

Tips and Tricks on Taking Efavirenz (Sustiva)

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Introduction

Ever since AIDSmeds.com was launched in March 2000, we have received a number of notices from readers concerned about the side effects of Sustiva®, a popular anti-HIV drug among healthcare providers and people living with HIV. Data from clinical trials have demonstrated that drug regimens containing Sustiva can drastically reduce viral load and increase T-cell counts in a wide range of people. And its once-a-day dosing has made it an attractive option for patients seeking easier treatment regimens.

But, like all anti-HIV drugs, Sustiva can cause side effects, especially during the first few weeks of treatment. Some of Sustiva's potential side effects are unique among anti-HIV drugs, mostly involving symptoms related to the nervous system. For this reason, there is a lot of discussion and concern among those who are thinking of starting or switching to Sustiva. What do we know about these side effects? Are there ways to prepare for or prevent them? How long do they last? If they don't go away, are there ways to manage them?

This lesson has been prepared to help our readers who are currently taking or thinking about starting Sustiva better understand some of the side effects they've been

experiencing or are hearing about. While it's true that side effects of Sustiva therapy can be frustrating and make life difficult, there are steps that can be taken to help lessen their severity and, in some cases, prevent them from occurring in the first place. This lesson is not an endorsement of Sustiva, nor is it a warning against taking the drug.

What is Sustiva?

Sustiva (efavirenz) is a non-nucleoside reverse transcriptase inhibitor (NNRTI). Like the other NNRTIs—which include Viramune® (nevirapine) and Rescriptor® (delavirdine)—Sustiva blocks HIV's reverse transcriptase enzyme, a protein that helps the virus invade the DNA inside human cells.

An anti-HIV drug regimen consisting of Sustiva and two regular nucleoside analogues (e.g., AZT and 3TC) is a popular option for HIV-positive people starting therapy for the first time. Sustiva only needs to be taken once a day, preferably on an empty stomach, usually at bedtime.

Sustiva is the only NNRTI recommended as a preferred choice by the United States Public Health Service (USPHS)—the federal agency responsible for setting health-related policies in the U.S.—for patients who have never

been on anti-HIV therapy before (the others are recommended as “alternative” options). This is because Sustiva has been shown to be associated with long-term benefits in people who have both low and high (>100,000 copies/mL) viral loads before starting therapy. While some protease inhibitors (PIs) are also recommended by the USPHS for patients starting therapy for the first time, Sustiva may not cause some of the long-term side effects being seen in some people taking PIs, such as abnormal body fat changes (lipodystrophy).

What are Sustiva’s Possible Side Effects?

Like all anti-HIV drugs, Sustiva has been shown to cause side effects. While some of the side effects, including rashes, are similar to those seen using other NNRTIs, Sustiva appears to cause a number of brain-related side effects not seen with other anti-HIV drugs.

In clinical trials, over half of the patients taking Sustiva reported one or more side effects related to activity of the brain or central nervous system (CNS). These symptoms included dizziness, insomnia, impaired concentration, drowsiness, abnormal/vivid dreams, anxiety, depression, nervousness, and even hallucinations (although very rarely).

Although very rare, serious psychiatric symptoms have also been reported in patients receiving Sustiva, including severe depression, suicide attempts, aggressive behavior, delusions, paranoia and psychosis-like symptoms.

While the percentage experiencing mild to moderate CNS symptoms seems high—a fact that has made many people nervous about starting therapy with Sustiva—there are a few factors to keep in mind:

- 1) Not everyone who takes Sustiva will experience side effects. Moreover, there is no way to determine whether or not you will experience side effects

before starting therapy. While some researchers say that, in general, people with high T-cell counts experience fewer side effects than those who have lower T-cell counts upon starting therapy, it’s not clear if this is true with Sustiva.

- 2) Most of the side effects caused by Sustiva are short-term problems. That is, they usually resolve within two to four weeks after starting therapy. While some people may experience side effects that are more severe than those experienced by other people—or may have side effects that last longer than a month—the vast majority of people taking Sustiva experience either mild or moderate problems that last only a few weeks.

What’s the Rash Like?

Rash is a common side effect among all the NNRTIs (as well as Ziagen®, an NRTI). With respect to Sustiva, approximately 26% of HIV-positive people who took the drug in clinical trials experienced a rash during the first few weeks of therapy. Fortunately, a Sustiva-induced rash usually goes away without any change in treatment.

These rashes are often pink or red in color. They may be itchy or painful, flat or raised, and often dry and scaly. Some people may see a rash develop on a specific part of their body, such as the top of their arms, while others may experience a rash that appears to spread and cover a much larger area (i.e., face, chest, and arms).

Severe, life-threatening rash occurred in less than 0.1% of people taking Sustiva in clinical trials.

What are the Central Nervous Symptoms Like?

As discussed in the previous question, just over half of the people who took Sustiva in clinical trials experienced one or more central nervous system

(CNS) symptoms. These symptoms usually begin during the first or second day of therapy and generally resolve after the first 2–4 weeks of therapy. While there are a number of ways to describe these problems, they can be broken down into five different categories:

- **Dizziness:** One of the most commonly reported CNS effects, patients can feel lightheaded or unsteady and, in some cases, experience a loss of balance. Some patients compare this effect to feeling “drunk”, “stoned”, or “hangover”.
- **Problems Sleeping:** Some people may feel drowsy and sleep more than usual, while others may have a difficult time falling or remaining asleep. Problems sleeping—which can also include vivid dreams and/or nightmares—are also considered common CNS side effects of Sustiva, and can last for several weeks after starting therapy.
- **Altered Moods:** Some of the mood changes include euphoria, disorientation, anxiety, irritability, nervousness, and depression.
- **Impaired Concentration:** A sudden lack of focus or feeling “spacey”. Short-term memory loss can also occur. These symptoms can be especially disconcerting to “high-functioning” people.
- **Serious Psychiatric Symptoms:** Although very rare, these can include severe depression, suicide attempts, aggressive behavior, delusions, paranoia and psychosis-like symptoms. Patients with a prior history of psychiatric disorders appear to be at greater risk for these serious psychiatric adverse experiences.

Are there any general tips to think about before taking my first dose? Starting a new medication for the first time can be scary, especially if you’ve heard other people talk about its side effects. When it comes to Sustiva and

its potential to cause side effects—especially CNS-related problems—there are a few tips to keep in mind before starting:

- 1) Always remember: side effects do not always occur and vary from person to person. Your experience with Sustiva may be very different from that of another person’s. At the same time, it’s important to be prepared for any side effects that you may experience.
- 2) Be aware of other drugs or over-the-counter products that might increase the amount of Sustiva in your blood and, thus, increase the chance of experiencing side effects. For example, the protease inhibitor Norvir can increase Sustiva levels in the blood by 20%. If your doctor has recommended that you take Sustiva and Norvir together, talk to him or her about starting either drug a few days—or even a week—apart. Also, taking Sustiva with food can also increase its levels in your blood, and make potential side effects seem worse.
- 3) Don’t be afraid to call your healthcare provider if a particular side effect seems severe or has you worried.
- 4) Establish a reliable support network. If you don’t feel well upon starting Sustiva, it might be helpful to have friends or family members you can rely on. They can help you if the going gets rough, and attend to things that you might not feel like doing (i.e., chores that need doing or errands than need running).
- 5) Avoid alcohol or drugs. Alcohol and recreational drugs, such as marijuana, cocaine, and speed, can worsen some of the CNS side effects of Sustiva.
- 6) Start Sustiva on a weekend and/or take a few days off from work. Sustiva can cause CNS side effects after the first dose has been taken and it may take



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you a few days to get used to any mental changes that occur. Not having to worry about work during this time can be helpful.

- 7) Take Sustiva before bedtime. Many of Sustiva's CNS side effects are strongest within a few hours after taking the drug. Thus, it's best to take the drug before going to bed and to "sleep off" the feelings of dizziness, impaired concentration, etc. While some people report that Sustiva actually keeps them awake, there are some potential ways to manage this insomnia (see below).
- 8) Avoid driving or using large machinery, especially if Sustiva causes sensations of dizziness or impaired concentration or if you haven't been sleeping well.
- 9) Switching from Sustiva to another anti-HIV drug is always an option. While most people are able to tolerate the side effects of Sustiva, severe side effects that last a long time can have a negative effect on a person's quality of life. *Note: it is dangerous to simply stop taking Sustiva or reduce the dose without first talking with your healthcare provider. This can lead to drug resistance and end up doing more harm than good.*

What about ways to manage specific side effects?

Unfortunately, it's not well understood why Sustiva—or any anti-HIV drugs—cause the side effects they do. It's still not known why Sustiva causes CNS problems and, as a result, it has been difficult to determine the best ways to manage them.

However, this does not mean that patients and their healthcare providers cannot improvise with treatments that are already out there, especially those that have been shown to be effective for similar problems in patients not taking Sustiva. Many of Sustiva's side effects can be helped using both "lifestyle" and "pharmacologic" assistance.

Note: Any and all side effects should be reported to your healthcare provider. As with any medical information found on AIDSmeds.com, it is important that you discuss the following tips with your healthcare provider before trying them on your own. While some may be helpful, others can make a side effect worse or cause their own set of problems.

Managing a Rash

- **Lifestyle Assistance:** Avoid things that can worsen rash, such as sun exposure, sunscreen products, perfumes, fragrant creams or lotions, or hot baths/showers. You should avoid scratching or rubbing the rash, as this may cause it to bleed or become infected. A rash and its surrounding area should be cleaned using a gentle soap and patted dry.
- **Pharmacologic Assistance:** Hypoallergenic moisturizers and creams can help keep the skin moist and control itching (check with your healthcare provider or a dermatologist). Dry, scaly skin can be helped using moisturizers or creams that contain ammonium lactate. If itching and/or scratching are severe, an over-the-counter or prescription antihistamine (e.g., Claritin) or steroid cream might be helpful.

Managing Dizziness

(lightheadedness, unsteadiness, loss of balance, feeling "drunk", etc.)

- **Lifestyle Assistance:** Improve "equilibrium" skills through relaxation, yoga, meditation, mild exercise, or physical therapy.
- **Pharmacologic Assistance:** Meclizine (Antivert®, Dramamine®) has been shown to help control dizziness during bouts of motion sickness. Also, try taking Sustiva about 12 hours before you need to be functional.

Managing Problems Sleeping (insomnia, drowsiness, vivid dreams/nightmares)

- **Lifestyle Assistance:** Change the timing of when you take Sustiva: for insomnia, consider taking it in the morning, and for drowsiness, try taking it earlier in the evening. Do not drink or eat anything with caffeine or sugar five to seven hours before bedtime. Also try relaxing before bedtime using techniques like yoga, breathing exercises, a soothing bath, or drink a non-caffeinated tea, such as chamomile. With respect to vivid dreams and nightmares, there have been some reports of people “controlling” the contents of their dreams by doing something relaxing or pleasant immediately before going to sleep. For example, falling asleep while watching a funny TV show may produce humorous dreams, whereas reading or watching erotica before dozing off has been said to produce sexually charged dreams (we kid you not).
- **Pharmacologic Assistance:** Sedatives such as Ativan® (lorazepam) and Restoril® (temazepam) can be used to help people fall asleep. You might even want to ask your doctor for a short-term prescription to one of these, just in case you need some help sleeping during the first few days and weeks of starting Sustiva. Also, certain antidepressants, like Serzone® (nefazodone), can help people who have difficulty remaining asleep.

Managing Altered Moods (euphoria, disorientation, anxiety, irritability, nervousness, depression)

- **Lifestyle Assistance:** Know that any sudden onset of crankiness, moodiness, irritability, euphoria, or depression is probably due to starting Sustiva. Also know that these sudden alterations in mood will gradually stabilize with continued use of Sustiva. Another tip: avoid recreational drugs, including alcohol.

- **Pharmacologic Assistance:** If moderate to severe, speak with your health-care provider about benzodiazepines (e.g., Ativan® or Valium®), antidepressants (e.g., Prozac®, Zoloft®, Wellbutrin®, Effexor®), or other mood stabilizers.

Managing Impaired Concentration (lack of focus, feeling “spacey”, short-term memory loss)

- **Lifestyle Assistance:** Use daily calendars, reminders, or diaries. Avoid “multitasking” at work and at home for the first few weeks after starting Sustiva. Allow extra time for activities. Feeling overwhelmed can cause unnecessary anxiety and frustration.
- **Pharmacologic Assistance:** Mild sedatives (i.e., low doses of benzodiazepines like Ativan® or Valium®) may be helpful. Ritalin® (methylphenidate) can be prescribed to treat ongoing impaired concentration.

Managing Serious Psychiatric Symptoms (severe depression, suicidal thoughts, aggressive behavior, delusions, paranoia, psychosis-like symptoms)

If you have a prior history of mental illness or substance abuse, discuss it with your doctor before starting Sustiva, since you might be at a slightly greater risk for these serious psychiatric adverse experiences.

This doesn’t mean you can’t take Sustiva—it just helps to be prepared. Knowing that these are rare but possible symptoms of the drug, and knowing that you have the option of stopping the drug, should help you and your doctor manage an adverse experience, if one should occur.

If a serious psychiatric adverse experience does occur, you should seek an immediate medical evaluation to assess the possibility that the symptoms may be related to the use of Sustiva, and if so, to determine whether the risks of continued therapy outweigh the benefits.

In Conclusion

Sustiva has been shown to do a good job in controlling HIV and increasing T-cell counts when used in combination with other anti-HIV drugs, but like all drugs used to treat HIV and AIDS, it can also cause side effects.

If there is one rule all people living with HIV should be aware of prior to starting Sustiva or any other anti-HIV drug, it is to BE PREPARED. Being surprised by a side effect can make it that much more difficult to handle, and ultimately manage.

Even then, no two people experience a drug in exactly the same way. Sustiva does not work for everyone. For some patients, the typical short-term side effects never go away, even with attempts to manage them. For others, the side effects can be extreme. In these cases, switching or stopping therapy can be the smartest course to take. And with a doctor's supervision, switching or stopping therapy can be done with little to no risk of developing resistance to the drugs you tried.

a note about this publication

This publication is reprinted here from another source (www.aidsmeds.com). We do not always have the resources at Project Inform to produce our own treatment information on every treatment topic. In these cases, we try to provide reliable information from other sources but cannot confirm that every fact in these publications is accurate. References to other materials have been pulled. This information is designed to support, not replace, the relationship that exists between you and your doctor or medical provider.

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