



CHAPTER 11

ART: Medicines for HIV

With ART treatment, healthy food, and other health care, children with HIV can grow well, become adults, work, live a full life, and even have children of their own. Children with HIV who take ART are less ill, feel better, and grow and develop better, avoiding the disabilities HIV can cause. They can do all the things children usually do.



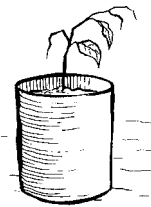
What is ART?

ART (Anti-Retroviral Therapy) combines several medicines called antiretrovirals. Antiretrovirals work in different ways against HIV, and combining them makes ART work well to stop HIV from making us ill.

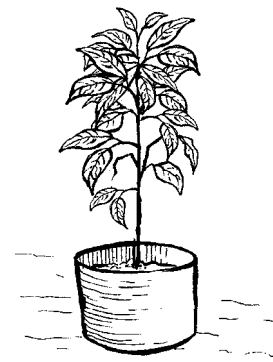
Taken every day, ART keeps the amount of HIV in a person's body low. With a small amount of HIV, a person's immune system is not so weak and HIV cannot harm the body as much. A person on ART can fight all infections better, including HIV infection.

However, ART cannot cure HIV completely. To keep HIV under control, a person with HIV must take ART every day.

HIV infection is like a bad pest problem in a plant. When there are too many pests, the plant is unhealthy and cannot grow. If you can keep most of the pests away or get rid of them, your plant will be strong and healthy, and can grow big and tall.



With too much HIV, we cannot fight illness or grow.



ART helps us be healthy by keeping our HIV low, as long as we take it every day.

Just as a plant needs water, sun, and good soil to thrive, children with HIV need ART, healthy food, clean water, regular health care, and lots of love to avoid illness and grow well. For more about these and other ways to keep young children healthy—with and without HIV—see Chapter 10.



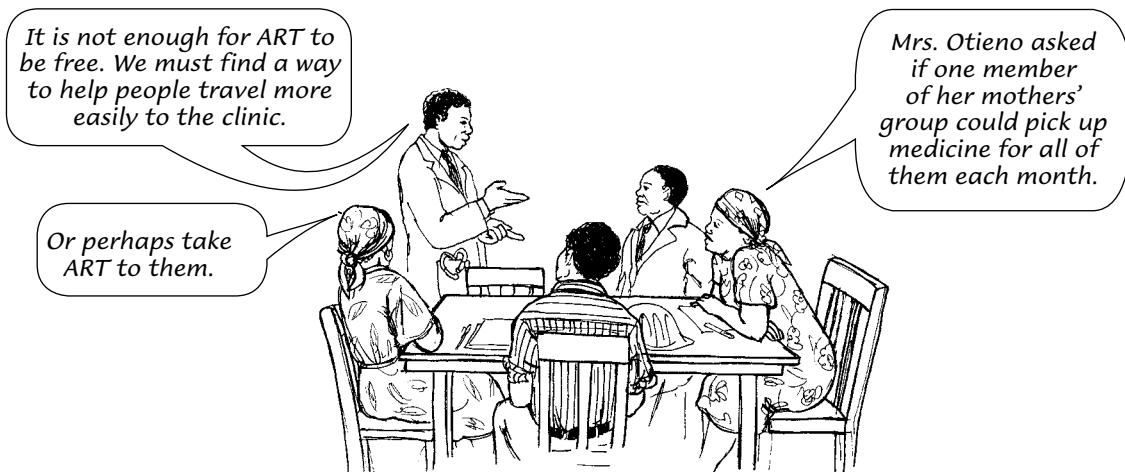
Is ART available in your community?

Because ART helps people with HIV live longer and healthier lives, and ART is less costly than it once was, it is now available in many communities. But sometimes people with HIV can only get ART by traveling several hours, or it is not easily accessible for other reasons. Difficulties getting medicine cause people to miss doses. When that happens, people are tempted to share medicines. Missing doses and sharing medicines are dangerous because for ART to work, the correct dose needs to be taken every day. Drugs and doses are often different for different people.

Talk with your health worker about how and where to get medicine. If you have difficulties getting to the clinic, or must pay for transport to get ART, you can ask the clinic for support. After all, what good are services if people cannot access them?

Governments and health programs can help people get the medicines they need at a reasonable cost. Find ideas on how to work in your community to make ART more available on pages 206 to 207 and in Chapter 15.

Warning: Do not buy ART in a shop or from someone outside a medical setting. ART must be given to you in the right amounts and the right kind for your child. Sometimes criminals or people who do not know any better sell fake (counterfeit) pills that look like ART but do not work at all.



When should babies and children start ART?

Any baby or child who has HIV should start to take ART as soon as possible. Starting ART while young children are still healthy keeps them alive, and protects their growing minds and bodies during their important first years of life, when they learn and develop more than at any other time.

If you do not know your child's HIV status and you suspect or wonder if he might have HIV, have your child tested. Health workers will test a child for HIV before they start giving ART. See Chapter 8.

Do not wait until your child is ill to start ART

You might think it is OK to wait and see. Adults with HIV may be infected many years without showing signs of illness. They may start taking ART only when they become ill, and recover their health then. But waiting until your child is ill is much more dangerous. HIV weakens a child's body and immune system faster and more seriously than an adult's, so his illnesses will be harder to treat and can quickly become deadly. Without treatment, more than half of children born with HIV die before age 3. But with treatment, they live.

If you have concerns about giving your child ART, ask other caregivers who give ART to their children how they manage it and how it has helped their children.



Note: Some babies take antiretrovirals for a few weeks after birth or while they are breastfeeding. This is a different use of HIV medicines to prevent HIV spreading from mothers to babies. For more, see page 121.

Giving ART to your child

For ART to work well, you must give the medicine each day, usually at the same time of day. Children can learn that taking a medicine is a part of their daily lives, like washing, eating, or getting dressed. You can teach them this, and encourage them to learn about and help keep track of their medicine.

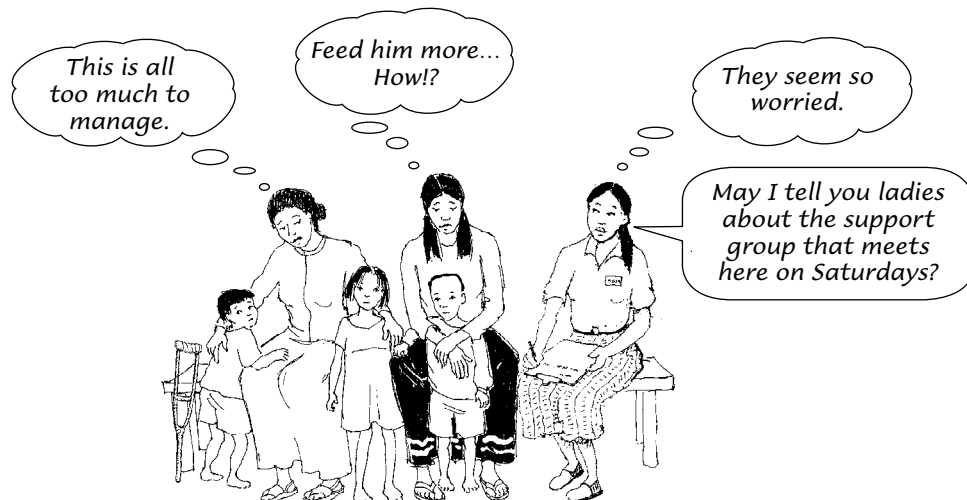
Some ideas for making it easier for your child to take medicine every day start on page 190. Ask others what works for them and their children. As your child grows, he will be able to take more responsibility for his medicine.

Getting ready to start ART

Even when you know your child has HIV and needs ART, you might need support to be able to start it or give it every day. Our lives are often complicated, and sometimes it is difficult to manage everything, including taking a daily medicine or giving it to a small child.

At your clinic or in your community, you may be able to:

- register yourself or your child to receive ART.
- learn about ART medicine, how to give it, and how to deal with problems.
- join a food program to help you have enough healthy food to eat, which people with HIV need — especially children — for ART to work well.
- find a support group, where hearing the experiences of others and sharing your own can help you manage the stresses of HIV and caregiving.
- tell a friend, partner, or family member about your or your child's HIV, so you do not need to hide your need to take the medicine from them.

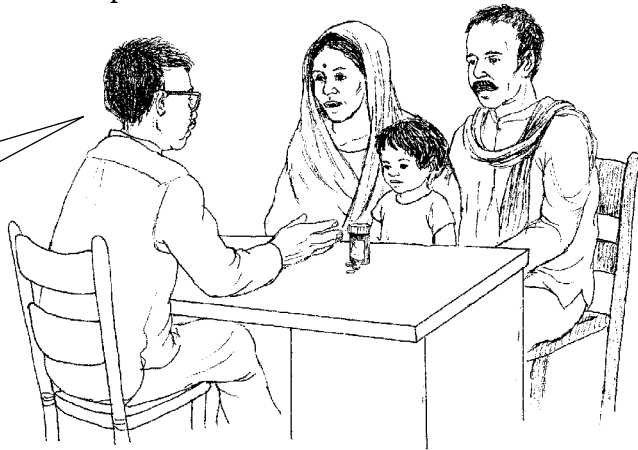


Basic information about ART

For ART, a person usually takes 3 medicines each day, which may be separate or combined in 1 or 2 tablets or liquids. Giving 1 pill or liquid is easiest. To give any medicine safely, you must know how much to give and when to give it, whether it must be given with food or on an empty stomach, if it can be divided or crushed, and if the medicine has any side effects (discomforts that can accompany taking a medicine, like a dry mouth or upset stomach). Some children have side effects with ART, but most side effects go away in a few weeks. For how to help children with ART side effects, see pages 198 to 203.

Knowing a little about what a medicine does may help you to remember to give it each day, to explain to your child why he takes it, or to prepare for how your child might feel and know how to help.

Each pill has all 3 medicines Avi needs. Give him 1 pill in the morning and 1 pill in the evening, with a meal or even just a bit of food. But he must swallow the pill whole, you can't crush it for him.



To remember how much medicine to give and when to give it, use one of the forms on page 308. You or a health worker can draw the amount and put it under the right time of day. You may need to do this for more than 1 medicine.

Name: <u>Mandisi H.</u>			
Medicine: <u>AZT + 3TC + NVP</u>			
For: <u>ART treatment</u>			
Dosage: <u>1 tablet, 2 times a day</u>			

Lydia's ART doses

For: April

	morning AM	evening PM
TDF/3TC 2 tabs twice	00	00
EFV ½-tablet at bedtime		⊙

15 kg weight

These are 2 ways to remember how often and how much medicine to give.

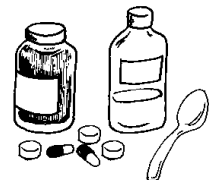
Keep track of when you will need to get more ART, so you will not run out and miss any doses. You must give ART correctly every day for the medicine to keep working.

Any missed dose gives HIV a chance to grow inside your child. A few missed doses each month lets the HIV germs change, so some of them are able to survive and multiply even when there is medicine in the child's body. If this happens, your child will need different ART. See page 205.



Different forms of ART

ART medicines for children come in different forms, depending on the medicine, the age of the child, and what a clinic has available. Babies need liquid forms of ART or something you can mix with milk or food.



Medicines designed for children include:

- liquids (suspensions or syrups, or powders to mix with water just before giving to the child).
- tablets with child-sized doses.
- sprinkles (tiny “seeds” of medicine you sprinkle on a child’s food).

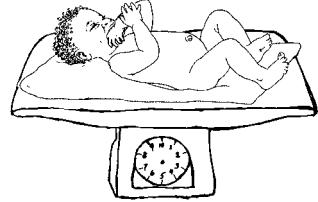
Tablets for children with child-sized doses make ART more effective for children than using tablets made for adults. The larger-dose adult tablets must be cut into pieces to give the dose the child needs. This means the child might get too much or too little medicine.

Many ART programs try to start children on tablets as soon as they can swallow them. Usually tablets are more affordable and they are easier to store and carry than liquids. Children as young as age 4 can learn to swallow a small tablet. See pages 190 to 191.

How much to give

Medicine doses for babies and children need to be measured carefully. Because their bodies are so small, it is easy to give them too much or too little.

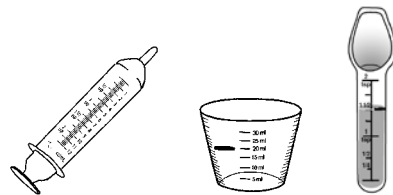
Because doses for children are based on the child's weight, they change as the child grows. Your child should be weighed each time you visit a clinic. The health worker can see if the child's dose should be changed and you can see how the child is growing.



Measuring tools for medicines

Your health worker may give you a measuring tool for your child's ART so you give the right amount. Measure medicine very carefully. Wash the measuring tool each time, before and after you use it. When you return for more medicine, you may need to show your health worker you still have this tool and that you have kept it clean.

Mark on your syringe, medicine cup, or medicine spoon how much medicine is your child's dose.

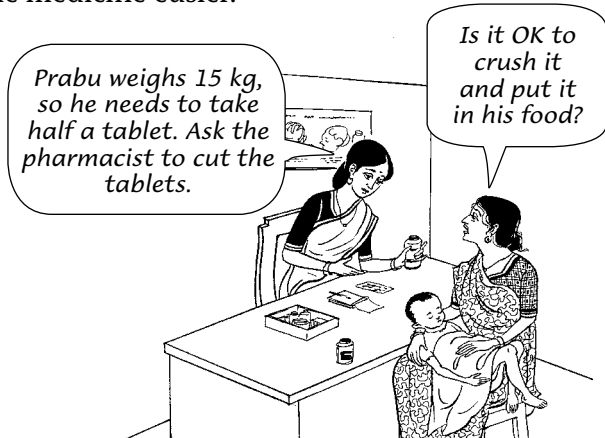


If you use a regular spoon, make sure you know how to measure your child's dose with it, and use the same size spoon each time. Wash the spoon before and after using it.



Your child might like to decorate a jar or box to store the tool for measuring his medicine. This may make giving the medicine easier.

Some treatment programs use the same tablets older children and adults take, but split them to make the smaller doses young children need. If possible, it is better not to cut or split tablets yourself to make smaller doses. Instead, ask for them to be split at the clinic, hospital or pharmacy, where they have special tools to cut pills. This can make sure the right amount of medicine for your child will be in each piece.



Give the medicine as prescribed. Make sure to ask your health worker any questions you have.

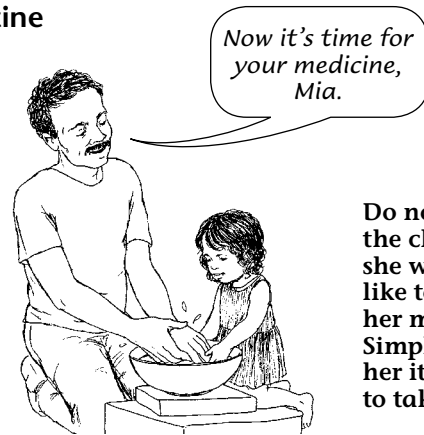
Helping your child take medicine

Starting daily medicine for a baby or child can be stressful. But with time, taking medicine can be a routine that children become used to.

How to make medicine a comfortable routine

Make the child's ART like a ritual — give it each day at the same time, in the same way, and in the same place. Routines feel good to children and help them go along with taking medicine. Be consistent, relaxed, and firm, and avoid battles or threats. Stay with the child until she has swallowed all the medicine.

If traveling often, you may need to create routines for traveling too.



Do not ask the child if she would like to take her medicine. Simply tell her it is time to take it.



Always praise a child when she takes her medicine and thank her for cooperating. Even a baby likes seeing your smile and satisfaction when she takes her medicine. This will help her take her ART each day.

A small reward for a child taking all her medicines in a week helps some children.

Sometimes you can distract a child's attention from the medicine with a song, story, or game. Some children may like it if you make up a song or a game about taking medicine.



A good routine will help children take more responsibility for their ART as they grow older. Continue to watch older children as they take their medicine, and tell them you are proud of them.

What to do about bad-tasting medicine

Some ART medicines taste bad to children. This happens more with liquids, but it can also happen if you need to crush a tablet to give it. Here are some ways to help children take these medicines.

- For a baby, use a dropper or syringe (WITH NO NEEDLE) and put the medicine far back in the child's mouth, between his cheek and tongue. He will not taste it as much that way.
- If your child is breastfeeding, give the breast right after giving the medicine.
- Offer a sip of juice, sweet tea, or fruit after the medicine.
- Mix medicine with something the child likes that is easy to swallow, such as mashed fruit. If you mix medicine into food or drink, make sure the child swallows all of it. If not, the dose will be too little.
- Before giving medicine, have the child suck an ice pop or ice cube to dull her sense of taste. Make liquid medicines cold.
- Use different foods to mask the taste, either with the medicine or before or after giving it. Different foods work for different children. Ask other families what has worked for them.



Push the medicine in slowly so the baby swallows without choking.



Teach children 4 years or older to swallow pills as soon as possible. Children can learn using small sweets or uncooked and dry beans. Help the child put one on the back of her tongue, and then take a swallow of water. At first, the child may need several swallows of water to swallow a pill. Always watch a young child taking a pill to make sure she does not choke on it or spit it out.

Respond to side effects

If a child feels bad after taking a medicine, he may try to avoid taking it. Most side effects go away after 1 or 2 weeks. There are ways you can help your child be more comfortable while his body gets used to the medicine. Sometimes the medicine that is causing the problem can be switched to another one without problems. See pages 198 to 203 for ways to help your child be more comfortable with side effects.



Remembering to give medicine each day

ART has to be given every day, and works best when the child takes it at the same time or times every day. That way there is always a certain level of the medicine in her blood. This is how ART keeps the HIV level low. Many people like to have a way to keep track of the medicines, to remember to give them, and also to know if they have been taken. For some people, a treatment buddy helps, someone who can encourage and remind you, and may help you solve any problems you have giving the medicine.

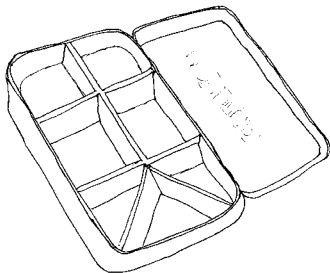
With your support and encouragement, an older child can often help think of ways to keep track, and do much of the tracking herself. Younger children need you to remember medicines, though some children will remind you themselves.



Having teenagers take responsibility for remembering medicine is appropriate for how old they are, and helps prepare them for living on their own.

How to make a weekly pill organizer

Many people use a pill organizer with 7 sections, 1 for each day of the week. They fill it on the same day each week. Each day, they know what medicine to give. And if they cannot remember later in the day whether they gave that day's medicine to the child, they can look and see. You can make a pill organizer out of cloth, wood, tin, or a collection of small bottles, envelopes or other containers. Label each section or container with a day of the week.



Use wood or plastic to make dividers in a metal tin. Each week, fill the 7 compartments with the pills you need for each day.



Link ART medicine with a daily activity

It can help you remember to give ART if you connect it to another daily activity. For example, give it:

- when waking and dressing your child.
- just before tending animals, or just before the child leaves for school.
- when you hear the morning or evening call to prayer.
- when a certain radio or TV program comes on.
- at sunrise or sunset.



Other ways to remember medicine

- Set an alarm on a watch or mobile phone.
- Agree with a friend to remind each other about giving medicine.
- Make a calendar — paint it on a wall or use paper or a piece of cloth. Mark each day your child takes her medicine.

Sometimes health workers have a chart you can copy and use to keep track. You or the child can mark it each time you give a medicine. If your child likes marking or drawing on her chart, she may take her medicine more easily.

Child's name Lydia Month April Medicine / Dose TDF+3TC ^{2 tablets} _{2 times a day} EFV ^{half a tablet} _{once a day}

Write your own words for the days →	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
	✓	✓	✓	✓	✓	✓	✓
	✓	✓		✓	✓	✓	✓
How do you feel today?	HEAD HURTS	diarrhea	diarrhea	Belly hurts	Belly hurts	OK	GOOD

This chart also has space to show how the child feels each day. See page 208 for a blank chart you can copy.

Any family member or older child who can write can help fill out the chart. You can also use pictures to remember new problems or questions that you want to discuss with a health worker at your next visit.

If you often have trouble remembering to give ART on time, think about why it is difficult. For example, if your child's medicine needs to be taken with food or on an empty stomach and you are giving doses late, maybe your medicine times do not work with your family's eating times. Talk to your health worker about changing the times you give the medicine.

If you and your child both take ART, ask your healthworker if you can both take your medicine at the same time (but never take your children's medicines or give your children your medicine).

Share what works for you with others, including your health worker. Your ideas can help other families be better able to take and track their HIV medicines.

Remembering ART when your routine changes



Plan ahead for changes in your routine. Visitors, events, weekends, holidays, and traveling can all upset a routine for taking or giving medicine. If you travel or go out, take the medicines you may need with you. If you know your activities will be different, try to think of how you will remember your child's ART. If you do not want others to know you are giving your child medicine, think of how to find time alone, such as helping your child bathe or take a nap, or by going for a walk or to a shop.

What to do if you miss a dose

No matter how careful you are, you may miss a dose of medicine. If this happens, give your child her dose as soon as possible. However, if it is almost time for the next dose, wait and give the next dose on time.

So if your child takes ART once a day, you can give the missed dose up to about 12 hours late. For a child who takes ART 2 times a day, you can give a missed dose up to 5 or 6 hours late. This cannot be a regular way to give ART though, only something that happens rarely, if at all. Missing doses can make your child's ART stop working. If this happens, her HIV level will increase and she will become ill.



If a child vomits just after taking a dose, wait until she feels a little better and then try again. However, if she vomits 30 minutes or more after she took the medicine, she got enough medicine into her system so you do not need to give her more. A child who vomits her ART several times should see a health worker.

A healthy child with HIV must keep taking ART

Within several weeks of taking ART, your child will probably be more active, growing better, and feeling well. Many children on ART look and act completely healthy. It might seem like you could stop giving him ART, or give it less often, but this would be a mistake. Feeling and looking better shows their ART is working, and they need to keep taking ART to stay well.

HIV is a dangerous infection. If someone stops taking ART, HIV will come back stronger and may become resistant to 1 or more of the HIV medicines, making their HIV more difficult to treat. Stronger, more expensive ART medicines with more side effects are often the only ones that will work – if they are available.

If a person is to stay healthy, once he starts taking ART, he must keep taking it and not stop. For more about how to talk to your young child about HIV or taking medicine, see Chapter 5.

Your medicine is like cleaning your teeth, but even more important. We need to clean our teeth every day so holes won't grow in them and they don't fall out.

Right! Your body needs your medicine every day.

Like grandpa!

OK, Sam.



Work with other caregivers

Good communication is important when different people give medicine to a child, for example, other members of your family, or a servant, teacher, or babysitter. If other people give your child ART, work together to make sure the child gets his ART at the right times. Help others understand why each dose of ART is important, and how to remember to give the medicine. Also share any ways you have learned to deal with problems, such as how you distract the child, or praise him, or what food helps him take his medicine.

Chin takes medicine every day, and you must not forget it on the days you watch him. I will show you how to do it.

Does he take it easily?



Common ART Medicines for children

Start a child on antiretroviral therapy (ART) as soon as you know that he has HIV. Since antiretroviral medicines usually are available only through HIV programs and clinics, you will probably not have a choice as to what medicines to use. However, it is still important to understand what medicines your child will be given and any side effects they may have.

ART is most often a combination (or “regimen”) of 3 different ARV medicines, one from each of 3 groups. Because each fights HIV differently, combining them is what makes them effective. The regimen given to your child depends on his weight or age, and what is available in your area. Sometimes the medicines are available separately, and sometimes combined in a single tablet. The doses for the medicines change as the child grows, and sometimes the medicines change too. These are the most common ART medicines for children:

Group 1		
Name	Comes as	Comments
AZT – Zidovudine (<i>Retrovir</i>)	Syrup 50 mg in 5 ml	For newborns.
	Tablet 60 mg	
ABC – Abacavir (<i>Ziagen</i>)	Tablet 60 mg	Can be used with AZT/3TC during TB treatment. Stop if allergic reaction develops. Do not start at same time as starting cotrimoxazole.
Group 2		
Name	Comes as	Comments
3TC – Lamivudine (<i>Epivir</i>)	Syrup with 50 mg in 5 ml	For newborns.
	Tablet 150 mg	
Groups 1 and 2 combined		
Name	Comes as	Comments
AZT + 3TC (<i>Combivir</i>)	Tablet with 60 mg AZT + 30 mg 3TC	For children 4 to 25 kilos.
ABC + 3TC (<i>Kivexa, Epzicom</i>)	Tablet with 120 mg ABC + 60 mg 3TC	For children 4 to 25 kilos. Most side effects go away after two weeks.

Group 3		
Name	Comes as	Comments
NVP – Nevirapine (<i>Viramune</i>)	Syrup 50 mg in 5 ml	For newborns.
	Tablet 50 mg	
EFV – Efavirenz	Tablet 200 mg Capsule 50 mg, 200 mg	Not for babies – only give to children older than 3 years. Give at bedtime. Side effects go away within 2 weeks.
LPV/r – Lopinavir + Ritonavir (<i>Kaletra</i>)	Syrup with 80 mg LPV + 20 mg /r in 1 ml	For small children who cannot swallow pills. Keep refrigerated. Give with food.
	Capsule with 40 mg LPV + 10 mg /r	For children under 10 kilos. Keep refrigerated. Give with food, high fat foods help it absorb better.
	Tablet with 100 mg LPV + 25 mg /r	For children over 10 kilos.
DTG – Dolutegravir (<i>Tivicay</i>)	Tablet 50 mg	For children 4 weeks to 10 years old.
RAL – Raltegravir (<i>Isentress</i>)	Powder for mixing 100 mg	For newborns.
	Tablet 25 mg, 100 mg, 400 mg	For children 3 to 25 kilos when other medicines are not available. Do not give to children taking rifampicin for TB.
Groups 1, 2 and 3 combined		
Name	Comes as	Comments
AZT + 3TC + NVP (<i>Duovir-N, Zidovex-LN</i>)	Tablet with 60 mg AZT + 30 mg 3TC + 50 mg NVP	For children under 3 years. Skin rash often occurs in first 6 weeks. Do not increase dose until skin rash goes away. Do not give to children taking rifampicin for TB.
ABC + 3TC + DTG (<i>Triumeq</i>)	Tablet with 600 mg ABC + 300 mg 3TC + 50 mg DTG	

Side effects while taking ART

While ART makes most children healthier within a few weeks, some children on ART have side effects, which are problems a medicine might cause even as it helps. Not all children have side effects with ART.

Most side effects from ART can be uncomfortable but are not serious. However, a few side effects are serious.

Dangerous side effects that ART might cause

These side effects are rare, but if your child has any of the problems listed here while taking ART, get medical help quickly, and bring the medicine with you:

- Difficulty breathing. Do not give more medicine if your child has trouble breathing after taking a medicine.
- Severe pain in the abdomen (tummy or belly).
- Severe rash with blistering skin.
- Yellow eyes (jaundice), sometimes with nausea or loss of appetite.
- Sudden weight loss.
- Seizures—sudden short periods of unconsciousness or changes in mental state, often with shaking movements.



Common ART side effects

Most side effects of ART are not dangerous. They may be different in different people, and it may take some time to learn what helps. Most go away on their own after a few weeks as the child's body gets used to the medicine. If they are more severe or do not go away, or if you know something is not right with your child, seek help at the HIV clinic. Do not stop giving the child ART without getting medical advice.

Be patient with your child while she gets used to taking ART and its side effects. This may be difficult if you are also taking ART and have your own side effects. Support from family, friends, and others taking ART can help you both get through the rough times and stay on your medicines.

Help your child be more comfortable — see the different problems and what to do on the next few pages. (Many of these tips may also help adults who take ART.) Chapters 12 and 13 also have information about how to help your child when she is not feeling well.

Sleepy Lizzie and her ART



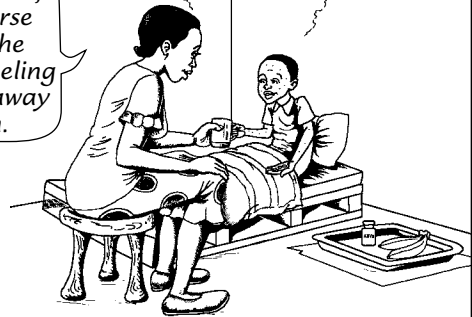
When my daughter Lizzie started her ART she was always so tired and sleepy. I did not think we would get through it.

Wake up Lizzie. Time for your medicine.

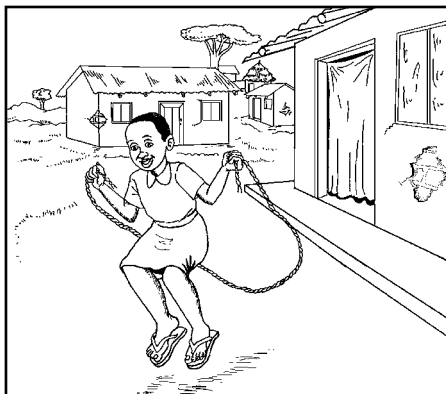


But my sister helped me. For 5 weeks she came to my door almost every morning to help.

Remember, the nurse said the sleepy feeling will go away soon.



She sang to Lizzie and helped her take her medicines.



Now, 4 months later, my daughter has gained weight and has so much energy — she plays and will go to school next term.

I told you it would get better!



And she feels so close to her aunt.

Feeling very tired

Allow your child to rest. It may help her sleep well if you wake her and put her to bed at the same times each day. During the day, take her outside and encourage her to play – having fun and moving around will help her sleep well when it is time. Make sure she is getting enough to eat. See pages 151 to 160.



Being very tired is sometimes a sign of anemia, also called weak blood. Discuss this problem with a health worker, since some ART can cause anemia.



To help with anemia, give more foods with iron, such as dark leafy greens, eggs, beans, fish, chicken, and meat.

Get medical help if your child's feet are swollen, if she is too tired to eat or move much, or if she becomes weaker and cannot do things she could do before.

Headache

Help your child rest quietly and away from bright light and noise. Cover his eyes with a cool, damp cloth. Make sure the child has enough to eat and drink. Lack of food or water can cause headache.



Give your child paracetamol (acetaminophen), see page 257. Avoid coffee, fizzy drinks, and tea with caffeine.



Gently rub your child's neck and the sides of his forehead with your thumbs. Older children can do this for themselves.

Get medical help if headaches happen often or are very painful, or if:

- the child's neck is stiff.
- the child has trouble seeing or says things look strange.
- paracetamol does not help.

Diarrhea

Give the child plenty of clean water, herbal tea, or rehydration drink to replace the fluids she is losing (see pages 216 to 219). If you are breastfeeding, breastfeed her more often. Give a few spoonfuls of food every 2 hours — bananas, rice, and soda crackers can help with diarrhea. Avoid spicy or greasy foods and animal milk. Peel fruits and vegetables to avoid germs that could make her diarrhea worse.



Get medical help if your child has:

- more than 4 watery or soft bowel movements in a day.
- diarrhea that lasts more than 2 or 3 days.
- blood in her stool.
- a fever that lasts a day or more.
- thirst, but will not drink.



Fever

Help your child rest in a cool place. Put damp cloths on his forehead, arms, and legs, or bathe him in cool (not cold) water. Give him paracetamol (see page 257) and clean water to drink. See page 229 for more ways to lower fevers.

Get medical help quickly:

- if the fever happens within a few days of your child starting ART or a new type of ART.
- if the fever goes very high (over 39°C or 102°F).
- if your child has convulsions.
- if your child has fever, nausea, or vomiting for more than 24 hours.



Nausea, vomiting, and no interest in food

Give your child ART just after breastfeeding or with food (check to see if you should avoid certain foods). Give small meals of plain foods (rice, porridge) more often, and avoid greasy or spicy foods. If he is vomiting, give sips of porridge or rehydration drink every few minutes until vomiting stops.

Try to prevent your child from losing weight. Give more of the foods he can keep down, to maintain his strength. Seek help if he is losing weight. See page 223 for more on helping children with nausea and vomiting.

Get medical help if:

- your child has sharp belly pains.
- vomiting lasts more than a day or has blood in it.
- he is thirsty but does not drink or eat.
- he also has a fever for more than 24 hours.



Dry mouth

Rinse your child's mouth with clean water and a pinch of salt. Give clean water and juices to sip often. Avoid sweets, cool drinks, and coffee. Get medical help if:

- your child's tongue or mouth is swollen.
- he has white or red spots on his tongue or in his mouth, which could be signs of thrush (see page 238).



Skin rash

Keep the child's skin clean and dry. Wash with unscented soap and water. Avoid very hot baths or showers. Use calamine lotion to calm itching. Keep the child out of the sun.

Get medical help if the child also has a general ill feeling, fever, muscle or joint aches, blisters or mouth sores, redness inside the eyelids, swelling of the face, or tiredness.

Seek medical help quickly if the rash spreads rapidly and is red or purple, or peeling or blistering — this is an emergency! Stop giving the child ART and see a health worker.



Dizziness or feeling “light-headed”

Help your child sit or lie down until the dizziness goes away. Give her plenty of water. Do not ask the child to lift anything heavy or move quickly until the dizziness goes away. If your child takes her ART once a day in the morning, ask your health worker if she can take the medicine just before going to sleep when the dizziness will bother her less.

Get medical help if dizziness lasts more than 3 days.



Strange or bad dreams, hallucinations (seeing things that are not there)



Help your child feel calm before going to sleep by rubbing his back, singing to him, telling a story, or remembering a nice thing that happened that day. Warm milk or water at bedtime may help. Do not allow him to watch television just before bedtime, and avoid tea or fizzy drinks in the evening, which can make a child wakeful. Let him sleep near you or near an older child if he is afraid.

Get medical help if your child cannot sleep at all for 3 nights or more.

Feeling very sad or worried

Talk with your child about his feelings and encourage him to talk with others. Encourage questions and try to answer them fully. Help older children by asking them how they feel, sharing good memories, including of people who have died, or discussing what they are worried about.

Get medical help if your child is so sad or worried he gets no rest from these feelings, or if he becomes violent or very scared and cannot be helped or comforted, or if he talks about harming himself.



Your child’s mind wanders or does not seem to work well

Sometimes a child on ART seems lost in his own world, very forgetful, or understands things less than other children. Be patient, and help him be patient with himself. Reassure him he will feel better soon, when his body gets used to the medicine. Remind him about tasks or chores without scolding him. Allow extra time for activities.

Get medical help if he becomes very confused or disoriented.



Treat other illnesses and infections

Children respond well to ART. However, it may take several months for ART to strengthen your child's immune system and lower her level of HIV. The younger a child is, the less developed her immune system is. So even with ART, she may still become ill. Watch for signs of illness and treat them more quickly than you would with a child who does not have HIV. See Chapter 12. As your child's body grows and gets stronger, she will become ill less often.

If a child becomes very sick soon after starting ART

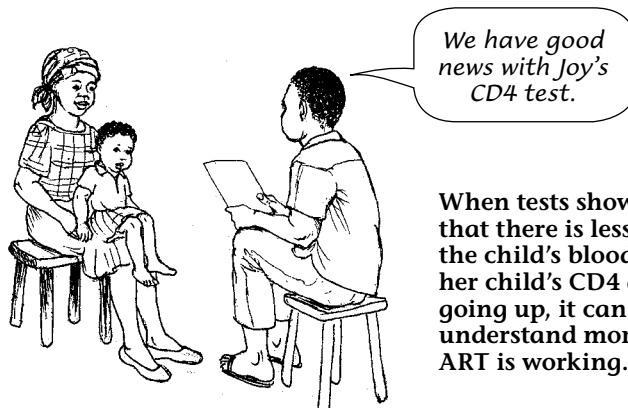
Rarely, when someone starts taking ART, the medicine begins to strengthen his immune system but he suddenly feels much worse. The signs are the common signs of illness — high fever, bad cough, sores and rashes, or difficulty breathing. This may happen because his stronger immune system can fight illnesses better. This problem happens much less in children who start ART while they are well.

Seek medical help quickly if a child becomes very ill soon after starting ART, and be sure to tell health workers that your child just started ART. Take your child's ART medicines with you when you go. Do not stop giving the child ART.

Knowing how your child is doing on ART

You know ART is working well when your child becomes healthy, stays healthy, and grows. A child who is growing and learning is doing well on ART.

Treatment programs may also use medical tests, usually blood tests, to measure how the child is doing on ART. The **CD4 test** shows how strong the child's immune system is by measuring the amount of CD4 cells in her blood. The **viral load test** measures how much HIV is in the child's blood. When the amount of virus is low, ART is working well. So you want the CD4 amount to be high or getting higher, and want the viral load to be low or getting lower.



When tests show a caregiver that there is less HIV in the child's blood, or that her child's CD4 amount is going up, it can help her understand more about how ART is working.

Your child's ART medicine may change

Sometimes children have a problem with one drug in their ART combination. If this happens, that drug might be changed to another one, especially if your child has a harmful or uncomfortable side effect that does not go away.

As babies and young children grow, their ART doses change because they are based on the child's weight. A child's ART may also change at a certain age because he can take tablets rather than liquid medicine, or the new dose of his ART combination is available in a single pill.

ART medicines also need to be changed if your child's ART stops working well.



What happens if ART stops working

ART can work for a very long time if taken faithfully and in the right doses. Many children with HIV are growing up healthy and strong because of ART. But sometimes ART stops working as well as it did. The cause of this is usually problems with taking the medicine every day and at the right time.

Missing just a few ART doses in a month allows HIV to change and adapt. When this happens, those ART medicines do not work as well and HIV can multiply again. This is called drug resistance. Drug resistance causes children to become sickly or develop illnesses that are difficult to treat even though they are taking ART. The child's CD4 or viral load tests will show that drug resistance has developed. Health workers will then try other ART medicines, if they are available.

The first medicines your child takes are sometimes called "first-line medicines," the first line of defense against HIV. If these medicines stop working, costlier medicines are needed, sometimes called "second-line medicines." If the new medicines work well, the child will regain her health. It is even more important to give these medicines faithfully every day, because if this second-line ART stops working, there may be no third-line medicines.

ART doses and drug resistance

Drug resistance can also happen when the child's ART doses are no longer enough for his size. As children grow — which is all the time! — their weight changes and they need more ART. If a child sees a health worker regularly, their dose of ART can be changed when necessary. This will make sure it continues to work and keep them healthy.

Making ART work in our communities



Treatment guidelines now say that everyone, especially children and women who are pregnant, should start ART as soon as they know they have HIV, not wait until until they are ill. More than 20 million people with HIV are now on ART. But at least 15 million more people with HIV still need it, including half of the children who have HIV. Many health workers are not yet experienced or comfortable providing ART. Health services are often understaffed, or do not exist, in places where HIV treatment is needed.

In many places, people with HIV have organized to help each other gain access to ART and take it successfully. They learn about and teach each other how ART works, what makes it not work, and what other health care or self-care will help them stay healthy (this is sometimes called “treatment literacy”). These groups also advocate for wider treatment access, better medicines, and cheaper prices for medicines, as well as ending the stigma of HIV.

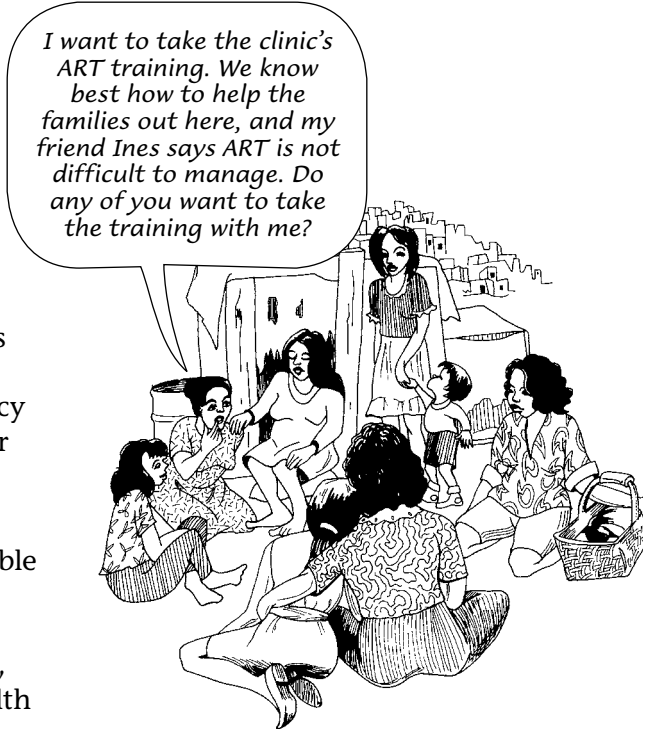


I used to think these demanding people with their HIV-positive T-shirts were so annoying! Now I cannot imagine life in the clinic without them. They brought the community to us, and now the community helps us. They trained our clinic committee and this support group. Treatment literacy has helped all of us.

Treatment support groups can work successfully with health workers if everyone respects the knowledge, abilities, and experience that different groups bring. Sometimes this is difficult for health workers, who are used to being the experts. For their part, community members who want better HIV services need to respect the difficulties health workers face, whether from overwork, lack of training, or lack of government support.

A community health committee working to expand and strengthen ART services for families can try to find ways to:










- train health workers new to ART, and people with HIV, in treatment literacy, including how HIV and ART are different for children.
- organize support groups at the clinic for anyone on ART, for pregnant women taking ART, for caregivers giving ART to children, or for older children on ART.
- provide counseling or support that health workers do not have time to provide during clinic visits, such as help disclosing HIV status, how to remember to take ART, or how to breastfeed.
- train community members for suitable health worker positions, such as pharmacy assistants, ART advisers, or HIV testing counselors.
- advocate with the government for more reliable supplies of HIV medicines, dispensing of medicines closer to where people live, and more funding for health facilities and health workers.





For more ideas about how to help communities and health care systems best support ART treatment for the most people, see Resources: Where to get more information, starting on page 309.

Record of how the ART makes your child feel

Child's name _____ Month _____ Medicine / Dose _____

<i>Write your own words for the days →</i>	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
							
							
<i>How do you feel today?</i>							

Child's name _____ Month _____ Medicine / Dose _____

<i>Write your own words for the days →</i>	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
							
							
<i>How do you feel today?</i>	