

Bloomsbury Clinic





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.



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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 HIV positive means you have been infected with the Human Immunodeficiency Virus.

Getting an HIV positive diagnosis does NOT mean that you have AIDS (Acquired Immune Deficiency Syndrome). In fact, early diagnosis and medication means that very few people with HIV will ever develop AIDS.

The most important thing to remember is 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.

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

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 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 doctor appointment.

What we test for

Blood tests taken on your day of diagnosis may include:

- **CD4 count** – monitors how well your immune system is coping with HIV. The virus uses particular white blood cells, CD4 cells, to produce more viruses. The higher your CD4 count, the better your immune system is working.
- **Viral load test** – measures the amount of HIV in your blood and other bodily fluids. The higher your viral load, the easier it may be to pass HIV on to others, and the greater the potential for damage to your immune system. Successful treatment reduces the viral load to very low levels. When this is maintained, it allows your immune system to improve.
- **Incidence test** – may show if you have recently acquired HIV.
- **Resistance test** – used to help select the most appropriate treatment for your HIV, when that becomes necessary.
- **Liver/kidney function** – these are monitored regularly – the frequency of these tests depends on whether or not you are taking 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 HIV Aware website – www.hivaware.org.uk

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.

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 Newly Diagnosed courses, or talk to a patient representative – 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 you tell may not be aware of the up-to-date position on HIV. It might be useful to have some information to show people.
- People with HIV do, unfortunately, suffer from prejudice and discrimination. Prejudice can be challenged, and information and education is often the best way to fight it.
- 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 your partner didn't know you were going for an HIV test, you will obviously be thinking about how to tell them – and when.

If you wait too long after getting your diagnosis before saying anything, your partner may be upset by the delay, which won't make it easy for you to work through this together.

On the other hand, don't just blurt it out without thinking about how you want to tell them and how they might react. You could talk it through beforehand with a trusted friend, a health adviser or a patient representative here at the Bloomsbury Clinic.

Make sure you and your partner are alone together in a place where you both feel comfortable and safe. Be prepared for them to be upset, angry or scared.

Your partner will probably want to get tested themselves, although it is by no means inevitable that they will also be HIV positive. And if they are found to be HIV positive, it doesn't mean they caught 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 43.

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. As this is a recent move, we suggest HIV positive healthcare staff should still consult their professional body for advice about telling their employer. Occupational Health departments within the NHS are used to dealing sensitively with employees with HIV.

The Disability Discrimination Act 2005 covers people with HIV from the point of diagnosis onwards, but in order for this to apply, your employer needs to be aware of your diagnosis.

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.

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 patient representatives.

Telling past sexual partners

It's important to consider telling previous sexual partners about your HIV diagnosis, as they may need to test for HIV themselves.

Those who are positive and unaware of it may be putting others at risk of catching HIV if they are having unprotected sex.

If you have had unprotected sex during the three month period prior to your last negative HIV test, you should consider informing those sexual partners.

If you don't want to contact partners yourself, but have their contact details, one of our health advisers can inform them that they need to have a test for HIV without having to identify you.

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 protect against this, it shouldn't be an issue.

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

Health advisers can arrange to spend some time with you and your partner to discuss how to keep risks of transmission to a minimum.

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, so long as you use condoms.

- 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 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 much more likely to remain healthy when 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. For more advice, see Enjoying sex on page 37.

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. But 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.

Patient representatives

Support and advice from people who live with HIV is available through the Bloomsbury Clinic's patient representatives.

The patient representatives have first hand knowledge of living with HIV. They understand how an HIV positive diagnosis may affect someone.

You can talk to them about literally anything. If you have a question that they can't answer, they will usually be able to find out for you.

Their office is in the main reception area of the Bloomsbury Clinic and they're available five days a week. You can phone 020 3317 5177 for an appointment, or just walk in to see them.

Newly diagnosed courses

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

We run about six courses per year. There are usually about 15 participants. It's an opportunity to meet, share and support others who are on a similar journey.

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,
- Keeping your immune system in good shape, and
- Building support networks.

All people living with HIV are welcome to 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 patient representatives on 020 3317 5177.

Patient Network

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

Besides the Newly Diagnosed courses above, the Network runs workshops, forums, a women's lunch club and social events.

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

Send an email to admin@bloomsburynetwork.co.uk or give your address to one of the patient representatives in person or via reception. You can also leave your details on 020 3317 5177 or visit them 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 42.

Further help

For further sources of guidance and counselling, see the Advice and Support section on page 43.



Your check-ups and treatment

Routine appointments

Your doctor or specialist nurse will need to see you regularly to review your progress.

Your doctor will discuss with you how often you need to be seen. The frequency varies, but for most people it's every six months.

You will need to attend for regular blood tests to monitor your health. It is helpful if you have these taken two weeks before your appointment with your doctor or specialist nurse, so they can discuss the results with you.

You might not always need to come to your appointment in person – you can receive your results by phone or by email. See 'Convenient clinics' on page 22.

Making an appointment

Call 020 3317 5100 to book an appointment. Please mention that you are a Bloomsbury Clinic patient. It's useful to have your clinic patient number to hand. This is written at the front of your clinic information card inserted at the front of this book.

Alternatively, you can book future appointments at reception while you're in the clinic.

If you have any problems making an appointment, please ask to speak to one of the reception managers or the nurse co-ordinator.

You will receive an automatic text reminder of your appointment date and time two days beforehand. If you are unable to attend an appointment, please let us know as soon as possible on 020 3317 5100, so we can offer your appointment slot to someone else.

Specialist nurses

Sometimes your doctor may recommend you see one of the specialist nurses for your routine appointments. The specialist nurse will carry out a similar consultation to that of the doctor.

Interpreters

If you need an interpreter for your clinic visit, please let the receptionist know **48 hours in advance**. We will make every effort to provide an interpreter. Occasionally this might not be possible – in that case we will use a telephone interpreting service.

If you are deaf and require a sign language interpreter, please let us know at least two weeks before your appointment.

Your own doctor

You will have a named doctor or specialist nurse who acts as your main point of contact.

However, it's not always possible or appropriate to see the same doctor or nurse every time you visit.

If you are unable to get an appointment with your regular doctor, or would prefer to see someone different, reception staff will be able to help you when you re-book an appointment.

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.

Blood tests

When you arrive

If you only require routine blood tests and don't need to see a doctor or specialist nurse, go directly to the lower ground floor, follow the signs to the Bloomsbury Clinic and use the ticket queuing system.

You can walk in and request blood tests at any time during clinic opening hours (see opening times on page 2 of your clinic information card inserted at the front of this book).

Waiting times to see a nurse may vary, depending on how busy the clinic is.

Early morning tests

Early morning blood tests are available from 8.15am on Fridays. This can be handy if you need to get to work, or if you need to have blood taken whilst fasting.

Types of test

We carry out blood 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,
- CD4 count,
- HIV viral load, and
- Syphilis.

Once a year we will run a broader spectrum of more enhanced blood tests.

We won't need to do all these tests every time you attend.

If you are on effective HIV treatment, CD4 counts may be performed less often. In some circumstances they may no longer be needed.

If you are having a lipid/cholesterol and glucose profile test, avoid eating and only drink water for 12 hours before the test.

Getting your results

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

- By a face-to-face appointment – book this on the day that you have the test done,
- Through a phone conversation at the 'At Home' clinic (see page 22) – you should book this on the day you come for your blood tests, or
- Through an email consultation (you need to register first – see the 'E-clinic' on page 23).

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.

Convenient clinics

Rather than come back to the clinic to discuss your test results each time, we offer telephone and e-mail clinics. If you're interested in taking advantage of these services, please discuss them with your doctor or specialist nurse.

The 'At Home' clinic

If you are stable on treatment, or are well and not on treatment, you may decide to be reviewed over the phone via the 'At Home' clinic.

You can book an appointment in the 'At Home' clinic up to three months in advance. On the day, your specialist nurse will telephone you. They will check who you are and ask if you are available to talk.

They will then discuss the results of your blood tests, arrange any repeat prescriptions, and so on. If your results indicate that you need to see a doctor, the nurse will be able to arrange an appointment for you.

If there have been any changes in your health or medication, it's important to mention this during the call. Changes may include herbal remedies, inhalers, over-the-counter medications and recreational drugs.

The E-clinic

If it's convenient for you, you can choose to receive your test results by email. You will also receive an email from your doctor or specialist nurse, explaining your results.

When you come to the clinic to have blood tests, you can book into an E-clinic appointment two weeks later to receive your results by email.

If your results suggest you need to see a doctor, we will usually call you rather than email.

Please note: This service is not available for the results of STI screening or to arrange repeat prescriptions.

Information about you that is stored on our computer system is protected by firewalls. When we email outside our system, we can't guarantee the security of the information in the email.

Starting HIV treatment

Most HIV positive people stay well for many years without taking any medication. But there is almost certainly going to come a time when you will have to start thinking about it.

Treatment for HIV is called combination anti retroviral therapy (ART). This is a combination of several different drugs which suppress the virus.

The aim of ART is to reduce the amount of virus in your blood to a very low or 'undetectable' level (less than 50 copies of virus per 1ml of blood).

When to start?

Your doctor or specialist nurse will usually suggest that you start taking medication to treat HIV if:

- Your CD4 count is around or below 350, or
- You have an HIV-related problem.

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 the number of people developing AIDS or dying from HIV each year in Britain from HIV related illness. This is a direct result of successful treatment for HIV.
- Modern drugs are generally well tolerated. However, some drugs used in HIV treatment can have side-effects. These tend to decrease in severity and frequency over time, and most people start feeling better after they have been taking ART for a few months. If necessary, you can get other medication to ease the side-effects until your body adjusts.
- Your doctor 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) – see their website at www.bhiva.org for more details.

continued overleaf

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-HIV-treatment/page/1230814/).

Treatment Advice Clinic

If you need help on whether to start or change treatment, or if you're having problems with treatment, Bloomsbury's Treatment Advice Clinic (TAC) can offer support.

If you feel that you are coping well with your treatment, you might not need any further support.

However, the first few weeks of treatment can sometimes be stressful or confusing. Unexpected problems can arise, such as issues with work, family, or an illness related to HIV or your medication.

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

You will be given the name and telephone number of your support nurse, who will help co-ordinate your tests and prescriptions, and offer advice when you need it.

The TAC team aims to support you until you are stable on treatment and are responding well. On average, this takes between one and three months.

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.

Treatment is most successful when you take it at set times, without missed doses. And when you start to see the benefits of treatment – such as a climbing CD4 count and a viral load dropping to an undetectable level – it becomes even easier.

It is really important to stick to your medication as exactly as possible, although the occasional missed dose should not be a cause for alarm.

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 three to six 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.

- There's more information on CD4 count at i-base: <http://i-base.info/guides/starting/cd4-count-and-guidelines>

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).

In the next few years, many HIV treatments will become available as generic rather than branded medications. This means they will be cheaper and just as effective.

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/hiv-in-the-uk-nhs-changes-and-new-generic-drugs>).

Home delivery

If you are stable on treatment, you can have your medication delivered direct to your door – at your home, workplace or local post office.

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 the South East. 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?

If you usually collect your medication from the clinic pharmacy and find that you are running low please call the Bloomsbury nurses on 020 3317 5143 requesting a repeat prescription.

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 families with HIV is held every Friday morning at Great Ormond Street Hospital (GOSH).

Parents and their children can be seen at the same time by an adult physician and liaison nurse from the Bloomsbury Clinic and the paediatric team from GOSH.

For further information, please phone the Bloomsbury nurses on 020 3317 5143.

Young people's clinic

The TEAM Clinic at the Bloomsbury Clinic provides a range of services specifically for HIV-positive teenagers and young people. 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 health care support worker who are all experienced in working with young people and HIV.

The TEAM clinic is held every second Tuesday from 4pm to 6pm.

To book an appointment, contact the TEAM mobile on 07747 795276, email team.clinic@nhs.net, or call the health advisers on 020 3317 5111.

Emergencies

During clinic times

If you feel unwell and think that your problem is related to HIV, please telephone and speak to one of the Bloomsbury nurses on 020 3317 5143.

However, if you feel that you need to be seen right away, you can use the emergency walk-in service for patients with URGENT medical issues that relate to HIV (see opening times in the clinic information card inserted at the front of this book).

Please check in at the ground floor reception. When you arrive, a nurse will assess you and refer you to the emergency doctor if necessary.

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

If you call outside clinic hours, you will hear a recorded message which will give you advice and alternative numbers to call – make sure you have a pen and paper handy.

Outside emergency doctor hours, you can get URGENT telephone advice by telephoning 08451 55 50 00 (between 6pm and 10pm weekdays and 9am to 10pm weekends and bank holidays).

Please ask to speak to the HIV doctor on-call. This number is for emergency advice only.

After 10pm you should call your GP, NHS Direct (111) or ring 999 for an ambulance if appropriate.

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 will be able to see you for a home visit in an emergency.

You can go to your nearest hospital Accident and 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 08457 90 90 90
- NHS Direct 111
- Mind 0300 123 3393

Exposure to HIV

If your partner is exposed to HIV, they should call to speak to a health adviser on 020 3317 5111 or come in to GUM services at the Mortimer Market Centre or the Archway Centre.

Outside our clinic hours, they should visit the A&E department at UCLH, the Whittington Hospital or their local hospital.

- For more information, and to help your partner decide whether PEP (post-exposure prophylaxis) is needed, visit www.pep.chapsonline.org.uk

Other treatments

Specialist clinics

We run a wide range of clinics and services, including:

- **Facial lipoatrophy** – a clinic for people who have developed facial lipoatrophy as a result of taking some of the older antiretroviral drugs, which are now rarely used.
- **Hepatitis** – a clinic for patients infected with both HIV and Hepatitis B/D or C is held every Wednesday and Friday afternoon in the Bloomsbury Clinic.
- **Neurology** – a clinic for those who have problems with their nervous system runs every Friday morning in the Bloomsbury Clinic.

- **Neurocognitive assessment** – a team specialising in assessment of cognitive difficulties, such as problems with memory and thinking, which may be related to HIV infection.
- **Oncology** – a weekly HIV/oncology service runs at UCLH for patients receiving treatment for cancer.
- **Renal** – a clinic for those who have kidney problems runs one morning a month at the Bloomsbury Clinic.

Your doctor will refer you to any of the above services if necessary.

Hospital care

If you should need treatment in hospital because of conditions related to HIV we will usually refer you to T8.

T8 is the base for the specialist HIV medical team at University College London Hospital (UCLH) based in the main tower of the hospital on the Euston Road. Many of the doctors who work on T8 also work in the Bloomsbury Clinic.



Living your life

Staying healthy

Because HIV can damage your immune system, it is important to be aware of things that you can do to prevent additional strain being placed on your body's natural defences.

A good diet, regular exercise and plenty of rest and relaxation will keep your immune system 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.

Depression is a potential concern for people living with HIV. Being diagnosed as HIV positive can be profoundly upsetting, and some people do suffer from depression as a result.

If you think you might be suffering from depression, tell your Bloomsbury doctor or specialist nurse as soon as possible. Alternatively speak to your GP, our emergency doctor or a health adviser in the Bloomsbury Clinic.

If stress is a particular problem for you, you may want to think about changes that you can make in your life. Activities such as yoga or meditation can help. You may also want to seek one-to-one or group counselling to help you.

It is often useful to discuss your options with a Health Adviser or Patient Representative – see Advice and Support section on page 43.

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

Enjoying 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.

Condoms are a proven means of preventing HIV transmission.

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.nhs.uk

Emergencies

Accidents of course do occasionally happen. Condoms can break or come off in the heat of the moment. If this happens, there could be a chance that your partner has been exposed to HIV.

If you are concerned about this, advise your partner to call or walk into the Mortimer Market Centre or the Archway Centre to enquire about PEP.

PEP stands for post-exposure prophylaxis. It is a 28-day course of HIV treatment. If PEP is started soon enough (within 72 hours of exposure), there is a high chance that it will prevent someone who has been exposed to HIV from becoming infected. Ideally it should be started as soon as possible.

PEP is also available outside of our clinic hours in any Accident and Emergency department.

For more information, and to help your partner decide whether PEP is needed, visit: www.pep.chapsonline.org.uk

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. However, you should be aware that you may have a different strain of HIV from your partner.

It is possible, therefore, that one or other of you could become infected with a different strain of HIV if you stop using condoms.

This can cause problems. Your immune system may be put under additional stress by dealing with two strains of HIV. It is also possible that you can catch viruses resistant to some HIV treatment drugs.

Other infections

Using condoms will also greatly reduce your chance of catching 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 infectious and more likely to pass on HIV to someone else. This may also be the case if you are on treatment and have an undetectable viral load.

The Bloomsbury Clinic offers walk-in sexual health screening and advice about contraception.

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 whose partner is HIV negative can use self insemination with his sperm, so that he will not be at risk of becoming infected with HIV.

Your doctor, specialist nurse or any of our nurses can provide more information about this.

Men

It may be possible for an HIV positive man to become a father while reducing the risk of his partner catching HIV infection – you can discuss this with your doctor or specialist nurse.

If you're both HIV positive

If both you and your partner are HIV positive, you may think that the easiest way to become pregnant is to stop using condoms. However, you should consider the risks

of either of you becoming infected with a different strain of HIV – see Enjoying sex on page 37.

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 bottle-feed, as breast milk may contain HIV.

The newborn babies of HIV positive mothers are also given a four-week course of HIV treatment.

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.
- You may need to consider changing the timing of your medication to make allowance for time differences in other countries. Please discuss this with your doctor, nurse or pharmacist.
- 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

You can apply online for a European Health Insurance Card (EHIC), which lets you get state healthcare at a reduced cost or sometimes for free. The EHIC is valid in all European Economic Area (EEA) countries, including Switzerland.

See www.postoffice.co.uk/health-insurance-card for details.

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 patient representatives, 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 NAM (www.namlife.org) 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 patient representatives 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 patient representative.

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 at the Mortimer Market Centre, the Archway Centre and the Margaret Pyke Centre are able to provide information, counselling and support for people infected or affected by HIV.

They offer short term counselling (usually six sessions), that can help you focus on issues such as adjustment to diagnosis, disclosure, HIV transmission, relationships where one partner is positive and the other negative), risk reduction, safer sex and living well with HIV.

To see a health adviser, please ask at reception or one of the nurses in the Bloomsbury Clinic, or speak to your Bloomsbury doctor or specialist nurse, or call 020 3317 5111.

Psychotherapy

The team of clinical and counselling psychologists based at the Mortimer Market Centre and Archway Centre are trained to provide psychological help, or psychotherapy.

Psychotherapy is an activity where talking is used to help solve difficulties, like problems with low mood, worrying thoughts, or behaviours that cause you distress.

Therapy is not about giving advice, but about helping people to understand their situation in different ways. It provides practical techniques to help improve psychological health both now and in the future.

The service is available to anybody who is a registered Bloomsbury Clinic patient. You can be referred by a Bloomsbury doctor, nurse, health adviser or patient representative.

When you are referred, the psychologists will invite you to come in for an initial consultation to see if a psychological approach could be helpful.

If they decide the service is right for you, you'll join the waiting list for therapy. As there can be a wait of up to three months, they will advise you at the assessment about other sources of support available to you in the meantime.

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 doctors, psychologists and psychosexual therapists. They deal with issues such as:

- Sexual desire difficulties/low libido,
- Difficulties with orgasm,
- Pain during penetration/sex,
- Sexual aversion – negative feelings about specific sexual acts, which significantly affect sexual relationship,
- Concerns about sexuality,
- Fears and compulsions around sex,
- Early ejaculation,
- Erectile dysfunction, and
- Feeling addicted to sex/concerns about sexual behaviour.

SPATS is based at the Margaret Pyke Centre. To ask for an appointment, call the Margaret Pyke Centre general appointments line (020 3317 3737) and ask for an appointment for a referral to be made. If your GP is in Camden or Islington, they can also refer you to SPATS.

SPATS has produced a range of booklets on sexual difficulties, the 'Better Sex' series. You can pick them up from the Bloomsbury Clinic.

SPATS also has a website offering information about different sexual problems and techniques to overcome them. Ask a doctor, nurse or health adviser for a username and password for the site:
www.sextherapyLondon.nhs.uk

Club drug clinic

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 non-judgmental environment.

The Club Drug Clinic runs by appointment in the Bloomsbury Clinic every Monday afternoon, and throughout the week at the Chelsea and Westminster Hospital.

The service specialises in non-traditional or 'club' drugs (i.e. crystal meth, mephedrone, GHB/GBL, ketamine and legal highs).

The Club Drug Clinic is a London wide partnership between psychiatrists and specialist nurses from Central and North West London NHS Foundation Trust and Antidote.

If you feel you need help with your drug and/or alcohol use, please speak to a member of the Bloomsbury Clinic team.

- Further information:
www.clubdrugclinic.com

Alternatively you could walk in and see one of the advice workers from the Antidote service provided by the Lesbian, Gay, Bisexual and Transgender (LGBT) health and wellbeing charity, London Friend.

An Antidote worker is on site in the male sexual health clinic at the Mortimer Market Centre every Monday morning. You can walk in to discuss issues around your recreational drug use.

- Further information:
www.antidote@londonfriend.org.uk/antidote

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, the senior nurse manager or the charge nurse. There are also comments cards available in clinic.

Alternatively, you can write to the Patient Support Service, CNWL Sexual Health & HIV Service, Margaret Pyke Centre, 44 Wicklow Street, London, WC1X 9HL.

Patient Support Service

The aim of the Patient Support Service is to help people find their way around local community health services and get the information they need.

The service can also help if you are having any difficulties with health services, and advise you on how the formal complaints process works.

Contact the service on 020 7685 5950 (Monday to Friday, 9am-5pm), or email patientsupport.cps@nhs.net. For more information on the service, visit: www.cnwl.nhs.uk/services/sexual-health

Citizens Advice Bureau at Bloomsbury

The specialist HIV team from Camden Citizens Advice Bureau (CAB) hold advice sessions for people affected by HIV in the Health Adviser and Psychology Department every Monday between 10am and 1pm.

You can make an appointment by calling 020 7380 8270.

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.
www.cnwl.nhs.uk/service/bloomsbury-clinic-mortimer-market-centre

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

Mayfly – counselling, life coaching and workshops for people across London.

www.mayflyonline.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

NAMlife – a website about living with HIV. For people who have been recently diagnosed, have lived with HIV for a while, know someone who is, or just want to find out more.

www.namlife.org

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: 0800 567 123, 9am to 8pm Monday to Friday, 11am to 4pm weekends.

Opportunity For All – provides culturally sensitive support and advice for people from the BME communities affected by HIV and AIDS.

Phone 020 8743 2403, 07956 693523.

Email: tojwang.opportunityforall@btconnect.com

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

Str8talk – a social peer support group for heterosexual people living with HIV.

www.str8talk.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: 0800 8021221 Monday to Friday 10am to 10pm, weekends noon to 6pm.
www.tht.org.uk

Drug users

Turning Point, South Westminster Drug and Alcohol Services – 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

Gay men

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 Positive East, the Metro Centre Ltd and West London Gay Men's Project. Services include groupwork, free counselling, mentoring, outreach and detached work.
www.gmipartnership.org.uk

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

London Lesbian and Gay Switchboard – information, support and referral service for lesbians, gay men, bisexual people and anyone who wants to discuss issues concerning sexuality.
Phone: 0300 330 0630, daily 10am to 11pm.
www.llgs.org.uk
Turing Network resources database (formally Queery)
www.turingnetwork.org.uk

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

PACE – the Project for Advocacy, Counselling and Education, offers a wide range of services aimed at promoting the health and wellbeing of the LGBT community.
www.pacehealth.org.uk

Rape and sexual assault

The Haven – offers medical help and forensic testing for all victims of rape and sexual assault (men, women and children). There are three Havens based in London at:

- Camberwell 020 3299 1599 from 9am to 5pm; at all other times 020 3299 9000,
- Paddington 020 3312 1101 from 9am to 5pm; at all other times 020 3312 6666, and
- Whitechapel at any time 020 7247 4787.

www.thehavens.org.uk

Survivors UK – a London-based specialist agency offering counselling, support groups and a telephone helpline for male victims of rape and sexual assault.

Phone: 0845 122 1201, Mondays, Tuesdays and Thursdays from 7pm to 10pm.

www.survivorsuk.org

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.

Phone: 0845 2234424, Monday to Friday, 10.30am to 4.30pm.

www.hepctrust.org.uk

If you would like information in another language or format, please ask us. Email: communications.cnwl@nhs.net

Sipas kërkesës, ky dokument gjithashtu gjendet edhe në gjuhë të tjera, me shkrim të madh dhe në formë dëgjimore.

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