



**Central and
North West London**
NHS Foundation Trust

Bloomsbury Clinic

Information for patients



Wellbeing for life

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Welcome

Welcome to the Bloomsbury Clinic.

We provide a free and confidential outpatient service for people living with HIV.

This guide includes information about our services and how they can help you. It also points to other sources of information and support that you might find useful.

If you have recently learned you are HIV positive, the first section of the guide is designed to help you consider some of the issues that may be on your mind. The further sections are there for reference whenever you need them.

If there's anything in this guide that you don't understand or want to ask about, please talk to a member of staff on your next visit. **You can also call the clinic for advice on 020 3317 5100 or drop us an email at b.patients@nhs.net**

HIV and you

When you were first told you were HIV positive, you might not have heard much else that was said.

A positive HIV result is a lot to take in. You might be feeling shocked, upset or angry.

Here we've set out the essentials about what your diagnosis means for your health, and what it might mean for you in a wider sense. We've also suggested some reliable sources of further information that you might want to check out.

HIV and your health

Being told you are living with HIV means you have been infected with the Human Immunodeficiency Virus.

Being diagnosed with HIV does not mean you have AIDS (Acquired Immune Deficiency Syndrome). AIDS applies to serious infections, cancers and symptoms that are only seen when someone has a very damaged immune system due to HIV. Early diagnosis and treatment means very few people with HIV will ever develop AIDS.

The most important thing to remember is that HIV is now generally considered a long term manageable condition.

This means you are unlikely to become ill or experience a lifetime of ill health.

U = U (Undetectable = Untransmissible). Evidence shows that once someone has an undetectable viral load for more than 6 months they will no longer be able to pass on HIV.

The life expectancy of most HIV positive people on treatment is now similar to that of those living without HIV.

We can also now say that when you have an Undetectable viral load on treatment (this is the blood test we use to make sure the HIV medication is working) there is a zero risk of transmitting HIV to your HIV-negative sexual partners.

In many ways, your life after diagnosis is likely to remain the same.

You will, however, need to get used to coming in to the clinic for regular check-ups and blood tests. These are an essential part of your care.

Your first appointment: what to expect

On the day of your diagnosis, you are likely to have had a full set of blood tests taken.

These tests are designed to check how well your immune system is working. They will provide a baseline to help us plan your care.

At the same time, a health adviser will have made a 'New Bloomsbury' doctor appointment for you.

Your first doctor's appointment at the Bloomsbury Clinic will be up to an hour long. This is to allow you time to discuss the results of all your blood tests and to ask questions. It might be useful to write down any questions you might have and bring them with you.

If you decided not to arrange any follow-up when you were first diagnosed you can make an appointment later by calling 020 3317 5100. Please state that you are a new HIV positive patient requiring a 'New Bloomsbury' appointment.

What to test for

Blood tests taken on your day of diagnosis may include:

- **CD4 count** – this is a type of white blood cell that fights infection, the higher the CD4 count the healthier your immune system. Without treatment the CD4 count goes down over time until you are at risk of serious illness, particularly infections. CD4 will go up when you start treatment and once you are undetectable with a good CD4 count (more than 500) we won't check your CD4 again routinely.
- **Viral load test** – measures the amount of HIV in your blood. The higher your viral load the more likely you are to have symptoms and the more likely you are to pass the virus on to sexual partners. Successful treatment reduces the viral load to 'undetectable' levels (less than 50 copies of virus per cubic milliliter of blood) - once this happens your CD4 goes up and you cannot transmit HIV.
- **Incidence test** – may show if you have recently acquired HIV. The test cannot tell you a precise date - it can only tell you if you are likely to have acquired HIV more than or less than 4 months ago.
- **Resistance test** – tells us if you have a virus that is resistant to some HIV medication this affects less than 1 in 10 people to help us choose the right medication for you.
- **Liver/kidney function** – these are monitored regularly to monitor your general health and to check for possible side effects from HIV medication.

For more details, download the booklet 'CD4 count, viral load and other tests' at www.aidsmap.com/booklets. This website also offers information on many other aspects of HIV care and treatment.

Living day to day with HIV

It's relatively easy to spell out what HIV means for your health and care. But what about the impact on your personal life?

How your diagnosis affects you will depend partly on your circumstances and the people around you.

But whatever your situation, and however overwhelming it may seem at first, being HIV positive doesn't need to dominate your life.

Here we consider some of the most pressing questions you may be asking yourself now – about who to tell, about your children, about having sex, and who you can talk to?

Real life stories

People with HIV tell of their experiences of being diagnosed at the Avert website <https://www.avert.org/living-with-hiv/stories>

Who should I tell?

Who you tell you are HIV positive, and how you tell them, is up to you. You might find it helpful to think about what this news means to you, and give yourself some time to accept your diagnosis, before you tell anyone else. Our Health Advisers can help. They are here to support and help you through this. You do not need an appointment, just walk in and tell reception that you need to see a Health Adviser. It might be useful to talk to other HIV positive people about their experiences before you decide who you want to tell. For instance, you might attend one of our regular Beyond Diagnosis courses, or talk to a peer support worker – see 'Who can I talk to?' on page 14.

How will they react?

People might respond to your diagnosis in different ways. Here are a few things to think about:

- Don't assume that everyone you tell will take the news badly. Those close to you may be upset, but that's because they care about you. People can't offer you support if they don't know that you need it.
- Remember that once you tell someone, you can't take this information back. Perhaps it is more useful to think about who needs to know.
- Be prepared to deal with some difficult questions and awkward silences.
- Some people may not be well-informed about HIV.
- How others react to your diagnosis may change in time once they have had the opportunity to think things through
- Some people you tell may not be aware of the up-to-date position on HIV. It might be useful to have some information to show them.
- People with HIV do, unfortunately, suffer from prejudice and discrimination. Stigma can be challenged, and information and education is often the best way to fight it.
- Your own feelings about HIV before your diagnosis can impact upon how you feel about HIV and yourself upon diagnosis (self stigma). Health Advisers, Peer support and Psychology are here to help and support you with this.
- Read other people's experiences of who they told, and what happened – on the Terrence Higgins Trust website (www.tht.org.uk/myhiv/Telling-people).

Telling your partner

If you're in a relationship and your partner doesn't yet know about your HIV diagnosis, you will likely be thinking about when and how to tell them.

You may want to take some time to think about how you want to tell them and how they might react. Waiting too long may make it more difficult and your partner may be upset by the delay in telling them.

When you tell them, make sure you and your partner are alone together in a place where you both feel comfortable and safe.

You could talk it through beforehand with a trusted friend, or with a Health Adviser or Peer Support Worker at the Bloomsbury clinic.

Your partner may want to get tested themselves (you can contact a Health Adviser to arrange this) although it is not inevitable that they will also be HIV positive. And if they are found to be HIV positive, it doesn't mean they contracted the virus from you (or you from them).

You may both want to consider having counselling, either individually or together. There are details in the Advice and Support section on page 47.

Telling your employer

You will not usually have to tell your employer about your HIV status.

However, you might find it useful to tell your employer – they will often be supportive, and there may be times when you need to take time out of work to attend clinic appointments.

In August 2013 the government lifted a ban on HIV positive healthcare staff carrying out invasive surgical procedures. Legislation for healthcare workers was updated in 2014. All new workers are offered testing for HIV and hepatitis & anyone performing procedures where HIV could be transmitted must have an HIV test. If you are living with HIV and performing certain procedures you are allowed to work if your viral load is undetectable (checked every 3 months) and you are under an occupational health clinician. Occupational health departments within the NHS are used to dealing sensitively with employees with HIV.

The Equality Act 2010 gives people with HIV the same protection against employment discrimination as disabled people. You can read more here:

<https://www.tht.org.uk/hiv-and-sexual-health/living-well-hiv/your-rights/equality-act-and-workplace>

Telling your GP

We strongly recommend that you tell your GP about your HIV diagnosis.

Your GP is the provider for most of your healthcare needs, so it's important they are aware you have HIV to enable them to make informed decisions about your care. There are several vaccines we recommend that are only available through your GP

Many of the drugs used to treat HIV interact with other medications, which could cause you harm or compromise the effectiveness of your HIV treatment. Your GP can only prescribe safely if they know about ALL the medications you are taking.

If there are reasons why you would prefer not to inform your current GP, you can register with another practice. You can discuss this with one of our Health Advisers or Peer Support Workers.

Telling future sexual partners

Telling a new sexual partner you are HIV positive is often a daunting prospect.

It is generally better to be up front and honest about your status at the very start of a relationship. If a new partner has a good understanding of HIV, how it can be transmitted and how to prevent this, it might not be an issue.

Telling new partners about your status before becoming intimate will give them the chance to decide what they want to do.

The evidence that an undetectable viral load on treatment means you can't pass the virus on can be very helpful when telling partners. If you have not started treatment and do not currently have an undetectable viral load your partner should consider other preventative options including condoms and pre-exposure prophylaxis.

Health Advisers can arrange to spend some time with you and your partner to discuss all aspects of living well with HIV including how to prevent transmission.

HIV and the law

There have been cases in the UK where HIV positive people have been prosecuted for 'recklessly' transmitting HIV to their partners.

In UK law you do not have to disclose your HIV status as long as you use condoms and also if you are undetectable and on treatment.

- For further information about HIV and the law, see the booklet 'Transmission and the law' at www.aidsmap.com

What about my children?

If you have children, we would like to talk to you to find out whether they need an HIV test. If so, we can ensure this is done without delay in a safe and supportive environment.

We understand that testing your child/children may be a difficult decision. Your HIV Doctor and the rest of the team are here to support you and talk through all your worries.

Through our links with self-help organisations like Body & Soul (www.bodyandsoulcharity.org), we can also arrange for you to speak to other parents who have been in this situation.

Although testing your child/children for HIV may be stressful, it is very important: infants and children are extremely likely to remain healthy if they are diagnosed early.

Is it safe to have sex?

Although HIV is most commonly passed on through unprotected sexual intercourse (vaginal or anal sex without using a condom), you can still enjoy a full and active sex life. And remember, if you have an undetectable blood viral load on treatment you cannot pass the virus on through sex. U=U. For more advice, see Enjoying sex on page 40.

Who can I talk to?

After an HIV diagnosis, you may feel alarmed, apprehensive or simply that you need to arm yourself with more information.

Your doctor, health adviser and other clinical staff here at the Bloomsbury Clinic are here to help and discuss your options. You might also feel it useful to discuss your feelings with someone in a similar situation, or who has already experienced what you're going through.

Peer Support Team

Support and advice from people who are 'living with HIV' is available through the Bloomsbury Clinic's Peer Support Team.

Peer Support Workers use their lived experience to bridge the road to recovery. By sharing their own experiences they can help you understand how to manage life after a diagnosis of HIV.

They offer understanding, acceptance and empathy based on shared experience. The Peer Support Team in the Bloomsbury clinic, model 'the gift of hope' by offering images of possibility, as well as providing practical information, support and ideas about coping strategies and problem solving based on their personal lived experience.

Peer Support can be defined as:

'a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful'. Mead (2003)

You can talk to them about anything regarding living with HIV. Their office is in the main reception area of the Bloomsbury Clinic and they are available five days a week. You can phone 020 3317 5177 for an appointment, or just walk in to see them.

Beyond Diagnosis courses

Join one of our courses specifically aimed at HIV positive people who are recently diagnosed or still struggling to come to terms with their diagnosis.

We run around four courses per year. There are usually about 10 participants and it's an opportunity to meet, share and support others who are on a similar journey.

Since the start of the Corona virus pandemic our Beyond Diagnosis courses have been run as online zoom events. We are currently considering whether these sessions should remain virtual or return to face to face meetings.

The aim is to help you gain an understanding of the condition, share experiences and determine your own future.

Topics include:

- The impact of diagnosis
- Telling others – who, why and how
- Medical aspects, including medication
- Love, sex and relationships
- Stigma
- Keeping your immune system in good shape
- Building support networks

All people living with HIV are welcome to attend - regardless of the clinic you attend. All course facilitators are HIV positive.

Child care and travel costs may be available for patients of the Bloomsbury Clinic.

For more information or to book a place on a course, contact the peer support workers on 020 3317 5177.

Bloomsbury Patient Network

Our Patient Network is run by patients, for patients, and is independent of the CNWL HIV Service and is a registered charity. If you're a Bloomsbury Clinic patient, you're welcome to get involved.

Besides the Beyond Diagnosis courses above, the Network runs workshops, forums and social events.

To be kept personally informed you can join our email list to receive weekly newsletters.

Send an email to admin@bloomsburynetwork.co.uk or give your address to one of the peer support workers in person or via reception. You can also leave your details on 020 3317 5100 or visit them in the Bloomsbury Clinic, at Mortimer Market, Off Tottenham Court Road, London WC1E 6JB.

Taking control

There's lots of information and advice out there about dealing with HIV. We've put together a guide on some of the most dependable sources, and how to go about doing your own research. See 'Taking control' on page **xx**.

Further help

For further sources of guidance and counselling, see the Advice and Support section on page 47.

Your check-ups and treatment

Routine appointments

Routine HIV care is provided by a team of doctors and specialist nurses (SPN), who can all prescribe your HIV treatment and other medications or vaccines relevant to your HIV care. If you have symptoms or concerns that require a physical examination (such as joint pain or shortness of breath) then you should ask to see a doctor. If you have difficulty taking your medication a specialist nurse may be the best option.

You will need to attend for regular blood and urine tests – it is helpful to have these done before your appointments with a doctor/SPN but we can be flexible depending on your needs. You may be asked to complete questionnaires when you attend for tests or online prior to your appointments.

Booking your blood tests on-line

You can book your next blood test when its convenient for you via our remote booking system Zesty. Zesty will show you what blood test appointments are available. To book on-line follow the link to Zesty <https://www.zesty.co.uk/practices/bloomsbury-rapid-blood-test-clinic>

Not all appointments are in person and we can offer phone, email and video options – the latest information will be on our website: <https://www.sexualhealth.cnwl.nhs.uk/clinic/bloomsbury-clinic/>

It is important to let us know about any changes to your health, lifestyle or medications (including illicit drugs, herbal treatments, medication you can buy over the counter, inhalers, nasal sprays and injections).

Making an appointment

Call 02033175100 or email us at b.patients@nhs.net. If you have an urgent medical problem you can call 07464 835124, this phone is monitored by a doctor and you will be called back within one working day. Please include your name, date of birth, nature of your enquiry and, if possible, your clinic number whenever you leave a message or send us an email.

When you have an appointment you will be put on a list to be contacted and reminded when your next tests and/or appointment are due.

If you have any problems making an appointment you can ask to speak to the Bloomsbury coordinator or a manager.

You will receive a text confirmation when any appointment is booked and usually a reminder about 2 days before the appointment is due. It is helpful if you can set your own reminder too, just in case. If you are unable to attend the appointment and need to cancel it please let us know as soon as possible on 020 3317 5100 or email b.patients@nhs.net so we can offer the slot to someone else.

Interpreters

If you need an interpreter you should let the clinic know as soon as possible so we can arrange an interpreter (by phone or in person) and can ensure you have a longer appointment to allow extra time. If you need a sign language interpreter we ideally need at least 2 weeks' notice.

Your doctor

You may wish to see the same doctor or nurse for your follow-up appointments and if so we will try to arrange this. However, it may not always be possible.

If you are unable to get an appointment with your regular clinician, or prefer to see/speak to a specific member of the team, speak to reception staff, call 020 3317 5100 or email b.patients@nhs.net with your preference.

Most doctors and specialist nurses run the same clinic sessions each week. Please check at reception to find out when your doctor or specialist nurse is working.

When you arrive

Always check in at reception on the ground floor when arriving for your doctor or specialist nurse appointment. Reception staff will be able to tell you where in the building your doctor or specialist nurse is based that day.

Routine tests

If you are attending for tests please check in at the Bloomsbury Clinic reception on the ground floor – these appointments need to be booked in advance unless you have been advised differently by a member of staff.

Although most appointments for tests are pre-booked some people attend with more complex issues so there may still be a wait. We will try to see you as close to your booked appointment time as possible.

If you only require routine blood tests, sexual health tests/ treatment or vaccines you don't necessarily need to see a doctor or specialist nurse. Go to Bloomsbury ground floor reception and tell the receptionist what you have attended for.

You can walk in and request blood tests or sexual health test at any time during clinic opening hours (see our website for up to date information or ask a member of staff).

Waiting times to see a nurse may vary, depending on how busy the clinic is, and may be more than 2 hours. You can book bloods and sexual health check-ups online - please see our website.

Early morning tests

Availability will vary depending on COVID and staffing. Please see our website for the latest information:

<https://www.sexualhealth.cnwl.nhs.uk/clinic/bloomsbury-clinic/>

Types of test

We carry out blood and urine monitoring to fit your individual circumstances. Your doctor or specialist nurse will discuss with you which blood tests you need to have, and how often you need to have them.

Routine blood tests may include:

- Full blood count,
- Kidney function,
- Liver function,
- HIV viral load,
- Syphilis.

There are some other tests such as hepatitis immunity, cholesterol and diabetes checks that we perform once a year or less often. We won't need to do all these tests every time you attend.

If you are on effective HIV treatment (HAART), CD4 counts are usually no longer needed. If you are having a lipid/cholesterol and glucose profile test you will usually not need to avoid eating/drinking before your blood tests. Your doctor or specialist nurse will tell you.

Getting your results

When you come for blood tests, make sure you have arranged how you'll receive the results. This may be:

- By face-to-face appointment: this should have been booked already otherwise you can book one at reception or ask the person taking your bloods to do this. If you are due a face-to-face but you and the person doing your tests think you can have a virtual appointment we can rebook as require.
- By virtual appointment (phone/video/email): this should have been booked already otherwise you can book one at reception or ask the person taking your bloods to do this. If any issues arise during your tests, such as you report symptoms or missing doses of your HIV medication, you may be advised to book a face-to-face appointment instead.

We cannot guarantee the security of emails sent outside the NHS Mail system.

If you have been asked to return for specific tests, your doctor or nurse will let you know how you'll get the results (they may phone you, for example).

Screening for sexually transmitted infections (STIs)

If you have symptoms that suggest you might have an STI, or if you would just like a routine sexual health screen, you don't need to book an appointment. Just go to the ground-floor of the Bloomsbury Clinic and ask to see a nurse at reception. You can also book online: please see our website.

Starting HIV treatment

We recommend that everyone with HIV starts treatment as soon as possible for their own health. It also means you do not need to worry about passing HIV on to your sexual partners thanks to U=U (see page xx).

You may have read about 'same day treatment' where you start your HIV medication on the same day that your diagnosis is confirmed. This is an option if you prefer though there is no evidence, at the moment, that this is any better than waiting a week or two for all your test results to come back. If you prefer to get the virus undetectable as soon as possible we will choose a combination that can be started on the same day – this may need to be changed once all your results are back.

Some people prefer to wait until they are ready to start treatment which can take a few weeks or longer – the team will talk to you about the options and any possible risks. At the moment taking treatment requires you to take one or more tablets every day and some people need time to adjust to this.

When to start?

There are some situations where we will strongly recommend starting treatment as soon as possible – nobody can force you to take treatment but they will talk to you about any risks to your health by not taking medication when it is recommended:

- If you have an HIV-related illness
- If you have symptoms of 'seroconversion' or very early HIV – this is due to the level of the virus being very high.
- You are diagnosed with HIV in the 3rd trimester of pregnancy
- If you are a man with a pregnant partner
- Your CD4 count is less than 350 (and especially less than 200)

There may be circumstances when you are advised to start taking ART earlier. Recent research suggests that an undetectable viral load may significantly reduce the chance of passing on HIV. If you feel that you would benefit from starting medication earlier than the current recommendations, please discuss this with your doctor, specialist nurse or health adviser.

Treatment: things to consider

The final decision of when and how to start taking ART is yours. Before you decide, there are some things you might want to think about:

- Since ART became widely available in the mid-1990s, there have been dramatic reductions in cases AIDS or people dying from HIV related illness. This is a direct result of successful treatment.
- Modern drugs are generally well tolerated and easy to take. Some HIV drugs can have side-effects. These tend to decrease over time, and most people start feeling better after they have been taking ART for a month or so. If necessary, we can switch your HIV treatment to an alternative or we can offer treatment for the side-effects.
- We will usually be able to find treatments that suit you (this can depend on your general health, lifestyle, other medications you are taking and whether your HIV has any drug resistance).

In the Bloomsbury Clinic we prescribe ART in accordance with national guidelines written by the British HIV Association (BHIVA) and NHS England Policy– see the BHIVA website at www.bhiva.org for more details.

There's further guidance on starting treatment at:

- **NHS Choices** (www.nhs.uk/Conditions/HIV/Pages/Treatmentpg.aspx),
- **Terrence Higgins Trust** (www.tht.org.uk/myhiv/HIV-and-you/Your-treatment/Starting-treatment), and
- **Aidsmap** (www.aidsmap.com/Starting-HIVtreatment/page/1230814/).

Treatment Advice Clinic

Your doctor or specialist nurse might recommend that you have an appointment in this clinic if they think it will be helpful for you.

The TAC team is made up of consultants, specialist nurses, trainee doctors, health advisers, pharmacists and psychologists. They can provide an individual plan of your care and follow-up after starting therapy.

The TAC team aims to offer a 'one stop shop' to provide extra support around starting/switching treatment or managing medication difficulties. They will usually refer you back to the general clinic but can offer you more support if needed in the future.

If at any time you need to change your ART, the TAC team can offer you treatment advice and support again.

Once you're on treatment

Most people adjust to the routine of taking ART relatively easily.

To be successful, treatment needs to be taken every day, at approximately the same time. You will also need to follow food requirements for some medications & avoid other drugs which might interact with your HIV medications and make them less effective. If you don't take your medication as recommended there is a risk that the virus will rebound and develop resistance to some drugs making it more difficult to treat. If your virus rebounds, there is a risk you will also feel unwell and it is likely that will be able to transmit the virus to your sexual partners.

If you do miss a dose or two of ART, as long as its not very often, there is usually no cause for alarm. Our clinic staff can tell you more.

If you have issues with your treatment, do not just stop taking it. Stopping your drugs suddenly can lead to your virus developing resistance to one or more drugs in your combination. If you can't cope with side-effects, discuss it with your doctor or specialist nurse.

Testing while on treatment

Once you start treatment for HIV, you will still need to have your blood tested regularly to ensure that your treatment is working.

Most people get to an undetectable viral load within one to two months of starting treatment for HIV.

Once HIV is being controlled, your CD4 count is unlikely to deteriorate. So when you have achieved and maintained an undetectable viral load, we will review whether and how often your CD4 count needs to be monitored, if at all.

- There's more information on starting ART, including information on CD4 counts at: <http://i-base.info/guides/starting>.

Branded or generic?

Branded medicines are those named by a drug company (such as Nurofen or Hedex). Generic medicines go under the name of their active ingredient (such as ibuprofen).

Over the last few years, several HIV medications have become available as generics: they are just as effective but cost much less.

The savings achieved for the NHS by using generics allow more patients to be treated for the same amount of money.

For more information on branded and generic drugs, see the i-base website <http://i-base.info/guides/starting/nhs-changes-and-generic-drugs>

Home delivery and Boots

If you are stable on treatment, you can have your medication delivered direct to your door at home.

All medication is delivered in unmarked packaging at a pre-arranged time to suit you.

We can also arrange for you to collect your medication from selected Boots stores across London and several other places outside London. As with home delivery, the medication comes in plain packaging. Home delivery companies deliver medications for a huge range of conditions, and the Boots staff won't know what's inside.

Besides saving you trips to the pharmacy, having your medication delivered to you saves the NHS around 20% on the cost of your treatment.

To join the scheme, please speak to your doctor, specialist nurse or the clinic pharmacist.

Running low?

Please call 0203 317 5100 or, if you have at least 1 week left you can email b.patients@nhs.net, to request an emergency prescription. Ideally, we need at least 2 working days' notice.

Please make sure you know exactly how much medication you have left so we can offer you the best option; this may involve booking you a phone appointment or asking you to attend the service to collect your medication.

If there is not enough time to deliver your medication and you cannot attend during usual opening hours we can arrange for you to collect your medication from the pharmacy at University College Hospital in the evening or a Saturday. Our pharmacy is open at least one evening a week. Please ensure that you give us **48 hours' notice**. It is useful to have your details and an idea of what medication you need to hand.

Research and clinical trials

The Bloomsbury Clinic has developed an international reputation for its research studies on HIV/AIDS.

We are particularly grateful to our service users here at the Bloomsbury Clinic, who have been enthusiastic in supporting and taking part in our research.

There are many HIV clinical research trials in progress in the clinic. If you are interested in taking part, please discuss this with your Bloomsbury doctor or specialist nurse, or contact one of the research nurses in the clinic.

For more information, call 020 3108 2056.

Family clinic

A clinic for children and young people with HIV is held every Friday morning at Great Ormond Street Hospital (GOSH).

Children and young people can be seen at the same appointment by an HIV physician from the GOSH paediatric team and a Health Adviser from the Bloomsbury clinic.

For further information, please phone the Bloomsbury Health Advisers on 07702 339298.

Young people's clinic - TEAM

The TEAM Clinic at the Bloomsbury Clinic provides a range of services specifically for HIV-positive teenagers and young people under 25 years old. Medical, psychological and social needs are all explored and catered for.

The clinic team includes doctors, a specialist nurse, health advisers, a clinical psychologist and a peer support worker who are all experienced in working with young people and HIV.

The TEAM clinic, based in the Bloomsbury Clinic, runs every second Tuesday from 4pm to 6.30pm.

To book an appointment, contact the TEAM mobile on 07747 795276 or call the health Adviser mobile 07702 339298.

Emergencies

During clinic times

If you feel unwell and think that your problem is related to HIV, you can leave a message for a doctor to call you back within one working day on 07464 835124.

If you have an issue you think is HIV-related and you cannot get through on the phone you can walk in during clinic hours (see website) but you may be advised to see your GP, attend and Emergency Department or return for a booked appointment with one of our team. We run an Urgent Clinic Monday-Friday but these appointments are prebooked. If you are attending without an appointment please tell the Bloomsbury ground floor reception staff you need to speak to the clinic coordinator.

If you have a productive cough (where some type of secretion comes up during coughing) or symptoms of a chest infection, please tell the nurses or receptionist about your symptoms as soon as you arrive in the clinic.

You should see your GP for other health issues that are unrelated to HIV.

At other times

Please call your GP, NHS 111 or ring 999 for an ambulance

You can leave a message on the mobile number above for a call back from a doctor within 1 working day.

Emergency mental health support

If you experience any kind of crisis related to your mental health when the clinic is closed, you have a number of options.

Your GP may be able to see you for a home visit in an emergency.

You can go to your nearest emergency department. They will have mental health staff available to help. This is particularly important if you feel suicidal.

You can also call the following agencies for help:

- Samaritans 116 123 (24 hours a day, 7 days a week).
- NHS Direct 111.

There are other options listed online at <https://www.nhs.uk/conditions/suicide/>

Prevention of HIV for HIV-negative partners

If your HIV-negative partner thinks that they might have been exposed to HIV they should come into the Mortimer Market (Green zone) during clinic hours and ask for PEP. PEP also can be accessed through other sexual health services and emergency departments. PEP needs to be started within 72 hours of a possible exposure. Remember U = U, if you have had an undetectable viral load for more than 6 months they will not need to take PEP as Undetectable = Untransmissible.

- If your viral load is not undetectable, or your partner has other sexual partners who may have a detectable HIV viral load, they may be eligible for pre-exposure prophylaxis (PrEP). PrEP means taking a tablet containing two HIV drugs every day or, in some situations, before/after sex. PrEP greatly reduces the risk of getting HIV. You can read more here: <https://www.iwantprepnnow.co.uk/> <https://www.sexualhealth.cnwl.nhs.uk/prep/>

Hospital care

If you should need treatment in hospital because of conditions related to HIV we will usually refer you to University College Hospital.

University College London Hospital (UCLH) is nearby on the Euston Road. There is a specialist infection team who look after people with HIV-related illness. Some of the doctors at the Bloomsbury clinic also work with the inpatient team. If you are admitted with a problem not related to HIV you may be under the appropriate specialist team with input from the HIV specialists if needed.

Living your life

Staying healthy

People with HIV may be at higher risk of age-related illnesses including heart disease.

A good diet, regular exercise and plenty of rest and relaxation will keep your immune system and general health in good shape and help you feel good.

Moderating alcohol, smoking and recreational drug use will also have a positive impact on your general health and the health of your immune system.

People with HIV are at higher risk of mental health problems including depression. Being diagnosed with HIV can trigger anxiety and/or depression in some people.

If you notice a change in your mood, tell your Bloomsbury doctor or specialist nurse as soon as possible. Alternatively, speak to our emergency doctor or a health adviser. They can refer you to our Psychology team for support with your mental health and wellbeing - see Psychological therapy on page 48.

You may also want to consider changes you can make in your life. Staying connected with friends and family and physical exercise can help towards maintaining emotional wellbeing. Our peer support workers can refer you to the Positive Health programme at the local YMCA.

It is often useful to discuss your options with a Health Adviser or peer support worker.

- There's guidance about healthy living with HIV at the Terrence Higgins Trust website: www.tht.org.uk/myhiv/Staying-healthy

Enjoying sex

We can now say with certainty that if you have an undetectable viral load on treatment and take your medication as recommended you CANNOT pass HIV to your sexual partners. Undetectable = Untransmissible.

Condoms are a proven means of preventing HIV transmission, and, even if you have an undetectable viral load, are an important way of preventing other sexually transmitted infections (STI) including hepatitis C.

If using latex condoms, use the correct size for you, and a water or silicon based lubricant. Non-latex condoms are available for those with a latex allergy.

Condoms are available free in the Bloomsbury Clinic. You can also buy condoms at the lowest possible prices from Freedoms Shop: www.freedoms-shop.com

Pre Exposure Prophylaxis - PREP

If your viral load is not undetectable your partner may be eligible for pre-exposure prophylaxis or PreP. PreP is anti retroviral medication taken by those without HIV to prevent them from catching it. More information on PrEP is available here: <https://www.iwantprepnw.co.uk/>

Emergencies

If you do not have an undetectable viral load and your partner may have been exposed to HIV (for example, if you didn't use a condom or the condom broke) they can get advice about post-exposure prophylaxis (PEP). This is a 28-day course of HIV treatment (a combination of 3 drugs). PEP works best if started within 24 hours can cannot be started more than 72 hours after a possible exposure, so they should go to a sexual health service of Emergency Department for advice.

For more information, and to help your partner decide whether PEP is needed, visit: <https://www.tht.org.uk/hiv-and-sexual-health/pep-post-exposure-prophylaxis-hiv>

If you're both HIV positive

If your partner is HIV positive too, you may both feel that you don't need to use condoms when you have sex.

If one of you has a detectable viral load and a virus that is resistant to some medications there is a possibility the other person can be infected with the different strain. This is very uncommon but please speak to your doctor or specialist nurse if you are concerned.

Other infections

Using condoms will also greatly reduce your chance of having other sexually transmitted infections (STIs), such as syphilis, hepatitis C, chlamydia and gonorrhoea.

If you are not on treatment for HIV and you catch a genital STI, the viral load in your semen or vaginal fluid may increase. That makes you more likely to pass on HIV to someone else.

If you have symptoms of a sexually transmitted infection please call 020 3317 5252 to book an appointment or check out our website at www.sexualhealth.cnwl.nhs.uk

If you do not have any symptoms you can have an STI screen when you attend for routine bloods appointments in Bloomsbury. Alternatively you can order a home testing kit from Sexual Health London <https://www.shl.uk/>

Having children

Many people living with HIV think that HIV will stop them having children – this is not the case.

Women

An HIV positive woman with an HIV negative partner can have sex and conceive naturally if she has an undetectable viral load on treatment. If she has a detectable viral load we will encourage starting or switching treatment to get this undetectable, otherwise she can self-inseminate with her partner's sperm. We can give advice on how to do this.

All women trying to conceive should take folic acid supplements and there are some HIV drugs we don't recommend in pregnancy so please speak to your clinician if you have or are planning to become pregnant. If your viral load is not undetectable your partner may be eligible for pre-exposure prophylaxis or PreP. More information on PrEP is available here: <https://www.iwantprepnov.co.uk/>
<https://www.sexualhealth.cnwl.nhs.uk/prep/>

Men

HIV positive men with an HIV negative female partner can have sex and conceive naturally if he has an undetectable viral load on treatment. If your viral load is not undetectable your partner may be eligible for pre-exposure prophylaxis or PreP. More information on PrEP is available here: <https://www.iwantprepnov.co.uk/>

For gay men there are also options including surrogacy and adoption - we can provide more information.

If you're both HIV positive

If you are both HIV positive then you can conceive naturally. For anybody having difficulty conceiving we recommend seeing your GP for further tests.

Becoming pregnant

If you think you are pregnant, or you are planning pregnancy, please tell your doctor or specialist nurse as soon as possible.

We have an antenatal team, including a specialist midwife and a health adviser for HIV positive pregnant women.

In pregnancy

A pregnant woman who is HIV positive should take anti retroviral therapy (ART) during her pregnancy. This will greatly reduce the risk of transmission of HIV from mother to baby.

If the mother's viral load is undetectable, a vaginal delivery is usually possible.

If you are pregnant, you will be involved in any decision about which form of delivery is best for you and your baby.

Mothers of newborn babies will be advised to bottlefeed, as breast milk may contain HIV.

The newborn babies of HIV positive mothers are also given a course of HIV treatment and tested for HIV.

As a result of these measures, over 99% of HIV positive mothers do not pass HIV on to their babies.

Going abroad

Travel clinic

You can get travel advice and vaccinations at the travel clinic provided by University College London Hospital (UCLH) at the Mortimer Market Centre.

Please note that you will be charged a fee for consultations and vaccinations in this clinic. You can also buy other travel healthcare products and books.

For an appointment, call 020 7388 9600.
UCLH Travel Health Line: 09061 337733.

Things to think about

If you are planning to travel abroad, it is important to think ahead and plan some things in advance.

- Some countries refuse entry to people with HIV (for details, see www.aidsmap.com).
- If you are on treatment for HIV you will need to make sure you take enough medication with you and you may need a letter from the clinic describing what medication you are taking.
- In general we recommend sticking to your usual medication times e.g. if you take your meds at 6pm usually then take the at 6pm at the new destination. Occasional longer or shorter gaps between doses are OK.
- Think about how you will be able to access healthcare, if you need it, in the countries that you plan to visit.
- Check that your travel insurance covers people with HIV.

European Health Insurance Card

The status of the European Health Insurance Card (EHIC) which lets you get free or reduced cost health care across Europe is uncertain post-Brexit. Check www.gov.uk for latest advice.

Taking control

Staying well informed about HIV issues can help you to make better decisions. It can also counter the sense of powerlessness that sometimes comes with an HIV diagnosis.

Discussing issues with Bloomsbury Clinic staff, including the peer support workers, is a good way to keep up-to-date.

There are also many other sources of information. Some are listed at the end of this guide.

As a good starting point, we'd recommend taking a look at the sites of AIDSmap (www.aidsmap.com) and the Terrence Higgins Trust (www.tht.org.uk).

The internet offers vast amounts of information on HIV and can be a useful resource. It's important, though, to make sure you are looking at up-to-date information from trusted sources. If you have any doubt about a particular website, the peer support workers are a good sounding board.

If you come across information that concerns you or that you think might be relevant to your treatment, please raise it with your doctor or specialist nurse.

Advice and support

If you have a concern or just need to talk something through, there are plenty of people at the Bloomsbury Clinic who can help. You could talk to:

- Your doctor or specialist nurse,
- A health adviser, or
- A peer support worker.

If you have more long term issues and think you could benefit from longer term support, there are a range of services available.

Counselling

Health advisers in the Bloomsbury Clinic at the Mortimer Market Centre are able to provide information, counselling and support for people infected or affected by HIV.

They offer short term counselling on issues such as adjustment to diagnosis, disclosure, HIV transmission, risk reduction, safer sex and living well with HIV.

You can walk in without an appointment to see a health adviser, just ask at reception. Alternatively you can call the Health Adviser mobile number on 07702 339298. If you wish to speak to a health adviser you can also ask your doctor, specialist nurse or one of the nurses or health care associates in clinic.

Psychological Therapy

The team of psychologists based at the Mortimer Market Centre provide talking therapies for anyone experiencing difficulty with their mental health and wellbeing in relation to their HIV diagnosis or treatment.

Our psychologists take a compassionate, non-judgemental and person-centred approach, using therapies that are known to be effective, including Cognitive Behavioural Therapy (CBT). They can help with difficulties such as low mood and anxiety, health-related worries, the effects of stigma and shame, as well as sexual problems. You can be referred by a Bloomsbury Clinic doctor, nurse, health adviser or peer support worker.

When you are referred, you will be invited to attend an initial consultation with a psychologist to gain an understanding of your difficulties and agree a support plan. This may be accessing psychological therapy and/or other sources of support. There can be a wait of up to three months to start psychological therapy.

Sexual problems assessment and treatment

If you are having sexual difficulties, the SPATS team (Sexual Problems Assessment and Treatment Service) may be able to help.

SPATS is a team of medical doctors and clinical psychologists. They can support you with difficulties related to the following:

- sexual desire or low libido
- difficulties with orgasm (early or delayed ejaculation, or anorgasmia)
- pain during sex
- erection difficulties
- concerns about your sexual behaviour, or feeling out of control with sex.

SPATS is based at the Archway Centre. If you would like to be seen in the SPATS service, please discuss your difficulties with any health professional in clinic, who can arrange an appointment for you.

Many people have sexual problems at some time in their lives and this can be more common in PLWH. If you are having a sexual difficulty or problem there is lots of help available within Bloomsbury. If you would like some help you can speak to your clinic doctor, a health adviser or a psychologist about this and they will advise you how to book an appointment with a member of the specialist team.

We can also provide you with booklets about common problems such as erection problems and painful sex.

Drug and alcohol advice and support

Recreational drug or alcohol use can be fun and manageable for some. For others they can start to become problematic. Many recreational drugs can interfere with your HIV treatment. Please discuss this with your doctor nurse or pharmacist.

Whatever way drugs or alcohol fit into your life, it's important to feel you can discuss them in a safe and nonjudgmental environment.

If you feel you need help with your drug and/or alcohol use, please speak to a member of the Health Adviser team or call us on 07702 339298.

Advice about care and services

Your care at the Bloomsbury Clinic

If you have any comments, suggestions or complaints about your care at the Bloomsbury Clinic, please discuss them with your regular Bloomsbury doctor, specialist nurse, or Bloomsbury coordinator. There are also comments cards available in clinic.

Alternatively you can contact CNWL Patient Support at:

Patient Feedback & Complaints Service,
CNWL NHS Foundation Trust
350 Euston Road,
NW1 3AX

Tel: 0300 013 4799

Email: feedback.cnwl@nhs.net

Useful websites and helplines

General

AVERT – UK-based international HIV and AIDS charity.
www.avert.org

Bloomsbury Clinic – offering free, confidential treatment and care for people with HIV. It provides a comprehensive range of HIV services and treatments, and its skilled professionals include HIV consultants, specialist pharmacists and nurses, health advisers and psychologists. <https://www.sexualhealth.cnwl.nhs.uk/hiv-and-hepatitis/>

Body & Soul – charity that supports children, teenagers, women, heterosexual men and their families who are living with or closely affected by HIV and AIDS. www.bodyandsoulcharity.org

The Cara Trust – peer support, advice, information, advocacy, psychological and spiritual support for people living with HIV.
www.caralife.com

Children with Aids Charity – provides direct financial support through a hardship and respite fund, assistance with transport and transport costs, and HIV education. www.cwac.org

Food Chain – home delivered meals, essential groceries and nutrition advice for people who are chronically sick as a result of HIV-related illness. www.foodchain.org.uk

i-base – up-to-date information and a wealth of free publications with a focus on treatment for HIV. <http://i-base.info>
Phoneline: 0808 800 6013 Monday, Tuesday, Wednesday between 12pm and 4pm.

Living Well – advice, support, complementary therapies, life coaching, counselling and youth work for people affected by HIV in 10 London boroughs. www.livingwellcic.com

NAM (National Aids Manual) – the UK's leading source of information about HIV/AIDS, offering an extensive range of factsheets, news and conference reports, and booklets. www.aidsmap.com

National Aids Trust – the UK's leading HIV campaigning charity. It champions the rights of people living with HIV and produces publications to help people fully understand their rights. www.nat.org.uk

National Sexual Health Line – for general advice regarding clinics, and specialist advice regarding sexual health and HIV. Phone: 0300 1237123, 9am to 8pm Monday to Friday, 11am to 4pm weekends.

Positive East – Social support, workshops and counselling for gay men and for African people. The gay men's team runs activities sessions for HIV-positive gay men, black gay men and Asian gay men. www.positiveeast.org.uk

Positively UK – a national charity providing support for all those living with HIV. Helpline: 020 7713 0222, Monday to Friday 10am to 1pm, 2pm to 4pm. www.positivelyuk.org

Terrence Higgins Trust – the UK's national HIV/ AIDS charity. Services include welfare and legal advice, information, counselling and emotional support, buddying/mentoring, complementary therapies and support groups (including groups for gay men and for African people). Phone: 0808 802 1221. Monday to Friday 10am to 6pm, weekends 10am to 1pm. www.tht.org.uk

Drug and alcohol services

FRANK - drugs and alcohol information, advice and support. Phone: 0300 123 6600 (24 hours a day, 7 days a week). Text 82111. <https://www.talktofrank.com/>

Turning Point – provides advice, support, information and treatment for people who are experiencing problems with drug/ alcohol use and for their families and friends. www.turning-point.co.uk

Club Drug Clinic – for those who feel they have problems with ‘club’ drugs or alcohol. www.clubdrugclinic.com

Antidote at London Friend – drug advice and support from the LGBT charity. www.londonfriend.org.uk/antidote

GRIP - The Stimulant and Club Drug Service. Phone 020 3317 6000. Email: grip@candi.nhs.uk

LGBT+

GMFA – a community-based organisation that aims to improve gay men’s health by increasing the control that they have over their own lives. www.gmfa.org.uk

GMI PARTNERSHIP – a partnership between charities Positive East, Spectra and Metro. Provides HIV prevention and support services in areas of East, West and South London. www.gmipartnership.org.uk

Careplace – services for the HIV positive residents of South London including: advice, advocacy, counselling, peer support and health information. careplace.org.uk

Switchboard – information, support and referral service for lesbians, gay men, bisexual people and anyone who wants to discuss issues including sexuality, gender identity, sexual health and emotional wellbeing. Phone: 0300 330 0630, 10am to 10pm Monday to Sunday 365 days per year.
<https://switchboard.lgbt/>

Naz Project London – provides sexual health and HIV prevention and support services to targeted black and minority ethnic communities. www.naz.org.uk

Galop - LGBT+ anti-violence charity, providing support to people from all LGBT+ communities who are experiencing hate crime, domestic abuse or sexual violence.
Phone: 0800 999 5428.
Email: advice@galop.org.uk | www.galop.org.uk

Sexual addiction

Sex Addicts Anonymous (UK) – information about advice and group work around sexual addiction. www.saa-recovery.org.uk

Hepatitis B and C

For general up to date information about Hepatitis B and C go to:
www.infohep.org | www.britishlivertrust.org.uk

The Hepatitis C Trust – national UK charity, providing information, support, awareness-raising and research.
Confidential helpline 020 7089 6221, email enquiries to helpline@hepctrust.org.uk | www.hepctrust.org.uk

Mental health

Mind – provides advice and support to empower anyone experiencing a mental health problem.

Mind infoline: 03001233393. <https://www.mind.org.uk/>

Samaritans – offers confidential, nonjudgmental listening and support to anyone struggling to cope or in crisis. Phone:

116123 (freephone, 24/7) Email: jo@samaritans.org

<https://www.samaritans.org/>

This document is also available in other languages, large print, Braille, and audio format upon request. Please email communications.cnwl@nhs.net

هذه الوثيقة متاحة أيضاً بلغات أخرى والأحرف الطباعية الكبيرة وبطريقة برايل للمكفوفين وبصيغة سمعية عند الطلب

Arabic

این مدرک همچنین بنا به درخواست به زبانهای دیگر، در چاپ درشت و در فرمت صوتی موجود است.

Farsi

এই ডকুমেন্ট অন্য ভাষায়, বড় প্রিন্ট আকারে, ব্রেল এবং অডিও টেপ আকারেও অনুরোধ পাওয়া যায়

Bengali

Dokumentigaan waxaa xitaa lagu heli karaa luqado kale, daabacad far waa-wayn, farta indhoolaha (Braille) iyo hab dhegaysi ah markii la soo codsado.

Somali

Mediante solicitação, este documento encontra-se também disponível noutras línguas, num formato de impressão maior, em Braille e em áudio.

Portuguese

நீங்கள் கேட்டுக்கொண்டால், இந்த ஆவணம் வேறு மொழிகளிலும், பெரிய எழுத்து அச்சிலும் அல்லது ஒலிநாடா வடிவிலும் அளிக்கப்படும்.

Tamil

Este documento también está disponible y puede solicitarse en otros idiomas, letra grande, braille y formato de audio.

Spanish

Dokument ten jest na życzenie udostępniany także w innych wersjach językowych, w dużym druku, w alfabecie Braille'a lub w formie audio.

Polish

આ દસ્તાવેજ વિનંતી કરવાથી બીજી ભાષાઓ, મોટા છાપેલા અક્ષરો અથવા ઓડિઓ રચનામાં પણ મળી રહેશે.

Gujarati

Be belge istenirse, başka dillerde, iri harflerle, Braille ile (görme engelliler için) ve ses kasetinde de temin edilebilir.

Turkish