

# Information for people recently diagnosed with HIV

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

You might find it hard to appreciate it at the time, but it is good that you've found out 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 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 with the right treatment and care people with HIV are living long and healthy lives (see the factsheet *Prognosis* for more information).

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

## Finding support

You may experience lots of different emotions when you first find out you have HIV and it is important to know that you don't have to deal with your diagnosis on your own. Family and friends can be a really valuable source of support, but if you don't feel ready to tell the people closest to you, there are other ways of finding 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:

- Sexual Health Line, 0800 567 123 (funded by the Department of Health)
- THT Direct, 0808 802 1221 (run by the UK's largest HIV charity, the Terrence Higgins Trust: [www.tht.org.uk](http://www.tht.org.uk)).

In addition to the support available through the NHS, such as through your GP or HIV clinic, there are charities that offer various support services, like information, advice, counselling and peer support. To find out what's available in your area, you could search our online e-atlas ([www.aidsmap.com/e-atlas](http://www.aidsmap.com/e-atlas)), call THT Direct, or ask your doctor.

For online support, including counselling and peer support through discussion forums, you may find THT's MyHIV website helpful. You can find it at [www.myhiv.org.uk](http://www.myhiv.org.uk).

## Treatment

Some people do not need to start HIV treatment straight after their diagnosis. But you should begin regular monitoring of your health to give both you and your doctor a better understanding of how your body is coping with HIV.

In some situations, such as if you are unwell because of HIV when you are first diagnosed, if you are pregnant, or if you have a CD4 cell count (which measures the strength of the immune system) of around 350 or lower, then you and your doctor will start talking about HIV treatment.

You will not have to make any decisions about treatment 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.

## 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 search for one using our online e-atlas.

In the UK, you don't have to go to the same 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 have regular check-ups. If you're well and don't need HIV treatment, then this might mean going to your HIV clinic 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 in a small amount of blood. 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.

## 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) and who you think will be the most supportive.

## 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. HIV viral load is very high at this time and people with primary infection are very infectious. Safer sex is particularly important to reduce the risk of passing on HIV to others.

You can find out more about this in our short illustrated leaflet *Very recent infection*.

## 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 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. It also includes first-hand accounts from people living with HIV, in a section called *In your own words*.