Supporting community action on AIDS in India

THE MAGIC PLACE
AT THE ICTC AND ART CENTRE
International HIV/AIDS Alliance

The International HIV/AIDS Alliance is a global partnership of nationally-based organisations working to support community action on AIDS in developing countries. The national partners help local community groups and other non-government organisations to take action on AIDS, supported by technical expertise, policy work and fundraising carried out across the Alliance.

The vision of the Alliance is of a world in which people do not die of AIDS. This means a world where communities have brought HIV under control by preventing its transmission, and where they enjoy better health and higher quality of life through access to comprehensive HIV prevention, care, and support and treatment services.

India HIV/AIDS Alliance (or, Alliance India), established in 1999, comprises a Secretariat in New Delhi, five lead partner organisations (the Linking Organisations within the global Alliance) and their networks of over 100 community-based non-governmental organisations (NGOs) and community-based organisations (CBOs) across five states – Andhra Pradesh, Tamil Nadu, Manipur, Maharashtra and Delhi. The Alliance’s project office in Hyderabad was formally launched in April 2008 as the fifth lead partner (or Linking Organisation) in India. Alliance India has also been working closely with a state partner organisation in Manipur. In 2007, the Alliance in India supported over 120 community-based projects through its NGO and CBO partners to prevent HIV infection; improve access to HIV treatment, care and support; and lessen the impact of HIV. The last including reducing stigma and discrimination, particularly among the most vulnerable and marginalised communities key to the epidemic – sex workers, men who have sex with men (MSM), injecting drug users (IDUs) and adults and children living with and/or affected by HIV.

Funding from the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) was awarded to the Alliance in July 2007, whereby the partnership in India has been broadened to include two new project-based lead partner relationships with two external organisations and their networks of implementing NGO partners.


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The Magic Place

Join teacher didi and her students of Jhalakumalaku School as they meet different people at the Integrated Counselling and Testing Centre (ICTC) and the ART Centre.

This is a story of school children who make a field visit to the nearby ICTC to learn about the testing and treatment for HIV. In the form of visuals and cartoons, the story has characters which children can easily identify with. Through their voices, it covers the basics of HIV testing, treatment and nutrition in a simple language and style.

The children visit a nearby ICTC in the government hospital and take a tour of the services provided at the hospital. They are guided by an illusionary character, hopping from charts to charts to see how the centre works and the facilities offered at the centre.

The characters in the chart also help the children to understand how to take the medicines for HIV and take care of their health by eating proper food if they have HIV and thereby, opportunistic infections.

The facilitator can use this story to talk to the children using the flipbook illustrations. The facilitator should familiarise himself with the story and be aware of the points that will be raised or the questions that will be asked by the children. In all cases, the groups may not be only of children, and there may be adults present. In such cases, the facilitator needs to be aware that there are some points where he needs to focus on, especially for the adults or older children in the age group of 14 to 16 years.

These points relate to the following:
1. What are the medicines for HIV?
2. How should people with HIV take care of their health if they need to avoid opportunistic infections?
3. Testing for HIV, where the facilitator needs to talk about risk perception with adults.
How to Use this Flipbook

Preparation
- Use this flipbook to talk and discuss about issues related to HIV/AIDS, testing, treatment and cure.
- Review the flipbook in advance to familiarise yourself with the contents and messages.
- Each page is accompanied by important messages that summarise the key points. Use the visuals to illustrate the points that you are talking about.
- Dramatise or play act to build excitement around the Magic Place as the children hop from chart to chart.

In the Field
- Build a rapport with the children and their parents.
- Seat them comfortably, in a semi-circle or facing you.
- Speak clearly, loudly and slowly. Use simple words, phrases and language. Check with the children if they can hear you.
- Explain each picture and allow enough time per picture to discuss the main points. Explain again if necessary.
- Ask the children to repeat the key points to ensure that they understand the messages.
- Explain each picture and allow enough time for discussion.
- Engage the children in the story telling. Ask them how they interpret the pictures. Do they remind them of something or somebody.
- Ask the children to repeat the key points to ensure they have understood the message/s.
- Encourage and prompt the children to ask questions, clarify doubts and express their thoughts.
- After every important message like how one can get infected by HIV, how it is spread, what is the treatment etc. repeat the message so that you are sure that it has been absorbed by everyone.
- Continue with games and activities to help the children better understand the key points.

Thank the children for paying attention, after the session.
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At the Government Hospital

The children have just returned from an exciting trip to Sheru’s body in the Magic School bus. It was great to be inside the body and see so many things. They learnt about HIV; how one can get infected; what are the myths and misconceptions related to HIV; and how care and support is crucial for those infected and affected by the virus.

They now want to know how HIV can be treated. Today, they will meet Dr. Aarty, who is a doctor at the Government Hospital.

Sitting quietly outside Dr. Aarty’s clinic, they see a number of charts on the walls that have many strange markings.

Raju and Reena, students of Jhalakumalaku School, are looking intently at a colourful chart. But what is this? A man from the chart winks naughtily at them.

On looking closely, they read: “What happens when you have HIV?”
Children enthusiastically look at the colourful charts
What happens if I have HIV?

The man in the chart is actually talking!

“No worries. Being HIV positive is like having diabetes or blood pressure.

You cannot take this infection out of the body, but you can manage it very well.

There are medicines available that can help you stay healthy.

You must take care of yourself though. Look at me.”

Important Points

- Being HIV positive is like having diabetes or blood pressure.
- There are medicines available that can help you stay healthy.
A man talking to the children from one of the charts displayed
Important Points

- The government hospitals have special centres where people can get tested for HIV.
- The test is done free of cost at all government hospitals.

Testing, Counselling and Medicines are Provided at Special Centres

Oh! said Raju and Reena. “Quick, come here and see what this chart is saying,” they call out to their friends. All the children crowd around the chart and feel themselves drawn right inside it.

They find themselves in a place that has different kinds of pictures put up on the walls. “Welcome,” says the man who had been smiling from the picture. “This is a place where we provide counselling and testing services to the people who are infected with HIV. I have HIV too.

This is the government hospital which has special centres where the doctor does a blood test every six months for people with HIV. This is done to see how strong your body is.

This test is done free of cost at all government hospitals.

And from the test the doctor will know when you need to take medicines for HIV. These medicines are provided at the ART Centre.”
The man takes the children into the ICTC
“But we saw something like ICTC written outside. What is that?” asks Reena. “You are at the ICT Centre with Dr. Aarty”, replies the man. This is the Integrated Counselling and Testing Centre (ICTC).

At the ICTC, the doctors and counsellors will test you for HIV, tell you how to take care of yourself if you are positive and also help you to talk about it, if you feel scared.”

“Look! Here is Shikha with her children.” The children turn to find a lady entering with two small children. “She is here to talk to Dr. Aarty and also take medicines from the ART Centre.”

“Oh! You have medicines!” exclaim the children.

**Important Points**

- The special centre where one can get tested for HIV is called Integrated Counselling and Testing Centre (ICTC).
Children at ICTC
“Yes!” replies the man. “The medicines are to help you keep the virus from multiplying. This is called ART. No, no it is not your drawing art, it is Anti-Retroviral Treatment! The medicine helps to kill the virus and prevent them from increasing in our body. These medicines are available free of cost at Government health centres. Shikha is taking ART, but her children are taking prophylaxis.”

“What is that?” ask the children.

“It is a medicine that will help you keep away other infections that can enter into the body once the immune system gets weak.” Let’s look at what Dr. Aarty is telling Shikha. “How can we do that? We are in the chart.” “Come with me,” replies the man and he walks into another chart on the wall. The children find that they are inside a chart in Dr. Aarty’s room, while she is talking to Shikha.

**Important Points**

- Anti Retroviral Treatment (ART) is given to HIV positive people which helps to keep away the infections.
- ARV medicines are available free of cost at Government health centres.

**ART Prevents HIV from Multiplying**
Shikha and her children with Dr. Aarty
“What are opportunistic infections?” Shikha asks Dr. Aarty.

“When HIV enters the body, it destroys the cells that help to protect the body from other infections.

This happens over a period of time, say 2 to 5 years.

When this happens, there are other bacteria or viruses in the surroundings like Tuberculosis (TB), Typhoid, Malaria, Diarrhoea etc. that attack an unprotected or weak body.

These infections are called ‘opportunistic infections’, because they use the opportunity to attack the body and cause it harm.

A person without HIV can fight off these bacteria or virus and not have the illness. But a person with HIV may not always be able to fight them. This makes him vulnerable to illness and infection because his immune system is weak.

“If you or your child have cough for two or more weeks, speak to the outreach worker or visit the nearest health centre and check for TB,” Dr. Aarty tells Shikha.

Important Points

- When HIV enters the body, opportunistic infections attack the body and cause it harm.
- If one has cough for two or more weeks, check for TB.
Dr. Aarty informs Shikha about opportunistic infections
If you have HIV keep yourself healthy by….

“So how can I avoid the infections, Doctor?” asks Shikha. Dr. Aarty shows her a chart and says, “You must avoid exposure to some of the organisms that threaten health.

• Be especially careful around uncooked meat and eggs, and domestic animals and lake or river water.
• You must take care of your health by eating food that is properly cooked and drinking water that is boiled for 20 minutes.
• Keep the surroundings clean. Do not throw garbage near the house and do not defecate near the house. Always wash your hands before eating.
• You must also take care not to smoke or drink or have sex without using a condom. You must stay away from drugs. This will help in preventing further infection.”

Important Points

♦ Eat properly cooked food and drink water that is boiled for 20 minutes.
♦ Keep the surroundings clean and adopt healthy habits.
Healthy living - avoid infections by being cautious
Can Shikha’s children go to school?

“What precautions must I take at home Dr. Aarty and can my children go to school?”

Dr. Aarty smiles. “HIV cannot be transmitted through normal social contact. Shikha you know that our daily acts like hugging, shaking hands, playing and eating together cannot transmit HIV.

Children, you must tell your elders in school though, that when you get hurt, make sure you bandage the wound immediately.

Also, you must be careful around other children who are not well so that you do not catch their infections.

And finally, you must tell your mother if you are not feeling well, so that she can bring you to see me before you get even more sick.”

Important Points

- One can’t get HIV by hugging, shaking hands, playing and eating together.
Dr. Aarty clearing misconceptions
“And now Shikha”, says Dr. Aarty, “I must tell you that I have to put you on ART.”

Shikha looks worried, but Dr. Aarty comes around and pats her back.

“It is all right. Your blood test shows that your immune system is weak, but if you take medicines we can kill the viruses and slow their growth in your body. You must not worry; we are all here to help you. ART cannot cure, but it can control the virus. Taking ART may make you feel better, but since the infection has not gone from the body, we need to take preventive measures.”
Shikha and her children being told about the benefits of ART
Take all your Medicines without Missing a Dose

“How should I take ART?” asks Shikha.

“Once you start ART, you must take all the doses as per the timing indicated by me,” advises Dr. Aarty.

The man from the chart is nudging the children and they turn to see the chart that he is showing.

It says:
- Take all your medicines in time and as advised by the doctor.
- This is important because if you stop taking the medicines for sometime, the virus will become powerful against it and when you re-start, the medicines will prove to be ineffective against the virus.
- Once this happens, the virus can become so strong that the medicines may not work at all. So we have to be very careful as to not stop taking medicines for any reason unless advised by the doctor.
- Set up reminders for yourself to take medicines on time.

Important Points
- Take medicines on time, else the virus will become powerful and the medicines will prove to be ineffective.
One should not miss any dose of medicines

Take all your medicines in time

Use a calendar to mark days

Use an alarm clock in order to remember the time for taking medicines
‘Medicines should be taken regularly’- Counsellor

The children now enter another chart and that shows a meeting taking place. A counsellor is sitting and talking to some people about how they can help themselves in taking their medicines regularly.

• You may be missing taking the medicines, especially if you are consistently unwell, or you may miss some doses.
• This may be because you forget, are busy, fall asleep at the time you must take medicine or are depressed.
• You may also be worried about side effects or find the dose too complicated to take or are simply tired of taking the medicines everyday and believe that alternative medicines can perhaps help you better.

This can be understood. However, anything that you do, you need to consult your doctor before you stop the medicines. Remember, when you stop, the virus get time to become more powerful.

If you miss the dose regularly, consult your doctor.

You may take the support of friends and family in taking your medication on time. We are always here to support and counsel you.

Important Points

♦ Consult your doctor before you stop the medicines.
A counsellor telling about the need for ART adherence
ART helps the Soldiers (cells) Fight HIV

“Come, let me show you how the medicines work,” said the man as he pulled them towards another chart. The children found themselves standing inside a human body where there were many cells at work. They recognised some of the cells whom they had met on their earlier adventure. “Here we are,” said the man.

“This is the factory that manufactures the soldiers. You can see that they have received some help and now have few viruses to fight with. This is because of the ART medicines.

They cannot remove the virus totally from your body, but they do succeed in keeping the virus under control and prevent them from multiplying.”

Important Points

- ART cannot remove the virus from your body but can keep it under control.
Children looking at how ART fights the virus
Speak to your Doctor/Counsellor about the Side Effects

The children see some cells being brought in to restrooms by the soldiers. “What are these?” they ask.

“All medicines are chemicals. In some cases, they may make you feel unwell when you take them. These are called ‘side effects’.” Most people have side effects when they take ART. Many will start having soon after starting ART, which will go away on their own after two to three months.”

Many of these side effects are mild and will settle down gradually.

Some of the common side effects include:
- Dizziness
- Nausea and vomiting
- Feeling tired all the time
- Rash
- Not sleeping properly
- Feeling drowsy or sleepy
- Headache
- Bad dreams
- Confusion

**Remember**: After initiation of ART, you must speak to the doctor or outreach worker if you notice any side effects. The doctor will also be asking your outreach worker to monitor your health after:

- 48 hours (follow up), 1 week, 15 days and 1 month respectively

Thereafter, you must check yourself with your doctor every six months.
ART adherence and the side effects of ART
When you are on ART, Take Care of your Nutrition

“When you take ART, you need to be careful of what you eat,” said the man in the chart. “Come let me show you.”

When you are on ART it is essential to take a balanced diet that includes proteins, starch, green vegetables and fruits.

When ART is started, some people may find that they become hungrier as the body starts rebuilding and needs more energy.

However, some medicines may reduce your ability to take in more food.

Some actions that you may take if you find that you are having difficulty in eating include:

<table>
<thead>
<tr>
<th>Side effect</th>
<th>What a person can do</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nausea</td>
<td>Eat small meals and drink plenty of liquid to help in digestion</td>
</tr>
<tr>
<td>Diarrhoea</td>
<td>Use some anti-diarrhoea medicine and drink plenty of fluids</td>
</tr>
<tr>
<td>Bad taste in the mouth</td>
<td>Try other foods; avoid foods which taste strong in the mouth</td>
</tr>
<tr>
<td>Dry mouth</td>
<td>Eat foods that are in liquid form such as soups, which are easier to swallow. Chew something which can increase the amount of spit (saliva) in the mouth.</td>
</tr>
<tr>
<td>Sore mouth or difficulty chewing</td>
<td>Eat foods that are in liquid form, because they will be easier to swallow.</td>
</tr>
</tbody>
</table>

Important Points

♦ When you are on ART, take a balanced diet.
How to deal with side effects
Our Meeting with Dr. Aarty

The children suddenly feel a gentle push out of the chart and as a result, they all tumble down from the chart. They get up to see teacher didi entering the waiting room along with Dr. Aarty.

“Oh! What have my children been up to?” asks teacher didi with a suspicious look.

“Didi, we just learnt that people who have HIV can live longer by taking medicines called ART.

Yes, we can also play with children who have HIV by just taking care of a few things.

We need to eat proper food when we have HIV.

We need to take all our medicines on time.

We need to do our tests on time.”

Dr. Aarty smiled and looked with pride at her students and said, “Well, well, so we have children who are really smart. Why don’t we now have a quiz?”

Important Points

- People with HIV can live longer by taking ART.
Teacher *didi* and her children with Dr. Aarty
About CHAHA

CHAHA project (meaning 'a wish' in Hindi), is extending care and support services to children living with and/or affected by HIV and AIDS, and their families especially women-headed households. With funding from Round 6 of the Global Fund to Fight Against AIDS, Tuberculosis and Malaria (GFATM), the India HIV/AIDS Alliance (as a civil society Principal Recipient), and its consortium of eight Sub-Recipients, is implementing this expanded child-centred home and community-based care and support project, in the states of Andhra Pradesh, Tamil Nadu, Maharashtra and Manipur. CHAHA is working closely with different stakeholders and Government Ministries to find ways to help keep children with their parents or extended families. Within a span of five years, the project aims to reach 64,000 children, in order to reduce HIV related morbidity/mortality in adults and children and address the impact of HIV on children.

Programme Context

- Focus mainly on children and families, especially women-headed households, who need access to care and support and treatment services.
- Development of a comprehensive package of care and support services for children living with and/or affected by HIV, including facilitating access to treatment services and related support.
- For long term sustainability, mainstreaming service availability for children through working with other departments/Ministries, e.g. Women & Child Development, Social Justice & Empowerment and Rural Development.

Approach & Continuum of Care and Support

With a rights-based approach, CHAHA empowers the community to identify their needs and then provide them with home-based care and support. This approach is based on the significance that Alliance attributes to a community-driven response to HIV, with the belief that family involvement and active engagement and leadership of the community is a pre-requisite for any HIV intervention. Building the capacity of the communities to access various government programmes to ensure sustainability of the interventions is an important element of this programme.

CHAHA provides a comprehensive package of services to address the needs of the children affected by HIV and their families that includes supplementary nutrition support, access to healthcare, education support, psychosocial support, and support for income generation programme and emergency household support.