

# Project Inform's position on when to start HIV treatment

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Project Inform is concerned that nearly half of all HIV-positive people in the United States do not know their HIV status or have not engaged in care and treatment that could prolong their lives and prevent new cases of HIV infection. We believe this results, in part, from a lack of understanding of the benefits of treatment, the fear of side effects of HIV drugs, the need for support services to make care and treatment possible, fears about disclosure of HIV status, and the belief that care and treatment services are unavailable to low-income people.

Although researchers continue to gather evidence regarding the optimal time to start treatment, federal guidelines have shifted in favor of earlier treatment. These guidelines allow for varied interpretation by HIV providers. In this document, Project Inform — a trusted provider of HIV treatment information for 25 years — presents its position regarding HIV testing, when HIV-positive people might consider engaging in care and treatment, and important considerations for starting care and treatment. Our position is not meant to be advice; people should work with their doctors regarding any treatment decisions.

- 1) Every person in the US aged 13 years and older should know his or her HIV status and consider getting tested every year as a part of routine medical care.
- 2) Some people concerned about testing for HIV fear that, if they are HIV-positive, people they do not want to know may find out or that they may experience discrimination. However, important federal and state laws prohibit both the disclosure of medical information and discrimination against people living with HIV/AIDS.
- 3) If one is HIV-positive, the idea of entering HIV care for life can be daunting. This includes coming to terms with an HIV diagnosis, disclosing one's status to others who should know, learning how to take care of oneself and take meds, and how to fit all of this into one's everyday life, as well as other concerns. Project Inform encourages people to use local support services such as case managers, social workers and support groups for help in navigating these life changes.
- 4) Whether or not they choose to start treatment right away, all HIV-positive people should be linked immediately to a qualified medical provider to monitor their health and consider starting treatment. People who learn they are HIV-positive can take steps that will greatly prolong their lives and reduce the risk of passing the virus to others.
- 5) Nearly 1 out of 4 people living with HIV also have hepatitis C. Project Inform encourages everyone to get a full physical exam and medical history done with the appropriate screenings, including those for possible viral and bacterial co-infections.
- 6) HIV treatment has greatly improved the survival and quality of life of people living with HIV. A healthy, newly infected person who starts HIV therapy immediately can reasonably expect to live a near-normal life span.
- 7) Based on current data, Project Inform believes that the long-term damage from untreated HIV is greater than the potential damage caused by long-term use of HIV medications.

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- 8) Compared to earlier drugs, newer HIV medicines are generally more tolerable and have fewer side effects, including those that may impact a person's appearance. In some cases, people can switch to a more tolerable regimen if their first one doesn't work out. However, others may still find it difficult to tolerate the drugs. Longer-term toxicities of newer drugs are still unknown.
- 9) HIV-positive people should be ready to stay on treatment once they start in order to maximize the benefits of their HIV therapy and to reduce the risk of drug resistance and other preventable health issues. Drug "holidays" are not recommended. Patients and providers should work together to routinely assess and secure housing, mental health, substance use services or other forms of needed support to ensure their ongoing adherence to care and treatment.
- 10) Based upon a review of currently available data, Project Inform believes that all HIV-positive people who are ready to begin treatment should start if their CD4 counts fall below 500.
- 11) Some evidence shows that starting treatment above 500 CD4s — or during acute infection to lower the chance of a low nadir CD4 — may decrease damage to the immune system, promote better longer-term health outcomes, and extend a person's life.
- 12) Deciding whether to start treatment above 500 CD4s is an individual choice to be made with a qualified medical provider. Project Inform believes that people who delay treatment should monitor their CD4 counts and viral loads and consider treatment if they experience any deterioration of these lab results or new symptoms of disease.
- 13) Keeping HIV under control with effective treatment may help HIV-positive people avoid transmitting the virus. However, treatment alone may not fully prevent transmission; therefore, it remains critical to engage in safer sex, prevent sexual infections, and/or use clean syringes.
- 14) Public and private programs are available to make care and treatment affordable for most people with HIV. However, the current state of the US health care system can sometimes make it difficult to find and access quality care and treatment.
- 15) Through its National HIV Treatment Hotline, Project Inform can provide support both to HIV-positive people facing these life-changing issues and those working to support them. We can also provide information about accessing free or low cost health care and navigating complex health care systems: 1.800.822.7422

Project Inform has developed this position from current study results and expert opinions. We encourage all individuals to consult with their medical providers to make informed and cooperative decisions about their health. The information found in this paper is intended to support, but not be a substitute for, the relationship with these providers. Please email us at [questions@projectinform.org](mailto:questions@projectinform.org) with any questions regarding this document.