

PERSONAL TRACKING CHARTS



personal tools that help you keep track of your health

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PROJECT

inform

Information,
Inspiration and
Advocacy for People
Living With HIV/AIDS

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In the following pages, you will find many different charts. These were developed to help you keep track of your health. They will also help you keep an ongoing health history and a history of your HIV-related treatments over time. ■■■ Project Inform has tried to think about the things that you may deal with when you take your medicines. If you find that one chart isn't exactly what you want, feel free to change it to suit your own needs. There are examples on how to fill out some of them on the last page. ■■■ One suggestion would be to take these charts with you to your doctor appointments. Going over them together can help make sure you understand what medications you're supposed to take and when to take them. This will also help you make sure to let your doctor know everything you're dealing with. ■■■ In addition to these charts, you will find a step-by-step diagram on the center spread, called *Walking your way through making a treatment decision*. This is a chart of basic information to use when making decisions about starting treatment. There's a lot to consider when starting treatment, so we've tried to break it down for you in this easy step-by-step diagram. ■■■ We also

hope you share these charts with others. Whether it's a support group you attend or your case manager, feel free to pass them on. And if you have suggestions on making them better or you would like more copies, please call us toll-free at 1-800-822-7422 or go to www.projectinform.org.



THIS PAPER BELONGS TO:

Walking your way through making a treatment decision

When considering therapy, there are many issues to keep in mind. Though research has not defined an absolute standard time to start anti-HIV therapy, some criteria can assist you in making a decision tailored to your needs. This road map highlights these criteria and may help you in this process. It may be a good idea to bring this with you to your doctor's office for discussion. Remember, take your time and don't feel pressured to make the decision today.

1

Your readiness and belief in therapy

Before you start any medical treatment, make sure that you're ready. Take time to consider how taking therapy might impact your life. Ask yourself questions like: Do I feel ready? What kind of expectations do I have? Do I have a support system or someone I can talk to about therapy? Am I scared? If so, what am I afraid of? Explore your own beliefs and fears about therapy. Ground yourself in knowledge rather than fears. Talking to other people about their treatment decisions can be beneficial. Just remember ... what works for one person does not always work for another.

2

Viral Load

What is your viral load? _____

Has your viral load trend ...

- gone up more than 3-fold (ie., an increase from 10,000 to 30,000) or
 gone down over your last few tests?

30,000 or below (generally considered low)

Therapy is generally not recommended, but if you experience symptoms or have very low CD4+ cell counts, considering therapy might still be warranted.

30,000–50,000

Federal guidelines suggest considering therapy if your CD4+ count is also below 350. However, if it's high (above 350), it's reasonable to wait.

Viral load levels, especially in the first 3–5 years after infection with HIV, may be different in women and men. While viral load levels of 30,000–50,000 is generally considered moderate/low in men, this may be high for a woman and signal a more pressing need to intervene.

100,000 or above (considered high)

Increased risk of disease progression. Federal Guidelines strongly suggest and encourage anti-HIV therapy.

For more information, read Project Inform's *Blood Work: A Useful Tool for Monitoring HIV*; *Wise Words #3*; and *Vaginal Candidiasis*.

3

CD4+ Cell Counts

What is your current CD4+ cell count? _____

Over your last few tests, has your CD4+ cell count trend ...
 gone up or gone down?

Is your CD4+ cell count generally declining or is mostly stable, with just modest movement (100 points or less) up and down? A person with a stable CD4+ cell count, as long as it's above 200, has less risk of progression than one with counts that steadily decline.

CD4+ cell count above 500 (normal range 500–1,500+)

Maintain good healthy habits (nutrition, exercise, monitor disease progression and lab tests).

Therapy is generally not recommended. If your viral load is high and/or you experience symptoms, therapy may still be warranted. However, if the CD4+ cell count is declining rapidly and consistently, and the viral load is high, some doctors might recommend treatment or more frequent monitoring.

CD4+ cell count 200–500

If you are in this range, you may want to consider therapy, especially if you have developed symptoms of immune dysfunction. Examples include shingles (zoster), and recurrent and aggressive yeast infections. When no symptoms are present, most doctors would consider delaying treatment at least until the CD4+ cell count consistently falls below 350.

Guidelines suggest considering therapy when CD4+ cell count is consistently at or below 350. If your CD4+ cell count stays above 200, and you experience recurrent fungal infections (thrush, etc.), preventive therapy for *Pneumocystis pneumonia* (PCP) is recommended.

CD4+ cell count 200 and below

At this range, there is an increased risk for developing serious and life-threatening infections (opportunistic infections), and therefore the Federal Guidelines highly recommend anti-HIV therapy.

If you choose not to use anti-HIV therapy at this point, talk with your doctor about preventive therapies against common infections, like *Mycobacterium avium* complex (MAC), cytomegalovirus (CMV) and toxoplasmosis. Monitor your lab values, weight, minor symptoms and overall sense of well-being.

If your CD4+ cell count and/or viral load levels change a great deal from one test to another, discuss this with your doctor. Large sudden changes are often the result of lab errors or other health factors (like a flu shot or stress).

For more information, read Project Inform's *Blood Work: A Useful Tool for Monitoring HIV*.

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The goal of HIV treatment

Take time to understand how therapy works. Get informed so you have solid foundation in understanding the goal of treatment. Learn about all of your treatment options. It's important to understand the risks and benefits of both starting and waiting. If you start now, what are the possible side effects and how will you monitor to make sure therapy is working for you? If you wait, or decide not to start at all, what is your risk of HIV disease progression?

Take time to talk with your doctor about his/her opinions and experiences with treatment and other people who you trust and have an understanding of therapy.

For more information, read Project Inform's *Anti-HIV Therapy Strategies*.

Opportunistic Infections

Have you had any opportunistic infections (OIs)? like MAC, PCP or CMV?

- Yes. If you have an active OI, talk to your doctor about treating that OI before you start anti-HIV therapy.
- No. If you have had a major OI, aggressive anti-HIV therapy is almost always recommended after treating the OI.

Drug Interactions

Are you currently on any other therapy (contraceptives, methadone, anti-depressants, etc.)? Yes No

There are known drug interactions between a variety of drugs, and even herb-drug interactions. These can worsen side effects and/or cause one or both therapies to be less effective. For example, some protease inhibitors can decrease the level of ethinyl-estradiol (chemical in oral contraceptives), making them less effective.

If you decide to take therapy, take all the medications, vitamins, supplements and/or alternative therapies that you're taking to your next doctor's appointment. Whenever you add or change a therapy or supplement, be sure to talk with all your health practitioners (and pharmacist) to make sure these products may be taken together safely.

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5

What about side effects?

All medications can cause side effects. There are many possible side effects from anti-HIV therapy. It's important that you are aware of them and learn how they can be monitored and managed. Not everyone experiences side effects (only 10-20% of people have serious ones). It's not uncommon for people to have some short-term side effects like nausea and headaches during the first 4-6 weeks of therapy. After this period, short-term side effects often diminish. Therapies can have long-term side effects too, including body changes (*lipodystrophy*) and changes in lab results like cholesterol.

For more info, read Project Inform's *Drug Side Effects: Lipodystrophy Syndrome(s); and Mitochondrial Toxicity and Lactic Acidosis*.

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If you come to the decision that you want to start therapy, here are 4 other points to consider before starting and as you develop your strategy.

Hepatitis C (HCV) Co-infection

Have you been diagnosed with Hepatitis C? Yes No

Some anti-HIV therapies, especially protease inhibitors and NNRTIs, can increase liver enzymes and/or cause hepatitis. Liver enzyme levels should be carefully checked soon after starting anti-HIV therapy.

Are you taking treatment for HCV? Yes No

A 1-2 month gap is suggested between starting HIV and HCV treatment. Treating HIV or HCV first will depend on the stage of liver disease and your CD4+ cell count and/or HIV viral load.

NOTE: You can be co-infected with other diseases besides HCV that also require you to plan your treatment strategy.

For more information, read Project Inform's *Hepatitis C*.

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6

Adherence

Adherence is crucial to treatment being effective. Adherence means taking medications exactly as prescribed by your provider. If anti-HIV meds are not taken according to instructions, the risk of developing drug-resistant HIV increases. Drug-resistant HIV may not respond to the anti-HIV drugs and, as a result, treatment options become limited. Many factors can influence adherence: the responsibility of children, your housing status, busy and demanding work, potential side effects from anti-HIV drugs, being in a domestic violence situation, among many others.

Take a moment to reflect upon the various factors that can make correctly taking your meds challenging. Discuss this with your doctor as you develop a treatment strategy. In addition, use those sources of support which will motivate you to stay adherent.

For more information, read Project Inform's *Adherence: Keeping Up With Your Meds and Drug Dosing Schedule*.

keeping track of my periods

MARK THE TYPE OF FLOW IN THE BOXES BELOW

L=exceptionally light N=normal H=exceptionally heavy S=spotting O=none

YEAR	MONTH	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
	JANUARY																																
	FEBRUARY																																
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	SEPTEMBER																																
	OCTOBER																																
	NOVEMBER																																
	DECEMBER																																

Example for filling out the CD4+ cell count and viral load charts on the second page.



For a little help in how to fill out the charts on the second page (charting your CD4+ cells and viral load), use the example shown here. The rest of the charts should be easy to fill out without examples. However, if you have questions about them, then please feel free to call Project Inform's toll-free National HIV Treatment Hotline at 1-800-822-7422.

