

Common questions about...

LIVING WITH HIV



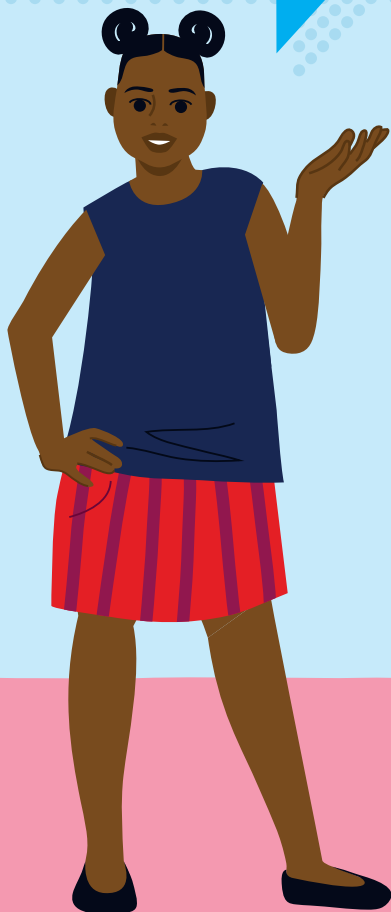
Young people living with HIV can have happy, successful and long lives, just like other young people who are not HIV positive. But learning how to live with HIV can mean you are dealing with more challenges than your friends.

Learning how to stay healthy with medication, how to talk about your HIV with others and how to explore relationships as a young person with HIV can be especially hard – particularly during your teenage years when you're already experiencing lots of changes.

Taking care of yourself is the most important thing, and this means looking after both your physical and mental health.



Finding people who you can talk to, and who can share their own experiences, will help you feel confident and ready to live positively with HIV.



All the questions in this Q&A are based on frequent examples received from young people through UNICEF digital platforms, social listening reports and IoT analytics. The answers were developed in collaboration with a reference group of young people from the ESAR region and reviewed by technical staff from UNICEF, UNFPA and UNAIDS.

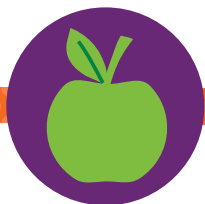
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What can people living with HIV do to continue to live healthy lives?



If you've tested positive for HIV, starting anti-retroviral 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 really important to take your treatment every day, as your doctor tells you. It will usually be at the same time every day. Missing doses, or taking it at different times each day, can stop the treatment from working properly and you may start to get ill.

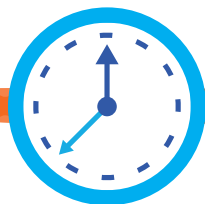
People living with HIV can also take the same steps to stay healthy as other people. These include:



Eating healthily



Getting regular exercise



Getting plenty of sleep



Avoiding alcohol and drugs, which can stop ART working properly and cause side effects.



looking after your mental health

2

Who should I tell that I'm living with HIV?



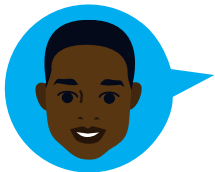
It's entirely up to you who you tell that you are living with HIV. It can be helpful to share this with someone else, but you should never feel that there is pressure to talk about your HIV status. You might want to take some time after testing to take in the news yourself before you tell other people.

Everyone reacts differently; some people may decide that they want to be completely open about their HIV status, while other people may decide just to tell a few people who they are close to and trust. Telling other people that you have HIV can be a big step and you might feel worried about how they will react.



Unfortunately, in many places there is still stigma attached to HIV. Some people may be afraid or judgmental and may not understand how HIV is passed on.

When you feel ready, talking to someone you trust about living with HIV can help you to process how you're feeling. Some people prefer to share the news with a partner, close friend or family member, while others find it helpful to talk to a counsellor or other people with HIV first, through a peer support group or network for young people living with HIV. They can provide support around accepting and sharing your status.



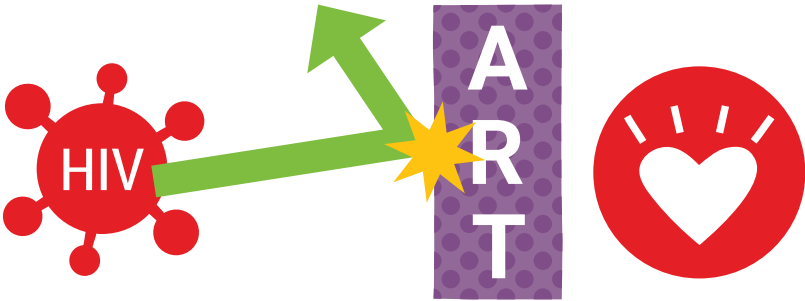
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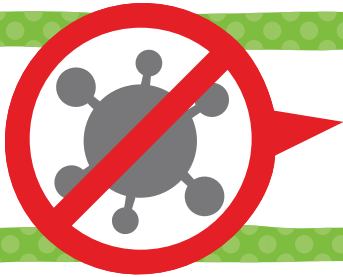
What treatment is available for HIV and how does it work?



HIV is treated using medications called anti-retrovirals (ARVs) or anti-retroviral therapy (ART). ART doesn't cure HIV, but it helps to keep the virus under control and prevent infections. ART works by preventing HIV from infecting new cells in the body's immune system and reducing the amount of HIV in the blood (called 'viral load') to very low levels. HIV treatment strengthens your immune system so that it can fight infections.



Starting ART as soon as possible helps people living with HIV to stay healthy. Once someone starts ART, it's really important to take the treatment every day. Forgetting or stopping altogether can prevent the treatment from working properly. This is called 'resistance' – you can become ill and have to start taking different types of ARVs.



ART works by **reducing** the 'viral load' and then keeping it as low as possible. When a person's viral load is very low, it is not possible for tests to measure it – this is called being '**undetectable**'.



When someone's viral load is '**undetectable**', they still have HIV, but it is being kept under control by the HIV treatment. If treatment is stopped then the immune system can weaken and people can't fight off infections. This is why it's so important for people living with HIV to take their treatment every day, exactly as prescribed.



4

I have been taking my HIV treatment for a year now, I feel fine – surely I can stop or reduce it?



Once you start ART, you'll need to continue taking it for the rest of your life and it's important to take your treatment every day at the same time. If you're feeling fine this is a sign that the treatment is working well and should remind you how important it is to keep going with your treatment, even when it's difficult or inconvenient. If you are experiencing side effects or worried about your treatment, make sure you speak to your doctor before you stop taking it.

It's your right to decide whether to take HIV treatment, when to start and whether to stop, but you should never just stop taking your treatment as this is dangerous for your health.



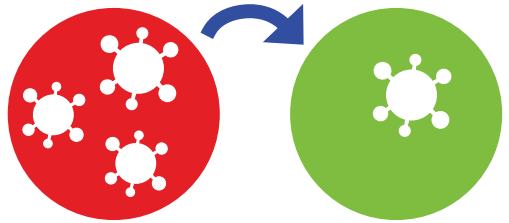
Stopping without advice can lead to 'resistance' to that particular ARV drug which means it doesn't work properly and you can be more likely to get other infections like TB.



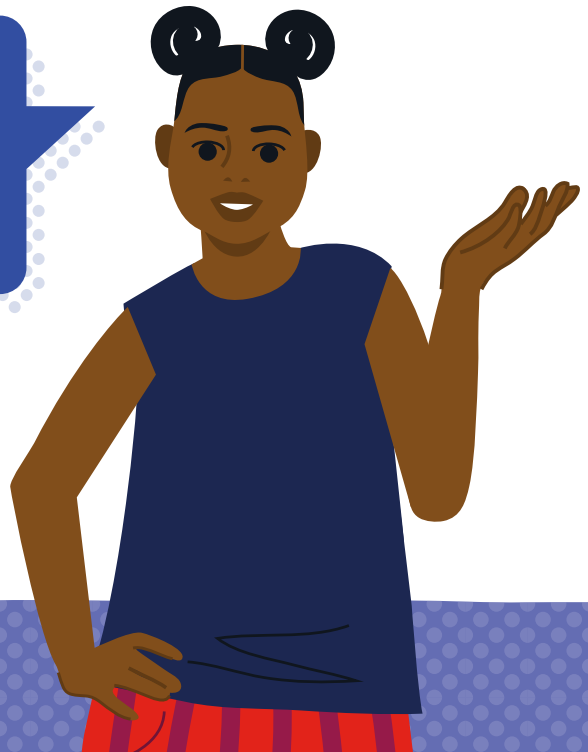
If your treatment fails you may have to be put on a different regimen called a '2nd line' treatment or sometimes a '3rd line'. These other lines of treatment can be difficult to get hold of, more complicated to take, and can also be very expensive, so it's important to follow whatever treatment you're on carefully so you don't need to change.



ART works by reducing the level of HIV in your blood (called 'viral load') so that it doesn't damage your immune system.

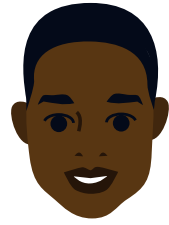


If you stop taking your ART, then your viral load will go up again, making it more likely for HIV to damage your immune system, for you to get sick, and for you to pass on HIV.



5

I've heard that if people take their treatment, they can't pass HIV on to other people – is this true?



The aim of HIV treatment is to lower your 'viral load' and then to keep it as low as possible. For many people who take ART as prescribed, the amount of HIV in their blood (their 'viral load') is so low that it is defined as 'undetectable'. Although you still have HIV, it is being kept under control by the HIV treatment and you can no longer pass it on to other people (it's 'untransmittable'). If you're undetectable you're untransmittable, – this is sometimes referred to as U=U for short.



However, just because you're taking ART does not necessarily mean that you cannot pass on HIV. This is only the case when your doctor confirms that regular blood tests have shown that the level of HIV in your blood is now so low that it is no longer possible to pass the virus on to others. Until then, it's so important to use condoms correctly and consistently (every time you have sex) and to take care not to share any injecting equipment, if you use drugs, to avoid passing on the virus to others and to avoid re-infection.



Remember that condoms also prevent against other STIs and pregnancy too.



6

I've met someone that I really like; when should I tell them that I'm HIV positive?



Meeting someone you really like and starting a new relationship can be very exciting. If you're HIV positive, it can also raise tricky questions – when should you tell them you have HIV? How do you start the conversation? How will they react? And how do you talk about safer sex and condoms?



There's no 'right' time to tell anyone, including a new partner, that you're living with HIV – it's whenever feels right to you. Deciding how and when to tell a partner means thinking through many of the same issues as disclosing your HIV status to family and friends. But it can also raise other questions too. They may want to know more about your previous sexual relationships or other personal things, so think about what you feel comfortable to discuss.

Remember that it's your choice how much to tell them, and when, but sometimes the longer you put it off, the harder it can be to have the conversation and your partner may be upset that you didn't tell them sooner.



You can talk to the clinic counsellor, or nurse, or discuss with members of a support group about how to tell someone. Staff at the clinic can also help you explain to a person about HIV.

If you're planning to have sex, using condoms (male or female) correctly every time you have sex, prevents passing on HIV, other sexually transmitted infections (STIs) and also protects against unplanned pregnancy. Talking about HIV before you have sex means that you and your partner can both be responsible for having safer sex. Lots of HIV clinics provide free condoms and other contraceptives, so don't be shy about asking.



If you're taking ART and it's keeping the level of HIV in your body (viral load) very low, the risk

of passing it on is much lower. If you're undetectable you're untransmittable, but remember that condoms also prevent against other STIs and pregnancy too.



7

How do I tell someone I am living with HIV? What words can I use?



Telling someone that you are living with HIV can be a difficult thing to do, it is impossible to know what their reaction will be, and you have to be prepared. If you have decided you do want to share your HIV status, there are things you can do to prepare. You can start some conversations with the person to see what their opinions are on HIV. This can open the conversation slowly, so you can decide, as you go along whether it feels right to tell them.

You could ask them if they have ever tested for HIV, or what they would say if a friend wanted to go out with someone living with HIV. Their answers to these questions will help you know what kind of attitudes they hold around HIV.



If you decide you do want to share your HIV status with them, then find a safe and quiet place where you will feel comfortable to talk.

After telling someone your HIV status they may need time to think about it for a while and might not be ready to talk. Just remind them you are ready to talk when they are. It is nice to end with suggesting you go and do something you would normally do together – get a coffee, play football or go shopping, reminding you both about your friendship.

Remember that while sharing can help you feel connected to people, and supported, you do not have to disclose your status. Also, remember people's reactions will be different and their emotions or reactions are not something you have to worry about.



You might want to arrange to speak to someone else afterwards to help you deal with any issues or feelings that come up from sharing your status, maybe another friend who knows you are living with HIV or a counsellor or health provider.

Each time you share your status with someone it should become a little easier. There may be some negative reactions, but most people find that sharing with a trusted person is helpful and positive.

So how do you start?

You will find your own words but here are some suggestions:

- ✓ Start by explaining you have something important to share.
- ✓ Explain that it is not an easy conversation but that you feel comfortable discussing with them.
- ✓ Explain that it is something you would like to keep between the two of you.
- ✓ Tell them that they shouldn't worry about you.
- ✓ Tell them you don't expect them to talk if they don't want, but you are happy to answer some questions.
- ✓ Tell them about the different ways you would like them to support you.
- ✓ Remind them about keeping this confidential.

Remember you don't have to have the conversation, you can stop and try another time if anything worries you. Be prepared for different reactions.



8

I'd like to try to get pregnant; what should I do to prevent passing HIV on to my baby?



Many women living with HIV have given birth to babies who are free from HIV. Advances in HIV treatment mean that the risk of passing HIV on to a baby during pregnancy or birth is now very low.



If you're thinking about having a baby, it's really important to talk to your doctor first so that they can give you advice and keep you and your baby healthy. If you're not already taking ART, you'll be advised to start treatment. Taking ART while pregnant and breastfeeding almost eliminates the risk of passing the virus on to the baby. It's important throughout your pregnancy to attend all your appointments and get the support you need to continue to take your ARVs.

When your baby is born, they will be tested for HIV and given treatment for the first four to six weeks. It is very important that the baby comes back for additional testing, as instructed by the health provider, even if the test is negative. If any of the tests come back positive, your baby will need to start treatment right away.

You should still breastfeed if you are living with HIV and taking ART. You should not mix breastfeeding with other food or liquids for the first 6 months.



9

I have HIV and I just want to talk to someone who gets what I am dealing with. Where can I meet other people who will understand me?



Everyone reacts differently when they find out they have HIV, but many people feel worried, shocked, sad or angry, especially to begin with. Talking to other young people who are living with HIV, who are going through similar experiences, and may have the same questions or worries as you, can really help.



Many clinics and HIV organisations run peer support groups for people living with HIV to meet up, chat and offer advice and support.



There are also online forums, if you feel shy about meeting up with people or just prefer chatting online.



Check local links for support.

10

Is COVID-19 more dangerous for people living with HIV?



It doesn't matter whether you're young or old, living with HIV, or another illness, everyone is at risk if in close contact with someone who has COVID-19. This is why it's important to follow the prevention advice given and get help if you show symptoms.



We still don't know if people living with HIV who are affected with COVID-19 become sicker than those who don't have HIV. But we do know that people with weaker immune systems are less able to fight infections and illnesses – including COVID-19.



Without ARVs, HIV attacks and weakens the immune system. That's why it's so important you continue to take your ARVs to make sure your immune system is as strong as it can be.



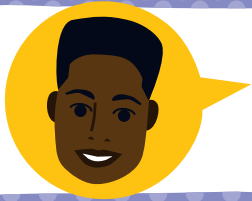
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Is it still safe to go to the hospital and attend clinic appointments during the COVID-19 pandemic?



In most countries, you can still attend medical appointments. It is best to check locally with your clinic to find out what options are available to you and how to get the services you need. If possible, it is best to do this by phone.

In some countries, if you're virally suppressed (with an undetectable viral load) and feeling well, you may not need to come to the clinic as often and you may be given a longer supply of ARVs. Your clinic may offer to speak to you on the phone instead of you having to come into the clinic. In some communities there are group collections where one person goes to the clinic to collect medication and makes sure everyone receives their ARVs safely.



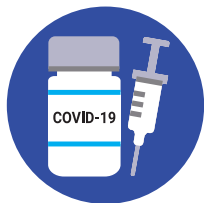
Make sure your contact details are up to date, so the clinic can get hold of you easily, and that you have the clinic's number in case you need to call them. If you're registered with a clinic far away, you may want to switch to a nearer clinic for a while.

If you need to use public transport to get to the clinic, follow the COVID-19 prevention advice to keep yourself safe. You may need a letter or proof of your appointment to travel - ask your clinic if this is needed.



12

As a person living with HIV, should I have the COVID-19 vaccine?



In most countries it is recommended that people living with HIV should have the COVID-19 vaccine. The COVID-19 vaccine is a painless injection – usually given in your arm – that can stop you becoming seriously ill with COVID-19. It can also help to stop you passing it on to other people. People living with HIV have taken part in research trials for the different brands of vaccine, with good results.



However, it is important to check what the recommendations are in your country, as different vaccines are being used in different places. A lot of young people are worried about possible side effects and are frightened by all the myths and stories about the vaccines.

Make sure you read about vaccines from reliable sources or visit your clinic, where they should be able to give you good advice.



13

I recently found out I am living with HIV how can I deal with all these feelings of anger and shame?



Finding out you are living with HIV can be incredibly stressful, especially at first. Everyone reacts differently when they find out, but many people feel worried, shocked, sad or angry. Sadly, there is still a lot of ignorance and stigma about HIV and worrying about other people's reactions can affect how well we're able to cope and impact our mental health.

Feelings of isolation, dealing with health concerns, or grief around losing relatives or friends to HIV, can trigger stress, anxiety and depression. It is important you know that these things are treatable and with support you will be able to manage those emotions.



There are lots of things that can support your mental health, such as: staying physically well, taking medication, eating healthily and sleeping well.

Exercise and time with friends can tackle feelings of isolation and talking to other young people who are living with HIV can really help. Remember some days will be better than others, so find the things that work for you and make time for them in your life.





Many clinics and HIV organisations run peer support groups for people living with HIV and offer the chance to meet up, chat and provide advice and support. There are also online forums if you prefer chatting online.



If your feelings become overwhelming, you must get help. Speak to your health provider or access local mental health services. These people are professionals who have supported many people in the same situation as you, so don't be worried to share the struggles you're having, they're there to help.



Check local links for support.

Further information and contact details

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