

Living well with HIV

Information for patients

When you are told that you have HIV you may not hear much else that is said to you. It can take some time for the news to sink in. Most people go on to keep it in proportion and live their lives. This booklet is for you to take away and read in your own time.

If you need any more advice or help, please phone our nurses on 020 3299 3707.

Contents

- Part one has information about HIV, explains some of the terms you may hear during your meetings with doctors and tells you more about medication.
- Part two lists our four sites where we offer HIV services, including opening times, addresses and contact numbers.
- Part three tells you how to get our clinics.
- Part four lists our specialist services.

Confirming your identity

Before you have a treatment or procedure, our staff will ask you your **name and date of birth** and check your **ID band**. If you don't have an ID band we will also ask you to confirm your address.

If we don't ask these questions, then please ask us to check.
Ensuring your safety is our primary concern.

Part one: HIV

Being diagnosed with HIV does not mean you will quickly become ill. Most people with HIV live for many years without illness. In fact, modern medicines mean that it is perfectly possible that you will have a normal life expectancy. You need to have regular health check-ups and blood tests. These may seem daunting at first, but they are vital to your care.

Blood tests

Blood tests include Viral Load and sometimes CD4. The CD4 is a count that shows the strength of your immune system, while the viral load shows how active the virus is. You will have other tests as well, which will be explained to you when you have them. They can be explained in as much or as little detail as you want.

Viral load: This measures the amount of the HIV virus in your blood. The higher the viral load, the more virus there is to cause damage to your immune system. A higher viral load also means that you are more likely to pass on the HIV virus to others. Regularly taking anti-retroviral medicines brings your viral load down to very low levels, leaving your CD4 cells (and your immune system) to fight off infections. You also reduce the risk of passing HIV to someone else.

CD4 count: HIV finds its way into an important part of your immune system known as CD4 blood cells. The virus uses these cells to make copies of itself and, in so doing, it destroys the CD4 cells, reducing your CD4 count. This leaves your body less able to fight off infections. Most people keep up a healthy CD4 level for many years, but if it begins to fall below 350, your GP (home doctor) will recommend you start anti-retroviral medicines to improve your immune system.

Regular check-ups

You usually have these every six months if you have healthy Viral Load and CD4 levels. The check-ups are in two parts:

- one of our nurses will take some blood to test and may ask you some general questions about how you are feeling.
- a couple of weeks later the results will arrive back in the clinic and your GP will go through these with you.

Starting medication

Everybody who has HIV will need to take medication to treat it at some point. This enables them to lead a normal life with a normal life expectancy. Guidelines on when to start are set by the British HIV Association (BHIVA). The most recent guidelines, published in 2015, suggest that starting at any CD4 count may have some benefit. You can discuss this with your Caldecot Centre doctor.

Treatment for HIV is often called 'combination therapy' because a combination of drugs is used at the same time. It is also sometimes called Anti Retroviral Therapy (ART) or Highly Active Anti Retroviral Therapy (HAART). There are many drugs available, and they fall into a number of different categories or classes. Each class works on the virus in a different way. Combination ART is the most efficient way of keeping HIV in check.

It is worth discussing your thoughts or concerns with your Caldecot Centre doctor before you start treatment. For example, you may be planning to start a family. You and your Caldecot Centre doctor can decide together which combination is best suited to you and your lifestyle. You are welcome to ask questions and raise concerns about any aspect of your care and treatment at any time.

All medicines have side effects. Some anti-retrovirals have fewer or milder side effects than others, so talk about these with your Caldecot Centre doctor; they may then be able to take this into account for you. Most of the side effects are short term, but if any persist mention them to your Caldecot Centre doctor as they may be able to find an alternative that is easier for you to take.

You need to take your tablets at the same time every day, to keep the concentrations of the drug at the most effective levels in your blood. Taking the pills on time every day can seem hard at first and some people worry about it.

One way you can make it easier for yourself is to take a vitamin pill at the same time every day before you start combination therapy. That way, you will get used to taking something health-related regularly. When you start ART, all you need to tell yourself is that you are adding a couple more pills to what you already take.

You can get more information about anti-retroviral drugs from HIV i-base. There are a range of leaflets that you can pick up in the Caldecot Centre, or ask your Caldecot Centre doctor or nurse for them. You can also download them from its website: www.i-base.info

Keeping healthy

It is important to stay as healthy as possible. You can do a number of things to help yourself, such as giving up smoking, eating a balanced diet and getting some regular exercise.

- If you smoke and you would like help with stopping, please mention it to your GP or your Caldecot Centre doctor.
- If you would like some advice on diet, talk to your doctor at the Caldecot Centre as you can see our dietician.
- Exercise does not have to be too serious. For some people, exercising at the gym regularly is ideal, while others prefer cycling or walking. It is important to find a type of exercise that you enjoy.
- The Central YMCA gym at Tottenham Court Road run a Positive Health scheme which was set up specifically to promote increased activity levels for people living with HIV. After referral members follow a personalised 12-week programme, which includes an initial fitness assessment, a tailored exercise plan and support from professional fitness trainers throughout. If you would like to take advantage of this, please speak with your GP.

Your mental health is just as important as your physical health. Stress and depression can be a major concern for people with HIV. If you find yourself becoming depressed, tell your GP or your Caldecot Centre doctor because they can refer you for help.

Stress and anxiety do not help you or your immune system, but you can avoid or manage them. There are many ways you can make a few changes in your life to help ease stress. There are several groups where you can talk through and share your concerns. Our Patient Representative or our Specialist Practitioner in HIV Welfare and Support can give you more information (see Part Four for contact details).

When you tell people you are HIV positive, some of them may take the news well and some may take it badly. Take your time you can tell as many or as few as you want, as and when you want. At first, it may be best not to rush into telling everyone you know – you cannot ‘untell’ people later.

Being open about having HIV can mean that you do not have the stress of keeping it a secret. According to the National AIDS Manual, people who are open about having HIV have a stronger immune system and less illness.

It is important to tell doctors and nurses that you are HIV positive so they can give you the right care and treatment. We recommend you tell your GP. Many people do this because they want their GP to be aware of their whole health picture. This is important, for example, if your GP has to prescribe you a medicine and they need to check if it can be taken with HIV medication. Remember, some drugs and treatments can be prescribed by your GP only, not by your HIV specialist doctor. So it is important to register with a GP.

Support groups

There are several support groups around London. Many of them are run by people who are living with HIV themselves. Some groups meet in person, some are online. You can discuss these with our Patient Representative and with our Specialist Practitioner for HIV Welfare and Support who can help you decide which group is best for you.

Research and clinical trials

If you are interested in taking part in any of the studies and research projects taking place at the Caldecot Centre, your Caldecot Centre doctor or our Clinical Trials team can give you more information. These research projects help us to understand HIV better, as well as many other aspects of health. If you choose to enrol in a research project you will still be seen here at the Caldecot Centre by one of the research team.

Tel: **020 7848 5776**

Email: caldecotresearch@kcl.ac.uk

Part two: Our clinics

King's College Hospital offers HIV services across four sites:

Main site:

The Caldecot Centre

15-22 Caldecot Road

Camberwell SE5 9RS

Tel: **020 3299 5000**

Appointments only

Monday 9am – 5pm

Tuesday 9am – 7pm

Wednesday 12.45 - 8pm

Thursday 8am – 5pm

Friday 8am – 4.30pm

Emergency walk-in service:

Monday 10am – 11.30am

Tuesday 10am – 11.30am

Wednesday 1.30pm – 3pm

Thursday 10am – 11.30am

Friday 10am – 11.30am

Pharmacy

Monday 9am – 5.30pm
Tuesday 9am – 5.30pm
Wednesday 1pm – 5.30pm
Thursday 8am – 5.30pm
Friday 9am – 4.30pm

Satellite clinics:

Paxton Green GP Surgery

1 Alleyn Park
Gipsy Hill SE21 8AU
Tel: **020 8670 6878**

Clapham Family Practice

Mary Seacole House
89 Clapham High Street
Clapham SW4 7DB
Tel: **020 3049 6600**

HIV OneClinic at Riverside Medical Centre

Hobart House,
St Georges Wharf
Vauxhall SW8 2JB
Fridays 7.30am to 7.30pm

For further information about satellite clinics please contact Matron, Caldecot Centre.
Tel: **020 3299 4383**

Part three: How to find us

The Caldecot Centre

We are part of King's College Hospital. We are just off the main site, in Caldecot Road, off Coldharbour Lane.

Parking: It is very difficult to park anywhere near the Caldecot Centre. There are limited spaces in the hospital car park and traffic wardens regularly patrol the streets locally. It is far easier to get here by public transport.

Train: The nearest station is Denmark Hill, which is about a five-minute walk from the centre and has lifts from all platforms. Loughborough Junction is about a 10-minute walk.

Bus: The following all stop at King's, either on Denmark Hill or Coldharbour Lane: 35, 40, 42, 45, 68, 176, 185, 345, 468 and 484.

Paxton Green

Paxton Green is at the corner of Gipsy Road and South Croxted Road, at the bottom of Gipsy Hill, on the far side of the roundabout.

Parking: There is on-street parking in the roads off South Croxted Road and around the park opposite the health centre. Disabled parking spaces are available in Alleyn Park.

Trains: the nearest station is Gipsy Hill, about a five-minute walk. Services run from Victoria and

London Bridge.

Bus: The following all stop close to the centre: 3, 450, 322.

Clapham Family Practice

Clapham Family Practice is on Clapham High Street, between Clapham North and Clapham Common Tube stations.

Parking: Parking is limited in this area. It's easier to get there by public transport.

Overground trains: The nearest station is Clapham High Street with services to Clapham Junction and Highbury and Islington.

London Underground: The surgery is close to both Clapham North and Clapham Common stations on the Northern Line.

Bus: The following all stop close to the surgery: 88, 155, 345.

Riverside Medical Centre

Based at St Georges Wharf complex on the south-east side of Vauxhall Bridge.

Parking: Parking is difficult in this area. It's easier to get there by public transport.

Overground trains: The nearest station is Vauxhall for services to Waterloo and Clapham Junction.

London Underground: The centre is close to Vauxhall station on the Victoria Line. Leave the station by exit six.

Bus: Vauxhall bus station is opposite the surgery.

Part four: Our specialist services

These are available only at the Caldecot Centre.

Antenatal clinic

We can help and support you throughout your pregnancy; our specialist midwife comes to the clinic every week. We also offer contraception, cervical smears and appointments in our HIV gynaecology clinic.

Cascaid

This specialises in mental health issues and provides help, support and treatment for people with HIV.

Dietary advice

Our dietician can give you advice about eating healthily, weight loss and weight gain.

Housing, immigration and benefits

Our Specialist Practitioner in HIV Welfare and Support can help you with these issues. If you want to speak with them, please ask our receptionist to make an appointment for you or phone 020 3299 2193.

Patient support/general advice

Our HIV Patient Representative has been living with HIV for more than 20 years. He is based in the clinic and is happy to speak with you about dealing with and overcoming your diagnosis, concerns you may have about medications and so on. If you want to speak with him, please ask

our receptionist to make an appointment for you or phone 020 3299 2193.

Pharmacy

The specialist pharmacists in the Caldecot Centre pharmacy have full knowledge and understanding of all the drugs we give you. They can also give expert and non-judgemental advice on actual or possible interactions between the drugs prescribed to you here and elsewhere, including over-the-counter medicines.

Who can I contact with queries and concerns?

If you need any more advice or help, please phone our nurses on 020 3299 3707.

PALS

The Patient Advice and Liaison Service (PALS) is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. The PALS office is located on the ground floor of the Hambleton Wing, near the main entrance on Bessemer Road - staff will be happy to direct you.

PALS at King's College Hospital, Denmark Hill, London SE5 9RS

Tel: **020 3299 3601**

Email: **kch-tr.PALS@nhs.net**

You can also contact us by using our online form at **www.kch.nhs.uk/contact/pals**

If you would like the information in this leaflet in a different language or format, please contact PALS on **020 3299 1844**.

www.kch.nhs.uk

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