

Taking Medications to Treat HIV/AIDS

A Treatment Adherence Guide for Parents of Children with HIV Infection

What is treatment adherence and why is it important?

Taking a medicine just as your doctor has ordered is called "adherence to treatment." Always taking a medicine the right way is very important for the medicine to work. Medicines that fight infections cannot work if they are not taken correctly. If your child misses a dose or takes half the dose, or if they stop early, the germ (virus, or bacteria) can learn to survive the medicine. Sometimes this causes it to change or get stronger. Then the medicine no longer works. This is called "resistance." This is a very big worry for doctors, nurses and pharmacists who treat children with HIV infection. It is a big worry for people living with HIV.

Treatment adherence can be difficult because everyone forgets to take medicine sometimes. Taking a medicine 3-4 times a day may be hard to fit into your child's schedule. The medicine may also have "side effects" that makes your child feel bad.

What are side effects?

Side effects are unwanted (sometimes harmful) effects of drugs. This term usually means a negative effect which may include headache, upset stomach, rashes and diarrhea. Any side effect from a medicine may make your child want to stop taking it.

Side effects may make it hard or impossible for them to start or continue to take more than one drug to fight the virus (known as combination anti-HIV therapy, sometimes called the "cocktail").

What can be done about side effects?

Talk with your child's doctor, pharmacist or nurse and learn about all the main side effects of the medicine they are taking. Remember -- it helps to know what to expect, but not everyone gets the same side effects from a medicine. Some people never get side effects or sometimes they are not so bad. Everyone is different -- children too. Some side effects may be temporary. Some may be easy to deal with. Tell your child's doctor, pharmacist or nurse as soon as you think they may be having a side effect from a medicine. It is important not to wait. The sooner a side effect can be dealt with, the better it may be for your child's treatment and how they feel.

Why is treatment adherence or medication compliance so important with anti-HIV medicines?

The medicines used to treat HIV infection are strong, powerful drugs. It is very important that all medicine used to treat HIV infection/AIDS be used just as your child's doctor orders. This means the right amount, the right time, the right way (with food, or on an empty stomach) and without missing or stopping a dose.

Not taking the medicines correctly could mean that the virus becomes resistant (changes or escapes the medicine). The medicine will not work or work as well. The virus may then grow stronger. If this happens, other anti-HIV medicines may not work very well either. This is called "cross-resistance."

IMPORTANT: Doctors, pharmacists, parents and patients need to know that forgetting to take medicines even some of the time may mean your child's viral load (the amount of virus in the blood or other tissues) won't come down or their CD4 (T cell) count won't go up. The strong

medicine just won't work. If your child is having trouble taking a medicine, talk to your doctor, pharmacist or nurse. It may be that medicines can be switched to different ones or on different schedules. This may be better than reducing the amount of the medicine.

What else may keep anti-HIV medicines from working?

A new medicine may not work well because the virus resists it from the beginning. In this case, the medicine may be changed to a different one. Your child's body may not absorb or use all of the medicine they take. This is called drug "bioavailability." Sometimes in children, the drug gets used up too fast by their bodies. Other medicines may interfere with the anti-HIV medicines. They make them too strong or too weak. Your child's doctor and pharmacist need to know that all of your child's medicines are safe to take together. Talk to them about this. Tell them about all the medicine you are giving to your child-- even the ones that you buy at the drug store or grocery store.

What are some tips to help my child to stick to the medicine schedule?

Think about problem times and plan ahead. Special instructions may make it hard for you to give your child their medicine. Some medicine needs to be taken with food, some before or after meal time. School time, play or daily activities may not fit with their medicine times. Taking medicine in public or in a social situation may cause embarrassment or emotional distress. Going on vacation, trips or camps may make it difficult to stick to their medicine schedule. It is very important that your child adheres to their treatment. Please continue reading for tips on improving your child's treatment adherence.

What helps?

- Make a schedule for medicines and daily eating times that will work for you and your child. Your nurse, pharmacist or doctor can help you with fitting the medicines into this schedule.
- Use reminders. Use a calendar or check-off list. Tape the calendar someplace you will see it. The front of the refrigerator is a good place. Check off each dose that is given to your child.
- Use timers or a watch with an alarm to remind you when to give the dose.
- Color code the bottles of liquid medicines with matching oral syringes. This helps make giving the right dose easier. Put the same color for the medicine on the calendar or checklist.
- Use a special marked dosing cup, measuring spoon or an oral syringe to measure the right amount. Don't use eating spoons to measure liquid medicines as size may vary.
- Pack the drugs in one-week packets and check weekly that all doses are given.

What are some tips to help me give my child's medicines?

- Remember- Be Positive, Be Consistent. Have a matter-of-fact attitude. You expect your child to take the medicine just as you expect him or her to put on a coat before going out in cold weather.
- Medicines should always be given with parental involvement. For young children, an adult should always draw up the dose.
- Stay with your child until he or she has swallowed the medicine.
- As children get older, it is important to involve them in taking their medicines. This gives them some control over their illness or infection.
- With parent supervision, many school-aged children can do a good job remembering and

- taking their medicine.
- Give the child a flavor choice for ddl liquid (cherry, lemon, or mint).
- Let your child pick a special medicine measure at the drug store. They are decorated with different animals.
- Teach your child to take large pills by practicing with candies (not for small children) or empty gel tabs. You can get these at most drug stores and health food stores.

Things to do for bad-tasting medicines.

- Give your child a lifesaver or some licorice after the medicine. This will stun the taste.
- You may also chill the medicine before giving it. Check with your pharmacist before you do this. Not all medicines can be refrigerated.
- Talk to your pharmacist or nurse about other ways to help with giving bad-tasting medicines.

How can I tell we have problems with treatment adherence?

Ask yourself the following questions:

- Do you forget to give your child medicine?
- Do you sometimes forget to follow the instructions about how to give the medicine-- with or without food or on an empty stomach?
- Do you give the medicine at the wrong time or on the wrong schedule?
- If your child complains, do you stop giving the medicine without talking to their doctor or nurse?
- Do you forget to get refills of medicine before you run out?
- If you answered "Yes" to any of these questions, your child's medicine may not work. You could be placing your child's health in danger.

Remember -- talk to your child's doctor, pharmacist or nurse about help in giving your child medicine.

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