

Booklet on combating hate speech

People who
live with
HIV/AIDS

Project implemented by



What is HIV and how does it work?

HIV is an acronym for Human Immunodeficiency Virus. It is transmitted through intercourse with an infected person, through contact with an infected person's blood or during pregnancy, delivery or lactation, from infected mother to child.

This virus attacks the immune system and multiplies while infecting the CD4 immune cells. Similar to any other virus, it aims to survive and multiply, except that HIV multiplies through vital cells for human survival and protection: immune cells. Thus, infected cells can no longer protect the body and are `corrupted` to produce more virions (viruses that haven't infected a host cell yet).

We have all heard of DNA and RNA, but not all of us know the difference between the two. DNA is the hereditary material which exists in almost all living organisms and the carrier of genetic information. HIV, however, carries a viral RNA, which is half of the DNA.

HIV belongs to a specific class of retroviruses; to create DNA, the virus uses its own enzyme (the reverse transcriptase), and then it integrates its newly-formed viral DNA into cellular DNA, corrupting the cell and forcing it to produce new virions.

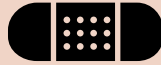
Consequently, what happens when this virus enters the human body? It increases the quantity of virus in the organism (also called viraemia or viral load) and immunity decreases.



What is SIDA/AIDS?

SIDA (Syndrome d'ImmunoDéfience Acquis) is the acronym for French for Acquired Immunodeficiency Syndrome (or AIDS). **AIDS is a syndrome, not an illness**, contrary to popular belief. More exactly, the syndrome is a combination of signs and symptoms. AIDS is a condition generated by HIV infection when the viraemia is very high, the immunity is deficient, and they lead to opportunistic infections (otherwise, the human organism could have protected itself if it had a healthy and fully functioning immune system).





Can you recover from AIDS?

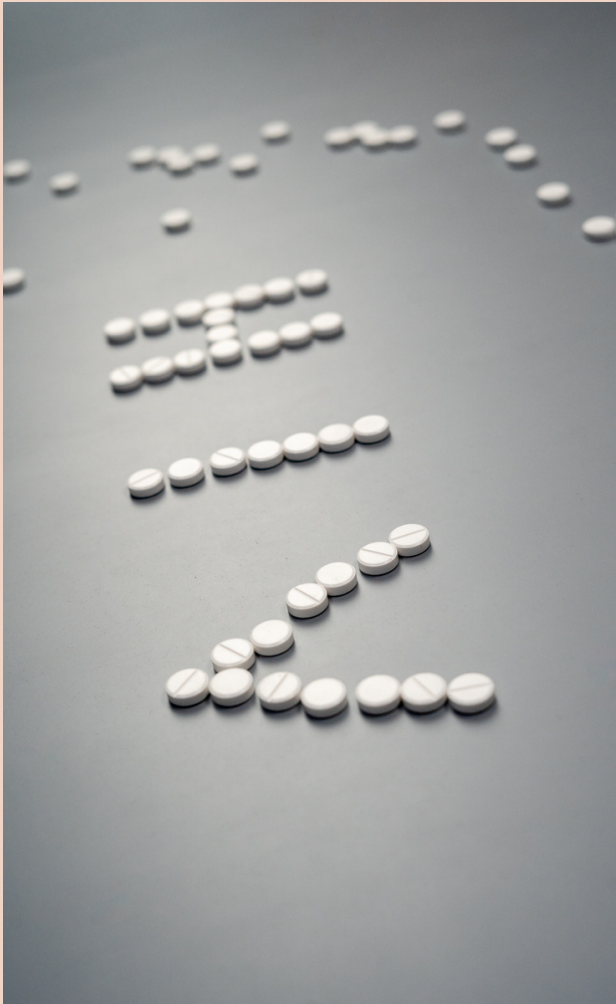
Yes! If you follow antiretroviral agents (anti-HIV medicine), also called ARVs, the amount of the virus in your body lowers, allowing the immune system to return to normal levels and become functional again. Moreover, opportunistic infections which appeared in the presence of HIV should also be treated.

Before the emergence of anti-HIV treatments, AIDS was the last stage of the infection and was inevitably followed by death.



Can you contract AIDS?

No! You can contract HIV, but not AIDS. AIDS is the syndrome generated by HIV infection. You cannot directly contract the late stage of an infection.



Can you die from HIV/AIDS, still?

Yes, there are still people who die from illnesses facilitated by HIV immunodeficiency, but this is only caused by either not being able to access treatment (which happens in countries or regions with precarious healthcare services or infrastructure), or because the infection is detected too late, when the opportunistic illnesses are too advanced for the organism to handle them. That is why it is important to get tested frequently to detect an infection early and avoid such situations.



Deconstructing myths

Myth: HIV was created in the lab.

Fact: HIV originates from SIV (Simian Immunodeficiency Virus), a similar virus found in two species of chimpanzees. HIV has existed in humans since 1950 but was only isolated in the lab in 1983.

Scientists believe that the virus was transmitted from chimpanzees to humans, in Africa, when a person who was hunting chimpanzees for their meat was wounded. The animal blood reached the human system, causing a mutation and creating a new human-adapted virus, called HIV[1].

A similar virus is also found in felines and is called FIV.



Myth: People who live with HIV can transmit the virus through casual social contact.

Fact: HIV exists in all body fluids, but it is in infectious amounts only in blood, genital and anal fluids (sperm, pre-ejaculatory liquid, vaginal secretion and anal secretions) and breast milk. HIV cannot be transmitted through saliva, tears, nor by using the same towel or cutlery.

What's more, HIV does not last long in contact with air. In a drop of blood, this virus only lasts for a few minutes after being exposed to air. So, if it reaches any surface, it will die very quickly[2].



Myth: A person who is infected with HIV lives less than a non-infected one.

Fact: The life expectancy for a person living with HIV is similar to a person who doesn't have the virus, only if they thoroughly follow their treatment. Precisely, in some cases, people who live with HIV can even live a longer and healthier life than the general population, because they monitor their health more closely. Once in a few months, they do blood tests to check their health and possible side effects of their treatment. The attention paid to their health brings a major advantage to their life expectancy, as most people visit doctors only when they feel sick or when pain occurs.



Myth: You don't have to take ARV treatment before you feel sick.

Fact: The treatment is recommended to everyone who lives with HIV, starting with the moment they learn they are HIV positive. The sooner the treatment is started, the less chances for the virus to develop and create health issues[3].

Moreover, a major advantage of ARV treatment is that, in most cases, it will bring the viral load to an undetectable level, which makes it impossible for the person living with HIV to transmit it through unprotected sexual contact. (Undetectable=Non-transmissible)

Even though ARV treatment lowers the viral load from the blood, it doesn't completely erase it, allowing it to multiply again, if the treatment is discontinued.

Myth: People who live with HIV transmit the virus every time they have sex.

Fact: HIV can be transmitted through unprotected vaginal, anal or oral sex. Statistically, the risk of transmitting the virus increases considerably if one of the partners has another sexually transmitted infection (S.T.I.), such as syphilis or gonorrhoea. If condoms are used, there is almost no risk of getting the virus (or most sexually transmitted infections), and if the person who is HIV-positive is taking their ARV treatment, this risk becomes even smaller.

If the HIV-positive person has reached the undetectable stage, when the viral load is so small it cannot be detected in the blood, then the risk of transmitting the virus through unprotected sexual contact is ZERO[4].

Studies have been made on large samples of sero-different couples (when one partner is HIV-negative and another is HIV-positive), on both heterosexual and homosexual couples, and there has never been a case of the virus being transmitted by an undetectable HIV positive person to the other. The phrase "U=U" (Undetectable = Untransmittable) is the best expression of this.

Myth: HIV is the virus of gay people.

Fact: HIV can be transmitted between opposite-sex partners and same-sex partners alike. It is true that the chances of transmitting it are higher for anal sex than for vaginal or oral sex.

Men who have sex with other men encounter a higher risk of contracting the virus, due to the anal tissue being more sensitive, which makes it more prone to injuries or microscopical injuries, allowing the virus to enter the body much easier. On the other hand, the risk is the same for heterosexual couples who have anal sex. Moreover, the number of gay and bisexual men who are diagnosed with HIV is high also because they test themselves more often, compared to the general population.

(more information on the same myth ->)



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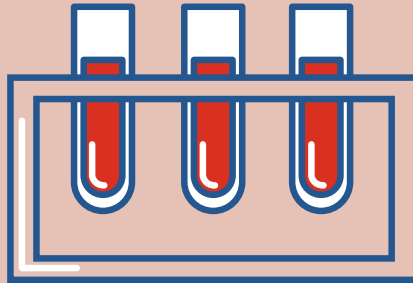
Fact: In Romania, there are approximately 17,000 people diagnosed with HIV, many of them having contracted it during birth or in the first years of life[5]. Around 10.000 people have been infected at birth, between 1988 and 1992, when medical institutions were reusing needles/syringes and giving blood transfusions with untested blood. Of these, 5297 are alive today [6].

There are currently around 38 million people in the world who live with HIV, including 20 million women and 2 million children[7].



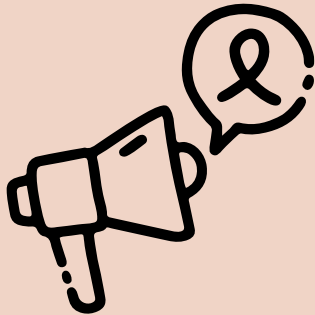
Myth: There is a cure for HIV, but pharma companies are gatekeeping it in order to earn money from ARV treatment.

Fact: There are many drug companies that are doing research on different treatments for permanent recovery, and they are competing against each other. If one of them finds the cure, they will definitely launch it on the market before their competitors, to earn as much money as possible. Also, several preliminary results have emerged for many vaccines which are still in the testing phase and the results are quite promising.





HIV and stigma



Stigma and discrimination associated with HIV can take the form of prejudice, negative attitudes or abuse directed at people who live with HIV. In 35% of the countries with available data, above 50% of the citizens have reported discriminatory attitudes against people who live with HIV[8].

One major issue that leads to discrimination is the lack of updated information about HIV/AIDS. Because it has been considered for decades a deadly disease and has been publicised as such, people started being vigilant and fearful of this medical condition. Today, we are fighting to remove outdated knowledge that, while correct and very useful at the time, is no longer reflecting today's reality.

At the time of HIV's emergence, and a long time afterwards, it was not known how the virus was transmitted, so people used to take exaggerated actions, like wearing masks, gloves and medical coveralls when being around people living with HIV, because it was not known if the virus was caught by touch, air or bodily fluids. It was certain, however, that this syndrome would lead to a relatively quick death, making people avoid it by all means.

Even now, in awareness-raising and prevention campaigns, HIV gets a dramatic overtone and, even if they successfully decrease the exposure by promoting protected sex, they sometimes do so at the cost of the dignity of people who live with HIV. It is necessary to mention that HIV can be kept in check, today's treatments are very efficient and a person who lives with HIV can live a long and healthy life.



A very important milestone we reached was in 2016 when CDC (Centers for Disease Control and Prevention), alongside 400 other international groups declared that people who live with HIV who have an undetectable viral load (usually as a result of treatment) cannot transmit the virus through unprotected sexual contact. Undetectable viral load is defined as under 200 copies/ml of blood. These pieces of information were obtained from several large scale studies started back in 2008 (listed below). Moreover, the undetectable viral load considerably decreases the risk of transmitting the virus from mother to foetus.



However, unfortunately, fear and information that circulated in the `80s-`90s still exist in society and, for this new information to reach the general population, it is important for us to have new campaigns to raise awareness, with updated information, that focus on eliminating the stigma associated with HIV/AIDS, as well as eliminating the discrimination of the HIV positive people.

Another stigma linked to HIV/AIDS is about associating this medical condition with homosexuality or socially unaccepted behaviour, such as sex work, infidelity, and drug use. Firstly, in Romania, approx. 37% of people who live now with HIV have been infected in their early childhood, through micro-transfusions, during the communist and early post-communist age[9].

Secondly, while it is true that any unprotected sexual act, with a person with an unknown status, can pose a risk of transmitting HIV, this doesn't only happen to men who have sex with other men or to sex workers, but it can happen to anyone who is sexually active.



Last but not least, in all of these situations, some distinctions need to be made between what is sexual orientation or some behaviour in itself (drug use, infidelity etc.) and the associated actions:

-  It is not homosexuality that increases the risk of transmitting HIV, but unprotected sex; the same goes for sex work and any heterosexual sexual act;
-  It is not drug use that increases the risk of transmitting HIV, but the use of injectable substances where the injecting equipment is used by multiple individuals.

An important factor in perpetuating HIV stigma is also the lack of updated information among health workers. There are many doctors who still do not have up-to-date knowledge about this virus, which leads to them refusing treatment, consultation or surgery to people who live with HIV, or to them changing their attitude towards the patient. This is why many HIV-positive persons prefer not to go to the doctor for other ailments, so that they wouldn't have to face their doctor's refusal or discrimination. Although discrimination towards HIV-positive people is punished by Romanian law (such as OG 137/2000 on preventing and sanctioning any forms of discrimination), many people are not knowledgeable of their rights and accept the refusal; they end up looking for another medic or just give up on going to the doctor.



In Romania, it is not mandatory to tell anyone that you live with HIV, except your own physician, and this information is protected by doctor-patient confidentiality, by law. However, HIV infection is the only medical condition mentioned in the Romanian Penal Code and it specifically criminalises people who infect other people with HIV (New Penal Code, chapter V, article 354). This specific mention in the New Penal Code leads to discrimination by the authorities' and people in general, singling out HIV from infections. Also, the wording is incorrect, because it says `transmitting AIDS`, and it is not this syndrome that can be transmitted, but the virus that generates it.

Furthermore, voluntary infection can be criminalised without mentioning the pathology of said person, because this only deepens the stigma and discrimination against people who live with HIV. Telling your partner that you live with HIV can be a difficult choice to make and HIV-positive people receive reactions of discrimination, shock, fear or panic from their partners. According to the New Penal Code, article 297, people who live with HIV are specifically protected from discrimination by civil servants, and discrimination against HIV-positive individuals represents an aggravating circumstance in hate crimes (art. 77, l. h).

What effect does stigma have on people who live with HIV?

Research conducted by ICRW (International Centre for Research on Women) highlights a few possible consequences of the stigma associated with HIV:



- Loss of income and quality of life;
- Loss of family and the option of having children;
- Discrimination in the medical system;
- Withdrawal of support of any kind from loved ones;
- Loss of hope and self-esteem;
- Loss of reputation and dignity.

UNAIDS (Joint United Nations Programme on HIV/AIDS) and WHO (World Health Organization) talk about how fear of the stigma and discrimination might be the primary factor of people refusing to get tested, not admitting their HIV status or not starting or continuing treatment for HIV. Reluctance when it comes to testing leads to many people being diagnosed late, when the virus would have already developed into AIDS, making treatments less efficient, transmission more frequent transmission and leading to an early death.

Self-stigmatisation - or internalised stigma - has an equally damaging effect on the mental health of a person living with HIV. This significantly lowers self-confidence and motivation to seek professional help.

The fear of negative reactions from the community can greatly undermine the efforts to bring awareness about the HIV epidemic, by perpetuating the burden of silence and shame associated with this virus.

Shame associated with HIV can lead to decreased treatment adherence, low self-esteem, but also depression, anxiety and suicide.



What can we do to reduce stigma?



- Normalising testing. HIV testing must become a usual thing and not an extraordinary situation
- Decriminalising AIDS as a separate pathology in the New Penal Code
- Reducing and removing the stigma and discrimination, at a national level
- Informing and educating in schools and in information hubs about sexual health and stigma associated with sex and medical conditions
- Understanding and respecting civil rights
- Informing ourselves about topics that can trigger discriminatory behaviour
- Addressing unfounded fears and removing them by informing people who have discriminatory behaviour.

Footnotes:

[1] Be in the KNOW, [Origin of HIV and AIDS](#), avert.org

[2] See also Checkpoint ARAS, [Cum mă infectez cu HIV?](#), translated title: How do I get infected with HIV, checkpointaras.ro

[3] See also Centers for Control Disease and Prevention, [HIV Treatment as Prevention](#), cdc.gov

[4] See also Checkpoint ARAS, [Nedetectabil](#), translated title: Undetectable, checkpointaras.ro

[5] National Institute of Infectious Diseases "Prof.dr.Matei Bals", [Evoluția infecției HIV/SIDA în România](#), translated title: Evolution of HIV/AIDS infection in Romania, 31 december 2020, observatoruldesanatate.ro

[6] Ministry of Health, [Planul Național Strategic pentru supravegherea, controlul și prevenirea cazurilor de infecție cu HIV/SIDA în perioada 2019 – 2021](#), translated title: National Strategic Plan for the surveillance, control and prevention of HIV/AIDS infection in the period 2019 - 2021, ms.ro

[7] Be in the KNOW, [Data](#), avert.org

[8] UNAIDS, [On the Fast-Track to end AIDS by 2030. Focus on location and population](#), 2015, unaids.org

[9] Ministry of Health, [Planul Național Strategic pentru supravegherea, controlul și prevenirea cazurilor de infecție cu HIV/SIDA în perioada 2019 – 2021](#), translated title: National Strategic Plan for the surveillance, control and prevention of HIV/AIDS infection between 2019 and 2021, ms.ro



Additional resources

- National Institute of Infectious Diseases "Prof. dr. Matei Bals", *Statistics HIV/AIDS Romania*, 2021, observatoruldesanatate.ro
- Be in the KNOW, *HIV History*, www.avert.org
- InformatHIV, *HIV and STI information website*, informathiv.ro/
- Be in the KNOW, *HIV Stigma and Discrimination*, avert.org
- Centers for Control Disease and Prevention, *HIV Treatment as Prevention* (engleză), cdc.gov
- Jennifer N. Sayles, MD, MPH, Mitchell D. Wong, MD, PhD, Janni J. Kinsler, PhD, David Martins, MD, și William E. Cunningham, MD, MPH, *The Association of Stigma with Self-Reported Access to Medical Care and Antiretroviral Therapy Adherence in Persons Living with HIV/AIDS*, 2009, National Library of Medicine, ncbi.nlm.nih.gov
- Rethink Mental Illness, *Discrimination and Mental Health*, rethink.org
- The Well Project, *Stigma and discrimination against women living with HIV*, 2021, thewellproject.org
- InformatHIV, *Transmiterea HIV și legislația*, translated title: HIV transmission and legislation, informathiv.ro
- NAM, *Undetectable viral load and transmission – information for HIV-negative people*, 2020, aidsmap.com
- NAM, *HIV Life Cycle*, 2020, aidsmap.com
- Romanian Anti-AIDS Association (ARAS), *SIDA Helpline*, arasnet.ro



About the author: **Sergiu Marinescu** has been working with MozaiQ since 2019 and has previously been involved in several other NGOs. He has experience supporting people with mental disabilities (at Fundacja Sprawni Inaczej in Poland), IV drug users (at ARAS), people living with HIV (at Asociatia Sens Pozitiv), having expertise in occupational therapy (through Erasmus+ programme), HIV/AIDS information/prevention and testing as a volunteer at ARAS, diversity education and training (at MozaiQ and ARAS), and art therapy.



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More about the project **Non-discrimination, beyond words:**
www.crj.ro/en/antidiscriminare/nediscriminarea-dincolo-de-cuvinte/

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