GLOBAL NETWORK OF YOUNG PEOPLE LIVING WITH HIV

World Hepatitis Alliance

LIVING POSITIVELY WITH HIV AND HEPATITIS

A DIGITAL TOOLKIT FOR YOUNG PEOPLE

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ABOUT THIS TOOLKIT

Many young people live with hepatitis and/or HIV and don't even know it. This is largely due to a lack of accessible and comprehensive information about these diseases. To bridge the gap, the Global Network of Young People Living with HIV (Y+ Global) and the World Hepatitis Alliance (WHA) have teamed up to create this digital toolkit.

Designed with young people in mind, this toolkit offers clear, easy-to-understand information about hepatitis and HIV. Our goal is to raise awareness, debunk myths, and empower you to make informed decisions about your health. Whether you're looking to understand the symptoms, learn about prevention, or find out how to get tested, this toolkit is here to support you every step of the way.

ABOUT WHA AND Y+ GLOBAL

The **World Hepatitis Alliance (WHA**) is an international network of over 330 civil society and community organisations in over 100 countries working towards the goal of eliminating hepatitis by 2030. Together, we lead the fight against hepatitis through advocacy, capacity building and awareness raising.

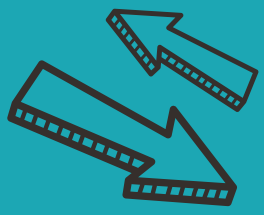
The **Global Network of Young People Living with HIV (Y+ Global)** is the largest global network of young people living with HIV, working with more than 120 implementing partners in over 41 countries. Y+ Global empowers young leaders to create, lead, and manage programmes that address crucial health and human rights issues, such as HIV, Sexual and Reproductive Health and Rights (SRHR), and LGBTQ+ issues.

Our mission is to empower young people living with and affected by HIV by amplifying their voices and meaningfully engaging them in political and programmatic spaces.

KEY MESSAGES

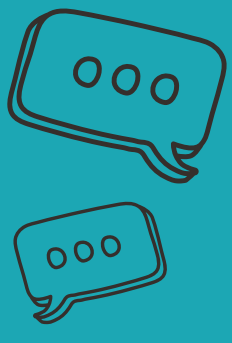
Many young people are living with hepatitis and/or HIV and don't even know it.

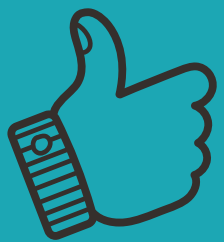
If you live with HIV, you are more likely to be diagnosed with hepatitis and vice versa because the diseases share modes of transmission.



The only way to know for sure if you have hepatitis and/or HIV is to get tested. Knowing if you have hepatitis and/or HIV will help you take steps to live a long and healthy life with hepatitis and/or HIV.

Speaking to people you trust and seeking guidance from medical practitioners can help you live with HIV and/or hepatitis positively.





More resources about young people living with hepatitis and/or HIV are needed. This toolkit is a great start!

HEPATITIS

WHAT IS HEPATITIS?

Hepatitis is an inflammation of the liver, most commonly caused by a viral infection. There are five main hepatitis viruses – types A, B, C, D, and E. Hepatitis B and hepatitis C are the most common forms of viral hepatitis and can become chronic.

Hepatitis A and Hepatitis E

Hepatitis A and E are primarily spread when an uninfected (and unvaccinated) person eats or drinks food or water that is contaminated with the faeces of a person living with hepatitis A or E. Hepatitis A is also closely related to unprotected sexual contact.

Hepatitis B

Hepatitis B is a life-threatening liver infection. It can cause acute or chronic infection, which puts people at high risk of death from cirrhosis (scarring of the liver) and liver cancer.

Hepatitis B is most commonly spread from mother to child during birth. Most people do not experience any symptoms when newly infected; however, some people with acute hepatitis B have symptoms that last several weeks.

There is a safe vaccine that offers protection against hepatitis B. There is no treatment for acute hepatitis B, as treatment is only required for chronic hepatitis B, which can be treated by oral medications.

While chronic hepatitis B cannot be cured, treatment can slow the progression of cirrhosis, reduce the risk of developing liver cancer and improve long-term survival and quality of life.

THINGS TO REMEMBER…

If you are pregnant, getting tested for hepatitis B is essential to prevent transmission to your baby. Your baby must be vaccinated against hepatitis B within 24 hours of birth.

Hepatitis C

Hepatitis C is a virus that can cause both acute and chronic hepatitis infection, which puts people at risk of cirrhosis and liver cancer.

It is most commonly spread by the reuse of syringes and needles, unscreened blood, sexual contact, and injecting drug use by sharing equipment. People living with chronic hepatitis C may not show symptoms for decades until they develop serious liver damage.

There is no vaccine for hepatitis C, but there is a cure (direct-acting antiviral (DAA) tablets) available to anyone over 3 years old. The treatment is usually taken over 8 to 12 weeks.

WHAT IS THE DIFFERENCE BETWEEN ACUTE AND CHRONIC HEPATITIS?

Hepatitis B and C can be either acute or chronic infections. When the hepatitis virus is acute, it is a short illness.

You may experience symptoms that last several weeks if you have acute hepatitis B, while if you have acute hepatitis C, you most likely won't have any symptoms.

However, acute hepatitis B can become more serious and lead to liver failure and later death.

Many people recover naturally from acute hepatitis B and C. Most adults with acute hepatitis B and around 30% (15–45%) of people with acute hepatitis C spontaneously clear the viruses without any treatment.

However, the younger you are when you are infected with acute hepatitis B, the more likely it is for it to lead to chronic hepatitis B. 95% of babies and young children with acute hepatitis B develop chronic hepatitis B, while only 5% of adults with acute hepatitis B develop chronic hepatitis B.

Acute hepatitis B and C can become chronic long-term infections. Chronic hepatitis B and C can lead to liver disease or liver cancer. It's important to get tested for hepatitis B and C and know your status so you can take steps to keep yourself healthy.

Hepatitis D

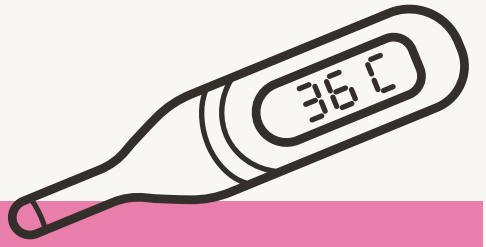
Hepatitis D is commonly spread through broken skin (such as tattooing or syringes) or infected blood. For a person to be infected by hepatitis D, they must already have hepatitis B.

A person who does not have hepatitis B cannot be infected by hepatitis D. Having both hepatitis B and hepatitis D is considered the most serious form of chronic hepatitis as it leads more quickly to liver cancer or liver-related death.

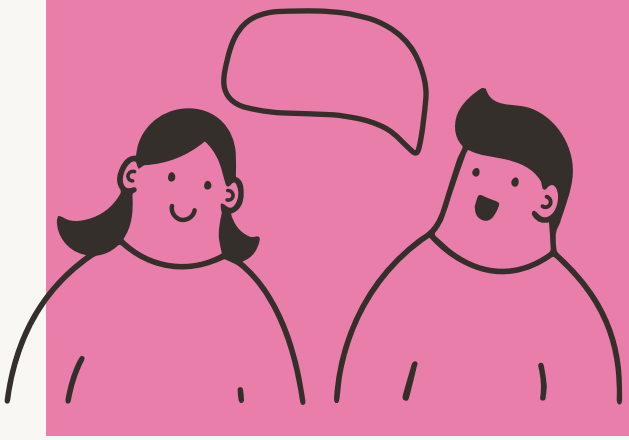
The only way to prevent hepatitis D is to get the hepatitis B vaccine. There are tests and treatments for hepatitis D, but they are not widely available.

Type of hepatitis	Vaccine	Treatment	Cure
Hepatitis A	Yes	Yes	Most people make a full recovery
Hepatitis B	Yes	Yes	In development
Hepatitis C	No	Yes	Yes
Hepatitis D	No (although hepatitis D only affects people living with hepatitis B, for which there is a vaccine)	Yes	No
Hepatitis E	No	Yes	Most people make a full recovery

SYMPTOMS OF HEPATITIS



The symptoms of the different types of viral hepatitis are very similar. However, many people who are newly infected will not have any symptoms at all.



Not everyone who is infected will have all the symptoms, but they may experience the following:

- **fever**
- **loss of appetite**
- **extreme tiredness**
- **diarrhoea**
- **nausea**
- **vomiting**
- **abdominal pain**
- **dark urine**
- **pale-coloured faeces**
- **jaundice (a yellowing of the eyes and skin)**
- **headache and/or joint pain**

People with hepatitis E may also experience itching or a skin rash.

HOW CAN I GET TESTED FOR HEPATITIS?

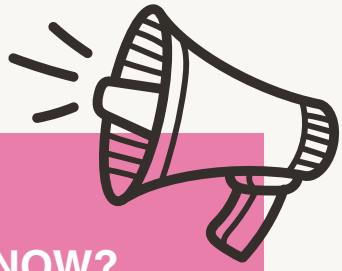
Available testing for hepatitis is different in every country. Unfortunately, hepatitis testing isn't often free or easy to access in some countries.

To find out more about access to hepatitis testing in your country, please find your local hepatitis organisation here: www.worldhepatitisalliance.org/our-members

The tests for hepatitis B and hepatitis C are different; getting confirmation of chronic infection can require more than one test.

You can also find more information about hepatitis testing below:

- www.worldhepatitisalliance.org/missing-millions/diagnosing-hepatitis
- E-learning modules on hepatitis B, C and D: www.worldhepatitisalliance.org/community-impact-programme



DID YOU KNOW?

Hepatitis is the most common cause of liver cancer

Chronic hepatitis repeatedly attacks the liver and overtime, this can lead to liver damage, which is the primary risk factor of liver cancer.

While more than half of all liver cancer cases are caused by chronic hepatitis, they can be prevented. The hepatitis B vaccine was the first vaccine to prevent cancer, and the hepatitis C cure prevents long term liver damage, which reduces the risk of developing liver cancer.

HOW CAN I PREVENT MYSELF FROM GETTING HEPATITIS?

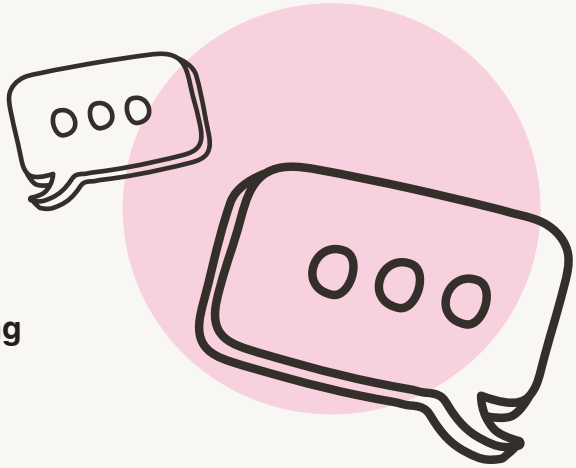
There are lots of things that you can do to prevent hepatitis transmission, including:

- Get **vaccinated** for hepatitis A and B.
- Use **condoms** every time you have sex. Both male and female condoms will protect you from getting hepatitis B and C.
- Taking **treatment for hepatitis B and/or C** as a tool to prevent transmission to others.
- **Avoid sharing needles** or any equipment used for injecting drugs, piercing, or tattooing.
- Taking **antiviral medicines** during pregnancy to prevent the transmission of hepatitis B from mother-to-child.
- **Drinking safe water** to prevent hepatitis A and E.

When I learned about my hepatitis status after my HIV diagnosis, I was scared and struggled to do things. But now I am happy. I am able to share my experiences. I am living with hepatitis and HIV, and today I am HERE.

Zipporah Achieng, a young HIV and hepatitis activist from Kenya

MYTHS ABOUT HEPATITIS



There are many MYTHS about hepatitis that have led to stigma and discrimination against people living with hepatitis. These are just a few:

MYTH

"Hepatitis is highly contagious and can be spread through casual contact such as shaking hands, hugging or kissing."

FACT

Hepatitis can't be transmitted by casual contact.

Some ways it can be spread include from mother to child during birth, reusing needles and syringes, or unclean water.

MYTH

"Hepatitis can be spread through sneezing, coughing, breastfeeding, or sharing meals or drinks with someone living with hepatitis."

FACT

Hepatitis can be transmitted through infected blood, but not bodily fluid such as sweat, saliva or breast milk.

MYTH

"Traditional medicine can cure hepatitis."

FACT

Traditional healers, holy water and herbal medicine cannot cure hepatitis. Not all types of hepatitis can be cured, but hepatitis C can be cured with direct-acting antiviral medicines.

MYTH

"Being diagnosed with hepatitis is a death sentence."

FACT

People living with hepatitis can live long and healthy lives!

There is a treatment for hepatitis B and a cure for hepatitis C, which can prevent hepatitis from progressing to liver failure or liver cancer.

To find out more about viral hepatitis, please visit the World Hepatitis Alliance's website: www.worldhepatitisalliance.org

HIV

WHAT IS HIV?

HIV (Human Immunodeficiency Virus) is a virus that can lead to AIDS if not treated. HIV attacks the body's immune system, making it harder to fight off infections.

WHAT IS AIDS?

AIDS (Acquired Immune Deficiency Syndrome) is a set of symptoms or illnesses caused by HIV.

SYMPTOMS OF HIV

There are several symptoms of HIV, but not everyone will have the same symptoms. The symptoms of HIV vary depending on the stage of infection.

This may look like:

- fever or chills
- rash
- night sweats
- mouth ulcers
- muscle aches and fatigue
- sore throat or swollen lymph nodes

In the very late stages of HIV infection, when people develop symptoms of AIDS, people may experience:

- rapid weight loss
- recurring fever or profuse night sweats
- extreme tiredness
- diarrhoea that lasts for more than a week
- sores of the mouth, anus or genitals
- prolonged swelling of the lymph glands in the armpits, groin or neck
- pneumonia, blotches on or under the skin or inside the mouth, nose or eyelids
- memory loss, depression, and other neurologic disorders

HOW CAN I GET TESTED FOR HIV?

Getting an HIV test is quick, easy and almost always free, and you can check online for services near you. Depending on the type of test used, you will get the results within a few minutes or a few days. In some places, you can do your own test at home, but you should always talk to someone about doing a self-test and ensure you have a follow-up test done in a clinic to confirm the result.

The three main types of HIV tests include antibody tests, antigen/antibody tests, and nucleic acid tests (NAT):

1. Antibody tests

Antibody tests look for antibodies to HIV in your blood or oral fluid. Antibody tests that use blood from a vein can detect HIV sooner than tests done with blood from a finger stick or with oral fluid.

2. Antigen/antibody tests

These tests look for both HIV antibodies and antigens. They are recommended for testing that involves drawing blood from a vein. A rapid antigen/antibody test involves extracting blood (usually through a prick on the finger) and testing it on a stick.

3. Nucleic acid tests (NAT)

NATS look for the actual virus in the blood. With a NAT, the health care provider draws blood from your vein and sends the sample to a lab for testing. This test can tell if a person has HIV or how much virus is present in the blood (HIV viral load test).

THINGS TO REMEMBER

If you receive a reactive result after being tested for HIV, it's important to remember that follow-up actions are necessary to confirm the validity of the test. A reactive result could also be a false positive, meaning that the test has reacted to something in your blood and further investigation is required. A diagnosis of HIV-positive is never made solely based on a single test, so follow-up confirmatory tests are essential.

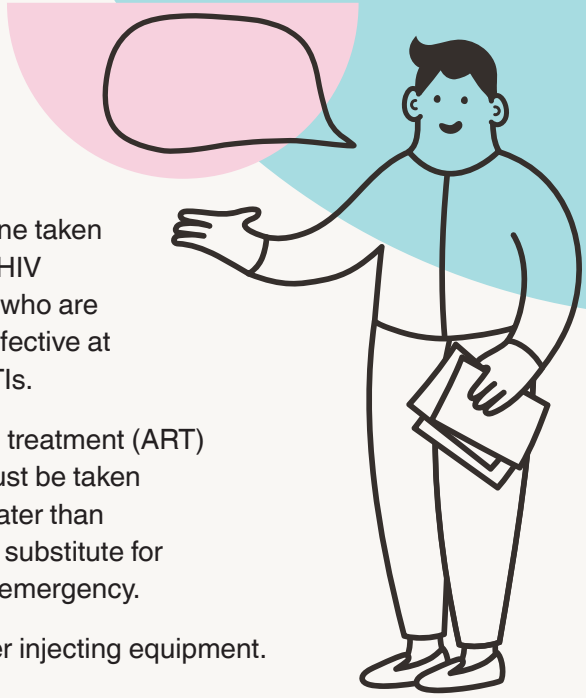
It's essential to remain calm, seek information, and schedule follow-up appointments with a healthcare professional who has access to accurate HIV testing technologies. It's also important to prepare questions for healthcare providers and seek support from trusted individuals. Counselling from peers and professionals can also help address any worries and concerns you may have.

Tools and resources are available that have been developed by youth-led organisations to help young people navigate questions they may have about sexual reproductive health, HIV, and testing services. These resources focus on education, healthy practices, managing anxiety, self-care, and future planning to empower and support young people throughout their health journey.
Here are some resources you can access:

- **HIV/SRHR SBC Toolkit for Adolescents and Young People** (UNICEF ESARO, 2gether 4 SRHR UNFPA UNFPA ESARO, and Y+ Global, May 2024).
- **Mental health and self-care: Information booklet for young people and young key populations** (Youth LEAD, 2022)
- **Self-Care Toolkit On Srhr And Hiv For Young People** (You(th) Care and Aidsfonds, 2023)

HOW CAN I PREVENT MYSELF FROM GETTING HIV?

Here are the most common ways a person can prevent themselves from HIV transmission:



- Use **condoms** every time you have sex. Both male and female condoms will protect you from getting HIV and STIs, as well as prevent pregnancy.
- **Pre-exposure prophylaxis (or PrEP)** is a long-term medicine taken to prevent getting HIV. PrEP is highly effective for preventing HIV when taken as prescribed. PrEP is recommended for people who are considered at risk of getting HIV. Importantly, while PrEP is effective at protecting you from other STIs.
- **Post-exposure prophylaxis (PEP**) is a strong anti-retroviral treatment (ART) or medicine that can be taken just after exposure to HIV. It must be taken as soon as possible to prevent yourself from getting HIV, no later than 72 hours after exposure. It is not 100% effective, so it is not a substitute for other prevention tools like condoms, but it can be used in an emergency.
- If you use drugs, **avoid sharing needles**, syringes, and other injecting equipment.

IMPORTANT TO REMEMBER THAT TREATMENT FOR HIV IS EFFECTIVE

Thanks to effective treatment, most people living with HIV do not progress to AIDS. If you have HIV and remain in care, take HIV medicine as prescribed, and get and keep an undetectable viral load, you will stay healthy and will not progress to AIDS.

If you've tested positive for HIV, starting antiretroviral treatment (ART) as soon as possible can help you to stay healthy. ART won't cure HIV, but it does keep the virus under control and helps prevent infections. Once you start ART, it's imperative to take your treatment every day, as your doctor tells you.

U=U stands for Undetectable = Untransmittable.

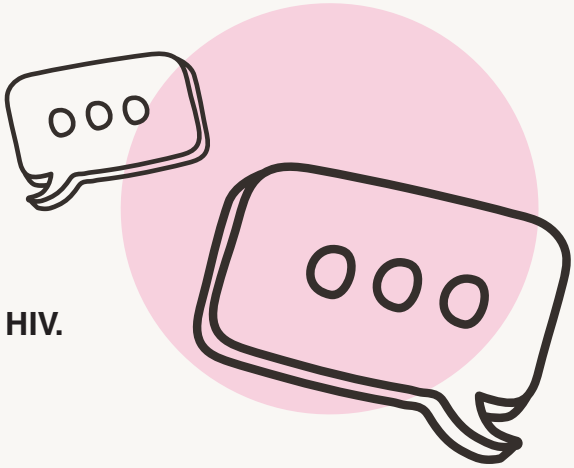
It means that when a person living with HIV is on regular treatment that lowers the amount of virus in their body to undetectable levels, there is zero risk of passing on HIV to their partners. The low level of the virus is described as an undetectable viral load.

You can find more information about how to live positively with HIV by looking at this information sheet in the HIV/SRHR SBC Toolkit for Adolescents and Young People.

As a young person living with HIV, I prioritise taking control of my health and making safe choices to enhance my well-being. Awareness of hepatitis is vital because it empowers me to manage my health proactively.

Priscilla Ama Addo,
Communications Graduate Trainee at Y+ Global

MYTHS ABOUT HIV



There are many MYTHS about HIV that have led to stigma and discrimination against people living with HIV. These are just a few:

MYTH

"I can get HIV by being around people who are HIV-positive."

FACT

This is the most common one. HIV isn't spread through touch, tears, sweat, saliva, or pee. You can't catch it by breathing the same air, drinking from the same water fountain, sharing eating utensils or hugging someone. You can only acquire HIV from infected blood, semen, vaginal fluid, or breast milk.

MYTH

"I can get HIV from mosquitoes."

FACT

HIV cannot be transmitted by having contact with animals or being bitten by a mosquito. When bugs bite, they don't inject the blood of the person or animal they bit before you.

MYTH

"Traditional medicine can cure HIV."

FACT

Traditional healers, holy water and herbal medicine cannot cure HIV. The bottom line is there's no cure for HIV, but prevention is cheaper and easier than managing a lifelong condition and the problems it brings.

MYTH

"My life is over."

FACT

No, it's not. It's important you tell yourself that and remind yourself there is more to life than your status. If you get on treatment and take care of yourself, you can live a long and productive life.

MYTH

"Can I acquire HIV if someone is on treatment?"

FACT

People living with HIV and on treatment who have a suppressed viral load have almost zero or negligible risk of transmission to their sexual partners. This is often referred to as U=U. To learn more about U=U, see this Factsheet by Prevention Access Campaign.

HEPATITIS AND HIV

Hepatitis and HIV are both viruses, but they affect the body in different ways. HIV primarily targets your immune system, while hepatitis affects your liver. While HIV does not cause hepatitis and vice versa, it can make it easier for the other to enter your system and may worsen the severity of the diseases, as well as your overall health. It's called a **coinfection** when you have two or more viruses at once.

People living with HIV and hepatitis B or hepatitis C coinfection have a more rapid progression to cirrhosis. Liver disease has emerged as an increasing cause of death among people living with HIV coinfected with either hepatitis B or hepatitis C.

Hepatitis C coinfection with HIV is reported across all key populations at higher risk of HIV, especially among people who inject drugs. This is due to the ease with which both viruses are spread through the sharing of non-sterile drug preparation and injecting equipment.

> **Although there is a lot of advocacy around HIV/AIDS, there is very little awareness about hepatitis B. There is still a lot of stigma about hepatitis. We are lagging behind.**
>
> Dr Edgar Mudoogo, a young medical doctor from Uganda

Young people are one of the groups most affected by hepatitis and HIV. People who are living with HIV are highly likely also to be diagnosed with hepatitis. Other groups who are also more likely to be affected by hepatitis and HIV include people who inject and use drugs, men who have sex with men, transgender people, young women and girls, migrants, and people with disabilities.

For more information, check out WHO's Consolidated guidelines on HIV, viral hepatitis and STI prevention, diagnosis, treatment and care for key populations, Policy brief.

DID YOU KNOW?

HEPATITIS B AND HIV CAN BE TREATED WITH THE SAME MEDICINES?

Hepatitis B is treated with antiviral medicines. The medicines work to help limit damage to the liver. Some HIV medicines are effective at treating both HIV and hepatitis B.

The choice of medicines to treat coinfections depends on the person. For example, some people may take HIV medicines that are also effective at treating hepatitis B. Other people may take HIV medicines and a hepatitis B antiviral medicine. If you are living with hepatitis and HIV coinfection, talk to your healthcare provider about the best medicines for you.

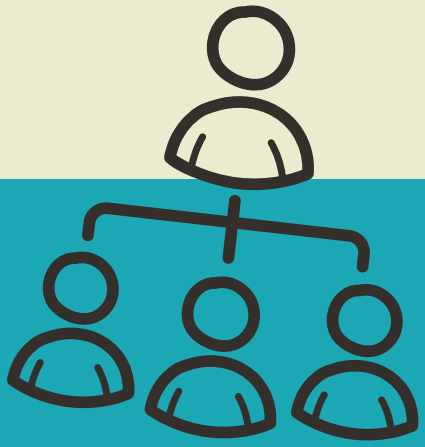
To learn more about hepatitis and HIV visit the Global HIV, Hepatitis and STIs Programmes hub on the World Health Organization's website.

HEPATITIS AND HIV SHARE MODES OF TRANSMISSION

Another reason why co-infections of HIV and hepatitis are more common is that they share modes of transmission, meaning young people with HIV are more at risk for hepatitis and vice versa. Some of the shared modes of transmission include mother-to-child transmission, injection drug use and unsafe sex.

I'M WORRIED I MIGHT HAVE HIV AND/OR HEPATITIS. WHAT SHOULD I DO?

The only way to know for sure if you have hepatitis and/or HIV is to get tested. Knowing your status gives you essential information so you can take steps to keep yourself healthy.



SPOTLIGHT ON LIVING POSITIVELY WITH HEPATITIS AND HIV

Ravel Gatoto's Story from Burundi

My name is Ravel Gatoto, and I am from Burundi. I am an advocate and a young person living positively with hepatitis and HIV. My journey in advocacy began with RNJ+, a national network of young people living with HIV in Burundi. This organisation has been instrumental in empowering young people through impactful peer education and support group initiatives.

Growing up in Burundi, I witnessed firsthand the challenges that young people face in accessing information and services related to HIV and hepatitis. I joined RNJ+ because I can make an impact and help others who might be struggling with their diagnosis. RNJ+ has provided numerous workshops and community outreach activities in both urban and rural areas to raise awareness about the linkages between HIV and other co-infections, including hepatitis. More importantly, we work to ensure young people know where they can access essential testing and treatment services.

Despite the progress made, significant gaps remain in comprehensive screening, testing, and treatment access for viral hepatitis, particularly in rural and hard-to-reach areas. Limited awareness and understanding of viral hepatitis and its links to HIV among the general population perpetuate stigma and reduce the uptake of hepatitis testing.

Through my work with RNJ+, I am committed to addressing these challenges and advocating for holistic care that integrates hepatitis services into HIV programmes. It is my hope that through continued efforts, we can ensure that young people in Burundi and beyond have the knowledge and resources they need to live healthy, empowered lives.

LIVING WITH HEPATITIS AND/OR HIV

Living with hepatitis or HIV can present unique health challenges, but with the right medical care, individuals can manage their conditions effectively and lead healthy lives. The most important thing to remember is that hepatitis and/or HIV can be successfully managed if you take good care of your health and remain on medication. Adherence is key!

Even though the treatment of hepatitis B and HIV includes the same medicines, it's important to know your hepatitis status so you are able to monitor your liver health. If you are worried about how multiple medications may interact with each other, such as for HIV and hepatitis C, please visit druginteractions.org for more information.

People living with hepatitis and/or HIV are at high risk of struggling with their mental health. Speak to a clinic counsellor, nurse, or community health worker to discuss your concerns. Finding support groups can be a great way to connect with people who have similar experiences and stories. Support groups can also provide support when taking medications.

Confiding in people you trust and seeking guidance from medical practitioners can provide you comfort in living with HIV and/or hepatitis positively.

There is a significant gap in the work being done around hepatitis and HIV, particularly around how co-infections impact the lives of young people who are most at risk. Young people play a key role in the hepatitis and HIV responses and can make a change in their local communities.

If you would like to share your story or examples of youth-led initiatives on hepatitis, HIV and co-infections, contact Eddy Rudram at Y+ Global at edrudram@yplusglobal.org and the World Hepatitis Alliance at contact@worldhepatitisalliance.org.

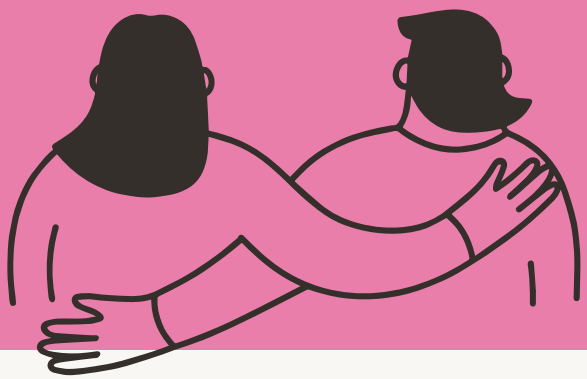
To learn more about young people living with hepatitis and/or HIV, please visit

- www.worldhepatitisalliance.org/youngpeople
- www.yplusglobal.org

OTHER RESOURCES ABOUT HEPATITIS AND HIV

Hepatitis

- www.who.int/health-topics/hepatitis
- www.worldhepatitisalliance.org/wp-content/uploads/2021/11/WHA-Report-2021-Final.pdf



HIV

- www.who.int/news-room/fact-sheets/detail/hiv-aids
- www.fhi360.org/wp-content/uploads/2024/02/HIV20Counseling20and20Testing20for20Youth.pdf
- www.youthpower.org/oha-toolkit-health-services
- www.unicef.org/eca/sites/unicef.org.eca/files/2017-10/Adolescents_Living_with_HIV.pdf

GLOBAL NETWORK OF YOUNG PEOPLE LIVING WITH HIV

www.yplusglobal.org | info@yplusglobal.org

World Hepatitis Alliance

www.worldhepatitisalliance.org | contact@worldhepatitisalliance.org

Illustrations by BadBrother.