

# Starting treatment

Plan ahead to reduce the risk of non-adherence

By Rachel Therrien



**Your doctor has just advised you that you need to start antiretroviral (ARV) therapy and prescribes a regimen that's likely to bring your viral load back down to undetectable levels. That's good. But unlike a short course of antibiotics, starting these medications means entering into a long-term relationship. Your health will depend on your ability to take them regularly and to find ways to deal with some of the side effects you may experience. The first few weeks may be difficult, but planning, knowledge and patience can help you incorporate ARVs into your life with a minimum of disruption.**

Adherence, or compliance, to anti-HIV drug regimens is essential to their success. The most common reason for the development of resistance and treatment failure is not taking the medications as directed. Despite these high stakes, less than optimal adherence is common. Sometimes it's because of personal factors like a precarious financial situation, insurance difficulties, or psychological distress or depression. Alcohol or drug use can also make it difficult to follow a regimen. Other times, problems related to the treatment itself can hinder adherence such as demanding schedules or conditions under which to take a drug, side effects from the medications, or poor communication with caregivers.

## Strategies for success

Research studies and clinical experience have identified effective ways of helping people improve their adherence to a prescribed drug regimen. These include education from your health care team about the nature of antiretroviral therapy, the goals of therapy and possible side effects. Also helpful are behavioural and planning strategies to improve your ability to take your medication regularly and manage side effects. Support groups can help overcome loneliness and anxiety, and provide a means for people experiencing similar problems to educate each other and pass on useful strategies.

Developing the skills you need to start and manage your medication regimen effectively will reduce the chance of non-adherence. Take the time to think about what you need and talk to your care team and to other people living with HIV about what to expect. Money issues, insurance criteria, side effects, schedules for doses, refills and medical appointments all come into play when you start treatment.

## Show me the money

Your doctor gives you a prescription, which you bring to your local pharmacy. The pharmacist says you have to pay \$1,200 up front, 80% of which will be reimbursed by your insurance plan. While it differs from province to province, the initial amount you have to pay for ARV therapy can be very

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high. In some provinces, ARV drugs are free of charge. In others, there's an annual cap on the amount someone would spend for his or her medications. Some people can't find the money and decide not to get some or all of the drugs their doctor prescribes. Others start with all the prescribed medicines, but then don't renew their prescriptions the following month.

It's often possible to make an arrangement with your insurance company and pay only the percentage of the cost that you're responsible for up front. The insurance company would send the rest of the payment directly to the pharmacy. Unfortunately, some insurance companies are resistant to this practice.

Some pharmacists agree to spread the amount owed over the year. This is more likely to work if your pharmacist knows you and considers you reliable. The pharmacist will expect a solid commitment from you and a contract will have to be signed. Many HIV/AIDS service organizations (ASOs) provide help with these practicalities. See pages 10 and 11 to find one near you.

## Adjust your routine

When you start or change drug regimens, it's worthwhile to sit down with the pharmacist or nurse to discuss the medication schedule you'll need to follow. The drugs must be taken every day, at pretty much the same time, for a long period of time. So it's important to choose a schedule that works for you. Try to integrate your drug regimen into your way of life, rather than forcing your life to fit in around your drug schedule. The less effort required to take your medicine, the better your chances of being able to adhere to the regimen over the long term.

Think of your routine. When are you usually at home? Taking medicines at home reduces the risk of forgetting them. If the drug has to be taken with food, think of when you most often eat a good meal. Breakfast, lunch, dinner? Irregular work hours, frequent trips, schedule changes on weekends: these are all factors that need to be taken into account in choosing your schedule. Look at all the possibilities and pick the best time(s). Tying your drug schedule to a daily activity, such as eating dinner, going to bed or brushing your teeth, will help you remember to take them.

## First encounters with side effects

The first few weeks of treatment can be made much more difficult by the appearance of side effects as your body adjusts to the medications. Make allowances for these in your schedule and find out about strategies to minimize them. It's important to know when a symptom could be serious and require medical attention.

The main side effects noted at the beginning of treatment with ARVs can be placed in four main groups: general side effects, gastrointestinal side effects, effects on the skin, and central nervous system effects.

### General effects

The most common general effects are fatigue, headaches, cramps and muscle aches. These tend to appear right from the start of treatment and diminish in intensity after the first week or so. In some people, they can persist for up to four to six weeks before the body gets used to the medications. Patience is required and rest is the best remedy. Acetaminophen (Tylenol®) can be useful for headaches.

### Gastrointestinal side effects

When you start treatment, gastrointestinal side effects such as diarrhea, loss of appetite and nausea sometimes accompanied by vomiting, are

fairly frequent, especially with drugs in the protease inhibitor class. Like general side effects, they tend to disappear over time. During the starting period, anti-nauseants such as dimenhydrinate (Gravol®) or anti-diarrheals such as loperamide (Imodium®) may be necessary. Nausea and diarrhea tend to improve with time. Dehydration is a serious concern with severe gastrointestinal side effects, so don't delay seeking help if you need it.

### Skin rashes

Some ARVs may produce a skin rash in the first two weeks of treatment. See your doctor to assess the severity of the reaction and decide whether you need to interrupt treatment. Usually, the redness is not severe and your doctor will ask you to continue with the medication but take an antihistamine such as Atarax® or Benadryl® to lessen the itch. In rare cases, the reaction can be severe and require that you stop taking the medication entirely.

Certain ARVs can turn the skin and eyes yellow. This condition, called hyperbilirubinemia, can also be caused by liver problems like hepatitis, but ARV-related hyperbilirubinemia usually tends to get better over time. It isn't dangerous, but if it bothers you, talk about it with your doctor.

### Central nervous system effects

Certain ARVs, notably efavirenz (Sustiva®), can produce central nervous system effects such as insomnia, morning blariness and disorientation,

Side effects will usually disappear after about two weeks, but they can persist to varying degrees in some

strange dreams, changes in mood, etc. For most people, these effects disappear after about two weeks, but they can persist to varying degrees in some. Rare more serious effects such as depression and psychosis have also been associated with Sustiva. If you have side effects that persist and hinder your activities or relationships, tell your doctor.

### When your meds run out

You only have a week's worth of medicine left, there are no more renewals on your prescription and your next doctor's appointment is a month away. What do you do? Ask your pharmacist to tide you over for a month and ask that, in future, he or she tell you when your renewals run out. That will give you time to plan ahead. At your next doctor's visit, make sure that your prescriptions will last until your next appointment. If they're not long enough, let your doctor know. If your pharmacist can't tide you over, call your doctor or a member of your care team to get a prescription until your next visit. **R**



## Call your doctor or pharmacist if....

Many side effects are transitory or manageable on your own. Some are signs of a serious problem that requires medical attention. Don't hesitate to call your doctor or pharmacist if you're unsure. Here are some of the danger signs in each category of side effect.

### General effects

- fever or skin rash
- shortness of breath
- pale skin
- profound fatigue
- other unusual and persistent effects

### Gastrointestinal effects

- loss of appetite or abdominal pain accompanied by nausea or vomiting
- vomiting every day

- more than three bouts of diarrhea per day
- fever
- persistent symptoms that become worse over time

### Skin rashes

When accompanied by the following signal a need for urgent medical attention:

- fever
- marked fatigue
- gastrointestinal effects
- mouth ulcers
- difficulty breathing

### Central nervous system

- persistent depression or mood changes that hinder your activities or relationships