

CAREGIVER EDUCATION: GROUP SESSION 2

Review Lessons Learned From Session 1

Begin today's session with a review of the main concepts from the previous session. You may use the questions below as a guide. Discussion should be participant-driven.

- What is HIV?
- How does HIV affect our immune system?
- What is adherence?
- Why is adherence important?
- Why might adherence be difficult for some people?

Overview of Medications

Use the actual medicines or pictures of the medicines available in your clinic to reinforce the concepts introduced in this section.

Children may receive different combinations of medicines, depending on their individual needs. Therefore, ***it is very important that children only take the specific medicines meant for them and that they never share these with other people.***

Some medicines come in capsule form, while others come in the form of a tablet, a powder, or a liquid. Some medicines can be combined together so that the child can take one pill that contains two or three different medicines. Caregivers and children should get to know the medicines the child is taking. You can make a list or just memorize their shape and color.

Tips for Administering Medications

*DEMONSTRATE each technique as described below.
Facilitate caregiver participation in the demonstrations.*

The following are some useful tips to help mask the flavor and make it easier for the child to take his/her medicines:

▪ **Infants/Children**

Liquid Medications

For liquid medications, first draw up the medicine in a syringe or measuring cup to measure the proper volume. (The doctor, nurse or pharmacist will tell you exactly how much you should give the child.)

Try to give the medicine to the child directly from the syringe or measuring cup. If the child does not like the taste of the medicine, you can combine the liquid dose with a small amount (1-2 teaspoons) of a good-tasting liquid such as juice, milk, or soft porridge. Do *not* combine the medicine with a large volume of liquid or food, as you need to be sure that the child ingests all of the medicine. Once you have mixed the liquids together, ***be sure that the child drinks the full amount.***

As an alternative, try giving the child small amounts of his favorite beverage or food right before and after you administer the medicine. Since children cannot choose whether or not to take life-saving medicines, give them a choice regarding the beverages and foods that they take with the medicines whenever possible.

Tablets and Capsules

Small children often have difficulty swallowing pills. If your child has difficulty swallowing pills, ask your doctor, nurse or pharmacist whether the pills your child is given can be safely opened, crushed or split to make swallowing easier.

The contents of capsules and crushed pills can sometimes be added to 1-2 teaspoons of food (such as jelly, jam, mashed banana, or porridge) to make it easier for the child to take them.

Again, it is important to ***be sure that the child eats the full amount.***

Remember to give lots of praise after each dose! **Positive reinforcement** is the key to including children in the process of administering medicines.

There are **some medicines** that have to be taken on an **empty stomach**, which means that **no food** can be taken either **1 hour before OR ½ hour after** the dose is given. In such cases, mixing the medicine with food or liquid is not an option.

Before starting treatment, the doctor, nurse or pharmacist will spend time with the family discussing each medicine very carefully to be sure that they understand exactly which instructions to follow.

- **Adolescents**

For older children, some medications in tablet form can be broken in half and swallowed.

If older children express a preference regarding the format of their medicines (for example a teen might prefer capsules instead of liquids), encourage them to ask the doctor or pharmacist about these alternatives. In many cases, the clinic staff can make changes to the regimen so that the patients will be happier.

Dosage & Schedules

It is very important to establish a **routine** for giving the child his/her ARV medicines.

Dosing schedules are designed so that the child always has a certain amount of ARV medicine in his/her system. Children need to take the ARVs at the proper time and in the proper dose so that the medicines continue to work.

Some types of ARVs must be taken every 24 hours, or once a day. However, most ARV medicines only work for 12 hours at a time. Therefore, they must be taken twice a day - in the morning and then again in the evening.

The doctor, nurse or pharmacist will tell each family how many times per day they should give the child each medicine.

We all forget sometimes, but forgetting to take ARVs can be dangerous. Therefore, it is a good idea for each caregiver to have someone they can trust – a family member or a friend – to help them remember to give the child his/her medicine at the right time every day.

- **Missed Doses**

If the child misses a dose, and the caregiver remembers **within four hours** from the time he/she was supposed to take the medicines, they should go ahead and **give the child the dose and then return to the regular schedule.**

If the child misses a dose, and it has been **more than four hours** since he/she was supposed to take the medicines, they should **skip this dose.** Then, take the next dose as scheduled.

If they forget a dose, they should not take twice the amount of medicine at the same time. **Never take two doses at the same time.**

▪ Vomited Doses

If the child vomits **within 30 minutes** of taking a dose of ARVs, the child should **repeat the dose** just given, and then continue with the regular schedule.

If the child vomits, and it has been **more than 30 minutes** from the time he/she took the last dose, the child should **not repeat the dose unless whole pills or capsules are visible in the vomit.** Simply continue with the regular schedule.

ARV Storage

It is important to **keep all medicines out of the sunlight and the heat.** When medicines are damaged by exposure to heat and light, they become less powerful in protecting our bodies from illness.

While most of the ARV medicines do not require refrigeration, there are a few medicines that must be refrigerated all of the time (*d4T, in liquid form, must be refrigerated*). An electric refrigerator or a specially-designed clay pot can be used to keep the medicine at the correct temperature.

Always store the ARV medicines in a **safe place**, out of the reach of toddlers and young children.

Reminder Strategies

Distribute sample medicine reminder charts and conduct an interactive demonstration of how they are used. You can use the chart provided as Visual Aid 12, or you can use other charts available in your clinic.

Many caregivers find it helpful to mark tic cards, or use **medicine charts** as reminders to administer the child's medicines. Caregivers can make weekly medicine reminder charts using a wall boards or a piece of paper at home. Each time the child takes a dose, they

simply tick off the corresponding block on the chart; this way, it is easy to know whether or not the dose has already been given.

Some people prefer to put the ARV medicines into divided boxes to help them keep track of which doses have been taken for the week and which still need to be taken.

Some caregivers also set **alarms** on their clocks, wrist watches or cell phones as an easy way to remind themselves of the child's dose schedule. Other people rely on **daily events**, such as a particular radio program, meal time, or the chickens coming out in the morning and going in at night.

Having a friend or family member who can act as a **treatment supporter** is extremely helpful, especially in the beginning. This person can assist in remembering to give the child the proper dose of medicine at the right time every day.

The clinic staff can help families think of ways to remember to give the child his/her medicines at the right time every day.

Planning Ahead

Use Visual Aid 13 to reinforce the concepts introduced in this section.

As we have emphasized, the child's health depends on him/her taking the medicine every day at the correct time. Therefore, it is important that families always plan ahead.

It is not okay to go to a funeral, wedding or holiday and miss a few doses here and there, even if otherwise the child always receives the medicine properly. If the caregivers must travel, it is important that they leave the child under the care of the treatment supporter or another reliable caregiver. If there is no one available to take responsibility for administering the medicines in the regular caregiver's absence, the child should be taken on the trip.

If the child is going to be **traveling**, families should pack more doses of the medicines than they think they need in case they are away longer than expected. It is a good idea to pack enough ARVs for an additional week away, just in case plans change unexpectedly.

It is important to never run out of medication. Families should make sure that they receive their new monthly supply of drugs before they run out.

To ensure that the HIV remains asleep, the child must take all of the medicines prescribed by the doctor. If the child takes only two of the three ARVs prescribed, the virus may become resistant to the medicines. **If the child runs out of one of the ARVs**, it is important to **not give the child the other two ARVs** unless instructed to do so by the doctor or nurse. Someone should come to the clinic immediately to replenish the supply.

Planning ahead also means that the caregivers must plan ahead for their own health. Even if they feel good and look healthy, ***all caregivers should be tested for HIV.***

We encourage all caregivers to ask a family member, friend, or another caregiver to come with you to the child's clinic appointments to help you remember what the doctor or nurse says. This person – known as a ***treatment supporter*** -- should:

- learn how/when to give the child his/her medicines
- ***help the primary caregiver to remember*** to give the child his/her medicines at the right time
- share responsibility for taking care of the child if the primary caregiver is not home, is sick, or needs to travel
- provide the caregiver emotional support to help reduce their stress level

Adverse Effects

Use Visual Aid 14 to reinforce the concepts introduced in this section.

When they begin taking ARVs, some children may experience discomfort called ***side effects***. This may include skin rashes, headaches, fever, abdominal pain, nausea, diarrhea, and vomiting. When you meet with the doctor before starting treatment, be sure to ask which side effects are most common with the specific drugs he/she is prescribing for the child.

Once treatment begins, ***tell the doctor or nurse right away if the child is having any side effects or health problems.*** Many side effects occur only at the beginning and will go away on their own, but some are more serious. Also, because children who are beginning ARVs usually have weak immune systems, they may get serious infections. It is important that patients and their caregivers communicate openly with the clinic staff when problems occur so that side effects and new illnesses can be managed appropriately.

It is also important that patients and caregivers ***inform the doctors and nurses of any traditional medicines*** that they are currently taking or have taken in the recent past. Some of these medicines can interact with ARVs and decrease the amount of medicine in the body, which in turn places the patients at risk for resistance. Sometimes side effects are worse when ARVs and traditional medicines are combined.

Disclosure/Involvement of Children in Their Own Care

Living a long and healthy life with HIV depends on taking necessary medicines every day. Being healthy also depends on feeling good about ourselves. In order for children to be able to take their medicines correctly for their entire lives and to feel good about themselves, they have to understand about their medicines and their infection in an age-appropriate way. When a child learns about his/her illness, we call this **disclosure**.

Disclosure for young children is a **process** that takes place over time.

Family is the most important partner in the disclosure process. We advise parents/caregivers to start disclosing as soon as possible in an age-appropriate way. The healthcare team will provide support in the disclosure process. Many of the visual aids that we use to explain about how the immune system, HIV and medicines work can be used to explain these things to children.

It is important for older children to know their status. Open communication about HIV will allow them to express their fears, obtain support, understand the infection, and improve adherence. Even if a child is too young to fully understand his/her HIV status, it is possible, through ‘partial’ disclosure, to:

- Teach children the names and doses of their medicines
- Have children share responsibility by asking for their medicine
- Ensure that children understand why taking their medicine is important (*Medicines help you to become and stay healthy.*)

When beginning the process of disclosure with young children, remember to:

- Focus on simple information in **language they understand**
- Discuss the nature of their illness (*the medicines will make them healthy by increasing the ‘soldiers of the body’; as long as their soldiers are strong, they can do whatever they want to in life, etc.*)
- **Use songs, dance** and any other activities that can **facilitate children’s participation in their own care**

Clinic staff must become comfortable and proficient in providing disclosure-related counseling. If families wish to disclose to their child but do not feel comfortable doing so, they should inform the clinic staff. Well-trained clinic staff will be happy to assist in the disclosure process. Regardless of the child’s age it is important to **always tell the truth**.

Stress positive messages!

Help children to plan for their futures.

Remember that illness is never anyone's "fault."

People with HIV can regain health and remain healthy with the help of ARVs.

Remember: ARV therapy alone will not make a child healthy. The child must receive other kinds of care such as proper nutrition, and appropriate amounts of sleep and exercise.

Universal Precautions

Begin this section by asking participants if they can name all of the ways in which HIV is transmitted. Then, probe further to see if participants are familiar with methods of prevention. Once caregivers have shared their current knowledge, review the main points summarized below.

Children should be reminded not to touch other people's blood and not to allow others to touch their blood. If someone has a cut, it is okay to hand them a towel or a bandage, but everyone should be careful not to touch open wounds. This will prevent the transmission of both HIV and other illnesses that can be spread through bodily fluids.

It is important not to share razors used for shaving people's heads or beards; always use a clean razor that has never before been used. Small amounts of blood on razors can allow for transmission of illnesses.

People who visit traditional healers, should insist that they use a clean instrument for any cutting of the skin.

People who are not abstaining from sex, should always practice safe sex, which means staying faithful to one partner and using condoms.

It is important to remember that ***even if someone is on ARV treatment, they can still pass on HIV through blood or sexual contact, and they themselves can get re-infected***, sometimes with a virus that is resistant to their ARVs.

Before ending the session, encourage participants to share any questions and concerns regarding what they have learned at any point during the adherence training.

Emphasize once again the critical importance of open and regular communication with the health team.