CHAPTER 4 Giving My Child Medicine



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Taking medicines the doctor orders is very important for your child's health.

How important are medicines the doctor orders for my child?

Most children with HIV need to take medicines each day.

Your child's doctor may order medicines for your child to:

- help fight **HIV**.
- prevent illnesses.
- treat infections.
- treat other medical problems.

Although it can be difficult, it is always important for your child to take the medicines his/her doctor orders. This is especially true for the medicines your child takes to fight **HIV**. Depending on your child's health, most doctors recommend that children with HIV take 3 or more medicines to fight HIV. These medicines are called **antiretroviral** (an tī' ret rō' vī ral) **medicines**.

- If your child <u>takes</u> every **dose** correctly and on time, **antiretroviral medicines** will help lower the amount of **HIV** in your child's blood. This will help your child's **immune system** get stronger, and he/she may have fewer illnesses.
- If your child <u>does not take</u> every dose correctly and on time, the HIV medicines may stop working. This means **HIV** can grow stronger in your child's blood, your child's **immune system** can get weaker, and your child may have more illnesses.

(See **HIV: The Basics**, How do medicines slow down or stop HIV? page 1–11 and Why do HIV medicines stop working? page 1–12.)

It is important for all of your child's health care providers to know the medicines he/she takes.

- Keep a list of all the medicines your child is taking. For each medicine, write down:
 - the name.
 - **dose** (how much is taken).
 - how often is it taken.
 - if it is taken with or without food.

OR

If possible, take your child's medicines in their containers. You can show the doctor what your child takes and keep your child on his/her medicine schedule if doses are needed during the visit or while traveling.

List or take all of your child's vitamins, supplements, herbal therapies, over-the-counter medicines, or home remedies. Bring the list or the medicines, vitamins, supplements, etc. with you every time you take your child to the doctor, dentist, emergency room, or other health care providers, such as a psychiatrist (sī kī' a trist) and nutritionist (nū trish' un ist). It is also a good idea to take the medicines or the list when you see your child's pharmacist (far' ma sist). This will make sure all of your child's health care providers know what medicines your child is taking.

(See **Keeping My Child Healthy**, How can I prepare myself for my child's doctor or clinic visits? page 2–13.)

Every time you take your child to a health care provider, list or take all of your child's medicines, vitamins, supplements, herbal therapies, over-the-counter medicines, and home remedies.



Check with the doctor before giving your child any medicine that is not ordered by your child's doctor – even acetaminophen or cough medicine.

Should I give my child over-the-counter medicines and therapies?

Always check with the doctor before giving your child any **over-the-counter medicines** or therapies. These are medicines or therapies you can get without a doctor's order. You might get over-thecounter medicines or therapies from places like the grocery store, drug store, or health food store. They include things such as: home remedies, cough syrup, **acetaminophen** (as ēt´ a min ō fen), or dietary supplements like vitamins, minerals, and **herbal therapies**.

It is important that the medicines ordered by your child's doctor work properly. Some foods, drinks, vitamins, minerals, or **herbs** can make the medicines ordered by the doctor:

- stop working.
- work too much.

This is called a **drug interaction**. Drug interactions can be very harmful to your child. If your child's **HIV** medicines stop working, they cannot control the HIV. If your child's HIV medicines work too much (**overdose**), the medicines can cause harmful **side effects**. Your child's doctor can tell you if any medicines or supplements you want to give your child will **interact** with his/her ordered medicines.

(See **Eating Healthy Foods**, Should I give my child a vitamin or mineral supplement? page 3–10, and Can I give my child herbal therapies? page 3–11.)

How do I choose a pharmacy or drugstore?

- Ask your nurse or doctor for suggested pharmacies or drug stores.
- Try to find a pharmacy where the **pharmacist** is friendly and helpful.
- Find out if the pharmacy takes Medicaid, ADAP, or your health insurance plan.
- Find out if the pharmacy is open on weekends and nights, and if they will open for you in an emergency.
- Ask if the pharmacy delivers medicines.
- Make sure the pharmacy carries the medicines your child needs.
- Ask if the pharmacy gives written information, in your language, about the drugs your child is taking.
- Find out if the pharmacy can keep track of all your child's medicines and can tell if there are possible drug interactions.
- Once you decide on a pharmacy, be sure to fill all the medicines ordered by your child's doctors at the same pharmacy.

Getting a pharmacy that will work with you is important.

It is important that the pharmacist keeps track of your child's medicines. Make sure to fill all the medicines that are ordered by your child's doctor at the same pharmacy. Make sure you know how and when to give your child his/her medicines.

What questions should I ask the doctor, nurse, or pharmacist before giving my child medicines?

How many times a day do I give the medicine?

Make sure you know when to give your child medicine. Some medicines must be taken exactly the same number of hours apart (such as every 6 hours or every 12 hours) night and day. You may need to wake your child during the night to give these medicines. Other medicines only need to be given when your child is awake. Work with the doctor or **pharmacist** to schedule the medicines at convenient times. Most children will not have to take medicines at school. But if your child needs to take medicine in school, see **Giving My Child Medicine**, What if my child needs to take medicine in school? page 4–19.

How much medicine do I give?

The medicine your child needs may come in tablet, capsule, powder, or liquid form. Be sure you know how much medicine is needed for each **dose**. If you have to measure your child's medicine, it is important that you measure it carefully. For example, if the directions say to give your child 1 teaspoon, be sure to use a measuring teaspoon like the ones used for cooking. Using a silverware teaspoon may give your child too much (**overdose**) or not enough medicine. Or, ask your doctor or **pharmacist** to give you a medicine cup or oral syringe. If tablets need to be cut in half, ask your pharmacist for a tablet cutter. Make sure you ask your nurse or pharmacist how to use it correctly.



Can I give my child more than 1 medicine at a time?

Sometimes, when taken at the same time, medicines can act differently than if they were taken alone. Medicines taken together may work too much or not work enough for your child. If your child is taking more than 1 medicine, always ask the doctor, nurse, or **pharmacist** if medicines can be taken at the same time.

Do I give the medicine with food or without food?

Some medicines work better when taken on an **empty stomach**. (An "empty" stomach means 1 hour before a meal or 2 hours after a meal). Other medicines may upset your child's stomach if not given with food. Be sure you know how to give each medicine.

Are there any side effects to this medicine?

Before your child starts to take a new medicine, ask about the medicine's **side effects**. The doctor, nurse or **pharmacist** can tell you:

- the medicine's main side effects
- what to do if the side effects happen.

Diarrhea (dī´a rē´a) is a common side effect for some medicine, especially when your child first starts taking it. If possible, start a new medicine at the beginning of a weekend so your child's body can start to get use to it before he/she goes back to school.

Other side effects can be mild, such as being more sensitive to the sun.

Always ask the doctor, nurse, or pharmacist if it is safe for your child to take more than 1 medicine at a time.

Call your doctor right away if your child gets a bad reaction to any medicine. Some side effects can be more harmful, such as rashes, or having trouble breathing.



Call the doctor right away if your child gets a bad reaction. The doctor can suggest how to treat the side effects and find other medicines that may be better for your child.

Be sure to write down the:

- medicine's name.
- dose.
- how often it was taken.
- what kind of reaction your child had.

WARNING

Keep all medicines. vitamins, supplements, herbal therapies, and home remedies out of the reach of children, even if the bottles have childproof caps. Remember, some of these look or taste like candy. Keep the Poison Control Hotline number by your telephone or inside your medicine cabinet in case someone takes the wrong medicine or takes too much medicine.

Where should I keep the medicine?

Ask the doctor, nurse, or **pharmacist** if the medicine needs to be kept in the refrigerator. Most medicines will be OK at room temperature. <u>Do not</u> keep medicine in:

- damp places, like the bathroom.
- direct sunlight, like on a window sill.
- a hot place, like by the stove.

If you do not use a pill organizer, always keep medicines in the containers they came in. These containers help keep moisture out.

Why should I talk with the doctor, nurse, or pharmacist about all the medicines my child takes before a new medicine is given?

Sometimes the same medicine can have different names. This happens when there is a name brand medicine and a **generic** (je nār' ik) **medicine**.

Examples of the same medicine with different names include:

- d4T = Stavudine = Zerit
- Nevirapine = Viramune
- Saquinavir = Invirase = Fortovase

It is very important that your child not get too much medicine. By going over all the medicines your child is taking, the doctor, nurse, or **pharmacist** can make sure your child will not take a name brand medicine with the same generic medicine.

How do I keep track of all my child's medicines?

Keeping track of the directions for each medicine can be confusing. A medicine chart can keep medicine information easy to see and easy to take to doctor or clinic visits. On page 4-10, a sample chart for an infant and a sample chart for an adolescent have been filled out. At the end of Giving My Child Medicine, there is also a blank medicine chart. Ask your doctor, nurse, or **pharmacist** to help you fill in the blank chart or make another chart to show when to give each medicine, how to give it, and how much to give.

To take medicine on time, it may be best to link it with one of your child's routines. For example, medicine taken in the morning may be given before or after your child's breakfast, or before your child brushes his/her teeth. Medicine taken before bedtime may be given before your child brushes his/her teeth. Ask your child's doctor, nurse, or pharmacist to help you make a medicine chart.





SAMPLE Medicine Schedules

INFANT When to Take								
Medicine Purpose	Strength Dose	Morning 9:00 am	Afternoon 12:00 pm	Night 9:00 pm	How to Take	Special Storage	Common Side Effects	Notes
Epivir Fight HIV	40 mg 4 ml	1		1	With or without food	None	Fever, tired, dizzy upset stomach, vomiting, diarrhea	
Zerit Fight HIV	9 mg 9 ml	1		1	With or without food	None	Tingling in hands and feet, tired, pale, dizzy, cough fever, diarrhea skin rash	
Viracept Fight HIV	500 mg 2 pills crushed	1		1	With a light snack	None	Diarrhea, headache	
Bactrim Prevent PCP	Pediatric 5 ml	✓ Monday Tuesday Wednesday			At the beginning of a feeding	None	Skin rash, diarrhea upset stomach, vomiting	

ADOLESCENT		When to Take						
Medicine Purpose	Strength Dose	Morning 9:00 am	Afternoon 12:00 pm	Night 9:00 pm	How to Take	Special Storage	Common Side Effects	Notes
Combirvir Fight HIV	3TC 150 mg ZDV 300 mg 1 tablet	1		1	With or without food	None	Headache, nausea tired, vomiting, diarrhea, anemia	
Sustiva	200 mg 3 capsules			<i>✓</i>	Do not take with high fat meal	None	Skin rash, tired, upset stomach, vomiting, diarrhea, trouble sleeping and concentrating, strange dreams or nightmares	Strange dreams or nightmares end in about 1 month after starting the medicine

There are also some items you can get to help keep your child's medicines on schedule. Ask your doctor, nurse, or **pharmacist** for information on where to get these items, and if they are covered by your insurance.

- Pill boxes. There are many different kinds of pill boxes. Some let you set up all the medicines your child needs to take during the day. Some can set up medicines for the week. If your child will not be home when medicine needs to be taken, some pill boxes are small enough to hold 1 dose.
- Electronic alarms. Watches with alarms can be set to remind you of medicine time. There is also a small electronic alarm that can be put on your key chain or worn on a chain around your neck. It will beep when it is time to give your child another **dose** of medicine.

What can I do if my child cannot swallow pills?

If your child cannot swallow tablets or capsules, ask your doctor, nurse, or **pharmacist** if there is a liquid form. If not, ask for advice. Here are some ideas that work for some children.

Mix medicine with food or drink.

<u>Always</u> ask your doctor, nurse, or **pharmacist** if it is OK to mix a medicine with food or drink. If it is OK, mix the medicine in a little milk, juice, or food. Make sure your child drinks or eats everything you Your doctor or pharmacist can suggest ways to make it easier for your child to swallow pills. give so he/she will get all the medicine. If the medicine tastes bad, try mixing it in jelly, ice cream, applesauce, chocolate syrup, or another food your child likes.

Crush tablets.

Ask your doctor, nurse, or **pharmacist** if it is OK to crush a tablet and mix it with milk, juice, or food your child likes. If it is OK to crush the tablet, put it in a spoon and place another spoon on top of it. Then, squeeze the 2 spoons together. Be sure to get all the powder off the spoons so your child gets a full **dose**.

Open capsules.

Always ask your doctor, nurse, or **pharmacist** if it is OK to open capsules and mix the powder or beads into food or drink. If it is OK to open the capsules, ask the best way to do it.

It is best to give your baby medicine at the beginning of a feeding.

What if my baby spits out the medicine?

It is hard for anyone to make a baby take medicine when he/she does not want it. Babies and toddlers do not understand why they must take medicine and may spit it out if it tastes bad. Ask the doctor or **pharmacist** if you can change the taste of the medicine by mixing it with food or liquid. This may make your baby more willing to take the medicine from a baby bottle or spoon. If the medicine can be given with milk, juice, or food, make sure to give the medicine at the beginning of a feeding so your baby gets the full **dose** of medicine. Other tips to give medicine to children follow.

Giving medicine to babies

- 1. Prepare and measure the medicine. Use a soft plastic dropper or a spoon for medicine.
- 2. If it is OK with the doctor, mix the medicine with liquid or food.
- **3.** Sit in a firm, comfortable chair.
- 4. Put a bib or towel on your baby.
- 5. If you are right handed, hold the baby in your left arm. Hold the baby's left arm with your left hand. Put the baby's right arm under your left arm and around your back.
- 6. Brace your baby's head against your arm or chest so his/her head stays still. Tilt your baby's head back a little.
- Put the medicine into the corner of your baby's mouth, along the side of his/her tongue. This makes it harder for your baby to spit.
- **8.** Give little amounts at a time so your baby does not choke.
- 9. Never yell or show anger. Speak softly and say kind words.
- 10. When all the medicine is finished, hold your baby sitting up for a few minutes and cuddle and comfort him/her.

Never threaten or punish your child for not taking medicine.

How can I help my toddler or young child take medicine?

Some children do not want to take medicine. Do not threaten, punish, hit, or yell at your child if he/she has a hard time taking medicine. This will only make it worse. Try to work as a partner with your child to overcome the problem.

Giving medicine to young school-aged children

- Never ask your child whether he/she wants, or will take the medicine. Be firm and say he/she needs to take it.
- If the medicine can be taken with food, try different foods to cover up the taste of the medicine.
- Offer your child choices.
 - What kind of food or juice does he/she want to take with the medicine?
 - Does your child want to take the medicine straight? If this is possible, does your child want to take the medicine in a pill or in a liquid form? (Ask your **pharmacist** if the medicine your child takes is in both a pill or liquid form.)
- Some children do best when they take a deep breath and drink the medicine down fast. Others take their medicine a sip at a time with a drink of juice in between. Sometimes it helps to count for your child while he/she takes the medicine.

- The bad taste of some medicine can be cut by drinking juice or eating plain crackers afterward.
- Offer a reward such as a sticker or star when your child takes the medicine. Get other people whom the child cares about to help encourage or reward your child.

Adapted from "Your Child, Your Family, and HIV" published by the National Pediatric & Family HIV Resource Center at the University of Medicine and Dentistry of New Jersey.

What if my child misses a dose of medicine?

It is important to give your child all of the medicine the doctor orders. But do not panic if your child misses 1 **dose**. Just give the dose as soon as you remember, or if it is almost time for the next dose, continue with the regular schedule.

Taking medicine to treat **HIV** is very important for your child's health. If your child misses HIV medicine **doses** because he/she is not feeling well or throws up after taking the medicine, call the doctor or nurse and ask what to do. If you are having trouble giving your child HIV medicine or you forget to refill the HIV medicine before it runs out, call the doctor, nurse, or **pharmacist**. He/she can give you some tips on what to do to keep your child's HIV medicine on schedule. If you are a member of a caregiver support group, the other members may also have tips. No matter what the Do not panic if your child misses a dose of medicine, but do your best to keep him/her on schedule. Ask the doctor or pharmacist what to do if your child misses a dose.

WARNING

Do not give 2 doses at the same time.

reason for your child missing HIV medicine **doses**, let your doctor or nurse know how many doses were missed. When doses of HIV medicine are missed, the medicine may stop working.

(See **HIV: The Basics**, How do medicines slow down or stop HIV? page 1–11, and Why do HIV medicines stop working? page 1–12.)

Be sure to keep enough medicine on hand.

- Keep track of your child's medicine to make sure you do not run out. Call your **pharmacist** for a refill when you are getting low on a medicine. Remember that it may take time to get the medicine if it has to be special ordered by the pharmacist.
- Plan ahead if you are going to take a trip. Count all the medicine your child will need while you are away. Ask for a refill if the medicine will run out before you get back home. Medicaid, ADAP, and insurance plans will let you get a refill early if you are going away.



What if my child will not take the medicine?

The first thing to do is try to find out *why* your child will not take the medicine.

- Does your child hate the taste of the medicine?
- Is your child angry or **depressed** about being ill?
- Does your child think the medicine is not needed because he/she feels OK?
- For an older child, has he/she talked to the doctor to help make decisions about the medicine?
- Is your child angry about something that has nothing to do with taking medicine?

Some children may try to use medicine-taking as a way to control you or get things. As an example, if your child says, "I will not take my medicine until you get me a new toy." Remember, you are the parent and you set the rules. Be firm, but do not yell. You might say something like, "You need to take your medicine to stay healthy. If you take your medicine on time for a week, we will talk about getting something for you."

If you also take medicine or a vitamin, take it at the same time your child takes medicine. Try having a contest to see if your child can take his/her medicine faster than you.

If your child hates the taste of the liquid medicine, ask your **pharmacist** if he/she can flavor it. There are over 60 flavors that can be added to liquid medicine including strawberry, bubble gum, It is important to find out why your child will not take the medicine. Listen to your child's concerns and fears and help your child deal with them. The doctor, social worker or mental health professional can help. Remember, unless a cure is found, you are helping your child learn how to take medicine for the rest of his/her life. chocolate, cinnamon, and root beer. Or, if it is OK with the doctor, you can try giving your child medicine with something else that has a strong flavor your child likes. Sucking on an ice pop or a mint candy before and after taking the medicine may also help.

As with all children who have a life-long health condition, sometimes they can become angry or **depressed**. Sometimes they may think they do not have a life-long health condition because they feel OK. These feelings need to be taken seriously and discussed with the doctor, social worker, or mental **health professional**. It is very important for an older child to understand the importance of taking medicine to stay healthy. Most older children do not want to be different from their friends. Taking medicine may make your child feel different. Older children also need to feel that they have some control over their health and that their opinions are respected. If you tell your child what to do without listening to his/her fears, wishes, or concerns, your child may be less likely to follow his/her treatment.

(See **Helping My Adolescent Deal with HIV**, What if my teen stops taking HIV medicines? page 8–29.)



Unless a cure is found, you are helping your child learn how to take medicine for the rest of his/her life.

What if my child needs to take medicine at school?

First, check with your doctor or **pharmacist** to see if your child's medicine schedule can be changed so all medicines are given when your child is home. If medicines have to be taken while your child is at school, check with the school nurse to find out if your child's school will give medicine that has been ordered by a doctor. Also, check to make sure the nurse is in your child's school building when your child needs to take his/her medicine. If the school nurse will give your child medicine during the school day, you will have to think about telling the nurse that your child has **HIV**. The nurse can give medicines, arrange rest periods, offer your child support, and help arrange for home tutoring or other special help, if needed. By law, the school nurse must keep all HIV information private. It is not appropriate for your child's teacher to give medicine.

(See **Legal Issues**, How does New York State protect the privacy of my child with HIV? page 10–2.) If your child needs medicine during school hours, talk with the school nurse to plan how this will happen. If medicine cannot be given during school hours, talk with your doctor.

MEDICINE SCHEDULE								
			When to Take					
Medicine Purpose	Strength Dose	Morning	Afternoon	Night	How to Take	Special Storage	Common Side Effects	Notes

4–20 Giving My Child Medicine

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