





Children Treatment Literacy Booklet for Caregivers



Dear Caregiver,

This booklet was developed by the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF)—Lesotho in collaboration with the Ministry of Health with the support of Gilead funding. It introduces pediatric HIV virtual case management that uses client-centered service delivery to ensure good treatment adherence and retain children up to 14 years of age in care.

The booklet gives guidance to parents and caregivers of children living with HIV. It focuses mainly on imparting treatment literacy to caregivers to ensure they take care of their children.

Our aim is to empower caregivers. To that end the booklet explains:

- What is HIV and what is AIDS?
- What is advanced HIV?
- · What is antiretroviral (ART) treatment?
- · What are the benefits of good treatment adherence?
- What is viral load and what is the importance of viral load monitoring?
- What is the nature and importance of disclosure?

The booklet further educates caregivers on different types of ARVs, how to administer ARVs to babies under 5, how to teach older children to swallow tablets, the different approaches to access services delivery, and when to seek help from health care workers through a phone call.

Please note that in order to prevent transmission of the virus that causes COVID-19, facilities are now allowing caregivers to seek help telephonically to avoid regular visits to facilities. This telephonic support will continue even after the pandemic. For further guidance on how to access this support, please ask your health care worker.

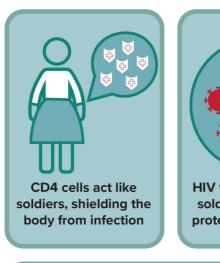
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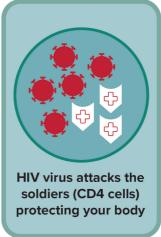
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What Is HIV?

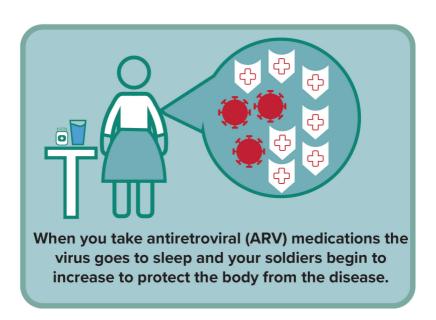
HIV stands for human immunodeficiency virus.

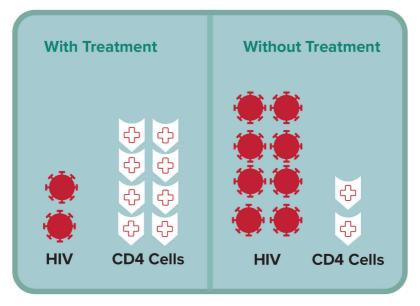
HIV is a virus that attacks the body's defense system and makes it too weak to defend itself against diseases. If HIV is left untreated it can lead to AIDS (acquired immune deficiency syndrome).





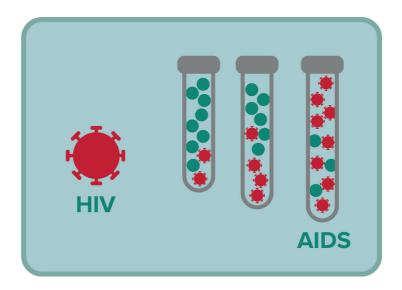






What Is AIDS?

AIDS stands for acquired immune deficiency syndrome.



AIDS is the advanced stage of HIV infection during which the body is attacked by multiple diseases such as tuberculosis (TB), oral thrush, meningitis, and malnutrition. People who are HIV-positive should not allow their body to progress to the AIDS stage, and parents and caregivers do not want to allow that to occur in children under their care. To ensure children live healthfully with HIV, do the following:

- Know the child's HIV status in a timely manner—that is, before he
 or she becomes very sick.
- If your child is HIV-positive, administer ARV drugs every day to your child, as prescribed by your health care worker; this is extremely important to keep him or her healthy and virally suppressed.
- 3. Your health care worker will adjust the dose as your child grows.
- 4. Ensure your child's viral load is monitored every six months or as guided by your health care worker.

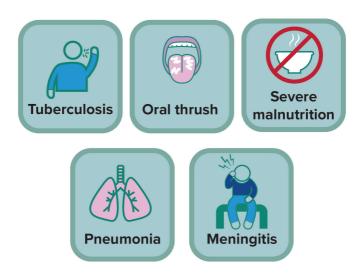
- 5. Do not miss the child's check-up appointments and refills.
- 6. If you have mild side effects as explained by the health care worker you may not need to return, but if the side effects worsen contact your health care worker and report immediately.
- 7. Screen for opportunistic infections and treat them on time.
- 8. If you are HIV-positive, begin taking antiretroviral (ARV) treatment as soon as possible.

Signs of Advanced HIV Disease

Advanced HIV Disease (AHD) is when CD4 cells count is less than 200 or when a child or a patient is attacked by diseases to show that is now having AIDS.

*Please note that all children with HIV younger than five years old are considered having AHD regardless of their CD4 cells unless if they have been receiving ARV for more than one year and are clinically stable.

The following are signs of advanced HIV disease:

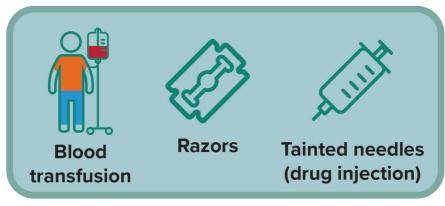


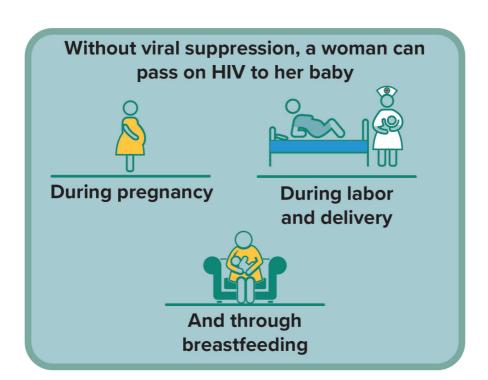
How Is HIV Transmitted?

HIV can be transmitted in the following ways:

- A person can acquire the virus by having sex with an HIV-infected person without using protection such as a condom.
- If a pregnant and breastfeeding woman is not virally suppressed, she increases her chances of transmitting HIV to her baby during pregnancy, during labor and delivery, and through breastfeeding.
- HIV can be transmitted through blood transfusion, as well as through the sharing of HIV-contaminated needles or the use of tainted needles (drug injection) and razors.







What Is Antiretroviral Therapy?

Antiretroviral therapy (ART) is treatment for HIV. The anti-HIV drugs are also called antiretrovirals (ARVs).

How well do ARVs work?

ARVs work to stop HIV from multiplying (making more copies of the virus) inside a person's body. This reduces viral load (i.e., the amount of HIV virus in the blood) to undetectable levels.

When is the right time to start taking ARVs for the first time?

Any person who has tested HIV-positive is encouraged to start taking ARVs as soon as possible, regardless of how healthy they feel.

How long will my child take ARVs if he or she is HIV-positive?

ARVs are a lifetime treatment. Remember, once your child have started ARVs, your child will take them every day for life. Technically, there is no cure, at present for HIV, but taking ARVs every day can reduce a person's viral load and turn HIV from a fatal illness to a chronic lifetime condition.

What are the best ARV options for children?

The health care worker at your nearest clinic will guide you on the best options for your child's age, sex, weight, and treatment history. Please note that ARV options continue to be improved and changed over time to improve clinical outcomes and patient quality of life. So, do not be surprised if, in the future, you are transitioned to a better option of ARVs. This booklet provides information on ARVs for children.

Are ARVs safe?

Yes! ARVs are very safe. Your health care worker will provide your child with an appointment date to visit the clinic for regular monitoring. Ensure that your child does not miss the appointment.

What happens when I forget to give my child the ARV pill?

If you forget to give your child the ARV medication, and you are closer to the next dose needed, wait for the next dose and then continue to give it consistently daily (do not double up on doses, back-to-back). If it is closer to the missed dose, then give the missed dose as soon as you remember.

What are common side effects of ARVs?

Headache, vomiting, diarrhea, skin rash, nausea, and dizziness are some of the common side effects of ARVs. Your child should not stop taking his or her treatment, but you should immediately report any side effects to your health care worker for help.

PLEASE NOTE: Different treatments, including ARVs, can have side effects. These side effects can be different depending on the child—for example, some people have only one side effect and others have two or more while others have no side effects at all. Some side effects are mild while others are severe. Do not worry—your health care worker will support you to manage your child's side effects. Please return to your health center and inform the health care worker about your child's side effects for assistance.

The Importance of Treatment Adherence

What are the benefits of taking ARV treatment?

HIV can make one vulnerable to other illnesses (opportunistic infections such as TB or meningitis), but if the patient takes ARVs consistently, the HIV virus is weakened and at times undetectable, which allows your or your child's immune system to protect itself properly from other illnesses.

What is treatment adherence?

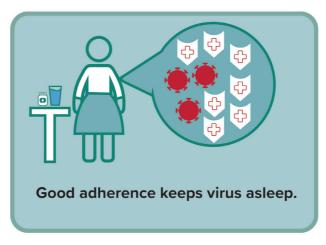
Adherence means your child is following the treatment plan you and your health care worker discussed. Adherence means your child is taking medication daily, as prescribed – no missed doses. Your child should not miss checkups and refill appointments to ensure that he or she always has their medication. **Adherence is sticking to the 4 R's:** Right drug, Right dose, Right time, and Right way.

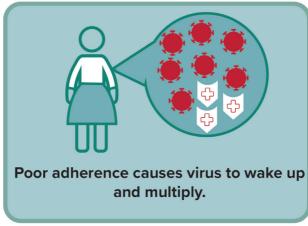
What is the importance of good treatment adherence?

Taking ARVs, every day, as prescribed by your child's health care worker, is extremely important to ensuring the health of your child. These drugs mute the virus, so that your child's immune system can defend his or her body against common infections. Maintaining good adherence also prevents or delays the onset of drug resistance, treatment failure, and the need to switch to second-line and third-line ARV drugs, ensuring that your child's immunity will have a continued boost against HIV.

What are the consequences of poor adherence?

If you don't give your child the medication as prescribed by your health care worker, it can result in HIV "waking up", multiplying to much higher levels in your child's body, thereby weakening your child's immune system. Once HIV gains strength, it compromises your child's immunity and makes them vulnerable to other illnesses — illnesses which would not be otherwise serious or fatal, can become so with a compromised immune system. All children or adolescents living with HIV should always remember to never miss their ARV treatment/dose.





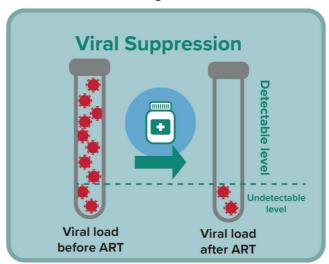
Viral Load Monitoring and Its Benefits

What is viral load?

Viral load is the amount of HIV virus in a person's blood. It is measured at the health center, through a blood test. A blood sample is processed at a lab where a machine detects levels of the virus, these results are relayed back to you by your health provider and give you an idea of HIV progression.

What is suppressed viral load?

If your child adheres to the optimized treatment, his or her viral load will be suppressed. This means the HIV virus is undetectable in the child's blood. The treatment will make the virus sleep—thus the virus will stop multiplying and the laboratory machine won't be able to see the virus in the child's blood. In other words, good treatment and good treatment practice, can wipe out HIV from your child's body almost completely, which then allows your child's immune system to act as it should. This does not mean that the virus is no longer in the child's blood; it is still in the patient's organs and tissue, but it is being well-controlled by the medication. Refer to the diagram below.



What is high viral load?

When a person living with HIV doesn't take ARVs, or when treatment failure is occurring, the virus will begin to, or eventually, rapidly multiply. The viral copy of HIV in the blood stream is highly detectable, and the child is at an increased risk of falling seriously ill from any illness as the immune system is attacked.

How will I know my child's viral load?

When you and your child visit a health center for checkups and ARV refills, health care workers will draw your child's blood. The blood for testing the viral load of your child will be drawn every six months. If the virus is suppressed (lower than the detectable limit), it means your child's treatment is working well. If it is unsuppressed (detectable), it means your child's treatment is not working well or your child is missing doses (poor treatment adherence). The health care workers will support you and your child to determine the reason for unsuppressed viral load. In some rare cases your child may need to have their treatment changed to an improved regimen.

What should I do if my child's viral load is high?

If the viral load results show that the child has a high viral load, the health care worker will refer your child for enhanced adherence counselling. There the counsellor will take your child's history and learn whether the child has challenges taking medication, and you will find a solution for the challenges together. Then your child will return to the clinic monthly or will be followed up telephonically for counselling sessions and for monitoring of their clinical condition and to check whether the solution you and the child opted for is working or not. After three months of adherence, blood will be drawn to see whether the child's viral load is improving or worsening.

What if the viral load continues to be high even after enhanced adherence counselling?

If your child has a high viral load even after multiple interventions, he or she will be referred to see a doctor. The doctor will look into a treatment regimen change at this point, and your child may switch to an improved, and stronger regimen to better control his or her viral load.

It is important for caregivers to ensure that children living with HIV are always healthy and have a suppressed viral load. If you need more information about HIV and AIDS, please ask your health care worker at your nearest health center.

Disclosure and Its Benefits

Disclosure is the process of informing a child of his or her HIV status. Sometimes disclosure may involve sharing the HIV status of the caregiver or other family members.

Disclosure is not a onetime thing, but rather it is a process—which means that it takes time and will involve multiple conversations until the child understands about his or her HIV status.



This booklet provides you with brief guidance to start a conversation about HIV with your child and choose which form of disclosure you will use. We encourage families to start disclosing to their children from about 5 years of age on, depending on the child's level of understanding.

Benefits of disclosure

Disclosure

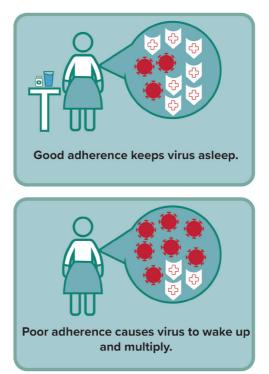
- allows children to accept their HIV status and learn to cope;
- allows children to open up about their status and reduce selfstigma and anxiety;
- · allows children to join peer support groups or teen clubs freely;
- enhances good treatment adherence;
- promotes independence and transitioning into independent care;
 and
- helps adolescents increase their self-esteem and make informed decisions.

Partial disclosure

Partial disclosure is when the caregiver decides to tell the child only some information about her or his illness. It takes place between 5 and 9 years. At this point HIV is not mentioned.

How to do partial disclosure

Explain to the child that there are viruses (these can be referred to as bugs, disease particles, etc.) in the blood that can weaken the immune system, and explain that the medicines the child is taking help to control the viruses and help him or her stay healthy.



If partial disclosure is being done, focus on adherence to medications and care and messaging on staying healthy. If you need assistance to start these conversations ask your health care workers.

Full disclosure

Full disclosure is when the family or caregiver decides to tell the child all the information about her or his illness. This should be done mostly when the child starts asking specific questions related to her or his illness, such as, "How did I get the disease?" Or "Why do I take daily medication? Am I sick?" This often occurs between 10 and 12 years of age.

How to fully disclose

Build on the available knowledge about chronic illness and proceed with full disclosure, naming HIV and explaining how it damages the immune system and how it can be treated.

Discuss modes of transmission and, more specifically, vertical transmission. Place an emphasis on protecting the mother's status within the family and the community, and explain that the transmission was not anyone's fault.

Nondisclosure

Nondisclosure is the failure or refusal to declare or reveal to a child his or her HIV status. Please note that one day the child will find out on his or her own, and hence, this is not recommended. If you cannot do it on your own, ask your health care worker to help you to disclose to your child.

PLEASE NOTE: Nondisclosure to a child about his/ her HIV status is violation of their right to be informed about their health in order to be actively involved in their own care when growing up.

ARV Administration for Babies and Children

Why are ARVs important?

ARVs

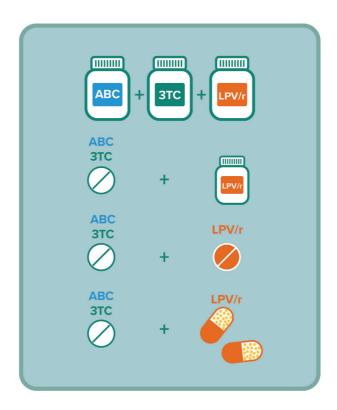
- suppress the viral load and allow our immune system to work properly;
- help us to live longer and healthier lives: and
- reduce the risk of HIV transmission to others.



What are the different types of ARVs for children?

There are many types and classes of ARV drugs; they are often given in a combination of three drugs. It is important to give all three ARVs to your child no matter how they are combined. A complete ARV regimen usually contains three different ARVs, but they may be combined in different ways. Some ARVs come already combined for easier administration. Take time to learn your child's ARVs by name, if you can.

- For all children below 20kg, the preferred regimen is ABC/3TC/ pDTG and other option can be ABC/3TC/LPV/r.
- A common ARV regimen for children above 20 kilograms is ABC + 3TC + DTG



Pediatric Dolutegravir (pDTG) 10 milligram (mg) dispersible tablet is a new improved children's ARV drug formulation that is used for children living with HIV (CLHIV) who are at least 1 month of age and weigh at least 3kg up to 20kg.

pDTG is easier to take because it is dissolved in water that the child drinks. It is more effective and resistance doesn't develop easily. When it is available, our children's treatment will be changed to this medication. The health care worker will tell you if your child needs to change to this new medication at your next routine appointment.



Guidance on Administration of Pediatric DTG 10mg Dispersible Tablet



step 1. Caregivers should add the prescribed dose of pDTG tablet to clean water, stir until the tablet(s) dissolves, and administer to the child.



Step 2. The child should drink all the water straight away or within no more than 30 minutes.

Step 3. If taking half or one and half DTG 10 mg tablets, should use 5 mL (1 teaspoon) of clean water.

Step 4. If any medicine remains in the cup, add a small amount of additional water to the cup, swirl, and give to the child. Repeat as necessary.

Guidance on Administering LPV/r Pellets or Granules

The following is guidance on the administration of the pellet or granule type of LPV/r. This type of ARV is usually used for children who are not yet able to swallow tablets. Health care workers will ensure that children are given the ARVs that are the easiest to administer to them.

Lopinavir LPV/r formulations

Lopinavir can be in the form of syrups, pellets, granules, or tablets.

Health care workers will aim to ensure they give you the type that is easiest for the child to use.

LPV/r pellets or granules are usually used for children who are not yet able to swallow tablets who are aged above 2 weeks.

Step 1. Set a clean

How to administer LPVr 40/10 pellets



Step 3. Open the bottle containing the pellets and take out the exact number of pellet pills to be given to the child or infant as instructed.





Hold each pellet pill at the ends with both hands and twist and turn to open.





Step 4. Pour the contents of the pellet pill onto a clean tablespoon.



Step 5a. If using liquid:

Add a small amount of the liquid on top of pellets, but do not try to dissolve.



Step 5b. If using semisolid:

Put a little food onto the spoon.



Step 6. Pour the required amount of the pellets on the food. It is advisable not to pour large quantities of pellets. Pour about one or two capsules at a time. Make sure that all pellets are on the spoon and that no pellets fall off.

Step 7. Pour some more food onto the spoon to cover the pellets.



Step 8. Give the food-pellet mixture to the child or infant. Ensure that the whole food-pellet mixture is swallowed by the child. Follow up with more food or liquid to ensure that the child swallows all the pellets.

Finally, check the child's mouth to ensure that no pellets remain.

How to administer LPVr granules—for infants not yet taking solid food (i.e., 14 days to 6 months of age)



Step 1. Place a clean and dry small cup or bowl and spoon on a clean table.



Step 2. Take a small volume of expressed breast milk or formula and put it in the small cup.



Step 3. Take the correct number of sachets (as prescribed by your doctor) out of the carton.



Step 4. Tap the sachet(s) to move all the granules to the bottom of the sachet(s) and completely tear or cut off the top of the sachet(s).



Step 5. Pour all of the granules from the sachet(s) into the small cup. Mix well.



Step 6. Administer the entire mixture to the baby immediately. If there are any granules left in the cup, add more breast milk or formula and administer the mixture to the child immediately.

Step 7. Follow up with more breast milk (or formula) to ensure that the child swallows all the granules.



How to administer LPVr granules with clean drinking water (for children older than 6 months)



Step 1. Place a clean and dry small cup or bowl and spoon on a clean table.



Step 2. Put a small quantity of clean drinking water in the cup (1 teaspoon of water for 2 sachets; 2 teaspoons for 3 to 8 sachets; 3 teaspoons for 10 sachets).



Step 3. Take the correct number of sachets (as prescribed by your doctor) out of the carton.



Step 4. Tap the sachet(s) to move all the granules to the bottom of the sachet(s) and completely tear or cut off the top of the sachet(s).



Step 5. Pour all of the granules from the sachet(s) into the small cup. Mix well.



Step 6. Feed the entire mixture to the child immediately. If there are any granules left in the cup, add more water and administer the mixture to the child, to ensure that the child swallows all the granules.

How to administer LPVr granules with soft food (for children older than 6 months of age)



Step 1. Place a clean and dry small cup or bowl and spoon on a clean table.



Step 2. Put soft food that your baby will eat such as porridge or other soft food available (approximately 1 teaspoon for 1 sachet, 2 teaspoons for 2 sachets, etc.) into the bowl.



Step 3. Take the correct number of sachets (as prescribed by your doctor) out of the carton.



Step 4. Tap the sachet(s) to move all the granules to the bottom of the sachet(s) and completely tear or cut off the top of the sachet(s).





NOTE: The granules should not be chewed or crushed. The mixture must be given within two hours of mixing with soft food. If not given within two hours of mixing, discard (throw away) the mixture and prepare a new mixture.

Teaching Children to Swallow Tablets

- Is your child ready to learn how to swallow tablets whole?
- Can your child follow simple directions?
- Can your child eat, drink, and swallow without problems?

Step 1. Getting ready

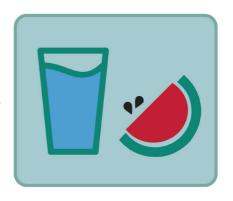
- Start teaching your child how to swallow tablets before tablets are prescribed, which usually occurs at the age of 5 years.
- It may take some time before your child is able to swallow tablets whole, but it is important to practice daily.
- A good time to practice is before or after your child takes ARVs.

Step 2. Practice with "practice tablets"

- Start with something small and easy to swallow, such as a watermelon seed, as a "practice tablet."
- When your child is comfortable swallowing the watermelon seed whole, try something just a little bit larger.
- Slowly increase the size of the "practice tablet."



If you are also on ARVs or taking other medicines, you can show your child how you swallow your own tablets. Your child will see that it is possible to swallow tablets quickly and easily.





Step 4. Try different head positions

- Start by giving your child a glass of water or a favorite drink such as milk or juice.
- Ask your child to take sips and swallow them using different head positions.
- Ask which position makes it easier for your child to swallow.



 Do this at the start of every practice session—and try different head positions.

Why do health care workers need to change ARV doses?

Your child's dosage may be changed for these reasons:

- As your child grows his or her dose may increase. It is important to check weight at each visit so the child gets the appropriate dose.
- When children become ill with an infection, such as TB, doses may need to be adjusted as some drugs may interfere with each other.
- When the health care workers identifies kidney or liver problems, they recommend a change.

When do health care workers change medication type?

As children grow, their medication also changes. It may change from syrup to pellets, and from pellets to tablets, as soon as the child is able to swallow tablets.

When do health care workers need to change drugs?

A drug change can be indicated, if

- newer, more effective drugs become available in the country;
- the child is being treated for some conditions, such as TB;
- the child shows signs of failing treatment despite taking medication well; or
- the child has had a serious reaction to a specific drug—in which case that drug has to be removed from your child's daily regimen.

Different Ways of Accessing HIV Services for Your Child

The health care worker will explain the various approaches to accessing HIV services and medicines for your child and help you select one that is suitable for your child's care needs, that is easy for you, and that will ensure that your child will adhere to his or her treatment. The services available to you and your child include:

Multimonth scripting and dispensing. Through this approach, your child can be given more than one month's treatment of ARVs (sometimes a 3 or 6-month supply of medicine) to reduce the number visits to a health facility. A child is only eligible for this type of reduced facility activity if the child has shown treatment adherence, reduced viral loads and has no other illness, which would require steady monitoring.

- Generally small children change weight frequently, and because of this their medication dosage will need routine adjustments. Therefore children generally will not start receiving a multimonth supply before they reach the age of 2 years.
- Community ART delivery. In some cases the clinic will arrange for drugs to be delivered right to your home or to a place close to your home! A health care worker may make the delivery, or the drugs may be placed at a pharmacy or community center close to you, or in some places in specifically designed safe lockers that you will have access to. Find out from your health worker what options are available in your area and whether your child qualifies.
- Community lockers. Community lockers are used when you agree with your health care worker that you will not take refills from a facility but prefer to collect the medication from a community locker.



- Family-centered models. You can decide to come for your checkup appointment as a family, which can include you, a partner, other children and these appointments can address all family members health needs at once.
- Weekend clinics. School-going children can be given weekend appointments so that they may collect their treatment refills when they are free from school. They also have an opportunity to attend peer support groups and share experiences of living with HIV with their peers during weekends.
- Mother-baby pairs. If you are a mother who is also living with HIV, you can share your appointment with your baby and get viral load

monitoring, counseling and drug collection for both of you in one visit to reduce regular visits to clinic and to avoid the child missing clinic appointments.

 Virtual support. If you provide your telephone number and provide consent, a health care worker can follow-up with you about your health and the health



- of your child through phone calls, SMS, or WhatsApp. Your health care worker will call you on your phone to check on the condition of the child and check whether the child is taking medicines well. You can also call health care workers at the clinic phone number provided if you have any questions or emergencies related to your child's health.
- Being followed telephonically can help you to reduce the number of visits to the health center, which protects you and your child in the COVID-19 context.
- Outreach clinics and health posts. These are specific sites in the community that health care worker teams visit on a regular schedule to provide services. Ask your health care worker about outreach services that may be available closer to where you stay and how you can access those services.

When to Seek Help from a Health Care Worker.

(Make a phone call immediately.)

Seek help immediately

- if the child has any side effects from the medications;
- if a child develops any new illnesses like cough, difficulty in breathing, fever, convulsions, and so on;



- when the child is not tolerating medications (for example, choking or vomiting pellets); or
- when you have any questions.

Contact Information

For more information or in any emergency, call the clinic hotline and speak to a health care worker:

•	Health facility name
•	Facility hotline number

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