

ADHERENCE: KEEPING UP WITH YOUR MEDS



ideas on how to keep up with taking your medications

Staying on a treatment regimen is difficult under the best of conditions. Even doctors and nurses find it difficult to take a simple course of antibiotics as directed. Taking HIV therapy sometimes requires a person to take a dozen or more pills a day, with specific timing and diet restrictions. Then, when a person also uses drugs for other infections, the total daily pill count can soar. Keeping up with your meds alone becomes a major activity. So it's little wonder that people have trouble keeping up with the program. Therefore, adhering to your HIV therapy means taking an honest and objective view of your life and daily activities.

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things to consider before you start therapy

Taking on complex, long-term treatment doesn't feel natural to most people. However, this challenge is not unique to people with HIV. Millions have learned to cope with diseases that require long-term management, including diabetes, mental illness and heart disease, among others.

Whether or not you feel you're able to adhere to a new regimen may be one thing to consider — along with your lab results and overall general health — in deciding the right time to begin HIV therapy. Your readiness, or ability to commit to the demands of therapy, is an important consideration to discuss with your doctor.

Why adhering to all your HIV drugs is important is because not taking them as prescribed every day will lead to inadequate levels of the drugs in your blood. This can result in many things, including no real therapeutic benefit, possible disease progression, development of resistance, and unnecessary side effects.

Giving careful thought to what benefits you hope to get from treatment, how you'll evaluate the benefit,

and how you might manage side effects will be helpful. Some people try a "dry run" before beginning therapy, like taking empty gel caps, or small candies like M&Ms, on the prescribed schedule while sticking to any diet requirements. While this doesn't prepare one for possible side effects, it can help you find times when remembering to take therapy might be more of a challenge.

Perhaps the first and most important aspect of adherence lies in choosing the right therapy for you in the first place. Drugs can differ in many ways including:

- ▶ whether or not they can be taken with food,
- ▶ whether they are taken by mouth or by injection,
- ▶ how many times a day they must be taken,
- ▶ how many pills per day are needed,
- ▶ what other drugs or complementary therapies they can and cannot be used with,
- ▶ their side effects and how they make a person feel, and
- ▶ some require refrigeration or other special handling.

Similarly, people differ widely in their habits and needs. A few examples include:

- › Some people are bound to rigid work schedules, such as hourly workers.
- › Some have constantly changing schedules, or they routinely move in and out of different time zones, like airline workers or truck drivers.
- › Some people are unable to work and their schedules are dictated by a seemingly endless string of medical appointments.
- › Some also have children, parents or partners to care for.
- › Some have people around to help remind them of their drug schedules, while others are alone and must rely on timers, pill boxes or other devices.
- › Some people have wasting syndrome or infections that might make eating difficult; others have no dietary problems but don't eat regularly.
- › Finally, some people have to deal with other challenges like substance abuse, homelessness or mental illness.

To find a treatment regimen you can live with, it's necessary to settle two sets of requirements: yours and the drug's. People who lead busy but largely unstructured lives might prefer drugs that can be taken easily with or without food. This may make it easier to fit therapy into changing routines. Others, whose time is tightly structured by work, might find it easier to go on more demanding regimens. These people can select a regimen purely on the basis of its potency.

People who have trouble eating or who struggle with weight loss may wish to avoid drugs that can't be taken with foods or even conversely, those requiring that they be taken with food. Others who take many other drugs for opportunistic infections or other health conditions might avoid HIV drugs that have many drug interactions. They might even avoid creating regimens that require taking many more pills. Also, the more HIV drugs you've already used, often the fewer choices you have about what to use next. Thus, often in more advanced disease, your drug history tends to dictate what can and can't be taken.

There may not be any perfect regimen for you, but there are options that are more and less easy to adapt to your life. The goal is to select a regimen you can live with — one that fits with who you are and how you live. Once you select a regimen, sticking to it requires planning, support and commitment.

Adherence is more than just taking pills ...

Properly adhering to your medicines involves sticking to an entire regimen:

- taking the full dose as prescribed,
- taking your pills at the prescribed times every time,
- obeying any food restrictions, and
- obeying interactions with other medicines, herbs and supplements.



One study suggests that about **12%** of people miss one dose in the past day, and **11%** the day before that. Other studies report that nearly all who failed to achieve and sustain a viral load below the limit of detection had greatly changed from their prescribed regimens for a month or more.

There are many reasons for failing to stay on your treatment regimen. One study showed that of those who missed one or more doses:

- 40%** simply forgot
- 37%** slept through a dose
- 34%** were away from home
- 27%** changed their therapy routine
- 22%** were busy
- 13%** were sick
- 10%** experienced side effects
- 9%** were depressed

planning

Stable access to drugs is critical for their effective use. People cannot stay on a regimen if they don't have constant access to their drugs. While it may sound obvious, many people taking HIV meds sometimes find themselves running short of one or another drug for a variety of reasons. This is often because of poor planning. Skipping doses because you've run out of a drug is still skipping doses.

Some drugs have different storage requirements than others, so your planning must also address these storage needs. This is primarily true of Norvir (ritonavir) and Kaletra (lopinavir + ritonavir), which for storage over one or two months respectively need refrigeration. Once storage is addressed, it's helpful to put aside a full week's supply, in an accessible place, right after getting your drugs, and then start using the rest of that supply. This creates an emergency stash should unforeseen circumstances cause your basic supply to run short. Your stash should be rotated or replaced once a month to keep it fresh. Some people use a small container attached to their key chains for a daily backup.

Keeping a steady supply of meds requires you to work closely with your doctor and pharmacist. And, when using AIDS Drug Assistance Programs or pharmaceutical company patient assistance programs, even more of the burden falls on you to make sure you order supplies as the program requires and still have a safety net for unforeseen situations. The main point is to always stay at least a week ahead of your needs.

People differ in their abilities to adhere to their regimens and this is influenced by lifestyle and other factors. People dealing with major life problems like active drug use or homelessness face difficult challenges with adherence. But that doesn't mean adherence is impossible. People with depression are also more likely to have difficulty with adherence. If you suffer from depression or mental illness and are considering treatment, consult a mental health expert as well as your regular doctor.

In reality, only you can decide whether you're ready and committed enough to maintain a steady course of treatment. If you are not ready or not in a position to make a serious effort at adherence, you may be better off delaying treatment. This doesn't jeopardize your ability to use effective treatment later. In contrast, *misusing* your drugs *can* jeopardize your future options by encouraging drug resistance. This can affect entire classes of HIV therapy.

Many things can get in the way of taking your meds properly:

- taking care of children or other family members
- feeling good
- forget to take the pills
- Saturday and Sunday schedules
- vacations
- not refilling on time
- no side effects present
- laziness
- depression
- language barriers
- job concerns
- moving
- hospital stays
- drinking or doing drugs
- sleeping a lot
- fear of the medicines





strategies for adherence

some of the following strategies and tools have worked for many people taking HIV therapy.

- ▶ Integrate your regimen into your daily routines. Most people find it easier to fit medicines into their lives, rather than scheduling their lives around their medicine. Use a daily activity, one that you do every day without fail like brushing your teeth, to prompt you to take your meds. Take them before the activity; it's easier to remember.
- ▶ Count out all your meds in daily doses for a week at a time. Use a pillbox, Mediset or nail organizer from a hardware store to hold each dose. Setting up a weekly pillbox also needs to become routine. Meds can also be divided daily by dose and put in separate bags or canisters marked with the dosage times — some use film canisters. Some people put each canister near the place they'll take a dose. For example, put the morning dose by the coffee pot, and evening dose by the TV.
- ▶ Keep a checklist or diary for doses that you've taken with a space to note how you're feeling.
- ▶ Use an electronic pillbox or beeping alarm to remind you when to take your meds. The downside of these mechanisms is that the electronic pillboxes are too small and the alarms may be very obvious.

Adherence strategies may not work for everyone. Because of cultural, gender and socio-economic differences, these suggestions are more appropriate for some people than others. Different issues are more important in some settings than others.

For example, some people have a great need for privacy around their HIV status and taking medicines. This places greater emphasis on planning ahead for moments of privacy each day. For people struggling with lack of housing, active drug use or untreated mental health conditions, adherence strategies will often go beyond what we cover here. Still, even in the most challenging situations, people have daily routines that can be used as triggers for taking meds.

Adherence strategies can and must vary from person to person. The best way to ensure success is your motivation and commitment to your regimen. It may help to know that many people have accommodated long-term treatment in their lives. People with chronic illnesses have long shown that it *can* be done. It may take a few tries before you find the approach that works best for you.

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- › Use a daily planner, especially at the start of a new regimen. Inserting your dosing requirements into a planner, as if they were appointments, can be a useful reminder. Others use hand-held computers or electronic organizers to remind them of daily doses. These kinds of devices can be bought for under \$50.
 - › Evaluate your regimen about two weeks after you start it. It may take a few weeks of experimenting to figure out how to best schedule your meds with other events in your life. For this reason it may be useful to start a *dry run* of therapy with small candies, allowing time to adjust your routines before actually taking the drugs.
 - › Plan ahead for weekends, vacations or moves. People often miss doses when they're away from home. For most, weekends are different from normal weekday routines, so it's important to plan ahead. Take into account the changed environment. Will you feel comfortable with your normal routine or will you need other strategies?
 - › Keep all your meds with you when you travel. Baggage can be lost or delayed.
 - › Plan ahead for privacy if you need to hide the fact that you're taking meds. In this situation, try to find at least one person with a similar problem with whom you can discuss strategy. You could adjust your lunch or break schedule to ensure privacy or keep water in your bedroom at all times.
 - › Keep a diary. Include whatever is important to you: when you took treatment, reason for missed doses, how you feel, etc. Keeping a record like this reminds you how well, or poorly, you're doing with adherence.
 - › Use your support network to remind you of your medication needs. Some people have a *treatment buddy* who can make daily reminder phone calls.
 - › Set up a support network for your emotional needs. It's hard to take treatment and also deal with daily stress, whether it's taking care of children, working or dealing with illness.

building a support network for yourself

Setting up a good relationship with your doctor is critical for maintaining your adherence. Your doctor should know the current standards of care for treating HIV. He or she should spend time with you to fully explain the benefits and the challenges of treatment.

If you decide to start treatment, it's important to clarify your regimen with your doctor. Knowing what

A USEFUL WAY TO UNDERSTAND YOUR TREATMENT REGIMEN IS WRITING DOWN INSTRUCTIONS AND REPEATING THEM BACK TO YOUR DOCTOR.

drugs you're taking and why will help you better understand the importance of adherence. One survey showed that the vast majority of people were unclear of their regimens only ten

minutes after talking with their doctors. Some understood the dose but were confused about diet restrictions. Others were unclear on the correct doses or the timing of them.

A useful way to understand your treatment regimen is writing down instructions and repeating them back to your doctor. You can check them again with your pharmacist when you pick up or order the drugs. Use the team approach. Your doctor, nurse, pharmacist and other providers can help you start and maintain effective therapy.

Since adjusting your diet can be difficult at first, it's important to know what and when you can and cannot eat. Just as important, try to understand exactly what is meant by the drug's diet requirements. For example, many people interpret them for Crixivan (indinavir) to mean that it should not be taken with food, which can be difficult for many people. The actual requirement is that it shouldn't be taken with *fatty* foods. Light snacks and non-fat foods can be taken with the drug without concern.

Similarly, the requirements for Viracept (nelfinavir) are often thought to mean that it *must* be taken with food. In fact, the label says only that it *should* be taken with food. In some cases, there's a genuine medical need to take a drug with or without food. In other cases, like for Videx (didanosine, ddI), taking it with food is recommended only to lessen its side effects or unpleasant aftertaste.

Some researchers note that people who foster friendly and supportive relationships with medical office staff get better service from them. Bringing another person — a family member, friend or advocate — to appointments ensures that two people can ask questions and get information.

Ask your doctor to be clear about side effects how to manage them. Being mentally prepared for side effects can make them easier to manage if they occur. Make a plan with your doctor around what to do if you experience a difficult side effect. Knowing that you will have timely contact with a doctor may reassure you that side effects will be managed well.

It is also important to find out what to do if you miss a dose. If you do miss one, ask your doctor how you should handle it — if you should make it up or just take the next scheduled one at the usual time. Also, note the missed dose and the reason for missing it. There may be a strategy you can use to avoid missing a future dose.

If you're unable to take all the drugs in your regimen, don't take a partial dose. Contact your doctor immediately if you can't take your full dose for whatever reason. In this situation it might be necessary for you to stop all of your HIV drugs until you're able to take a complete dose in the regimen again.

committing to staying on your therapy

Resistance is another reason to adhere to your regimen. Today's potent combination therapy has brought new hope and new challenges to people living with HIV. However, if therapy is not used properly (like skipping doses, taking lower than prescribed doses or not taking them on time), drug resistance will probably develop faster. In this case, the potential benefits of therapy can be lost.

In order to prevent drug resistance, it's important to keep enough drug in your bloodstream 24 hours a day. Each time you miss a dose, the drug blood level falls below the minimum necessary level for several hours. This creates an opportunity for HIV to develop resistance to the drug(s).

Moreover, resistance to one drug may result in resistance to other drugs of the same class, called *cross-resistance*. This is particularly true about NNRTIs. High level resistance to one of the protease inhibitors almost certainly passes on some degree of resistance to almost all the others.

There's little debate about it being difficult to always adhere to today's complex regimens. It is somewhat less clear how much non-adherence is tolerable before

resistance becomes a threat. There are no data telling us exactly when resistance begins. There is, however, plenty of evidence that people who are adherent have better and more sustained anti-HIV responses. While no single episode of a skipped or late dose is likely — by itself — to trigger resistance, the more often they occur, the more likely it is to develop drug resistance.



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a final thought on keeping up with your meds

Perhaps the greatest way that adherence to HIV treatments differs from adherence in other chronic illnesses is the lack of immediate symptoms or consequences when adherence fails. This lack of a rapid response places more of the burden for adherence on the mind and less on the immediate reaction of the body. A person living with HIV must take a long-term view in order to have a long-term future.

Adherence also challenges many of the support systems for people living with HIV. Some doctors have less time to spend educating their patients. As well, most doctors have little or no training in the tools that might help people stay on their treatment regimens. Sometimes, in order to be fully supported, people may need to seek help from others, like treatment support groups, case managers or treatment buddies.

The best long-term solutions for treating HIV — outside of a cure — must focus on making better and longer-lasting therapies. These include ones that are easier to use, more easily absorbed, have fewer side



effects and drug interactions, and maintain more consistent drug levels in blood. This work is underway for some treatments that may require only once-a-day or even once-a-week dosing.

In the meantime, there are many ideas for what you can do to make the most out of your treatment regimen. Consider the ones presented here or come up with your own solutions that make the most sense for your life.

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