms of treatment must support it. For example, if people feel cared for in their family or community and have food and clean water they are likely to make better use of their medication.

Treatment/care needs are varied depending on the stage of illness, the socio-economic status, cultural and religious environment and gender.

Treatment/care can happen in different places and requires different resources depending on the stage of illness.

The needs of PLWHAs should be central in deciding where and what kind of treatment and care is provided.

PLWHAs need treatment and care to be accessible in different locations at different times. Sometimes it can start in one place (such as a hospital) and continue in another (such as a person's home). When treatment and care are being given in different locations, it is important to have effective coordination of information, resources and services between the different locations.

Scenarios that may be used for this exercise:**Scenario for group 1**

X is 22 years old. He is living with his parents and siblings in a small town. He is HIV positive, but healthy. His family is supportive of him, but he wants to work. He has applied for many jobs, but nobody is willing to employ him. He is feeling very depressed and lonely.

What kind of help does X need?

Where and how can he get help and support?

Scenario for group 2

H is 19 years old. She is not educated and has been living in the slum of a large metropolitan city. She works as a waitress in one of the bars. She is HIV positive and prone to frequent illnesses. She is very sad and alone. Her friends are unable to help her, as they do not have the time and the resources. She goes to the local health care centre for treatment but she is unable to buy the medication they prescribe.

What kind of help does H need?

Where and how can she get help and support?

Scenario for group 3

G is 16 years old. He lives on the street, as he has no family. He is a drug user and a sex worker. He is very ill and the doctors have told him that he has TB. His friends take care of him but they cannot ensure regular treatment and care. G is very ill and unable to do anything for himself.

What kind of help does G need?

Where and how can he get help and support?

Scenario of group 4

S is in the hospital. She has been in the hospital for the last month but she wants to go home. Her family members think that she should stay in the hospital as they do not have the time and do not know how to take care of her. S is becoming depressed and restless.

What kind of help does S need?

Where and how can she get help and support?

Scenario for group 5

M is 24 years old. She is widowed and has one child who is also HIV positive. She lives alone with her child and works as a clerk in a bank. She is very worried about the future of her child. She is frequently depressed with the prospect of her own death and the effect it will have on her child. Her husband's family refuse to help her and have denied her all rights to her husband's insurance money. Of late, M has been falling sick, but she refuses to take her medication.

What kind of help does M need?

Where and how can she get help and support?

Scenario for group 6

O is 21 years old. He is working in an advertising agency and has many friends. They support him and take care of him when he is sick. His partner is also very loving and supportive, but O is obsessed with the idea of death. He is losing weight and ignoring his doctor's instructions. He is slowly losing interest in his work and refusing his friends' offers of help. He lies in bed for days on end and refuses to respond to anyone.

What kind of help does O need?

Where and how can he get help and support?

Session 9.6

Is there a Link between HIV/AIDS Prevention and Treatment/Care?

Expected Outcomes

Participants will be able to identify the links between HIV/AIDS prevention and treatment/care.

Participants will be able to address treatment and care issues in their prevention work.

What Is The Link?

Objective To enable participants to make the link between HIV/AIDS prevention and HIV/AIDS treatment and care.
To demonstrate that HIV/AIDS prevention and treatment/care support each other in many ways.

Materials Flash cards, markers.

Time 1 hour.

Process Invite the participants to sit in a circle on the floor.

Explain that the exercise will focus on brainstorming and drawing links between HIV/AIDS care/treatment and HIV/AIDS prevention.

Ask two volunteers to help in the facilitation of the exercise. Give them the flash cards and markers. Let them sit in the centre of the group.

Ask the participants to brainstorm on the subject and create a diagram showing the links between HIV/AIDS care/treatment and HIV/AIDS prevention. For example HIV/AIDS prevention messages, when designed and disseminated in an effective manner, can lead to testing and counselling for HIV/AIDS. In turn, this will lead to early treatment for those who may be infected.

Allow 30 minutes for this activity.

Participants may be unable to draw any links. In this instance, help them by giving examples.

When the exercise is complete facilitate a discussion using the following questions:

- How easy or difficult was the exercise? Why?
- *Can people living with HIV/AIDS play a role in prevention of HIV/AIDS? How?*
- *How can you help the people living with HIV/AIDS in their efforts towards prevention of HIV/AIDS?*

Note for the Facilitator

People living with HIV/AIDS can help in the prevention of HIV/AIDS. Youth can also make significant contributions. This exercise generates ways in which they can contribute.

HIV/AIDS prevention aims to prevent the transmission of HIV. HIV/AIDS treatment and care aims to improve the quality of life of people living with HIV/AIDS. HIV/AIDS prevention and treatment support each other in many ways:

Well designed HIV prevention activities can lead to increased voluntary counselling and testing, which in turn can lead to broader and quicker access to treatment for people with HIV/AIDS.

Well-designed HIV prevention activities can reduce fear and stigmatization around HIV/AIDS. This improves the quality of life for PLWHAs, as they become more accepted and better understood by their families and communities.

Through Voluntary Counselling and Testing (VCT) people can learn about HIV/AIDS prevention, and if they are HIV positive, they can be given information on how to live safely with the virus and plan for the future. VCT also helps people gain assistance early on and learn about possible treatments for health problems that may occur. For example, VCT can be helpful in preventing tuberculosis and STIs.

Prevention programs and VCT allow women with HIV/AIDS to access services that will reduce the chance of them passing HIV to their unborn or newborn children. If they become pregnant, women and men might also choose to increase contraceptive use.

Access to care and support increases condom use and other preventive behaviour amongst people with HIV/AIDS. These positive changes can be reinforced when care and treatment programs deliberately promote and distribute condoms.

Increased availability of care and increased visibility and acceptance of PLWHAs makes the broader population more aware of HIV/AIDS and increases safer behaviour.

Examples

In Cambodia, homecare teams from local organisations support a large number of families affected by HIV/AIDS. Most of the people with HIV/AIDS found that there overall well being improved due to the visits from the home care teams. Families spent less money on medication and had to make fewer visits to hospitals. In addition, neighbours, friends and family members learned more about HIV/AIDS. They also became less afraid of the virus, and there was less of a stigma around HIV/AIDS in the community, making it easier to provide education on HIV/AIDS prevention.

In a workshop in Africa participants made the following diagram to show these links:

Epidemic begins The availability of treatment gives messages of hope.
As there is hope, more people get tested.

People accessing treatment feel good about planning for the future.

People with HIV/AIDS become more visible and speak out about positive living.

There is more acceptance of people with HIV/AIDS.

PLWHAs feel empowered.

Empowerment and quality of life encourage people working in prevention.

Epidemic slows

More people become involved in prevention.

Session 9.7

Availability and Access to Treatment and Care

Expected Outcomes

Participants will become aware of issues regarding the access and availability of treatment and care for PLWHAs.

Participants will be able to design treatment and care interventions that consider availability and access as important issues

It Is There, But Where?

Objective To enable participants to think about the availability and access of HIV/AIDS treatment and care options.

Materials Chalk, flash cards, markers.

Time 1 hour and 30 minutes.

Process Divide the participants into groups based on their community/geographical similarities. For example, if the participants come from a single locality and town they can be asked to form one group. If the participants belong to the same peer group, they can be formed into one group.

Explain that they will draw maps of their locality showing their houses (if possible) and services available within the community. The groups may draw maps of their village, town etc.

Once the map is ready they should think of a person living with HIV/AIDS within that community/locality and focus on the places and services that can be accessed and used by the person.

Ask the participants to use the chalk, markers, flip charts to draw the map. It is good idea to use chalk for the drawing, as it enables one to make changes.

After the exercise is complete, review the map. Ask the participants about the facilities available in a particular place, the distance to be travelled and the resources that may be required.

Focus on the needs/requirements of the person living with HIV/AIDS and whether they would be able to access those services. It is one thing for a service to be available, but access is the key issue. Encourage the group to think of ways in which services can be made accessible and the ways in which they can help to do so.

Note for the facilitator

Mapping in its simplest form identifies the comparative location and importance of different resources/services within an area. The key components of a map are spatial analysis of a wide range of different issues and identification of key elements

important to different groups of people. Maps are also useful in providing a framework for discussion, highlighting resources/services of importance to different groups, analyzing the present status and location of resources/services, stimulating discussion over the importance of specific resources/services and enabling location of different services/resources and places.

For people to use medical treatment, care and support it must be available – meaning that it can be found anywhere that is appropriate. For example, a medical treatment is available if the materials needed to treat a health problem can be found in that community (basic drugs). Care and support is available if the person living with HIV/AIDS has a family and friends and support networks.

Helpline for the peer educator

This material can also be used to make handouts.

Some reasons why an HIV related treatment, care and support might not be available include the following:

- The drug is new and access is restricted by law.
- The drug is not imported into the country for commercial reasons.
- The public health system does not allocate funds to purchase the drug.
- Only specialists are allowed to prescribe the drugs.
- Families are scared of contracting HIV/AIDS because they do not have information on how to protect themselves or how the infection is transmitted.
- Friends have little awareness and limited resources.
- There are socio-cultural taboos that increase the isolation of PLWHAs.
- There are religious and legal sanctions that prevent people from supporting and caring for PLWHAs.

For people to benefit from treatment, care and support they must be available. More importantly though, they must also be accessible. Treatment, care and support should be found in appropriate places and should be easy to obtain and use. Sometimes treatment, care and support are available but ***not accessible because of a variety of reasons, such as:***

- People cannot afford the right drug.
- The treatment provider discriminates against people with HIV/AIDS and refuses to give them the drug.
- The treatment provider does not have the right skills to administer the drug.
- It is too difficult for people with HIV/AIDS to get to the drug.
- The caregiver does not have the right knowledge and skills.
- The caregiver does not live with the PLWHA.
- The support networks and services are too far away (usually found only in towns and cities).

A barrier to access treatment, support and care is anything that prevents a person from getting the treatment, care and support that they need. ***There can be many barriers for PLWHAs. These may be related to:***

A. Service: cost, staff attitudes, skills or facilities offered. For example, a clinic might only be open during the day when many PLWHAs are working.

The Context: political, economic and cultural situation in which treatment is provided. For example, women may not be able to access treatment for STIs because sex is a taboo subject or because of the stigma of being seen at an STI clinic.

Attitudes: knowledge and beliefs of the community members. For example, local people might believe that HIV counselling is only for the members of high-risk group, such as sex workers.

There are many different types of barriers to accessing HI/AIDS related treatment/care. These include:

Financial barriers – the cost of drugs and the need to prioritise other general supplies such as food.

Organizational barriers – the poor administration of treatment services and lack of skilled staff.

Physical barriers – treatment facilities in distant locations and transport not being available.

Social barriers – the stigma associated with a treatment and people being concerned about confidentiality.

At a workshop participants came up with the following barriers to effective medical treatment

Organizational	Physical	Social	Financial
Negative attitudes of health care workers	Distance to health facilities	Traditional beliefs	Poverty
Lack of materials needed for treatment	Lack of transport	Stigma	Cost of drugs
Delays in treatment/health care workers not available		Ignorance	Expense of user fee in hospitals
Corruption in health care facilities		Denial	Cost of transport to health care facilities
		Myths and misinformation about HIV/AIDS	Lack of medical insurance schemes

Session 9.8

Relationships that Enable People to Live Productive Lives

Expected Outcomes

Participants will learn that a web of relationships exists in everyone's life.

Participants will become aware that these relationships can be tapped and supported to create a web of support and care for people living with HIV/AIDS.

Web Of Relationships

Objective To enable the participants to explore their relationships with different people in their lives.

To enable understanding of the fact that we all have a network of relationships that allows us to lead useful and comfortable lives.

Materials Flip charts, markers, chalk.

Time 1 hour.

Process Divide the participants into small groups of 4 to 5.

Explain that they will be drawing a web of the relationships in their lives. Everyone has a web of relationships that sustains and supports them. The friends we have have relationships with other friends, with our family and with many other people known and unknown to us. The web will enable us to understand their relationship to us and others and how the combinations help us in our lives.

Ask each group to draw a web of relationships. They can choose one person in their group and draw a web of their relationships or they could draw a common group web.

If the task is difficult to understand, give an example by showing a web diagram on the board or a flipchart. You may want to use the example given at the end of this exercise.

Give the groups 30 minutes to do the exercise. Ask them to put up their outputs on the wall. If they have used chalk and the floor to do the exercise, the groups could visit each other's web.

Encourage the participants to ask questions and discuss why and how the web of relationships is helpful. Also encourage discussion on how relationships can be nurtured and improved to enhance the quality of our lives.

You may want to use the following questions to facilitate a discussion in the large group:

- *In the web of relationships are there some relationships that help you more than the others? Which ones, and why?*
- *How do different relationships help you and each other?*
- *Can a similar web of relationships exist in a community? Why, and how?*
- *Can you draw a web of relationships that may be useful in improving the lives of people living with HIV/AIDS? Ask the participants to draw the web.*
- *How can you become a part of this web and support a person living with HIV/AIDS?*

Note for the facilitator

Drawing a diagram of relationships allows the participants to examine the role of different relationships in their lives and the way in which these relationships interact with each other. The drawing enables a visual context to the discussion and enables focused discussion. Men and women may have differences in their webs and it would be interesting to examine the reasons for this.

Helpline for the peer educator

This material can also be used to make handouts and posters.

Helping-relationships aim to improve the quality of peoples' lives. They are at the core of providing effective treatment and care for PLWHAs. ***Helping-relationships are important because:***

- They bring together someone who needs treatment and care and someone who can respond to those needs in a supportive and effective manner.
- They are based on identifying the needs of the person seeking treatment and care and helping them to lead a better and longer life.
- They are two-way and both parties need to be open, cooperative and informed.
- They are based on trust and confidentiality and grow over time.

Session 9.9

Attitudes, Behaviour, Knowledge and Skills Needed for Care and Support Work

Expected Outcomes

Participants will understand what attitudes, behaviour, knowledge and skills are required to become an effective caregiver for PLWHAs.

Participants will make an attempt to develop the attitudes, behaviours, knowledge and skills required for taking care of PLWHAs.

Taking Care Is Serious Work

Objective To enable participants to understand that the knowledge, skills and attitudes of a person combine to provide care and support for a person living with HIV/AIDS.

To allow discussion that will lead to the discovery of the knowledge, skills and attitudes required to care and support a person living with HIV/AIDS.

Materials Flip charts, markers.

Time 1 hour.

Process Ask the participants to divide into 3 groups.

Explain that, in order to care for a person living with HIV/AIDS, certain knowledge, skills and attitudes and behaviours are mandatory. A combination of these three can lead to an improved quality of life for the person.

Ask the groups to do the following tasks and prepare a presentation:

Group 1: Make a list of the knowledge one would need to be able to take care and provide support for a person living with HIV/AIDS.

How can you gain this knowledge and help others access this knowledge?

Group 2: Make a list of the skills one would require to take care and provide support for a person living with HIV/AIDS.

How can you acquire the skills needed and help others to acquire them?

Group 3: Make a list of the attitudes and behaviours one needs to develop in order to take care of and provide support for a person living with HIV/AIDS.

How can you develop these attitudes and behaviour and promote them among others within the community?

Allow 30 minutes for this exercise.

Ask each group to make their presentation.

Encourage and facilitate discussion after each presentation. Elicit the socio-cultural, religious, economic and gender dimensions present within each.

Note for the Facilitator

This exercise is useful in creating awareness about the various knowledge, skills and attitudes/behaviours required to take care of and provide support to people with HIV/AIDS. Alternatively, you could use this exercise to create awareness about the roles of medical personnel, family and friends in the lives of people with HIV/AIDS. You could ask group 1 to work on the knowledge, skills and attitudes/behaviours of medical personnel, group 2 to work on the family and group 3 to work on friends. You could also use role-plays. Use your own judgment to decide which method is most appropriate for the make up of the participants.

Helpline for the peer educator

This material can also be used for making handouts.

Knowledge, skills, attitudes and behaviours are all important for establishing helping relationships and providing effective care and treatment to people living with HIV/AIDS.

Knowledge - an understanding of information and ideas. It is important for HIV/AIDS related care and treatment because it allows the caregivers to understand what is going on. They can reassure the person seeking help and suggest the most appropriate plan of action. It is important that knowledge is kept up to date so that it can be the basis for providing the best possible care and treatment.

Skills - knowing how to do something. They might relate to technical work (such as how to prescribe medication) or “people” work (such as how to support a person with HIV/AIDS to communicate their care and treatment needs). Some of the most essential skills for providing effective treatment and care include listening, planning and taking action.

Attitudes - the way in which individuals view issues and other people. Appropriate attitudes are vital for people involved in HIV/AIDS related care and treatment work. For example, if a person is open and genuine rather than condemning or pitying of people living with HIV/AIDS, it will help the PLWHAs to come forward for help and take care of themselves. It is also important for people involved in care and treatment to be respectful and accepting of socially marginalized groups, such as sex workers, prisoners, men who have sex with men or injecting drug users.

Behaviours Mean the actions and expressions used by people to demonstrate their feelings, concerns and views. These are often a combination of knowledge, skill and attitudes.

Some examples of the knowledge, skills, attitudes and behaviours needed for effective HIV/AIDS care and treatment:

Knowledge	Skills	Attitudes	Behaviours
Basic of HIV/AIDS	Communication related to asking questions, listening and confirming	Compassion	Listening
Nutrition		Respect	Giving a hug
Health education	Planning/managing in consultation with the PLWHA	Sensitive	Discussing feelings and concerns
Positive living		Non - judgmental	Helping in chores and running errands
HIV/AIDS related treatment related to symptoms and causes, common problems, drugs and new treatments	Follow up and referral	Honesty	Picking up medication and giving medication
	Training	Common sense	
	Counselling	Equality	Giving an injection or administering an IV drip
Human rights issues	Building trust	Positive and encouraging	Writing and distributing information
Psychosocial issues	Moving at the PLWHAs pace		
Vocational possibilities	Sharing information		Attending support meetings

Good information is vital for care and treatment work, as it enables the PLWHAs and the caregivers to make joint decisions about what will be appropriate and effective. The relevant information needs to be:

- Objective** Meaning that it is “neutral”, not affected by discriminatory attitudes, and free of bias.
- Accurate** Meaning that it is up to date and gives people a clear idea about their situation and possibilities.
- Simple** Meaning that it is communicated in a way understood by the persons involved.

No one person or organization can address all of the care and treatment needs of a person living with HIV/AIDS. Working with others can help to improve access to treatments, care and other resources that may be required. It can also improve the quality of care and treatment and help to reach more people who may be in need of similar help and support.

- Community and solidarity groups/peer groups can provide personal support for PLWHAs and keep others in touch with their needs.
- NGOs/CBOs can provide training, information, ideas, material support and skills such as counselling, finances and treatment.
- Government systems can provide policies, leadership, human resources and material support such as skilled health workers and medication for treatment.

- Businesses provide financial or “in kind” sponsorship for treatment and care and encourage public support for PLWHAs.
- Professional associations and academic institutions can contribute to knowledge, guidance, information, research and generating new knowledge that may be helpful in improving care and treatment.
- Donors can provide funds for care and treatment and facilitate learning from the experiences of other countries.
- Religious organisations can provide volunteers for care and treatment and mobilize community support and help to reduce stigma and discrimination.
- Media can provide accurate information about care and treatment issues and help to raise awareness and reduce stigmatization.

The following table indicates people and places that can be helpful to PLWHAs:

Home/family	Community/peer group	Health care facilities
Universal precautions to prevent transmission of HIV. Safer sex practices including family planning. Personal and environmental hygiene practices. Emotional support for PLWHAs. Nutrition and safety of food and water supply. Using medicine and traditional remedies correctly and adhering to treatment regimes. Sharing information about where to access more support.	Social support and counselling. Access to volunteers and testing. Support groups for sharing work and information. Accompanying people for treatment. Nutritional/food needs. Providing condoms, bleach and clean syringes. Access to family planning services. Advocacy. Assistance to vulnerable groups such as orphans or young people living alone. Financial support. Legal support. Management of drug supplies. Bereavement and funeral support. Sports and recreational activities. Emotional support.	Voluntary testing. Access to safe blood and blood products. Clinical management of pain, malaise, fever and opportunistic infections. Treatment of STIs. Preventive treatments. Nutritional assessment and counselling. Antiretroviral therapies. Clinical and laboratory monitoring of progression of illness. Access to breast milk substitutes.