COMMUNITY PRESCRIPTION SERVICE

InfoPack

HIV+ owned and operated

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CPS *InfoPack*

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Community Prescription Service's InfoPack is provided free of charge to all active CPS customers, AIDS service organizations and referring doctors. For more information about CPS or to be placed on our mailing list, call (800) 842-0502.

Russian Roulette?

by Stephen Gendin

Early this spring, Community Prescription Service surveyed by phone 400 people with HIV. We wanted a picture of what it's like to be living with HIV right now. We talked to CPS customers, *POZ* magazine subscribers, *POZ* Life Expo attendees and subscribers to this newsletter, *InfoPack*. We wanted to separate the hype from the reality of being on medication. We wanted to hear about the hopes and fears people are experiencing taking their meds. There's a lot of talk in the media about how wonderful combination therapy is. We wondered if people with HIV and AIDS share this optimism.

In the end, the picture we got wasn't all that clear. On the one hand, most people we talked to were on triple combination therapy and felt like they were doing better than they were the previous year. The large t-cell increases that people reported support that optimism. There was also very high satisfaction with the combinations people were taking. Plus, people reported feeling very good about the relationship they had with their doctors, and most also stated that their doctor was very knowledgeable about HIV. And most people self-rated their adherence to their treatment regimens as being very high. Ninety percent of people stated they have enough information about medications. All this is good news.

But there is another side to the picture that isn't as pretty. First off, adherence isn't nearly as good as people initially reported. When questioned about missed doses in the past day and the past week, nearly 40% of people reported missed doses or doses taken incorrectly. Many others reported taking drug holidays—times when they deliberately stopped taking medication. A surprising number of people didn't know how to take their medication properly. This was a particular problem with medications that have food restrictions; many people weren't following these regimens correctly. Yet almost everyone reported that they were very confident that they knew how to take their medication.

Pick Your Shot

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Putting Some Heart into HAART

by Tim Horn

Let's face the facts: The promise of highly active antiretroviral therapy (HAART) to keep people alive and healthy for an indefinite period of time is easier said than done. The true potential of new drug combinations to improve the lives of those who are sick and prevent those who are healthy from becoming ill can be realized only if people living with HIV adhere to difficult treatment regimens. "Take your pills every time as prescribed," is the war cry of our doctors. Yet, they're not talking about incorporating multiple daily dosings, side effects and dietary restrictions for just a few months. Chances are, they're talking about a lifetime of therapy. Put it that way and the task sounds even more daunting: "Take your pills every time, as prescribed, for the rest of your life." The results of this CPS survey are similar to those of other surveys and studies being conducted around the country. But first, a little about the survey: 91% were male, 78% were Caucasians, 11% African-American and 6% Hispanic. Forty-six percent had experienced at least one AIDS-defining illness in the past and 61% were also taking at least one treatment to prevent opportunistic infections (prophylaxis). At the time of the survey, approximately 355 participants were taking some kind of antiretroviral therapy; 339 were taking two or more drugs to treat HIV and 16 were taking only one drug (of these, 75% had taken two or more drugs within the year prior to the survey). Of those currently taking two or more drugs, 76% had been on therapy from anywhere between seven months to more than three years. One of the most interesting results from the study had to do with the participants' perceptions of compliance. For example, 85% of those surveyed—as determined by a response of either 8, 9 or 10 on a scale of 1 to 10—believed that they were good about taking their medication directly as prescribed by their doctors. Yet, the same participants had little faith in their HIV-positive peers; only 32% of those surveyed felt that others taking a similar survey would give themselves such high ratings.

While 85% is a fairly impressive adherence rate, let's take a closer look at some more detailed responses. Approximately 21% reporting missing a dose of their medication once a month, 18% reported missing drug dosages a few times a month and 8% reported missing a dosage once a week. Approximately 5% and 2% reported missing a drug dosage a few times a week and once a day, respectively. In fact, 18% reported either missing a dose or inaccurately taking one of their drugs the day before the survey, along with 37% within the week prior to answering the survey. Perhaps perceptions of adherence don't quite match up with the realities of adherence after all.

The CPS Adherence Study consisted of 400 thirty-minute interviews conducted by telephone in March 1998. A random sample of CPS clients, POZ Life Expo attendees and Infopack/POZ subscribers were called. All respondents interviewed are HIV+. With a sample size of 400, sampling error is plus or minus 5%.

The survey was designed and conducted by
The Henne Group of San Francisco, CA.

Despite the fact that 90% of all survey participants were very confident in their level of understanding as to exactly how they're supposed to take their pills, a number of potential problems were discovered. For example, the most commonly recommended dose of Videx (ddI) is two tablets (either chewed or diluted in water) on an empty stomach twice a day. Yet, of 57 people taking the drug at the time of the survey, 24 (42%) of those surveyed were only taking the drug once a day. Although a handful of researchers have suggested that four ddI tablets taken once a day is equally safe and effective as taking two tablets twice a day, these reports have only been presented at a few very recent medical conferences and have not been published in any medical journals. While it is entirely possible that a few up-to-date and high-minded healthcare providers are prescribing once-daily ddI, something in the survey suggests that not all patients taking once-daily ddI are consuming the necessary four tablets: With 42% of those surveyed taking the drug once a day and only 25% of those taking ddI reported taking four tablets at one time, approximately 17% of those taking ddI once a day are not taking the necessary daily requirment. Moreover, 14% were unsure or didn't think it mattered if the drug was taken with or without food, when in fact it must be taken either one hour before or two hours after eating. Likewise, some individuals taking Crixivan reported curious dosing schedules: 1% of those surveyed reported taking only one capsule every time they took the drug, while 4% reported taking four or more capsules (the recommended dose is two tablets three-times-daily and some researchers have found three tablets twice daily to be equally effective). Numerous discrepencies were reported for all drugs listed in the survey.

Drug holidays—deliberately stopping one or all drugs for indefinite periods of time—were also fairly common occurrences among those surveyed. Eighteen percent reported taking a drug holiday over the past six months. Of those who reported taking a drug holiday, 48% reported taking two or more holidays during the past six months, with 66% taking a drug holiday ranging from three days to more than thirty days.

One of the most common questions raised by both patients and physicians has been how many doses they can miss without causing resistance and, ultimately, drug failure. Yet, this question will most likely go unanswered for many years to come. As illustrated at a November 1997 meeting on adherence—sponsored by the Forum for Collaborative Research, the National Minority AIDS Council and the National Institutes of Health—many patients are taking combinations of drugs that have not been studied together in controlled clinical trials, making it impossible to know how safe and effective they are under the best of adherence circumstances. Patients also differ significantly in terms of weight, metabolism, absorption, stage of disease, viral load and HIV strains, thus making it difficult to conclude that what's right for one person will be okay for someone else.

Another highly registered complaint and reason for noncompliance, especially among those surveyed, was the vast number of pills needed to be consumed at multiple times throughout the day. This complaint is extremely valid and is currently being addressed by numerous pharmaceutical companies and researchers. Despite promising study results—such as those discussed above regarding ddI and various two-times-daily protease inhibitor studies—these results are still limited, at best. While some studies have found simpler dosing schedules to be effective in terms of reducing viral load initially, it is still not known whether or not easier doses will provide the long-term benefits as seen in studies using three-times-daily doses.

While research continues to churn out simpler dosing schedules and, quite possibly, less toxic anti-HIV drugs, strict adherence will remain a difficult issue for both patients and doctors. However, the obstacles associated with adherence are not insurmountable.

Adherence Tips

Ask questions of your doctor and demand detailed explanations until you understand everything to your satisfaction. Drug information and food restrictions are very important.

Read newsletters for the latest advances in the field.

Be honest with your healthcare provider about missed doses or doses taken incorrectly. If they don't know, they cannot help you.

Russian Roulette?

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Add to this the side effects that people are experiencing. The majority of people we spoke to are experiencing side effects, many of them quite severe. A good percentage of people reported skipping doses because of these side effects. Almost one in five people reported that their doctors never went over the possible side effects they might experience from their meds. Even more people reported that when they started treatment their doctors didn't provide them with a plan for dealing with side effects.

The most disturbing piece of information was that less than 50% of people reported that their viral load was undetectable. By traditional means of evaluating therapy, this means these combinations aren't working for most people. Many could start having viral load rebounds and develop resistance to the medication they are on. Of course, this bad news needs to be balanced against the fact that most people are having t-cell increases and are also reporting that they are feeling better. We know that someone's viral load doesn't have to be undetectable in order to get some benefit from the drugs they're taking. Plus, the group of people we surveyed were perhaps sicker than the typical person with HIV; 43% had been hospitalized because of an HIV-related illness. We know that people who've taken lots of antivirals don't respond as well as those who are treatment naïve. We also know that people with lower t-cell counts may experience more side-effects and get less results than people who start medication with higher t-cell numbers.

Still, the high number of people with a detectable viral load is scary. Just under 50% of the people we talked to have been on combination therapy for a year or less. This is the time when these combinations should be working best and yet we still see a large population with detectable virus. In fact, 23% of the people we talked to had a viral load of 20,000 or higher. I worry that a year from now, these people with high viral loads won't be doing as well; many might develop resistance to the combinations they are taking as well as cross-resistance to new drugs. And while there are more and more drugs becoming available, many of them have cross-resistance to other drugs. For example, Glaxo's new nucleoside analog—variously called 1592, abacavir or Ziagen—definitely has cross-resistance with other nucleosides and doesn't work very well for people who've failed lots of other drugs. One study indicates that DuPont Merck's new NNRTI—called DMP-266, Efavirenz or Sustiva—won't work for people who've failed Viramune or Rescriptor. The promise of these powerful new drugs might not apply to treatment-experienced individuals.

That's what this issue of *InfoPack* is about. Read through and see how your experiences compare to the people we talked to. Think about your own experience of taking these meds. How are the side effects? Do you miss doses? What do you like least about the drugs you are on? This issue of *InfoPack* also provides a lot of helpful hints for making your meds easier to take. We give you advice on planning your schedule, increasing your compliance and dealing with side effects. There's a lot of data in this issue, but HIV is a complicated disease, so bear with us.

Thinking About Adherence

by Bob Munk

The word "adherence" suggests that treatment is a team effort, that the patient's desires make a difference.

Why do we care about adherence? Easy: Medications can't work if we don't take them properly. And antiviral drugs are not very forgiving. With antiviral drugs, we're shooting at a moving target. As long as HIV is multiplying, it's mutating. And as long as it's mutating, one of those mutations might be able to get around the drugs we're taking. We can lose the use of a medication fairly easily.

Poor adherence can allow HIV to develop resistance to our current medications. We can use up all of the available combinations and run out of treatment options. Public health doctors worry that non-adherence could lead to the development of a new wave of the HIV epidemic, with HIV that is already resistant to most of the antiviral drugs we've developed.

Measuring Adherence

Adherence can be measured in several ways. You can ask the patient how well they did. Unfortunately, this is not a very objective or reliable measurement. You can count how many pills they have left in the bottle, but that won't tell you if the pills were taken with or without food, or on time—or were dumped down the toilet. Some researchers use blood levels to measure medication intake. Others rely on computerized caps for pill bottles, which report exactly when the bottle was opened—but not how many pills were taken out or what the patient ate. And with all of these methods, there's the "lab-coat effect": adherence gets much better in the couple of days before and after a medical appointment.

Stopping all your meds for a few days (taking a "drug holiday"), can be a special case of non-adherence. If you run out of one antiviral medication or have to stop taking it because of a bad reaction, you minimize the risk of developing viral resistance if you stop taking all your medications at the same time.

How much adherence is enough? In several studies, patients were considered adherent if they took 80% of their medication doses on time. That might work for high blood pressure medications, but maybe not for HIV. It's hard to know how much slack we have. What about taking medications with or without food, or with the right kind of food? The manufacturers tell us that this can make a big difference in how much of the drug gets into our bloodstream—but how much is enough? Individual differences in drug metabolism and absorption have not been carefully studied. If we could take higher doses of medication, we would increase our margin of safety. Unfortunately, for many antiviral drugs, the "therapeutic window"—the amount of drug high enough to suppress HIV and low enough that it doesn't cause serious side effects—is very small.

Perfect adherence is not realistic. HIV regimens, unfortunately, seem designed for poor adherence. They involve multiple medications that have to be taken two or three times a day; some have specialized food or storage requirements; and they can make you feel worse instead of better. We don't have any solid information on how quickly resistance develops if you miss a dose, or have too much food in your stomach, or not enough, or the wrong kind. **And no level of adherence can guarantee that your virus won't develop resistance.** The most realistic approach is to know that the more adherent you are, the better the chances that your medications will work.

Using Measurements of Adherence

Researchers want to know how adherent patients are so that they can decide how many treatment failures were because the drugs didn't work and how many because the patients didn't take the drugs properly. Some public health officials have suggested using adherence as a test for deciding who should get access to antiviral medications. But most research on adherence has shown that patients are better at predicting their adherence than their physicians are, and that it's just about impossible to predict who will be adherent and who won't.

Adherence is a measure of how well the treatment plan fits the patient. Our job as patients is not just to "follow the rules," but to help write them.

Once you have agreed to a treatment plan, be complete, accurate and honest in your reporting to your doctor. Adherence includes every aspect of your treatment plan. For medications, it includes taking the correct number of pills, with or without the right kind of food, at the correct time intervals.

If you don't report accurately, the only person you hurt is yourself. Pleasing your doctor shouldn't be the goal of your reporting on adherence. If you aren't being adherent to your treatment plan, don't fudge your report so that you look good. Come up with ways to make it easier to stick to your plan, or change the plan!

Bob Munk has been living with HIV since the early 1980's. He is a community representative in several AIDS clinical research activities, including the Forum for Collaborative HIV Research. He is a frequent writer on HIV/AIDS topics. Bob lives near Taos, New Mexico.

Belief in Drugs

by RonniLyn Pustil

Ever since July 1996 at the 11th International AIDS Conference in Vancouver, where first-hand accounts of powerful protease inhibitors paved the way for speculation of HIV becoming a chronic, manageable disease, there has been growing optimism about AIDS. In the Vancouver afterglow, first came the articles about "the cure." *The New York Times Magazine* ran a cover story called "When Plagues End" in the fall of 1996. *Time* magazine named Dr. David Ho, of the Aaron Diamond AIDS Research Center, its Man of the Year in 1996 . Newspapers and news programs recounted Lazarus stories about people with AIDS coming back from the brink of death and returning to work.

After a decade of activism and research, the long-awaited magic bullet was here. Or so we thought. Talk of a cure was not only premature—it also ushered in a growing sense of complacency about AIDS. Though many refer to protease inhibitors as "miracle drugs," not all people with HIV and AIDS have been privy to the Lazarus syndrome. These drugs have failed tens of thousands of pretreated PWAs. Some cannot tolerate the side effects. And why should we be surprised? Look at AZT monotherapy—hailed as a cure 10 years ago and now discredited as dangerous.

It's been two years since the advent of protease inhibitors and the honeymoon appears to be over. Though the drug ads show strong, healthy people climbing mountains, we're beginning to hear different stories. Many PWAs are now "breaking through" the treatment and becoming resistant and cross-resistant to the drugs. One conference last winter revealed that these drugs have failed up to 50% of people who take them. For many, the treatment bandwagon has turned into the treatment rollercoaster. If you're still undetectable but you've got friends who are breaking through, how are you supposed to feel? How do you keep the faith?

When asked to rate how confident they are that their t-cell or CD4 count will not decrease and their viral load will not increase, almost a third of CPS survey respondents said "very confident," 44% said "somewhat confident" and 15% were "not very confident." When asked if over the course of the next year they think their health will improve, remain the same or worsen, just more than half said they think they will remain the same, and a third said they think they will get better. Eight percent believe they'll get worse, and 2% were not sure. This indicates a much greater sense of hope than existed before these drugs came along, but people do seem to be cautious about putting too much faith in the hands of their meds.

Dozens of studies of HIV positive people have shown that poor health habits as well as prolonged periods of intense negative emotions can significantly depress immunity, thereby hastening symptom development and progression to AIDS and death.

Belief in Something Else

Where do we find the strength, courage, faith and hope it takes to live with HIV and maintain our wellness on a daily basis? When asked how important spirituality is to their lives, 55% said it was very important, while another 26% said it was somewhat important. That's a whopping 81% in favor of living a spiritually connected life. Looking at the terrible challenges inherent in this disease, I am amazed that the 19% who said spirituality was not important can face them without it.

The majority who did think spirituality was key to survival were not asked about their spiritual practice or belief systems, and rightly so. There are many ways people get in touch with a power greater than themselves for help and guidance. Whether or not you practice an organized religion is not the point of spirituality in the HIV community.

Outside of organized religious practice, the way people approach this topic is varied and very personal. Some people in recovery obtain an understanding of a "higher power" through 12-step work. Prayer, meditation and dependence on a higher power is thought to be the key to working a good program. Meditation itself is part and parcel of many spiritual paths.

Maintaining and developing a conscious relationship with the spiritual may involve nothing more than the belief in a universal field of energy or a deep appreciation of nature and the world we live in. AIDS activism in itself can be a spiritual outlet. Activists, while trying to assist others in obtaining the drugs and rights they need to survive, also help themselves on a spiritual level. Devoting time and volunteering service for others is a satisfying activity that people use to step out of their own disease and make a difference in the world. If we have belief, then one person can make a difference in this world. Belief in what?... How about life?

Finding Your Way

by Becky Trotter

It's time to take your meds. You're running late to meet a friend for coffee, and it would take at least thirty minutes to get home. You can't remember the last time you ate, and you've just discovered that your pills are in a fancy container sitting next to the toaster on your kitchen counter. You tell yourself that a missed dose doesn't matter this one time. Your mind starts to wonder about resistance. You've been feeling good, working out and, thankfully, your viral load is down. You start to wonder if your viral load will go up if this dose is missed. You try to stay calm, it's just this time. Then you remember that it happened last week and a few times last month and the month before. You decide to go home.

When you finally get home you fish out the right pills, choke them down with a glass of water, and fall into your favorite chair. Your head is pounding after the emotional trip you've just taken and you're too exhausted to leave. You fall asleep. Wakened from a dream, you feel panicked and realize that it's time to take the final dose of meds for the day.

LIVING WITH HIV USED TO BE LIKE PLAYING CHECKERS AND NOW IT'S LIKE PLAYING CHESS.

Though difficult, adherence to anti-HIV drug combinations is possible. I know this because, like many friends I've talked to, I've experienced moments of frustration when it comes to my meds. I wish I could sing you a tune of "ding dong the wicked witch is dead"; unfortunately it seems as though HIV is here to stay. The good news is that we finally have drugs other than AZT to fight HIV. The bad news is that these drugs are complex, expensive and difficult to take at times. However, finding your own individual way to deal with how and when to take medications is achievable.

In this recent survey of HIV-positive subscribers to POZ magazine and clients of Community Prescription Service (CPS), 401 people responded to questions regarding their HIV treatment regimens. While this survey has limitations, and the sample should not be taken as representative of people with AIDS as a whole, it does provide some interesting insight into some people's experiences with antiretroviral medications.

Interestingly, 85% of respondents who have taken antiretroviral meds rated themselves on or close to "very good" at taking their medications exactly the way their doctor has recommended, regarding the number of times per day, on a full or empty stomach, and the correct number of pills taken each time. This is a surprisingly high number of people who report that they are able to stick to their treatment regimen as prescribed. Notably, when asked how well they think others are able to adhere to a treatment protocol, those who rate their peers on or close to "very good" drops to 32%.

Two things may account for the disparity between the way respondents report their own ability to stick to a regimen versus the perceived inability of their peers to adhere to a regimen. First, many people are in denial about the number of times that they have missed doses or taken doses at odd hours. It's easy to repress that information, especially now, when there is so much hype about the promise of these new drugs, coupled with the demonizing of people who have difficulty with adherence. Frankly, we are reluctant to talk to one another truthfully about the multitude of reasons for straying from adherence—from forgetting the meds at home to being unable to manage the food/med schedule.

Second, when the survey participants were asked how long they have been on two or more antiretroviral medications at the same time, 44% reported being on them for less than a year. The length of time that one is on combination therapy may correlate negatively with adherence. For many, the longer that we are on the drugs, the easier it becomes to get too relaxed about rigid adherence. It would be very interesting to survey the same people in six months to a year and see how/if adherence changes.

Although a large number of participants surveyed stated that they are taking their medications the "right" way, it is necessary to look at the data of those who admitted having problems adhering to their combination. According to the CPS survey, the three most common reasons people miss taking their drugs are (1) forgot, (2) scheduling problems and (3) purposely did not take them. Fifty-six percent of those who missed doses stated that they forgot because they were in a rush, didn't bring pills with them, couldn't remember if they had already taken them or were too busy to take them. Fifty-two percent stated that scheduling problems occurred because they were at work or with friends unexpectedly, overslept or fell asleep, and didn't eat or couldn't eat. The smallest percent stated that they purposely missed doses because they were too sick, ran out of pills, were tired of taking so many pills, and/or the side effects were too hard to manage.

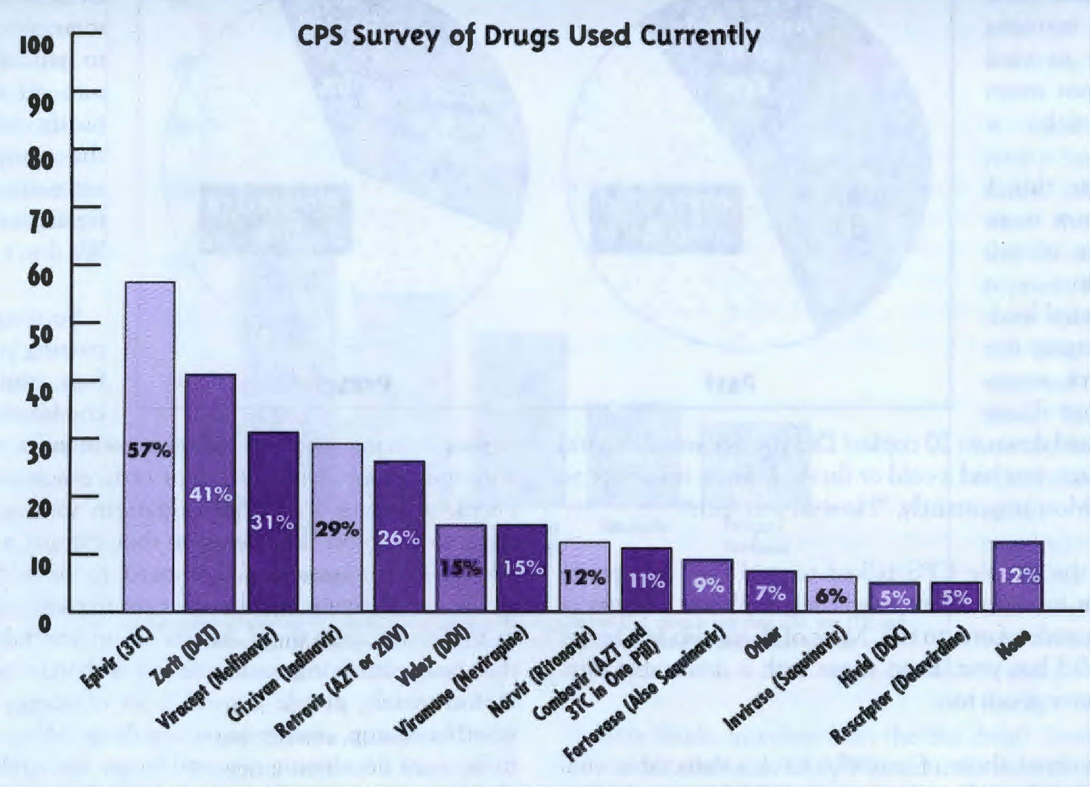
Living with HIV is more complex than it has ever been. There is no argument that these medications are helping many people to live longer. But, without paying close and rigid attention to adhering to them we have learned that building up resistance can happen very easily. We must do our part, and in so doing it takes more than just swallowing your pills if and when you remember to. Pay close attention to how many pills you have with you when you leave your house. If you meet Mr. or Mrs. Right and go home with them, make sure you have enough pills to complete your dosing before you get home. If you are having a difficult time remembering to take your pills, buy a beeper or small alarm. If this drives you crazy, leave yourself notes or find some friends/lover(s) to call and help remind you. A good thing to try to do is keep one or two doses at work in your desk or in your bag, purse or whatever you carry. If you are just sick and tired of taking your meds please be aware that you are not alone. Talk about it. Vent, yell, bitch and get your frustrations out, or you will consciously or subconsciously sabotage your combination therapy.

Internal dialogue is normal and necessary to the process of living with these medications. The struggle does not end if and when you decide to take these drugs. It doesn't even end if and when you finally get your viral load down to undetectable. The real challenge is to take control over events in your life that cause stress and may hinder you from getting the benefit you want from your drug combination. Most importantly, openly grappling with the issues I've mentioned is the key to living successfully with HIV. The struggle is not over now that we have these drugs. Actually, they make the struggle more complex. I have said to many friends that living with HIV use to be like playing checkers and now it's like playing chess.

The CPS survey is an important beginning to the dialogue that needs to happen around drug adherence. It highlights the fact that many people who have chosen combination therapy say that they are managing to adhere—but for how long? We need to further explore the possibilities for long-term adherence. Why are most in this study so successful in not missing doses? Will those who admitted to missing doses continue to miss doses or will they get better at adhering? It's important that some of these questions are finally being posed. When I tested positive a man in a support group said the experiences of those before him helped him to survive. With shared experiences we can find our way.

Becky Trotter is a lecturer, survivor, activist, writer, artist, and is currently on an extended drug holiday due to side effects.

Although 85% report use of two or more drugs, use of protease inhibitors (PI) seems low. Press caverage creates the impression that PI is the "cure" and that most infected people use some form of the drug. Reality versus perception differs regarding long-term effectiveness. For example, one quarter of the patients in Dr. David Ho's triple combo therapy study have had their virus rebound from "undetectable" levels. (Source: "The Agenda Ahead" by Michael Harrington, TAGline, Vol. 5, Issue 3, April 1998)


CPS Survey of Drugs Used Currently

How Does It Feel to Be a Failure?

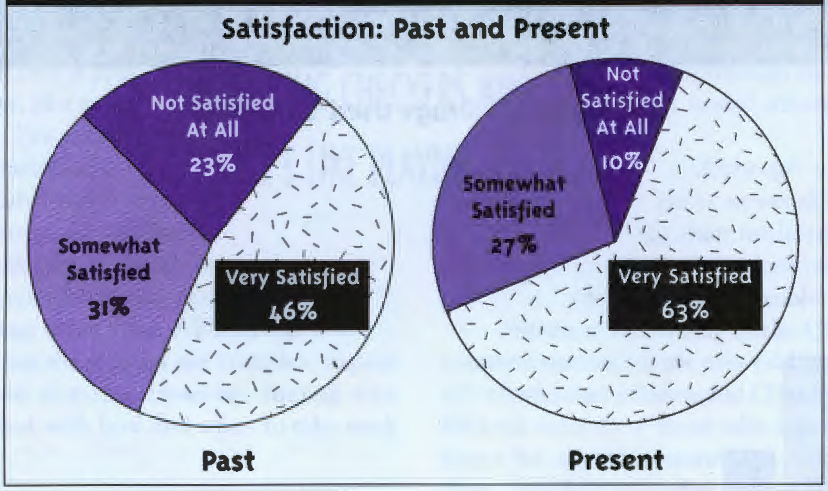
by Lorna Gottesman

Fifty-seven percent of the people taking anti-viral drugs that CPS surveyed had a viral load above the level of detectability. Since the goal of antiviral treatment is an undetectable viral load, this is considered treatment "failure". But should it be?

The fact that over half of the people surveyed had a detectable viral load seems to poke a hole in the drug company hype surrounding combination therapy. Stories of "miraculous recovery" have been getting a lot of play in the media's AIDS coverage lately. As a community, it's important to remember that not everyone does well on antiviral drug combinations.

For the past 18 years, people with HIV/AIDS have been figuring out how to live happy lives and still keep track of their blood work. There's much more to someone's physical well-being than the numbers on their blood work. We have learned that the sun does not rise and set based on a t-cell count. Now we are learning that a rise in viral load does not mean someone is sick.

The satisfaction level was based on a 10-point scale with satisfaction in the 6-10 point range. This graph shows that people are more satisfied now than they were one year earlier.



As I write this, I want to know more about those of you who have a detectable viral load. Are you getting the Roche ultra sensitive test that shows your viral load down to 20 copies? Did you get your last viral load test when you had a cold or flu shot, when it was apt to be higher? Most importantly, "How do you feel?"

Most of the people CPS talked to said they felt pretty good. Seven in ten of them rated their health as a seven or higher on a scale of one to ten. Most of them also felt better than they did last year. Even those with a detectable viral load felt pretty good, too.

My guess about those of you who have a detectable viral load is that you have been living with HIV for several years. I think that you have already taken most of the antiviral drugs on the market. You probably took most of these drugs as monotherapy, since that was how they used to be prescribed.

What they also found in these so-called "failures," is that like most of the people that CPS surveyed, said they felt pretty good. People who are not able to get or keep their viral load below the level of detection still benefit from taking antivirals.

By removing even some of the pressure of the virus from the immune system, the immune system comes back. The longer the drop in viral load, the stronger the immune recovery. Just a little bit of immune recovery can mean feeling better.

People with HIV who have been failed by their drugs are left with lots of unanswered questions and few options. The big question being "what now?" We do not know what someone should take if their virus is resistant to a combination of antivirals, especially if they are resistant to a protease inhibitor. Should someone stay on a combo they have developed resistance to? If they do, they risk developing a higher level of resistance, which may limit options in the future. What if they have nothing else to change to? Should they recycle drugs that have benefited them in the past? Does a combination someone is resistant to put enough pressure on the virus to justify the toxicity of the drugs? Should someone just stop treatment for a while? We don't know.

Some doctors are putting patients on four and five drug combinations. A lot of people living with HIV who are resistant to their current antiviral combo don't have four or five new drugs to take. People are stuck in a holding pattern waiting for enough drugs to come on the market so they can get a new combination. Other questions that need to be addressed: Can we live a relatively healthy life carrying some level of virus in the blood, over time? And is an undetectable viral load the only satisfying outcome to a battle well fought? Unfortunately, people expend a lot of energy questioning whether to stop, change or recycle drugs. More energy needs to be spent developing new and better antiviral options and answering these questions.

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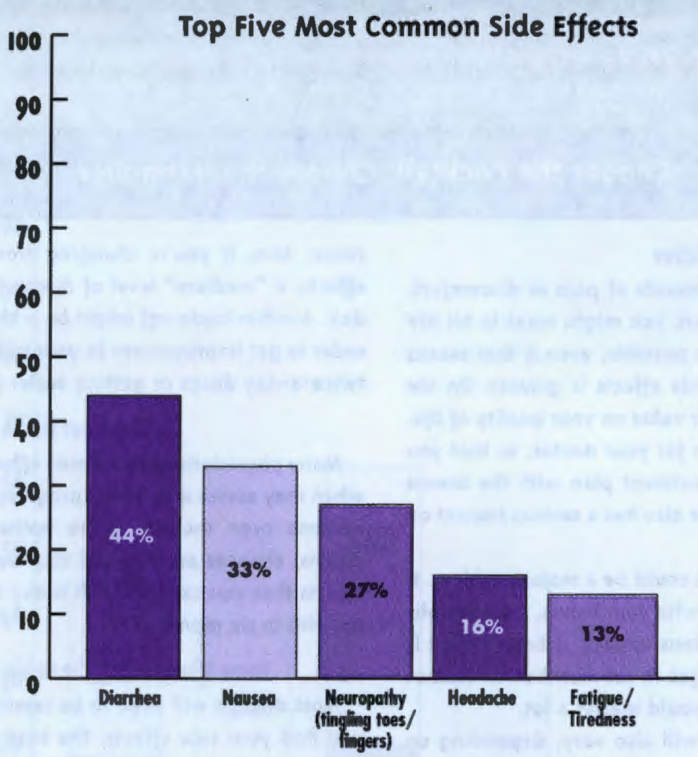
Food Matters

by RonniLyn Pustil

They say food is the best way to a man's heart. Allow us to slightly alter this cliché: Food is the best way to a PWA's HAART (highly active antiretroviral treatment). Keeping on weight is one of the most important things a person with HIV or AIDS can do. Good nutrition is a co-therapy that can help maximize your medical management of HIV, as well as prevent or delay wasting syndrome. Not only do strong connections exist between what you eat and your immune system's ability to fight off disease, but food plays a crucial role in the absorption of your meds.

As combination drug therapy becomes more complex, adherence gets trickier. And food is a big issue when it comes to adhering to drug regimens in terms of when, what and how much to eat. With people taking two-, three- and four-drug combos—all with varying food restrictions—eating can dominate the lives of many PWAs. Those on combination drug therapy often must revolve their days and meal schedules around their drugs.

Top five side effects experienced by antiretroviral drug users were diarrhea (44%), nausea/upset stomach (33%) neuropathy/tingling in toes/fingers (27%), headache (16%), and fatigue/tiredness (13%).



Less common were vomiting (7%), rashes (5%), gas/bloating (4%), change in taste (2%), change in body shape (5%), fever (1%), and heartburn (1%). Gas/bloating and heartburn were rated the most severe by over a third of the people experiencing them.

When asked to rate how good they are about taking medications exactly the way their doctors prescribed them—with regard to the number of times per day, on a full or empty stomach, and the correct number of pills taken each time—half of the CPS survey respondents answered "very good." Asked to rate themselves on a scale of 1 (not at all good about taking meds) to 10 (very good about taking meds), only 1% of respondents answered with number 1. An impressive 96% gave an answer of 6 and up.

But when asked whether their drugs have to be taken with or without food, many respondents who thought they were "very good" at adhering to their regimens had no clue how much food matters. People are over-confident that they are taking their drugs correctly, and that is a dangerous assumption. Check with your doctor to see if you're eating the right foods at the right times. You may dutifully take all your pills exactly when you're supposed to, but if you screw up your food intake, what's the point? Food is frighteningly important when it comes to the absorption of these drugs.

- Ritonavir (Norvir): To avoid stomach upset and improve absorption of the drug into your body, Ritonavir should be taken on a full stomach. Sixty-five percent of Ritonavir-takers surveyed knew they should take the drug with food, but one third answered that it doesn't matter. Only 3% said Ritonavir should be taken on an empty stomach. Taking the drug with a fatty meal reduces its main side effect, upset stomach. Taking it with low-fat foods doesn't affect how well your body absorbs the drug, but it can worsen the side effect of nausea and vomiting.

- Crixivan (indinavir): Survey respondents on Crixivan were the most in-the-know of protease poppers: Ninety percent answered that the drug has to be ingested without food. Crixivan-takers are faced with a scheduling nightmare. They are required to take it on an empty stomach—one hour before, or two hours after, meals—because foods, especially fatty foods, interfere with the the drug's absorption into the bloodstream. Only 7% said it doesn't matter how you take the drug, and 3% said it should be taken with food.

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Although the FDA still recommends that Crixivan be taken on an empty stomach for maximum absorption, there's now some good news: The American Dietetic Association developed a list of low- and no-fat snacks that you can take along with your Crixivan if you must eat at a scheduled dosing time—provided you limit yourself to the suggested serving size. And don't forget to drink lots of water (at least six 8-ounce glasses a day), to avoid kidney stones.

- Saquinavir (invirase): It must be taken *within* two hours of a hefty meal. Three quarters of respondents on this drug knew that. Saquinavir taken without food may have less bioavailability, but 19% said it doesn't matter if you take the drug with or without food and 6% weren't sure.
- Fortovase (new-and-improved gel form of saquinavir): Take it with, or up to two hours after, a full meal that includes carbohydrates, proteins and fat.

Here is a list of drugs you can eat with anything at anytime. There are no food restrictions with them, unless you take them in combination with a protease inhibitor:

- Epivir 3TC
- Hivid ddC
- Retrovir AZT
- Zerit d4T
- Combivir (AZT & 3TC)
- Rescriptor
- Viramune

A little more than half of the respondents on Fortovase knew that it should be taken on a full stomach. One third said it doesn't matter and 8% weren't sure. When taken on an empty stomach, the amount of Fortovase absorbed into the blood is lower and may not fight HIV as well.

- Viracept (nelfinavir): Eighty-two percent of Viracept-takers said it should be taken on a full stomach, 17% said it doesn't matter. Well, it does. You have to eat a meal or light snack when swallowing this drug in order to get the proper absorption.

Food is so much more than what we put in our mouths. Food is love. Food comforts and soothes us. Feeling down? Not getting any action between the sheets? Often, a quart of chocolate ice cream can fill those voids. Food is friendship and sharing, but grabbing a quick bite out with a pal can be anything but spontaneous due to the culinary complications of protease inhibitors.

Choose the Cocktail, Choose the Hangover

It's All Relative

People can tolerate different amounts of pain or discomfort. When you plan an antiviral regimen, you might want to hit HIV with the most potent combination possible, even if that means your chances of uncomfortable side effects is greater. On the other hand, you might put a higher value on your quality of life. This is very important information for your doctor, so that you can work together to design a treatment plan with the lowest risk of serious side effects. Lifestyle also has a serious impact on adherence.

If you travel a lot, then diarrhea could be a major problem. If you walk a lot or do detailed work with your hands, then peripheral neuropathy would have a serious impact. If body image is very important to you, then changes in fat distribution (sometimes called "protease paunch") would matter a lot.

The importance of side effects will also vary, depending on your health and prior medications. If you're asymptomatic, and starting your first antiviral therapies, the medications could make you feel sicker. The fewer the side effects the easier it would probably be to stick to the treatment plan. On the other hand, if you've had an opportunistic infection, medication side effects could seem like a small price to pay to avoid a recurrence. Also, if you're changing from a drug with major side effects, a "medium" level of discomfort could seem like a holiday. Another trade-off might be a higher level of side effects in order to get improvement in your pill-taking schedule, by using twice-a-day drugs or getting easier food requirements.

To Change or Not to Change?

Many physicians consider side effects to be fairly unimportant when they assess a patient's progress. If you don't change medications even though you're bothered severely by the side effects, chances are you will skip doses in the future. The side effects that you can live with today might be impossible to put up with in six months.

Know When to Hold the Cards, Know When to Fold

Most doctors will need to be reminded about how significant you find your side effects. The best antiviral combination isn't necessarily the first one that effectively suppresses HIV; it's the one that works and that you can keep taking for the longest time. If you start skipping doses or taking drug holidays to try to reduce the side effects, you increase the risk of developing resistance to the regimen. Then you really will have used up a treatment option.

Preparing For Side Effects

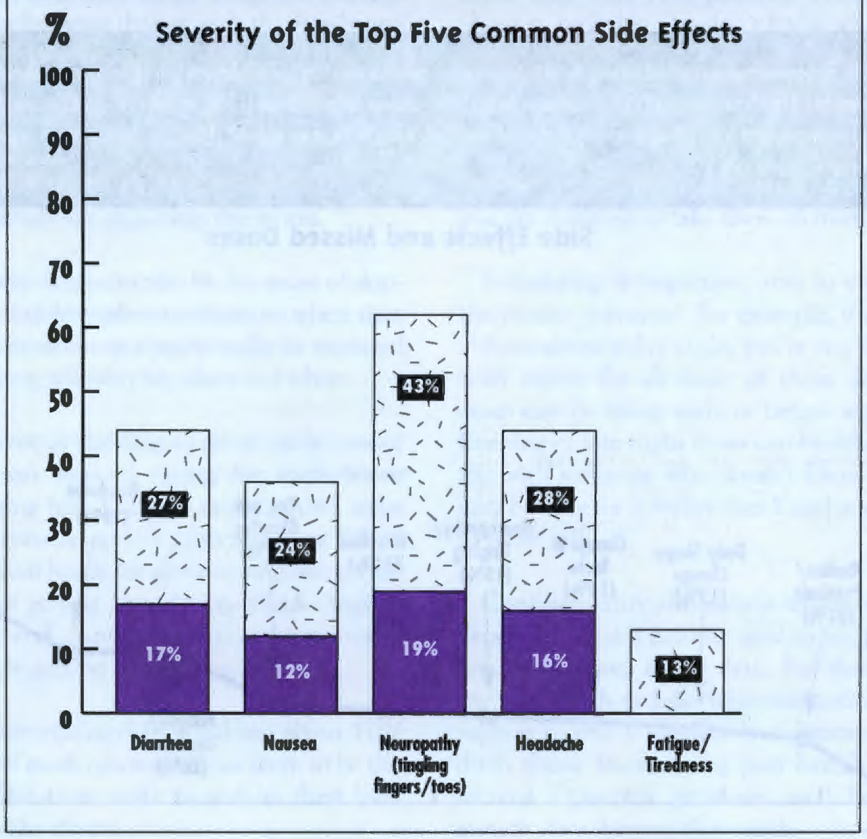
by Bob Munk

Ready or Not

At least 20% of the people who responded to the CPS survey have experienced a side effect that they rated as somewhat or very severe. And side effects were a reason for not taking medications, at least once, for as many as half of those who experienced vomiting, nausea/upset stomach, fatigue and headache. There's no way to predict who is going to have a hard time with any particular medication and who is going to sail on through with no problems.

Unfortunately, most people with HIV disease don't get good information from their doctors about the side effects of medications they will be taking. But it is proven that people who know what to expect, and how to deal with it, are probably less likely to be upset by side effects or to stop taking their medications.

In measuring the severity of side effects, it was reported that of the 44% who experienced diarrhea, 27% said it was somewhat severe and 17% rated it as very severe; nausea (33% of total) 24% said it was somewhat severe, and 12% reported it as very severe; neuropathy (27% of total) 43% reported a somewhat severe effect, while 19% said it was very severe; headache (16% of total) came in at 28% somewhat and 16% very severe; fatigue/tiredness (13% of total) 13% reported a somewhat severe effect.



Planning Ahead

Before you leave your doctor's office, get written information on all of your medications, including their side effects. Your best bet is to get information from your doctor whenever you are planning to add or change medications. Be sure you can answer all of these questions:

- **What are the most common side effects?** Side effects should be explained in clear language. Ask for a definition of any words you don't fully understand, like "peripheral neuropathy." Find out the percentage of people who get each side effect. Remember, these are averages and everyone is different. You might not experience any of the side effects. If one side effect shows up that doesn't mean the others will.

- **How do the side effects show up?** Ask if there are warning signs for some of the side effects. For example, pain in your side can be an early sign that you are developing kidney stones. Peripheral neuropathy can start as a tingling in your toes.

- **When do they start?** Some side effects come on right away when you start taking a new medication. Others might not appear for several weeks. This information can help you know if what you're feeling was caused by your medications.

- **Will they get better or worse? How long should they last?** Some side effects start up at "full strength," gradually get better and disappear within a few weeks. Others can come on gradually and might keep getting more intense. Most side effects go away if you stop taking the medication that's causing them, but others can have lasting effects. It's important to know how long to tolerate a side effect before you need to take more serious action.

- **How should I deal with them?** This is probably the most important question to ask. Talk with your doctor about the best way to deal with each possible side effect, and then talk to others, if possible, who are on the same regimen. You usually have time to make

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up your mind, so before you "marry" a combo, do some research. Call an AIDS Service Organization, like PWAC or Project Inform, for information. Here are several bits of advice you may receive:

- Grit your teeth and tough it out
- Eat or avoid certain foods
- Use certain vitamin supplements or herbal preparations
- Get massage or acupuncture
- Use over-the-counter remedies
- Use a prescription medication
- Call the doctor's office
- Go to the emergency room

Be sure you discuss with your doctor whether there are any side effects or reactions that mean you should stop taking one or all of your medications.

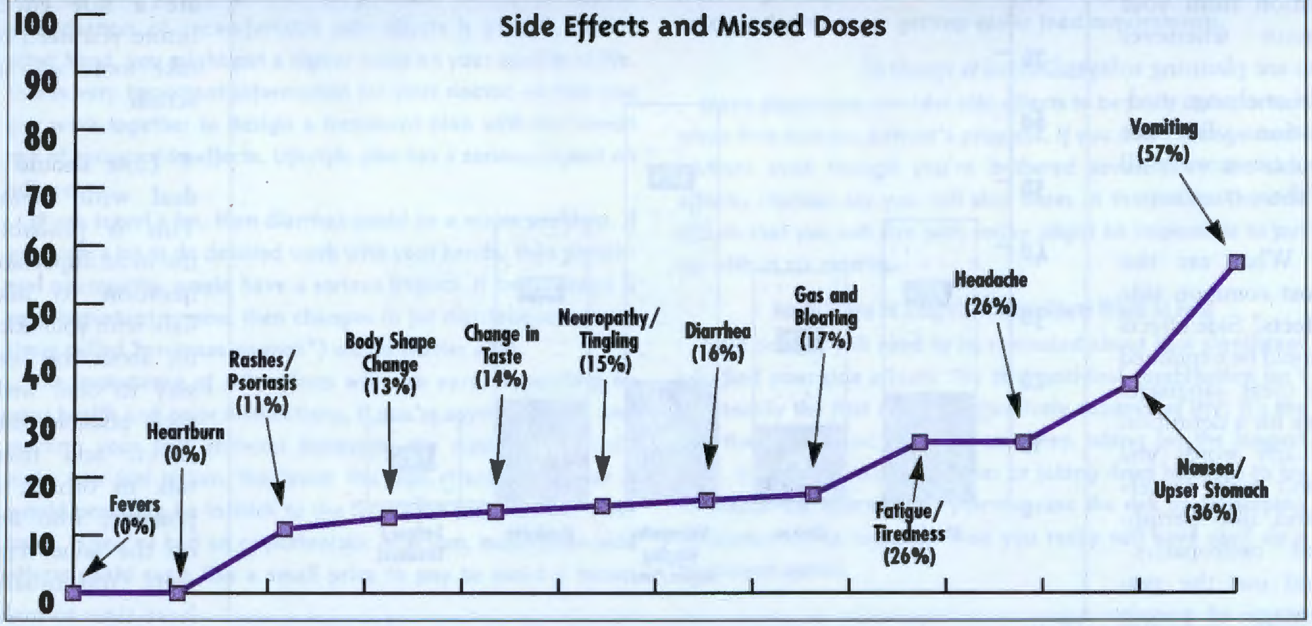
- **Do your shopping:** If there are foods, vitamins, prescriptions or herbs that can help with possible side effects, you might want to have them on hand.

- **Plan ahead:** You probably won't have every side effect you hear about, but think about what you will do if they happen. What changes could you make in your daily schedule? What arrangements might be needed at work? If diarrhea becomes a problem, do you know the locations of bathrooms you could use along your daily route?

When the Side Effects Happen: First, take the actions you've already planned. Keep your doctor informed about any symptoms that might be related to your medications, especially anything that you didn't discuss in advance. There may be side effects that the manufacturer doesn't know about yet, so report it to your doctor.

Don't discontinue any of your medications without first talking to your doctor. On the other hand, don't feel like you have to keep taking them no matter how uncomfortable you feel. Before you stop or miss doses, talk to your doctor to see if there are other things you can do to reduce the side effects. If not, discuss your options for changing medications.

Side effects that caused the respondents who reported having them to miss a dose included vomiting (57%), nausea (36%), fatigue/tiredness (26%), headache (26%), gas & bloating (17%), diarrhea (16%), neuropathy (15%), change in taste (14%), change in body shape (13%), rashes (11%). Fevers and heartburn, although rated as a severe side effect, kept no respondent from taking a scheduled dose of medicine. Refer to chart on page 9. (Example: 44% reported experiencing diarrhea. Of that group 16% said it caused them to miss a dose.)



Postcards from Protease Vacations

by Kevin O'Leary

Everyone knows the *Peanuts* Halloween special where the gang goes out trick or treating and they all have a great time except poor Charlie Brown. While Lucy shrieks with glee about her chocolate bars and Linus brags about lollipops, our Chuck gets nothing but rocks. For someone with HIV, a "no-frills, no fun," life on meds can make you feel a lot like Charlie Brown. So it's no wonder that so many PWAs choose to take "drug holidays" both permanent and temporary.

"I was getting bad reactions like shortness of breath and a swelling of the neck that made it difficult to breathe so I went off the drugs," admits one of the many survey respondents who cited debilitating side effects as their number one reason for going off meds. A common answer was also that the drugs made them feel so generally awful that "they needed a fresh start."

What is a person with HIV to do when a strict diet keeps favorite foods way off the menu? Submitting to these cravings cause some to worry that taking their meds will upset their stomach further and they skip that day's dosage. Also, some PWAs said that the holiday season was a time that they took a planned vacation from their meds. Imagine a scenario in which you're at Thanksgiving dinner with the family and suddenly you're faced with the choice of taking your Crix or eating grandma's turkey to avoid conflict or disclosure.

Some said that a literal vacation was the reason behind their "drug holiday." Tethered to a bottle of pills is not how anyone wants to feel when out exploring the world.

Speaking of trips, street drugs can also be the cause of skipping meds. People who find themselves in situations where they are not able to make clear decisions cannot really be expected to keep track of how many pills they've taken and when.

Finally, the issue of cost in deciding to go off meds cannot be overstated. One man stopped taking his medications because they were costing him $3,000 a month. Also, some treatments require refrigeration and it's a fact that some PWAs don't have a roof over their heads, let alone a refrigerator. Add to this the difficulties of getting prescriptions filled—including pharmacist error and confidentiality concerns—and you've got a lot of people getting off the protease track.

One can become overwhelmed by thinking about HIV 24-7. Choosing to go off meds can sometimes seem to be the one active decision PWAs can make to reclaim their lives from timers, pills and side effects.

Justice Not Always Blind

by Frank Pizzoli

Confidentiality, in spite of all of our best efforts, remains a thorn in the side of HIV-infected individuals. Whether in the work force or keeping some other type of schedule, people inevitably run into awkward moments around pill taking.

People do miss doses over fear of others' judgements. Thirty-seven percent of survey respondents reported that they worry about other people seeing them swallow pills. Rather than viewing your situation as one of "visibility," perhaps you can rethink the scenario as one of "accommodation."

For example, role play with a friend what situations may arise and your rehearsed answers. To Nosy Rosy at work (they're everywhere), just say "Vitamins, hon." and let it go.

If you would rather not show up at exactly the same time at the company water cooler, then carry your own water. Accommodate yourself, even if others may not.

Another 18% of survey respondents said that they had not taken their pills because they were with people who did not know they were HIV positive. Those people, if you think about it, probably also don't know what a protease inhibitor looks like. For those stickier situations, you can always be sure to keep your meds in a nondescript container. Saying "excuse me" and leaving is another good out. Turn the corner and head for the water fountain or rest room. Just because you're carrying the water and pills does not mean you are required to take them in front of others.

Scheduling is important, too, in creating and preserving the privacy you need. For example, if you take your meds on a three-times-a-day cycle, you're not likely to be at work or with others for all three of those dosage times. Morning doses can be taken early or before work or other activities. Evening or late night doses can be taken alone. If you're living with someone who doesn't know your health status, it may be time for a reality check and good old fashioned heart to heart talk.

Confidentiality also means taking others into your confidence. It is not a healthy goal to see how many people you can fool or keep in the dark. Put that energy into explaining your needs to folks who may understand and even be of support to you. If they don't understand, then dig a hole and ditch them. Maintaining your health is not about keeping secrets. Openness promotes well being and higher self esteem. You deserve that much.

Confidence Game

by Kevin O'Leary

You know those survey folk who always seem to call during dinner—or at least what passes for dinner if you're on a Crixivan diet—to ask you for your thoughts on current events or brands of detergent? Well, the results of *this* survey might reveal a lot more about you then what you think of your long distance calling plan. These questions focused on possible variables that may contribute to fluctuations in the measurement of your t-cells and viral load.

First of all, see how you measure up: The average t-cell count of the CPS survey respondents was 376, with 42% clocking in between 200-499. Meanwhile, the average viral load weighed in at 49,000 with 41% proudly saying that theirs was undetectable. If these figures make the 59% of you who have a detectable viral load feel like losers left back in HIV school, rest assured that you are not alone. Nearly 25% of the PWAs surveyed admitted having no confidence that they would have better scores in the next year, while three quarters of respondents said they were confident that their counts would improve. Adherence to a drug regimen is not the only factor that affects health, but often people are blamed for their "treatment failure" with accusations of non-adherence. It's wrong that this happens at all. Playing by the rules of good adherence can be a major confidence builder for the PWAs who are getting good results from their drugs and a nightmare for those who adhere and still get sick.

What else may be influencing the differences in the health of the PWAs surveyed, and what does it mean for you? Like everything with HIV, it's complicated. Issues of adherence, side effects, attitude and cash flow all fall into the mix.

Those who have not taken a drug holiday in the six months were more confident about their health looking up than those who had fallen off the protease wagon. Indeed, the proof seems to be in the numbers: Of those who say that they sometimes skip doses, 40% report t-cell counts lower than 200. Those who are able to follow the strict adherence requirements boast higher t-cell counts and much lower viral loads. If you haven't been as effective taking your drugs as them, try to think of why. Then you can make an informed personal decision as to how you'll handle it in the future.

Popping pills on the run is a pain for everyone. But those with well-oiled systems for taking medications away from home were far more confident about the future than those who had trouble doing it. And the people who did have that difficulty said they felt emotionally awful about it later. According to the statistics, those who said they "feel like a failure" when they miss a dose are also still the ones still hopeful for better counts at the next visit to the doctor (79% of this group said that they think things will be looking up). Whereas, those who said they did not feel like a failure when they missed doses came up with a significantly smaller amount of confidence in the future of their health. Failure is an inappropriate response for and an incorrect description of someone who's not an adherence saint. Let's hope that people who said they felt like a failure use it simply as aversion therapy to avoid further slips in their drug regimens. Indulging in this kind of negativity may work, but what a price to pay!

It's certainly no surprise that PWAs dealing with opportunistic infections and nasty side effects can find their confidence—and t-cells—plummeting. Keep in mind that both situations can not only seriously affect adherence, but can distort blood levels, too. If you're laid up in the hospital and can't eat a thing due to side effects, your doctor may or may not urge you to switch meds or take a break. As always the decision to stay, change or stop medications is ultimately up to you.

In the end, is it true that money changes everything? Maybe. Those who report a household income of less than $15,000 seem to have more of a problem keeping their t-cells up than those with fuller bank accounts. The same is true in regard to viral load. What the survey doesn't show is whether the people with more money are able to buy better numbers with better treatment, food and supplements, or if money woes just increase stress levels—and the viral loads—of less affluent PWAs. Along these lines, the survey also showed that people unemployed and at home have slightly lower t-cells and higher viral loads than their employed counterparts. Again, is it the increased cash flow or the more concrete sense of purpose inherent to the button-down, 9-to-5 life that makes people see light at the end of the testing tunnel? We'll let the psychologists and immunologists duke that one out.

These statistics may shed some light on why some people aren't as successful in the numbers game as others. To some degree attitude (positive or negative), money (or lack of it), and employment are factors that this survey has linked to t-cell and viral load levels. It amounts to a small scratch on the social skin of this disease, nothing more.

Clocks, Calendars & Containers Track Doses

68% put pills in date/time containers. *Keep your container in view (bathroom counter/bed table.)* ● **61%** take medicine by "cue activity" (Walk the dog...take pills) *Time your pills with a walk or workout. The activity will move the drugs quickly into your bloodstream.* ● **31%** used beepers or alarms as reminders. ● **20%** have a friend call and check up on them. *Helping others with their adherence helps the caller be more adherent too.* ● **13%** used a calendar to remind them. ● **6%** employed a reward system, which was the least used method.

Community Prescription Profile

by Ajax Greene

A Brief History

The company now known as Strubco was founded in 1983 by Sean Strub. Sean, with various business partners along the way, operated it as a direct mail consulting and list management organization. They did much of the early direct mail fundraising for Gay Men's Health Crisis in New York, AIDS Project LA and a variety of gay/lesbian organizations. In 1990, when Sean decided to run for the US Congress as an openly gay and HIV+ candidate, he chose as his campaign fundraiser Stephen Gendin. Their relationship was formed in the early days of ACTUP where they met and worked together for several years. In 1991 Stephen showed a Strubco client, a mail-order pharmacy, that their marketing efforts could be improved. This successful partnership continues today with Stephen as the president of Community Prescription Service, the company Sean and he founded. CPS was created to do what we do best: marketing, educating, empowering and providing caring client advocacy for PWAs.

In the early days, HIV/AIDS education was difficult because so little information was available. Sean and Stephen would make photo copies of any articles they could find, pack them together and mail them to friends and clients. This was the beginning of InfoPack, the CPS treatment newsletter. The success of InfoPack lead to the founding of POZ magazine in 1994. InfoPack has remained true to its roots, still focusing exclusively on treatment issues, while our sister company POZ has used its pages and image to expand the debate about the complex world of HIV/AIDS.

CPS Today

Striving to supply affordable, confidential, hassle-free access to their medications for many clients who choose to utilize our nationwide network of 35,000 retail pharmacies or our mail-order option. With either option, most of these clients have taken advantage of the financial hardship program we offer to qualified individuals. This program provides access to medications they may not have been able to afford otherwise. Since the very beginning, the concept of informed survival has driven the production of POZ and *Infopack*. Our response to the community need for education has been expanded to include community forums that we bring to cities around the country. The forums feature expert panelists and a moderator who discuss possible solutions and answer questions about today's treatment challenges. We also send out drug alert mailings that offer in-depth reviews of individual drugs and what they mean to you. We maintain an up-to-date web site, and provide weekly fax updates to HIV healthcare providers. A new one-on-one treatment counseling program is another way we are trying to fulfill the needs of our clients. In addition, we are searching for compatible AIDS service organizations nationally to join us in partnership for everyone's benefit. PWAs will benefit by receiving more treatment education and the ASOs will get a financial donation for every client referral who chooses to use our service.

Is CPS Different?

Prescription drugs are a commodity, available from over 50,000 retail and 200 mail-order pharmacies with nominal price differences. With so many choices why would someone with HIV want to consider CPS over larger, better known mail-order operations or the drugstore on the corner? Many of you know that CPS is HIV+ owned and operated, but did you also know 100% of our staff is either positive, or has an intimate connection to some who is or sadly was. Completely committed to diversity, CPS employs a very mixed group of individuals. Gays, straights, men, woman, blacks, whites, latinos are all represented in our office. Spanish-speaking client advocates are available when needed. That's not to mention the three or four dogs that are regulars in the office. Two of our dogs, Matty and Zoom look forward to meeting you at a POZ Expo in a city near you. Chances are someone here shares something in common with you, be it treatment history or the joys and tears of being a caregiver. Since the founding of our sister company POZ in 1994, CPS has used our profits to fund the production and distribution of over one million POZ magazines and 375,000 *Infopack* newsletters for free to PWAs. The cure for AIDS may exist in the our natural world. The rainforest is the source of many drugs, 25% of prescription drugs have a natural origin. To preserve the environment CPS is trying to do our part by recycling paper, cans and bottles in the office and by printing this newsletter on 50% post-consumer recycled paper. In the near future we hope to improve our efforts by printing on 100% post-consumer recycled chlorine-free paper and by using soy inks. We are a business like many others. Unlike most, each day we strive to weave social justice, community, cooperation, education, sustainability and innovation into our daily tasks.

We sincerely hope you feel like you know more about our organization, because we are extremely proud of where we work and what we're trying to do. If at times this profile sounded a little too much like an ad...GOOD! Every person who chooses to use our service is another opportunity for us to try to make the world a better place.

Seven Reasons Why We Should Be Your Prescription Service

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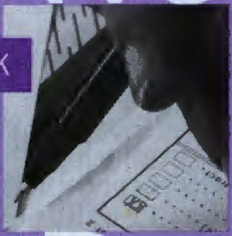

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