

# Information for people recently diagnosed with HIV

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Finding out that you have HIV is a life-changing experience.

You might find it hard to appreciate it at the time, but it is actually good that you've found out that you have HIV. Put simply, finding out that you have HIV could save your life.

This is because you will now have the opportunity to have regular check-ups to monitor your HIV. Doctors and other skilled staff will then be able to provide you with the care you need, including HIV treatment and medicines to prevent other illnesses and infections.

It is worth knowing that doctors are now optimistic that with the right treatment many people with HIV will be able to live a more or less normal lifespan (see the factsheet Prognosis for more information).

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## Getting support

In the UK, there are two national helplines that can provide valuable support and information after you've been diagnosed with HIV.

They are:

- National Sexual Health Helpline, 0800 567 123
- THT Direct, 0845 122 1200 (find out more on the Terrence Higgins Trust website)

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## Making decisions

The time of your diagnosis can be a difficult time to make decisions about your future. Such decisions might include starting HIV treatment or telling close friends and family about your diagnosis.

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## Treatment

Most people do not need to start HIV treatment soon after their diagnosis. Instead it is more likely that you will begin regular monitoring of your health to give both you and your doctor a better understanding of how your body is coping with HIV.

If you are unwell because of HIV when you are first diagnosed, or if you have a low CD4 cell count (which measures the strength of the immune system), then you might have to consider HIV treatment sooner.

You will not have to make an instant decision at the clinic on the day of your diagnosis. It is likely that you will be given an appointment to come back and see a specialist HIV doctor in the next few days or weeks when you'll be able to talk through your options.

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## Medical care

On the day of your diagnosis a follow-up appointment should have been made for you with a specialist HIV doctor. If this wasn't done and you need to find a specialist HIV clinic, THT Direct can help you find one, or you could try searching in the organisations section of our website, aidsmap.com.

You don't have to go to the clinic where you were diagnosed. In fact, you can go to any HIV clinic in the country. It's important that you feel comfortable at the clinic you go to. Some people prefer larger clinics, others like smaller, less busy ones.

It's very important that you go to a specialist HIV clinic at regular intervals for check-ups. If you're well and don't need HIV treatment, then this might be every three to six months. But if you are unwell, or need to start HIV treatment, you'll need more regular appointments. At these appointments you will be asked how you are feeling, if you have any symptoms, and you'll have blood tests.

There are two key tests to monitor HIV. A CD4 cell count measures the number of key CD4 immune system cells. It is currently recommended that HIV treatment should be started when your CD4 cell count is 350. The other key test is called a viral load test, and this measures how active HIV is in

your body. You'll also have other tests to check on your heart, liver and kidneys.

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## Telling people you have HIV

Take time to think about who you are going to tell that you have HIV. Also think about how you are going to do it and what sort of support you'd like them to give. Can you anticipate what a person's best, worst or most likely reaction will be?

You might want to begin by telling people you trust most, or who are closest to you (partner, family, or trusted friends, for example) who will be the most supportive.

Consider waiting to tell anybody else, for example your employer.

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## If you've been infected very recently

Some people are diagnosed with HIV soon after they are infected with the virus. The first few weeks after infection with HIV is called primary HIV infection, or acute HIV infection. Some people experience an illness that includes a high temperature, swollen glands, sore throat and rash at this time. HIV viral load is very high at this time and people with primary infection are very infectious. Safer sex is particularly important at this time to reduce the risk of passing on HIV to others.

Research is underway to see if there is any benefit in starting HIV treatment soon after you've been infected with HIV.

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## Finding out more

Ask questions at your clinic if there is anything you don't understand. The chances are that they will be supportive and helpful.

NAM produces an online resource called [namlife.org](http://namlife.org) that might provide answers to some of the questions you find yourself asking. It also has first-hand accounts from people about their lives with HIV, including their experiences of finding out they had HIV.

NAM also produces a website with comprehensive information about HIV called [www.aidsmap.com](http://www.aidsmap.com) where you can find lots of information resources and you can sign up for free email news bulletins.