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# Guidelines for Care and Support of People Living with HIV

Compiled by

The Humsafar Trust



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## Foreword

The Humsafar Trust has been working on various aspects of HIV since the past 25 years. In the light of high prevalence of HIV in the MSM and Transgender community, The Humsafar Trust has undertaken several pioneering innovations towards prevention and treatment of HIV. While working closely with national programs, we have come across multiple areas for improvement in the treatment, care and support of HIV. Considering the needs of MSM and Transgender Community, a support group was set-up at Humsafar in 2003 for community members living with HIV, which was registered in 2010 as 'Sanjeevani'.

Since last 15 years, Sanjeevani has been working as a community support group which provides holistic care and support to people living with HIV, connects them with one another, is committed to address HIV-related discrimination and aims to change societal attitudes regarding issues related to HIV. What sets apart Sanjeevani is the fact that it is an initiative for the community by the community itself, in which MSM and transgender people living with HIV not only motivate each other but also struggle together for their rights. This initiative is different from the work done under national programs and other non-community organizations because its *modus operandi* depends on the specific needs of the MSM and transgender community which has been living on the margins.

In the last fifteen years, we have worked with many government and non-governmental organizations and have made a strong model of holistic care and support. Through these guidelines, we want to share with other organizations what we have learnt over time.

Sanjeevani's health facilitators have been the foundational pillars of this model. It is the outcome of their relentless perseverance that today Sanjeevani's work is deemed with great respect by the medical fraternity in Mumbai and the community alike. Community-based organizations can use these guidelines in training of community health facilitators. Through these guidelines, we want to create a team of such health facilitators, who not only possess the scientific and practical knowledge of HIV, but can become true companions in the journey of people living with HIV and make their lives easier in all possible ways.



Vivek Anand

Chief Executive Officer- The Humsafar Trust

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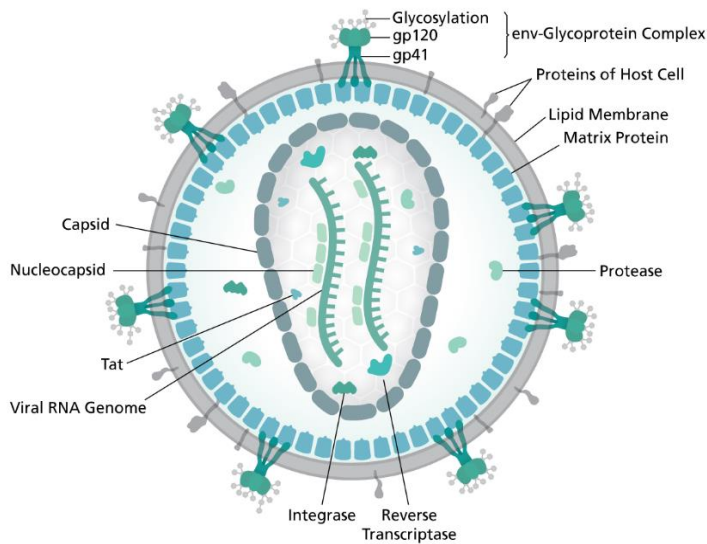
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## Chapter 1

### Information about HIV

#### What is HIV?

HIV or Human Immunodeficiency Virus is a virus which attacks the human immune system and weakens it.



Viruses are particles which can only replicate inside a living cell. Outside the cell it remains inactive but activates once it enters a living cell. Viruses cannot replicate without a living medium or living cells of the host.

**Image 1: Diagram of HIV Virus**

Two HIV species are known: HIV-1 and HIV-2. HIV-1 is more virulent and infectious and is the cause of the majority of HIV infections globally. HIV-2 is largely confined to West Africa.

#### How does HIV spread?

HIV can be transmitted through blood, semen, vaginal discharge, pre-ejaculate or mother's milk. The transmission of HIV is mainly caused through the following routes:

- *Sexually Transmitted:* Most HIV transmission is caused by unprotected sexual intercourse.
- *Blood and blood products:* Usually contact with infected blood causes HIV transmission. HIV-infected needles, clinical equipment and infected blood transmits HIV.
- *Parent to child:* HIV is transmitted to the child by their parents during pregnancy (in utero) during delivery (intrapartum), or while breast-feeding. However, with availability of antiretroviral treatment and caesarean section, this risk can be reduced to almost 1 percent.

Prevention of Parent to Child Transmission - PPTCT is part of the national program which works with the aim of preventing infection in children during pregnancy and birth. There are many precautions mentioned in the guidelines of PPTCT related to anti-retroviral drugs, pre-natal and post-natal care, breastfeeding and hygiene which can significantly minimize HIV transmission from parent to child.

## How does HIV work in the human body?

HIV infects cells key to the human immune system, such as helper T cells, macrophages, and dendritic cells. All of these cells have a protein called CD4 on their surface. HIV binds with CD4 and other surface proteins and enters the cells.



### Simply Put

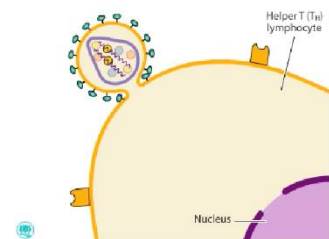
Helper T-cells, macrophages and dendritic cells present in the human body protect the body from various diseases and external infections. HIV increases the possibility of contracting infections by infecting and destroying these cells.

There are different stages in the replication cycle of HIV. To understand how HIV attacks on cells and how it weakens the human immune system, it is necessary to understand the replication cycle of HIV.

### Stages in the replication cycle of HIV

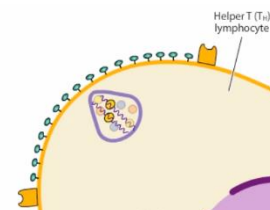
#### Binding and Fusion

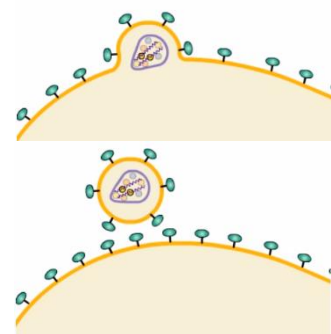
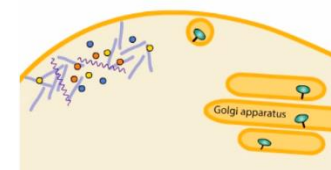
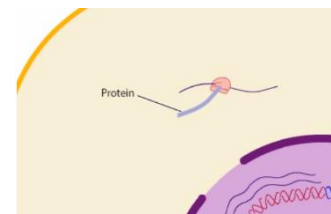
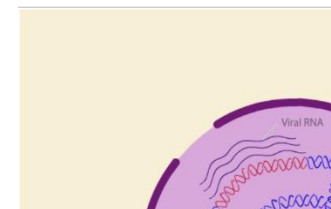
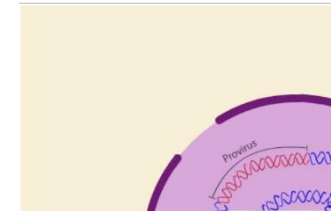
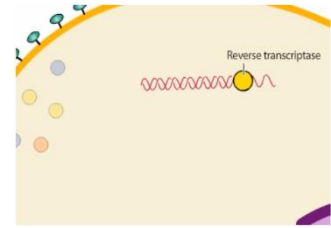
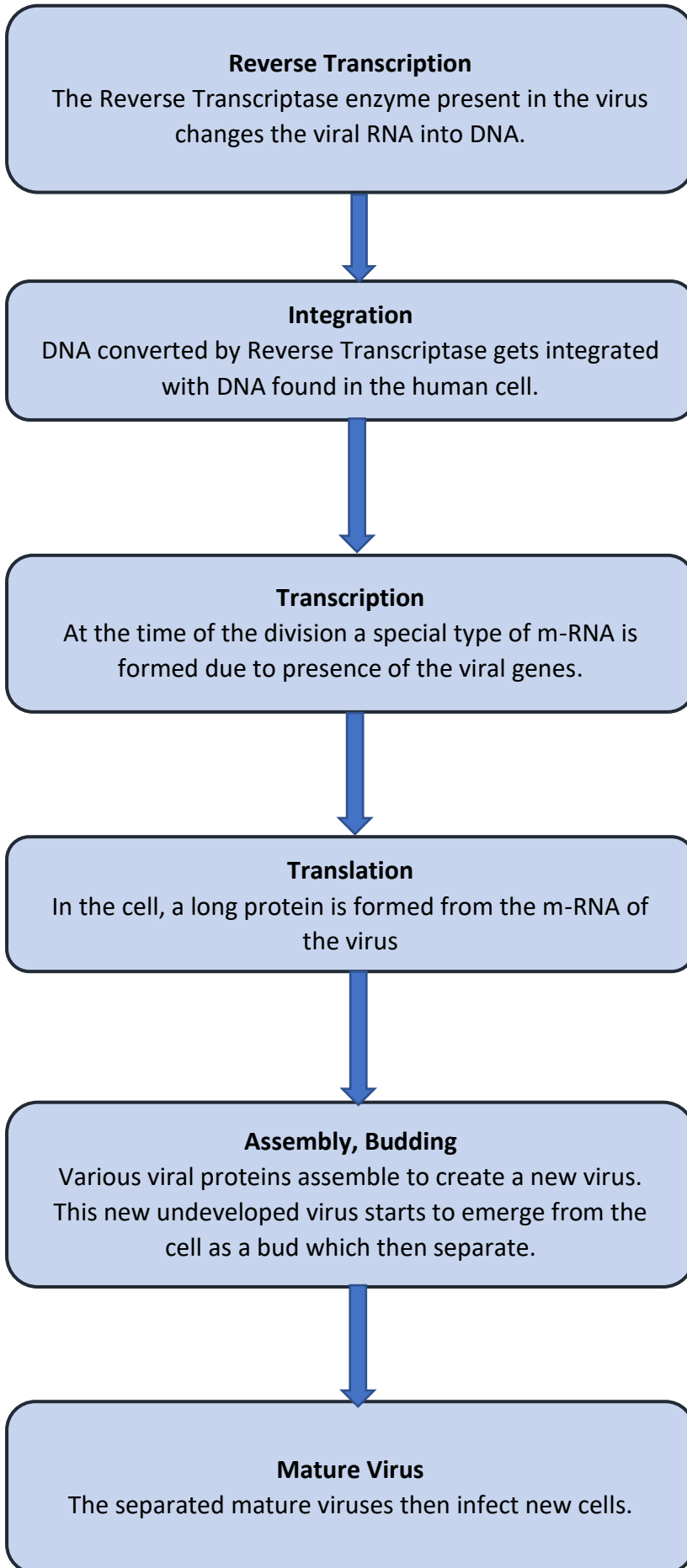
At the surface of the cell there are several receptor particles. HIV binds with some of these receptors and fuses into the cells.



#### Infection

After binding and fusing into the cell, genetic material of the virus enters the cells and the process of infection begins







### Simply Put

HIV enters in human body cells and uses them to create many copies of HIV like photocopies. These copies destroy the host cells and attack other cells in the body.

Anti-retroviral therapy (ART) is a treatment by which the virus replication mechanism is stopped before completion and healthy cells of the immune system are saved from getting affected. At every stage of HIV replication mechanism, different medicines are used to prevent its progress. Sometimes even after administering medicines, the virus keeps on replicating because the person's body does not respond to any of the drugs. It is called drug resistance.

## Opportunistic Infections (OIs) and other HIV-related infections (Co-infections)

There are several bacteria and viruses present in our body. When our body's immune system is working properly, it keeps these bacteria and virus in control. But when the immune system gets weakened due to HIV or other reasons then these bacteria and virus cause various diseases and health problems. Infections which take advantage of a weakened immune system and grow are known as Opportunistic Infections.

### 1. TB - Tuberculosis



TB is a common but deadly infectious disease caused by a type of bacteria called *Mycobacterium tuberculosis*. This bacteria spreads through air. When someone with an active TB infection coughs, sneezes, or transmits their saliva in some other way then it increases the probability of transmitting infection to other people. Most infections are latent, but one out of ten infections eventually turn to active infection. If left untreated, it causes death in over 50% infected people.

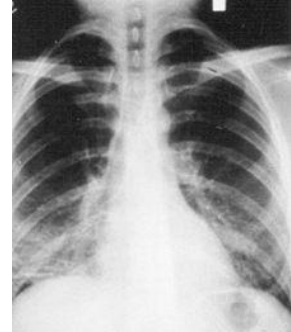
People living with HIV are more prone to contract active TB infection. Usually TB affects lungs but it can also affect other body parts. Symptoms of TB can be chest pain and prolonged cough and mucus. In some cases, lymph node enlargement may also be observed. Approximately 25% =infected people may not have any symptoms, i.e. they can remain asymptomatic. Occasionally, a small amount of blood may be present with cough, and in very few cases, the infection can reach the pulmonary artery, which can lead to massive bleeding.

In 15-20% of active cases, infection spreads outside the lungs, which can lead to other types of TB. In people living with HIV, this happens in over 50% cases with TB co-infection.

According to National AIDS Control Organization (NACO) guidelines, people living with HIV should be promptly investigated and treated for TB (Detailed information on management of TB in Chapter 3)

## 2. *Pneumocystis pneumonia*

*Pneumocystis pneumonia* is a common opportunistic infection. In absence of right treatment, about 85% people living with HIV are likely to have *Pneumocystis pneumonia*. Although this disease can be completely cured and prevention is also possible, approximately 10% of people die from it. This disease is caused by a fungus called *Pneumocystis jirovecii*, which attacks the lungs. Its initial symptoms include difficulty in breathing, fever and dry cough. Most people lose weight and experience weakness, which increases the likelihood of a re-infection. *Pneumocystis pneumonia* can be avoided by initiating ART on time and adherence.



## 3. Candidiasis – Thrush



Candidiasis (thrush) is a common opportunistic infection caused by a common fungus called *Candida*. This fungus is found in most people's bodies. A non-compromised immune system keeps this fungus in control. But when the immune system weakens from HIV, then this fungus starts growing. *Candida* usually infects the mouth, throat, and vagina. In Candidiasis, white patches or red sores arise on the tongue, in the throat or the vagina resulting in sore throat, difficulty in swallowing, vomiting, and lack of appetite. This infection can spread to the brain, heart, joints and eyes too. The infection can be controlled very easily from anti-fungal medications. Candidiasis can be avoided by initiating ART on time and adherence.

## 4. Herpes zoster – Shingles

Herpes zoster or shingles is caused by a type of herpes virus, *Varicella Zoster*. This is the same virus that causes chicken pox in children. The virus could into an inactive state post infection. When immune-compromised, the virus can again become active and cause shingles. This includes people living with HIV. The herpes zoster virus grows in the body's nerve cells. At the onset of infection, one could experience itching, numbness, tingling, or severe pain in the chest, back, nose and eyes. Few people may also present with herpes outbreaks on the face and around eyes. The infection could emerge as a red rash on the skin, which converts into small blisters. In most cases, these blisters get cured in a few weeks, but could cause severe pain for months in some cases. Herpes zoster mainly occurs in individuals with previous history of chicken fox. People who have not had chickenpox may be infected by contact with an active infection. There are many types of antiviral drugs and painkillers used for the treatment of herpes zoster.





## 5. Kaposi's Sarcoma



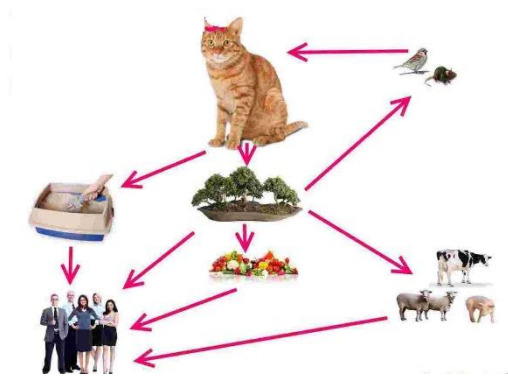
Kaposi's sarcoma is a type of cancer that observed among those immunocompromised, with HIV infection being the most common reason. It presents as red or purple spots on the face, hands or feet or the abdomen.

With the advent of effective ART medicines, incidence of Kaposi's sarcoma has decreased by 80%.

## 6. Toxoplasmosis

Toxoplasmosis is caused by a parasite called *Toxoplasma gondii* commonly found in soil, raw vegetables, raw meat, cat stool etc. It can also enter the body through the dust and is widely present in human bodies but a healthy immune system prevents it from causing any complications.

However, in immunocompromised conditions, the likelihood of multiple infections increases. The most common infection in this case presents as encephalitis. Toxoplasma can infect other parts of the body as well and result in coma and death. Early symptoms include fever, shivering, confusion, headache, or personality changes. Other symptoms include seizures, poor muscle control, palpitations, etc. Early initiation of ART can prevent toxoplasmosis. There are also medicines available for its treatment, which shows improvement in 80% of cases in 2-3 weeks.



## Sexually Transmitted Infections - STIs

Sexually Transmitted Infections are transmitted from one person to another by vaginal, anal, or oral sex. Some sexually transmitted infections can also be transmitted through the following mediums:

- By using infected needles/syringes or shaving blades
- Breastfeeding
- From open wounds or scratched skin
- By sharing clothes, bed, personal hygiene items or towels with an infected person

## Some Common Sexually Transmitted Infections:

### 1. Herpes



Sexually transmitted herpes is caused by Herpes Simplex Virus 1 - HSV 1 and Herpes Simplex Virus 2 - HSV 2. Generally, HSV 1 causes ulcers near oral areas and HSV 2 causes sores around genital areas. However, HSV 1 can infect genitals and HSV 2 can infect mouth area via oral sex. Initial symptoms include painful blisters or clots of inflamed papules and vesicles, itching, tingling, and

burning sensation at site of infection. Apart from this, there may be fever, body aches and swelling of lymph nodes. In some cases, there may be inflammation around the urethra requiring the use of catheters for urination. There may also be inflammation and burning sensation around the rectal sphincter due to herpes (rectal inflammation). Individuals could also be asymptomatic carriers. While sores/ulcers can be treated, herpes cannot be cured. In pregnant women, herpes can infect the child around and during gestation and delivery causing blindness, brain damage, or even death. Available anti-viral medicines could reduce the severity and frequency of occurrence of genital herpes. During pregnancy, the infant can be protected from virus infection by taking antiviral medicines and via caesarean delivery.

### 2. Gonorrhoea

Gonorrhoea is an infection caused by bacteria called *Neisseria gonorrhoeae*. It is one of the most common infections transmitted during sexual intercourse. It often affects the urinary tract, the vagina, the rectum or the throat and can be transmitted from an infected mother to child during delivery commonly affecting the infant's eyes. Early symptoms of gonorrhoea include irritation and pain during urination, pus formation in the penis, swelling or inflammation of the penile urethra, testicular inflammation or persistent pain in throat or a sore throat. Individuals could be non-symptomatic carriers. Untreated gonorrhoea can cause infertility in women and men. Gonorrhoea can be easily treated by antibiotics.



### 3. Chlamydia



Chlamydia is a sexually transmitted infection caused by a bacteria called *Chlamydia trachomatis*. Chlamydia symptoms and transmission methods are very similar to gonorrhoea. The most common symptoms related to Chlamydia include painful urination, yellow or green discharge from genital regions, pain in the lower abdomen, pain in the testicles, pain during intercourse. Chlamydia infection can also occur in rectal regions leading to pain or

bleeding. Oral sex can also cause infection in the throat and symptoms like soreness, cough or fever may occur. Individuals can also be asymptomatic. Chlamydia can be cured easily with antibiotics.

#### 4. Syphilis

Syphilis is a sexually transmitted infection caused by bacteria *Treponema palladium*. The first stage of syphilis is a small, round, painless blister around the mouth, genitals or anal regions.. This blister, known as a chancre, lasts for 2-6 weeks and then disappears due to which one may miss it. The secondary stage of syphilis presents as non-itchy rashes usually on palms and soles of the body around 6 months after the appearance of a chancre. The rashes clear soon after with no more symptoms appear for many years. However, syphilis remains present in the body and affects the body internally. In the third and final phase of syphilis, syphilis affects vital organs of the body and could result in cardiovascular syphilis, meningitis, mental illness, memory loss (neurosyphilis), damage to bone, skin lesions that may lead to death. Syphilis can be completely cured by penicillin antibiotic. However, the treatment cannot reverse the damage done earlier and thus early treatment is highly recommended.



#### 5. Genital warts



The genital warts are caused by *Human Papilloma Virus* (HPV). These are small bumps of flesh color with a cauliflower-like appearance. These warts can be found on the scrotum sac, anus, penis or vagina. Usually they do not cause pain but may present with itching and swelling. If there is swelling in a wart, then it can also cause bleeding from the urethra, vagina or anus. If the warts develop around or near the urinary tract, then they can inhibit the normal flow of urine. Treatment includes fine surgical procedures and medicines. Genital warts can be treated, but even after that, HPV remains in the body and sometimes warts could recur after treatment. The virus could clear on its own in some instances.

#### 6. Chancroid

Chancroid is a bacterial infection caused by bacteria called *Haemophilus ducreyi*. This STI presents as ulcers on and around genital regions. These ulcers release blood or fluid that transmit the STI during oral, anal or vaginal sex. Chancroid can also spread through the skin contact with an infected person. It can be successfully treated by medicines or surgery.



#### 7. Scabies



Scabies is an STI that causes itching, burning or rashes on the skin and is caused by a parasite *Sarcoptes scabiei*. Scabies is very contagious and spreads very easily from one person to another by close contact with the infected person even sharing of personal items such as clothes, bedding. Its symptoms include itching (mainly at night), rashes, scabs, and crusted on the skin. To prevent infection and transmission all clothes, towels, bedding

and private items from upto three days before starting treatment must be cleaned/washed using antiseptic detergents and exposed to sun. Further, all individuals living in close quarters and sexual partners of the infected person must receive treatment. For treatment, parasitocidal medicine is to be applied as directed by the physician.

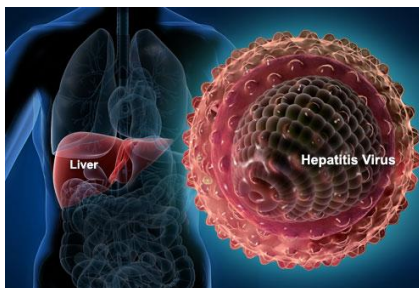
#### 8. Pubic Lice or crabs

Pubic lice are very small parasites that stick to the skin or hair near genital regions and suck blood. These parasites look like very small crabs. They spread very easily during sexual or intimate contact. Its symptoms include itching and rashes. Pubic lice can be treated easily with medicines in the form of shampoo, gel, or liquid. Sexual partners and close inhabitants of the infected person must undergo treatment. Disinfecting personal items such as bedding, clothing is crucial to avoid reinfection.



Using condoms during sexual intercourse can avoid a number of infections mentioned above. However, condoms are not very effective against STIs that are located in higher areas of genitals or non-genital regions.

## HIV and Hepatitis



Inflammation of the liver is known as hepatitis. Hepatitis could be caused by 5 main types of viral hepatitis: - Hepatitis A, B, C, D and E. Hepatitis A and E occur through contaminated food and water; Hepatitis B is sexually transmitted, is transmitted by a mother to child at the time of pregnancy or birth, infected needles, contaminated blood products and also some fomites. Hepatitis C both can spread through infected blood and infected needles/syringes.

Some people living with HIV are also infected with hepatitis B (HBV) and C (HCV). This is called co-infection. Hepatitis infection increases rapidly with HIV and creates serious, life-threatening problems. HIV–Hepatitis co-infection produces complications in the treatment and management of HIV. Treatment and management of hepatitis B and C is possible but requires caution. Both infections are treated with anti-viral drugs which affect the liver. While managing treatment of HIV and Hepatitis B/C co-infections doctors take care of contraindications of antiretrovirals on the other infections as well as side effects.

According to the advice of the World Health Organization (WHO), all HIV positive persons should be tested for Hepatitis B and C. There are vaccines for the prevention of hepatitis B, which should be given to each hepatitis B negative person.

## Chapter 2

### Post investigation of HIV

#### Investigation Of HIV



HIV antibodies, antigens, or RNA are detected in different ways while testing or investigating HIV.

Antigens are substances that are found in any virus or bacteria. When these viruses or bacteria enter the human body, the body produces antibodies to control the antigen. The body creates different antibodies to fight different antigens. These antibodies attach to the antigen and make the virus or bacteria inactive and protect the body from many diseases.

#### **Antibody test**

There may be four weeks to six months between HIV acquisition and measurable antibodies in the body. This is known as the window period. After the window period, antibodies can be tested through ELISA, Western Blot or Rapid Test.

#### **Antigen Test**

In antigen tests, P-24 protein found in HIV is tested and can be done within 2-4 weeks of infection. New Gen 4 ELISA tests can test both antibody and antigen.

#### **RNA Tests NAAT - Nucleic Acid Amplifications tests**

This test has been developed to detect HIV RNA with a technique called polymerase chain reaction. With this test HIV infection can be diagnosed in initial 4 weeks, even before antibodies are formed. This although expensive compared to other tests is currently available in India and is used in emergencies.

## Pre and Post Test Counselling



Counselling is an important part HIV testing. Before testing, Pre-test Counselling is offered through posters, flip-charts, brochures and videos. In this, the person is prepared for HIV test and general information about HIV and AIDS such as the medium of transmission, window period, methods of prevention and treatment and support is provided. The person is also told about the confidentiality of the

testing process and their rights related to investigation. According to the National Guidelines, efforts should be made to give results on the same day, and the person should be offered post-test counselling before giving the result. Whatever the outcome of the investigation, it is mandatory for each person to get post-test counselling. If the results of the person's first investigation reveal a positive result then a confirmatory test is done at another check centre (SA-ICTC) prescribed by NACO. If the test is positive again then post-test counselling should be done keeping in mind that being HIV positive is a life-changing event.

In post-test counselling the person is explained about the result of the investigation and provided adequate time to deal with his feelings. Further, proper information is provided about ART such as where ART is available, when it should be started, how many medicines have to be taken, what to check before starting ART, what are the advantages and side-effects importance of ART adherence, importance of proper nutrition and a healthy, intoxicant lifestyle, why it is important to avoid unprotected sex and opportunistic infections.



## Accepting HIV status

It is very difficult for most people to accept their HIV positive status. Many people refuse their HIV positive status for a long time and do not start treatment. Many people go into depression and their desire to live ends. For these reasons, many times HIV-positive people break all contact with health facilitators and the organization and it becomes difficult to reach them. Many migrants go to their village or native place and it becomes more difficult to contact them. Such cases are called lost-to-follow-up cases (LFU).

## Role of PLHIV Health Facilitator

PLHIV health facilitators have an important role in reducing LFU cases and connecting HIV positive people with ART. In The Humsafar Trust, our PLHIV support group Sanjeevani, assists persons living with HIV and has made several efforts to connect people with treatment.

After post-test counselling, Positive Living Counselling is done, which encourages people to adopt positive attitude towards life. Many health facilitators living with HIV, who themselves disclose their HIV status voluntarily, are the source of inspiration for others and also help them to live life with new enthusiasm. Health facilitators tell people about the facilities available in Sanjeevani and The Humsafar Trust, establish their contact with nutritionist for proper nutrition and tell them about government hospital procedures, ART registrations for treatment and management of TB, hepatitis and other sexually transmitted infections. Once tested positive, it is also important to know the importance of test and treat. In addition, another positive person is identified for assistance and peer support in treatment as their treatment buddy.



## Chapter 3

### ART Linkage

#### Test and treat

In 2015, the World Health Organization (WHO) announced that all HIV positive persons should be started on treatment as soon as possible. According to this suggestion of "treat all", all qualifying criteria should be removed for a person to get on treatment. Extensive use of ART treatment not only increases the likelihood of a person's healthy life, but also reduces the possibility of infection in their sexual partners (Treatment as Prevention).



In April 2017, the Indian government also implemented the 'Test and Treat Policy'. According to this policy, all people living with HIV should begin ART treatment regardless of their CD4 count, their health or their clinical condition and irrespective of the age group or population group they belong to.

#### Process of Registration in ART Centre

All individuals who test positive for HIV are referred to the nearest ART centre.

Efforts are made that every positive individual gets registered at the nearest ART centre from their homes so that they can take ART from the centre on time and without any interruption to ensure ART adherence. However, due to societal stigma and discrimination associated with HIV, people prefer to register at a centre which is far away from their homes. In such case it is critical that health facilitators explain the importance of taking ART regularly so that the people do not miss their ART dose in any situation.



During post-test counselling, an individual should be given the full address and telephone number of the ART centre. The person has to take the following three things at the time of ART registration:

- 1) Government ICTC report
- 2) Original and copy of Aadhaar card or a valid address proof
- 3) 2 Passport-Size Photographs



During registration at the ART centre, some general information about the person is recorded in the Patient Treatment Record or White Card.

White Card

The ART No. or ART Registration No. \_\_\_\_\_  
 ID No. as per child health card \_\_\_\_\_

ART Registration Number : \_\_\_\_\_  
 Date of start of ART : \_\_\_\_\_

**PATIENT TREATMENT RECORD**  
 (To be stored in a locked cabinet at the ART centre and arranged serially by registration number to be filled for all patients)

<p><b>1. Identification Data (Write complete information)</b></p> <p>Date of Registration: <u>15/01/2010</u> Treatment status at registration: On ART <input type="checkbox"/> Not on ART <input type="checkbox"/></p> <p>Name of ART Centre / City: <u>MS&amp;CS, Thane</u> ART Centre Code: _____                  State: <u>MHARASHTRA</u></p> <p>Name of patient: _____                  Age: (state of birth: _____) Sex: <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> TGTS*</p> <p>Patient's phone number: _____                  Address: _____                  City/Village: _____ District: <u>Thane</u> State/province: <u>MAHARASHTRA</u></p> <p>Caregiver's name: _____                  Caregiver's address and phone number: _____</p> <p>Date confirmed HIV+ test: _____ Place of HIV Test: _____</p> <p>Entry point (services referring the patient for HIV care): <input type="checkbox"/> VCTC <input type="checkbox"/> TB-RNCP <input type="checkbox"/> Outpatient <input type="checkbox"/> Inpatient  <input type="checkbox"/> 5-Private <input type="checkbox"/> 6-PPTCT <input type="checkbox"/> 7-STI clinic <input type="checkbox"/> 8-Private practitioner <input type="checkbox"/> 9-Other NGO <input type="checkbox"/> 10 Self referred  <input type="checkbox"/> 11-IGU outreach <input type="checkbox"/> 12- Sex worker outreach <input type="checkbox"/> 13-PLHA network <input type="checkbox"/> 14-NGM <input type="checkbox"/> 15-Other _____</p> <p>Patient transferred in on ART from: <input type="checkbox"/> ARTC <input type="checkbox"/> Private _____                  Name of previous clinic: _____ Date transferred in: _____</p> <p><b>2. Personal History (Mark all applicable)</b></p> <p>Risk factor for HIV: <input type="checkbox"/> 1-Heterosexual <input type="checkbox"/> 2-MSM <input type="checkbox"/> 3-Injecting drug use (IDU) <input type="checkbox"/> 4-Blood transfusion <input type="checkbox"/> 5-Mother to child <input type="checkbox"/> 6-Probable unsafe injection <input type="checkbox"/> 7-Unknown</p> <p>For IDU: Substitution therapy <input type="checkbox"/> Y <input type="checkbox"/> N</p> <p>Education: <input type="checkbox"/> Non-literate <input type="checkbox"/> Primary school <input type="checkbox"/> Secondary school <input type="checkbox"/> College &amp; above</p> <p>Employer: <input type="checkbox"/> Yes <input type="checkbox"/> No Occupation: _____</p> <p><b>3. Family History</b></p> <p>Mental status: <input type="checkbox"/> Single <input type="checkbox"/> Married <input type="checkbox"/> Divorced/separated <input type="checkbox"/> Widowed <input type="checkbox"/> Live-in</p> <p>Estimated monthly household income: _____</p> <p>Family members: <input type="checkbox"/> Spouse <input type="checkbox"/> Children <input type="checkbox"/> Parents <input type="checkbox"/> Grandchildren</p> <p>Age: _____ HIV sero: _____ ART status: _____ Regid. No: _____</p> <p><b>4. Antiretroviral treatment History</b></p> <p>Were ARVs received? <input type="checkbox"/> Yes <input type="checkbox"/> No Initial CD4 count No. _____ % _____ Place of ART: <input type="checkbox"/> Private <input type="checkbox"/> Govt. <input type="checkbox"/> NGO</p> <p>Drugs and duration: _____</p> <p>If yes: <input type="checkbox"/> PMTCT <input type="checkbox"/> ART <input type="checkbox"/> PEP</p>	<p><b>5. Clinical and Laboratory Investigations (Summary)</b></p> <table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th>Date</th> <th>WHO clinical</th> <th>Weight</th> <th>Height</th> <th>Functional</th> <th>CD4 count</th> </tr> </thead> <tbody> <tr> <td>At 1st visit in clinic</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>At ART medical eligibility</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>At start of ART</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>At 6 months ART</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>At 12 months ART</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>At 24 months ART</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>At 36 months ART</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>At 48 months ART</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> </tbody> </table> <p><b>6. Antiretroviral Treatment (Summary)</b></p> <p><b>SUBSTITUTION within 1<sup>st</sup> line, SWITCH to 2<sup>nd</sup> line, STOP, RESTART</b></p> <table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th>Date</th> <th>Substitution, switch or stop</th> <th>Reason (code)</th> <th>Date restart</th> <th>New regimen</th> </tr> </thead> <tbody> <tr> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> </tbody> </table> <p>Reasons for SUBSTITUTION: 1- Toxicity, side effects 2- Pregnancy 3- Newly diagnosed TB                  4- New drug available, 5- other reason (specify) _____</p> <p>Reasons for SWITCH: 1- Clinical treatment failure 2- Immunological failure 3- Virologic failure                  Reason for STOP: 1- Toxicity, side effects 2- Pregnancy 3- Treatment failure 4- Poor adherence 5- Illness/hospitalisation                  6- Patient lost to follow-up 7- Patient non-compliance 8- others _____</p> <p><b>7. Tuberculosis treatment (RNCP) during HIV care</b></p> <p>Diagnosis (date): _____ TB regimen (code): _____</p> <p><input type="checkbox"/> Primary TB <input type="checkbox"/> Category I <input type="checkbox"/> TB registration  <input type="checkbox"/> Extra-pulmonary <input type="checkbox"/> Category II <input type="checkbox"/> Dissect <input type="checkbox"/> TB Unit  <input type="checkbox"/> Extensive disease <input type="checkbox"/> Category III <input type="checkbox"/> Health Centre  <input type="checkbox"/> S. equipment <input type="checkbox"/> Other severity <input type="checkbox"/> TB number  <input type="checkbox"/> Past history of TB <input type="checkbox"/> HIV co-MDR <input type="checkbox"/> Rx number                  Date start TB Rx: _____ Date last visit: _____</p> <p>Treatment outcome: <input type="checkbox"/> Cure <input type="checkbox"/> Rx completed  <input type="checkbox"/> Rx failure <input type="checkbox"/> Died <input type="checkbox"/> Default <input type="checkbox"/> Transfer out                  Date: _____</p> <p><b>8. Reasons for Stopping ART</b></p> <p><input type="checkbox"/> Death <input type="checkbox"/> Transferred out <input type="checkbox"/> On medical advice <input type="checkbox"/> Lost to follow-up (&gt;3 months)</p> <p>Date of death: _____ Date last visit: _____                  Date last visit: _____ Date last visit: _____</p> <p>New ART centre name: _____</p>	Date	WHO clinical	Weight	Height	Functional	CD4 count	At 1st visit in clinic						At ART medical eligibility						At start of ART						At 6 months ART						At 12 months ART						At 24 months ART						At 36 months ART						At 48 months ART						Date	Substitution, switch or stop	Reason (code)	Date restart	New regimen																				
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Instructions: Sections 1-3 to be filled by Counselor. Sections 4-13 by Physician/Doctor.  
 \*TGTS: Transgender/Transsexual. Functional status: W - Working - able to perform usual work in or out of the house. Non-Work - Able to perform activities of daily living but not able to work.  
 † - Bedridden - Not able to perform activities of daily living.  
 © National AIDS Control Organization (NACO), Ministry of Health and Family Welfare, Government of India, February 2007

<p><b>9. Medical History</b></p> <p>History of Alcohol use: <input type="checkbox"/> Moderate <input type="checkbox"/> Social <input type="checkbox"/> Never</p> <p>Habit of Smoking: <input type="checkbox"/> Current smoker <input type="checkbox"/> Past smoker <input type="checkbox"/> Never</p> <p><input type="checkbox"/> HIV carrier <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown</p> <p><input type="checkbox"/> HCV carrier <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown</p> <p><input type="checkbox"/> STI <input type="checkbox"/> Diabetes <input type="checkbox"/> Hypertension <input type="checkbox"/> Cardiovascular disease</p> <p>Coexisting conditions: _____</p> <p>Current Medication: _____ Drug allergy: _____</p> <p>Contraception: 1- Condoms 2- Oral contraceptives 3- IUD 4- Tubal ligation 5- Vasectomy 6- None</p> <p><b>GYNECOLOGICAL HISTORY</b></p> <p>G: _____ P: _____ A: _____ Last Menstrual Period: _____ day _____ month _____ year</p> <p>RMP smear: _____ Pregnant now: <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>Gynecological exam: Refer to PPTCT: <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>Other Remarks: _____</p> <p><b>10. Linkages to NGOs/Care Institutes</b></p> <table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th>Date</th> <th>Name of Institute / Organization and type*</th> <th>Purposes**</th> </tr> </thead> <tbody> <tr> <td> </td> <td> </td> <td> </td> </tr> <tr> <td> </td> <td> </td> <td> </td> </tr> </tbody> </table>	Date	Name of Institute / Organization and type*	Purposes**							<p><b>11. Pediatric Patients (under 15 years of age)</b></p> <p>Staying with: 1- Own family 2- In a center but contact with family                  3- In a center but no family contact 4- Others _____</p> <p>Guardian / Caregiver: 1- Self 2- Parents 3- Relatives 4- Friends 5- Others _____</p> <p>Sex: <input type="checkbox"/> Male <input type="checkbox"/> Female Age: _____ years Date of birth: _____ day _____ month _____ year</p> <p>Guardian/Caregiver's highest education: <input type="checkbox"/> Non-Literate <input type="checkbox"/> Primary School <input type="checkbox"/> Secondary School <input type="checkbox"/> College and above</p> <p>Birth History: 1- Normal 2- Caesarian 3- Vacuum 4- Forceps                  Birth Weight: _____ Neonatal complications: _____</p> <p>Infant feeding: 1- Breast (stop _____ months of age) 2- Replacement 3- Mixed</p> <p>DNA PCR results: 1<sup>st</sup> _____ 2<sup>nd</sup> _____                  Others: _____</p> <p>Neurodevelopment Normal: <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p><b>Immunization Record</b></p> <table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th>Age</th> <th>Vaccine</th> <th>Due on</th> <th>Given on</th> <th>Age</th> <th>Vaccine</th> <th>Due on</th> <th>Given on</th> </tr> </thead> <tbody> <tr> <td>Birth</td> <td>BCG</td> <td></td> <td></td> <td>15-18 months</td> <td>MMR</td> <td></td> <td></td> </tr> <tr> <td></td> <td>OPV 1</td> <td></td> <td></td> <td></td> <td>DPT 1 booster</td> <td></td> <td></td> </tr> <tr> <td></td> <td>HBV 1</td> <td></td> <td></td> <td></td> <td>OPV 6</td> <td></td> <td></td> </tr> <tr> <td>6 weeks</td> <td>DPT 1</td> <td></td> <td></td> <td>5 years</td> <td>DPT 2 booster</td> <td></td> <td></td> </tr> <tr> <td></td> <td>OPV 2</td> <td></td> <td></td> <td></td> <td>OPV 7</td> <td></td> <td></td> </tr> <tr> <td></td> <td>HBV 2</td> <td></td> <td></td> <td>10 years</td> <td>TT 3</td> <td></td> <td></td> </tr> <tr> <td>10 weeks</td> <td>DPT 2</td> <td></td> <td></td> <td>15-16 yrs</td> <td>TT 4</td> <td></td> <td></td> </tr> <tr> <td></td> <td>OPV 3</td> <td></td> <td></td> <td colspan="4" style="text-align: center;">Others vaccines</td> </tr> <tr> <td>14 weeks</td> <td>DPT 3</td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td></td> <td>OPV 4</td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>8-9 mths</td> <td>OPV 5</td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td></td> <td>HBV 3</td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>9 months</td> <td>Mumps &amp; Var A</td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> </tbody> </table>	Age	Vaccine	Due on	Given on	Age	Vaccine	Due on	Given on	Birth	BCG			15-18 months	MMR				OPV 1				DPT 1 booster				HBV 1				OPV 6			6 weeks	DPT 1			5 years	DPT 2 booster				OPV 2				OPV 7				HBV 2			10 years	TT 3			10 weeks	DPT 2			15-16 yrs	TT 4				OPV 3			Others vaccines				14 weeks	DPT 3								OPV 4							8-9 mths	OPV 5								HBV 3							9 months	Mumps & Var A						
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\* 1- NGO, 2- Community Care and Support, 3- PLHA network, 4- Others  
 \*\* 1- Adherence, 2- Education, 3- Psychological support, 4- Others

All this information is recorded by the ART Counsellors in their own HIV registers and a Green Book which is given to the HIV positive person.

**Green Book**

**NACO Patient Booklet (Green Booklet)**  
(To be retained by the patient)

Name of ART Centre/LAC/LAC plus \_\_\_\_\_

District: \_\_\_\_\_ State: \_\_\_\_\_

Patient's name: \_\_\_\_\_ Age: \_\_\_\_\_ Sex: \_\_\_\_\_

Current address(Full): \_\_\_\_\_

Village/City: \_\_\_\_\_ District: \_\_\_\_\_ State: \_\_\_\_\_

ICTC PID No. and Date: \_\_\_\_\_

Permanent Address (Full): \_\_\_\_\_

Village / City: \_\_\_\_\_ District: \_\_\_\_\_ State: \_\_\_\_\_

HIV Care (PreART) registration number & Date \_\_\_\_\_

ART registration number & Date: / /

Date of ART initiation: / /

LAC/LAC plus registration number / Date: / /

Name of care giver / guardian: \_\_\_\_\_

Phone number of care giver / guardian: \_\_\_\_\_

Address of care giver/guardian: \_\_\_\_\_

Alternate Contact Number: \_\_\_\_\_

Patient's photograph

**Summary**

Name of ART centre/LAC PLUS: \_\_\_\_\_

State: \_\_\_\_\_ District: \_\_\_\_\_

Baseline Cd4: \_\_\_\_\_

WHO Clinical stage at start: \_\_\_\_\_

Initial Regimen: \_\_\_\_\_ Date: \_\_\_\_\_

Changed Regimen: \_\_\_\_\_ Date: \_\_\_\_\_

ATT Regimen: \_\_\_\_\_ Start: \_\_\_\_\_ End: \_\_\_\_\_

Pregnancy: \_\_\_\_\_ Date: \_\_\_\_\_

Reason for "Stopped" treatment: \_\_\_\_\_ Date: \_\_\_\_\_

Remarks (if any): \_\_\_\_\_

**Counselling / Clinical Notes**

Date of Visit: \_\_\_\_\_

Counselling Notes: \_\_\_\_\_

Investigations: \_\_\_\_\_

Chief Complaints: \_\_\_\_\_

Treatment: \_\_\_\_\_

Clinical Examination (Major Findings): \_\_\_\_\_

Weight: \_\_\_\_\_

WHO Clinical Stage: \_\_\_\_\_

Sign: \_\_\_\_\_

Opportunistic Infections	Date	Date	Opportunistic Infections	Date	Date
Tuberculosis (Pulmonary)			Herpes Zoster		
Tuberculosis (Extra-Pulmonary)			Bacterial Infections (Respiratory)		
Candidiasis			Toxoplasmosis		
Diarrhea			CMW Retinitis		
PCP			MAC		
Bacterial Infections (Skin)			Herpes Simplex		
Herpes Simplex			Malignancy		
Other (Specify)			Other (Specify)		

**CD4 Test Reminder**

**Pre ART Phase till initiation of ART**

Recommended Schedule	Baseline 0 Month	At 6th Month	At 12th Month	At 18th Month	At 24th Month	At 30th Month
Date (test done)						
CD4 Count						

**After initiation of ART**

Recommended Schedule	Baseline 0 Month	At 6th Month	At 12th Month	At 18th Month	At 24th Month	At 30th Month
Date (test done)						
CD4 Count						

**Unscheduled CD4 Tests**

Date (test done)	CD4 Count	Indication

**लक्षात ठेवा**

- प्रत्येक वेळेस तपासणीसाठी येताना हे पुस्तक सोबत आणावे.
- सर्व औषधांची मात्रा न विसरता घ्यावीत.
- सर्व औषधे दिलेल्या वेळेवर घ्यावीत.
- आपली औषधी मात्रा संपूर्ण घ्यावीत. औषधे परिवारत किंवा मित्रात वाटून घेऊ नयेत.
- उपचारातील नियमितपणामुळे तुमचे बदन चांगले, परीणामी सुधारला पाहिले काटेरास व देखिल कामे सुरूकित करू शकाल.
- निरोगी आरोग्यासाठी अनाकारदार जीवनशैली अवलंबा.
- प्रत्येक भेटाच्या वेळेस वारंवारलेली गोळ्यांची डबी/पाकेट सोबत आणावे.

तातडीच्या उपचारासाठी संपर्क: \_\_\_\_\_

(उपचार वेळ/आरोग्य कर्मचारी यांचे नाव/पत्ता/फोन नं.) \_\_\_\_\_

**पुन्हा भेटाची तारीख**

वेळ	१	२	३	४	५
१	१३	२५	३७	४९	
२	१४	२६	३८	५०	
३	१५	२७	३९	५१	
४	१६	२८	४०	५२	
५	१७	२९	४१	५३	
६	१८	३०	४२	५४	
७	१९	३१	४३	५५	
८	२०	३२	४४	५६	
९	२१	३३	४५	५७	
१०	२२	३४	४६	५८	
११	२३	३५	४७	५९	
१२	२४	३६	४८	६०	

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## HIV Assessment



Before starting ART, clinical assessment of every person is done, their clinical history is taken and their physical examination is conducted so that:

- The clinical state of HIV infection can be traced (to what extent the infection has progressed and what diseases and symptoms related to the infection are present in the body)
- Chronic diseases can be detected, especially those that are related to HIV
- Current illnesses related to HIV can be found out, for which treatment is needed.
- Such opportunistic infections, sexually transmitted diseases or other health conditions or treatments can be detected which may influence the choice of ART regime an individual is put on.

### Drugs available under Anti-Retroviral Treatment (ART)

At present, under the National Program, the following drugs are available as first-line ART

- Zidovudine - 300 mg + Lamivudine - 150 mg
- Tenofovir - 300 mg + Lamivudine - 150 mg
- Zidovudine - 300 mg + Lamivudine – 150 mg + Nevirapine - 200 mg
- Efavirenz - 600 mg
- Nevirapine - 200 mg

## Essential and Periodic Investigations

According to the National Guidelines, following tests are deemed necessary or mandatory before starting ART treatment:

- Haemogram or Complete Blood Count
- Urine for Routine and Microscopic examination
- Fasting Blood Sugar
- Complete LFT and RFT (Blood Urea, ALT / SGPT etc.)
- VDRL
- CD4 Count
- Chest X-Ray – PA View
- Sputum Smear Microscopy and GeneXpert test
- Anti-HCV and HbSAg
- Lipid Profile

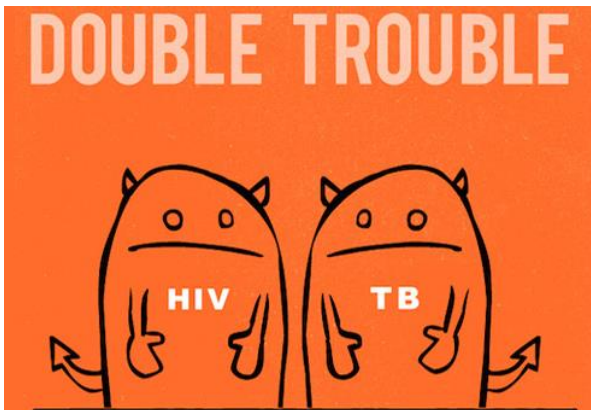


### Following tests have been mentioned to check the effectiveness of treatment:

- Mandatory tests (applicable for everyone)
  - CD4, Haemoglobin, TLC, DLC, ALT (SGPT)
- Tests for those who start TDF-based regimen
  - Complete RFT (tests for blood urea, creatinine etc.) every 6 months or sooner, if needed
- Tests for those who start AZT-based regimen
  - Haemoglobin test after 15 days of starting treatment, then monthly for the first 3 months and then every 6 months or whenever needed.
- Tests for those who start NVP-based regimen
  - ALT / SGPT after 15 days, then in 1 month and then every 6 months
- Test for those who start EFV-based regimen
  - Lipid Profile once in a year
- Test for those who start ATV-based regimen
  - LFT after 15 days, then after 1 month, then after 3 months and then in every 6 months
- For those who start PI-based regimen
  - Blood sugar and lipid profile in every 6 months

All the above-mentioned investigations can be done before the scheduled time as per the assessment or instructions of the doctor. Similarly, doctors can prescribe some other investigations, if needed.

### Treatment of opportunistic infections before starting ART



ART should not be initiated in the presence of an active opportunistic infection. Normally it is necessary to control all opportunistic infections before starting ART. Some opportunistic infections are exceptions in which starting ART itself is the right treatment for them.

Amongst opportunistic infections TB offers the toughest challenges. Treatment of HIV and TB together becomes complicated since drugs used to treat one interrupt with the absorption and effectiveness of the other. This is called drug interaction. Apart from this, challenges in drug adherence for both, effect on liver and kidney due to excessive drugs or drug toxicity etc. further make treatment of HIV and TB together difficult.

People with active TB infection, who are tested positive for HIV are given treatment for TB according to the Revised National Tuberculosis Control Program (RNTCP) guidelines. ART is then started after considering the effects of medicines on body, drug interaction, counseling needs etc. TB drugs are available in ART centers under the 99DOTS scheme.

If those who are already on ART test positive for TB, then some changes can be made to their ART regime. If a person's CD4 count is less than 200, they are given Isoniazid Preventive Therapy (IPT) and OI prophylaxis for prevention from TB



## First 6 months after starting ART

The first 6 months of starting ART are sensitive. Although after starting ART, improvement in health and immunity is expected, often these improvements are not apparent or visible. Sometimes side effects also result from the drugs. In some people, the drugs do not seem to work as expected and their condition seems to get worse. These problems are seen during initial days of starting ART amongst people whose immunity system is already weakened or there is an opportunistic infection present in its advanced stage. In such cases, it takes time for ART to control HIV.

It is important to keep in mind is that the cause of these problems is **not** treatment failure, but a change in the body's immune system, due to onset of treatment. It is crucial that after initiating ART, sufficient time should be given before deciding whether the treatment is working or not.

### Increased CD4 Count

In most people, CD4 count increases after initiating ART. However, in those cases where baseline CD4 count itself was very low, improvement is not as much as others upon introduction of ART. In most cases, lower the baseline CD4 count, greater is the time taken for improvement.

### ARV toxicity

ARV drugs produce many types of toxicity in the body. Toxicity means the accumulation of drugs in the blood, which can have negatively impact organs like liver and kidney. Some types of toxicity are not acute (mild toxicity). Symptomatic treatment is done in these cases. In some cases where there is severe toxicity or a life-threatening toxicity, then some ARV drugs may need to be changed (drug substitution) or there might be need for discontinuation of ART till the person's situation is stable and toxicity is in control.

It is important that the health facilitators discuss in detail the side effects and ARV toxicity before the treatment starts. People living with HIV need help and proper information to deal with all kinds of side effects. Health facilitators can monitor the results of complete LFT and RFT tests of HIV positive people so that if signs of acute toxicity are shown, they can warn the doctor on time and doctors can take necessary steps.

## Treatment failure and switching to new line of treatment

ART discontinuation or poor or non-adherence are some of the biggest causes of treatment failure and HIV progression. HIV is a virus whose genetic make-up is different in different individuals. This structure also changes over time. Occasionally some ARV-resistant strains of HIV develop which are resistant to some drugs. During sex, this resistant strain of HIV can enter the bodies of other HIV-positive people and create resistance against some drugs within them as well. Therefore, HIV-positive people should use condoms regularly during sex.

Despite proper adherence to ART and continuous use of condoms, the treatment fails in some cases and the drugs stop working. In such cases, doctors decide to change the drugs and start new regimes.

According to the National Guidelines, following criteria are used to determine failure of treatment:

1. *Clinical failure* - New or severe opportunistic infections or HIV-related health problems arising even after proper adherence to ART for at least 6 months
2. *Immunological failure* - Current CD4 count drops even below the baseline CD4 count, up to 50% drop from the highest CD4 count after initiating ART, or CD4 count consistently remain below 100
3. *Virological failure* - Even after proper adherence to ART for at least 6 months, viral load in plasma stays more than 1000 copies per ml.

On the basis of these failures, doctors in the ART centre decide whether the first line of ARV drugs are working successfully or not. This can vary for each person, according to their health and their body's response to the drugs. If according to ART centre's assessment, first line ART is declared unsuccessful, they recommend changing the treatment of the individual to District State AIDS Clinical Expert Panel (DACEP) or State AIDS Clinical Expert Panel (SACEP). DACEP and SACEP are district and state level committees which constitute of senior officials of ART Center, ART specialists and senior government officials working on HIV. These committees examine all the cases in detail and take final decisions regarding changing of ART treatment starting second line ART. The National State AIDS Clinical Expert Panel (NACEP) is a national-level committee that decides to initiate third-line ART on the failure of second-line ART

Health facilitators need to keep in mind that many people start treatment of ART with the advice of private hospitals and doctors, where second-line ARV drugs are at times administered as first line. In such cases, it is necessary that the person's full medical history is presented to the government ART centre doctors so that the second-line medicines can be determined accordingly.

## Chapter 4

### Holistic Care and Support



Needs of people living with HIV, especially for men who have sex with men (MSM) and transgender people (TG) are not limited to connecting them with ART centres. Due to their sexual orientation and gender identity, they are subject to compounded social stigma and discrimination, in addition to HIV-related stigma. In such cases, the role of a support group becomes vital for holistic care and support.

Sanjeevani is such a support group of The Humsafar Trust which facilitates fulfilment of all the needs of MSM and TG living with HIV.

People affected by HIV get an opportunity to become part of a supportive and caring community. After knowing about one's positive status, connecting with a community can make the future challenges easier. It ensures that treatment and counselling services are completely non-discriminatory. Sanjeevani works as a community dedicated to ensuring the mental and physical well-being of its members. It helps people living with HIV to connect with each other, enable and empower them.

#### Major components of holistic care and support

##### Facilitating access to ART services

As stated in the previous chapter, process of availing ART facilities from government hospitals can be quite complex and lengthy. ART registration in government ART centres, periodic CD4 testing and all other necessary investigations are part of this process. It is also important to make people living with HIV aware of the test and treat policy, HIV viral load tests and help those already on ART manage opportunistic infections.



To change the line of treatment, SACEP and DACEP committees are formed at the state and district levels. Attending SACEP and DACEP meetings, when required, is important for changing the treatment.

In many cases, when people are struggling to accept their HIV status, it is very difficult for them to understand government processes and avail ART-related services. This makes the role of health facilitators extremely pivotal. It is important for health facilitators understand NACO's guidelines and government procedures properly so that they can offer every possible support to HIV positive individuals. Health facilitators also need to build rapport with the concerned employees of government hospitals and officials of all ART centers in the city so that people living with HIV can get the services without any discrimination or hassle.





The following are important for physical health:

- ART and DOTS adherence counselling
- Treatment of STIs, OIs and general ailments
- Regular check-up by doctor



Adequate provision for mental health related needs is not available under the National Program. For physical health as well, medicines and counseling is extremely limited for common illnesses other than STIs and OIs. In order to overcome these lacunae, mental health counselling and regular doctor consultation are available at The Humsafar Trust. Drugs for general illnesses other than medicines for STIs and OIs are also provided free of cost by the doctor. These facilities are particularly beneficial for those HIV positive people who are financially in need.

### **Nutrition Consultation and Support**



Proper nutrition is extremely vital for people living with HIV. For this, it is important to consult a nutritionist who can advise on proper nutrition and food options based on an individual's treatment history, lifestyle and financial status. Those who are financially needy also require nutritional supplements.

The Humsafar Trust not only offers consultation by Nutritionist but also provides monthly nutrition supplements. Sanjeevani health facilitators network with other organizations and to make ration support available to those who need it. (More information about this is in the next chapter)

### **Support group meetings**

Being part of a support group enhances the morale and confidence of people living with HIV and provides them with new hope for life. People can discuss the challenges associated with HIV and learn from each other's experiences in these periodic support group meetings. In these meetings, sessions related to healthy living, such as nutrition, exercise, yoga, regular check-ups etc can be taken by external experts. In these sessions legal experts can also discuss legal and human rights of HIV positive people. Apart from this, entertainment activities like sports, picnic etc. can also be organized in the meetings, in which people forget their problems for a while.



Support group not only provides a safe platform for open discussion on various issues related to positive life, but also offers opportunities to become each other's support system for people who do not have family support so that they can share the ups and downs of their lives

### **Legal support and consultation**



Due to the social stigma and discrimination associated with HIV, people living with HIV, especially those whose HIV status is known, may face different types of discrimination. Many people have to deal with bad behavior from employees of government hospitals, some lose their jobs and others are evicted from their homes by their landlords. Many have to face discrimination even from their families in the form of disinheritance from their share in

ancestral property or being thrown away from home etc. Legal aid and counseling are a major part of holistic care.

Along with legal aid, there is also a need for advocacy with institutions or individuals who discriminate against people living with HIV so that they can be sensitized on HIV issues.

### **Reaching out to female partners of men who have sex with men**

Several men who have sex with men are also married to women. In most cases, their female partners do not have information about their husbands' sex lives. Hence, it becomes very difficult to reach out to the female partners and give them information about HIV. At times, due to putting too much pressure in this regard, some men break all contacts with the health facilitators. That is why it is important that health facilitators should exercise caution in such cases. Sanjeevani health facilitators explain during counseling, the importance of getting their female partners tested for HIV and in case the results are positive initiating treatment at the earliest.

### **Assistance in hospitalisation**

People living with HIV may often need to be hospitalized for the treatment of HIV-related complications or opportunistic infections. They may need assistance from health facilitators regarding the process of hospitalization as well as getting care during their stay at the hospital.

The most important role of health facilitators in the lives of people living with HIV is personalised care and support. Every person is given support as per their needs and their detailed case history is maintained in the form of documents/records. These case files contain their complete clinical history (details of previous investigations, infections and treatment history). This information proves to be very useful in their future treatment. Complete confidentiality is maintained for each member.

## Chapter 5

# Advocacy and Networking



Advocacy and networking play an important role in the care and support of people living with HIV. Where advocacy is needed to address discrimination related to HIV and to bring about a change in societal attitudes on HIV-related issues, networking helps in providing medical and other services to the individual.

### HIV-related advocacy

Advocacy related to HIV can have many objectives:

#### **Changes in HIV-related policies and law**

There has been a lack of strong laws related to HIV in our country for a long time. Due to this, people living with HIV have been having difficulties in obtaining legal recourse against discrimination due to their HIV status. In the absence of these laws, they also need to struggle to maintain confidentiality about their HIV status and to obtain proper treatment and regular medicines.



With the passing of the HIV/AIDS bill by Parliament in April 2017, fighting against HIV-related discrimination has become much easier. As per the provisions of this bill, legal route can be taken to address all HIV-related discrimination along with demanding necessary treatment and investigations (such as viral load tests) for all HIV positive people.

To get this bill passed, groups working on HIV-related rights have struggled for several years. Sanjeevani's health facilitators have also been associated with these groups and have been contributing regularly by participating in their meetings and activities.

In addition to changes in law, changes in policies of government and non-governmental organizations and companies also require advocacy. It takes many years to change the laws, but changes in the policies of institutions are possible sooner. Sanjeevani's health facilitators have made constant efforts to bring changes in the policies of several government hospitals and ART centers after coming across incidents of discrimination. In the same way, the Advocacy team of Humsafar has also worked to

include policies that protect the rights of people living with HIV in many companies and education institutions.

Health facilitators need to keep in mind that in order to bring about changes in policies of an organization or company they need to approach such officials who are position to change policies or can influence the whole process. Generally, such officers are there in the organization's senior management.

Another thing to keep in mind is that the process of making changes in policies and laws should be continued continuously. Needs of the community keeps changing and accordingly, changes in policies and legislation should also take place. Health facilitators need to be aware of the changing needs of the community and need to constantly advocate for changes in policies and laws.

### Changing public attitude about HIV



Along with changes in the laws related to HIV, it is also important to change public attitude towards HIV and create sensitization on HIV-related issues. In order to do so, health facilitators talk about issues related to HIV and the rights of people living with HIV from time to time in hospitals, ART centers, companies, educational institutions etc. and spread awareness.

On 1 December, on the occasion of World AIDS Day, cultural programs and movies, plays and street plays made on issues of HIV are also used to spread awareness about HIV in the public. Health facilitators play a key role in organizing these events.

### ART Centre Monitoring

Due to recurrent shortage of ART drugs, Sanjeevani's health facilitators started monitoring of ART centres once a month. In these monitoring visits, health facilitators try to obtain the following information:

- Since when has the ART centre been functional and people who are registered to the centre come from which areas
- Exact address and contact information of the ART centre (e-mail, phone number, etc.)
- How many people are registered at the ART Center
- Amongst those who are registered, how many are on ART

- How many Pre-ART, On-ART and lost to follow up LFU cases are there
- How many people come to take ART drugs every day
- How much is the stock of various ART drugs
- Availability of kits and machines for CD4, viral load and other necessary investigations
- Staff availability at ART centres
- Who are the current Nodal Officer, Medical Officer and other senior officers of the ART Centre
- Information about other organisations related to the ART centre and facilities available with them

Through this data it is possible to know about the status of stock of ARV drugs, kits for investigations and other resources in an ART centre. If there is a shortage or possibility of shortage seen, health facilitators may take this up with officials of the ART Centre or officers working in the National Program in time.

## Networking with government and non-government organisations



Many services that are essential for holistic care and support of people living with HIV are not available in government hospitals or are not mandatorily provided under national program to HIV positive individuals. If these services are not available with the organisation or the support group as well, then health facilitators need to network with many government and non-governmental organizations.

Sanjeevani's health facilitators not only network with the officials of all the major government hospitals and ART centers in the city, but also with several other non-governmental organizations for the following services:

- With Medical Social Work (MSW) Departments of government hospitals and private laboratories for free or concessional treatments or investigations, in addition to the treatment of ART and opportunistic infections, which are not part of the national program
- With Médecins Sans Frontières – MSF or Doctors Without Borders for second and third line anti-retroviral treatment, treatment of Multi-drug resistant (MDR) and Extensively Drug Resistant (XDR) tuberculosis and for the management of hepatitis C infections
- With Family Planning Association of India (FPAI) Hepatitis-B screening and vaccination and reaching out to female partners of men who have sex with men
- With community care centers (CCCs) such as Damini Trust, Karunya Trust and Ojas for need-based ration support

- With CCCs like Niramay Niketan and Sahara for treatment and management of opportunistic infections, assistance with hospitalization and blood investigations at free or concessional rates

It is important for health facilitators to keep finding out about new organizations and the facilities related to HIV available with them, establish rapport with them, and try to build long-term relationships with them.