

HIV Service Users Guide

Who is this information leaflet for?

This leaflet is for people living with HIV who attend for care within Tayside. This leaflet may also be useful to partners and carers of people living with HIV.

What is the aim of this leaflet?

This leaflet will give you information about the way the HIV service operates, what you can expect when you attend for a clinic appointment and why we do blood tests. This leaflet will also answer some frequently asked questions and direct you to other sources of information.

What is the HIV service?

The HIV service is staffed by specialists including consultants, nurses and pharmacists. The HIV service runs clinics at Ninewells Hospital in the East Block Out-patient Department (chest/infection clinic) and in the Tayside Sexual and Reproductive Health Service. There are also clinics in Perth and Angus.

The HIV service is run by the NHS Tayside Infection and Immunodeficiency Unit. It is accountable to the Blood Borne Virus Managed Care Network.

Who can I expect to see at my clinic visits?

Reception staff: On arrival you will meet the receptionists who will let the nursing staff know you have arrived.

Out-patient clinic nurse: One of our clinic nurses will then weigh you, check your blood pressure and ask you for a urine sample. They will also offer you condoms.

Medical team: You will then be seen by one of the specialist medical team. There is a consultant who has overall responsibility for your care however at your clinic visits you may see a consultant, an associate specialist, a specialist registrar or a specialist nurse. If there is a particular doctor you would prefer to see then please ask the clinic nurse. Unfortunately we cannot guarantee that you will see the doctor of your choice.

Phlebotomist: After you have seen the doctor or specialist nurse you will have your blood taken by a phlebotomist. These are people who are trained in taking blood.

Pharmacist: If you are on treatment for your HIV you will also see

the pharmacist to be given your medicines. If the pharmacist is not available at the clinic your medicines may have already been supplied to the clinic for you to collect or other arrangements will be made with you.

Reception staff: before you leave the clinic please book your next appointment at reception

What happens if I have been recently diagnosed with HIV?

If you have recently been diagnosed with HIV you should have received a leaflet called "HIV - Frequently Asked Questions?" which will take you through the usual patient journey. You should be given contact details for the specialist nurses who are available to help answer any of your questions.

What happens if I have recently transferred my care from somewhere else?

One of the specialist nurses will take your personal details and the contact details for the hospital or clinic where you previously had your HIV care. With your consent we will contact them to ask for a summary of your HIV care which will include: date of HIV diagnosis, baseline blood results, details of any HIV treatment, vaccination history and details of other illnesses and medications.

What is an annual review?

Every patient will have an annual review which may take up to 45 minutes. This allows us to address some issues that may only need to be discussed once a year. These include:

Other medical problems: These might have been diagnosed by your GP or another specialist. New medications prescribed by your GP or another specialist. Our pharmacist will usually contact your GP for a list of medicines and vaccinations before this appointment.

Vaccinations: We will check that you are up to date with vaccinations. Vaccinations are usually given by your GP.

- **Hepatitis A** this is recommended to everyone with HIV. Hepatitis A is passed usually by contaminated food and water. It can cause serious liver inflammation. Some people have had it without knowing and we will do a blood test to see if you need the vaccine or not. The vaccine can be given together with the hepatitis B vaccine.
- **Hepatitis B** this is recommended to everyone with HIV. Hepatitis B can be caught from infected blood or through sexual contact. It can

cause liver inflammation which can be chronic and result in cirrhosis and liver cancer. The vaccine is given as a course of three to four injections. Some people will need booster injections.

- **Pneumovax** this is recommended to everyone with HIV on a 5-yearly basis. Pneumonia can be more serious in HIV and it can be recurrent. This vaccine will protect you against some (but not all) strains of bacteria that cause pneumonia.
- **Annual seasonal flu** this is recommended to everyone with HIV every year. Although you are not at a high risk of getting flu, you are at higher risk of some of the serious complications if you did pick it up.

Cardiovascular health: People with HIV and people on some HIV treatments are at higher risk of having heart attacks and strokes compared to people who don't have HIV. For that reason we are interested in your blood pressure, your cholesterol and your smoking in order to improve other risk factors that contribute to the overall health of your heart.

Bone health: People with HIV and people on some HIV treatments are at higher risk of bone-thinning (osteoporosis). For that reason we are interested in asking about other risk factors for bone health including smoking and alcohol intake in order to improve other risk factors that contribute to the overall health of your bones.

Sexual health: Since it is possible to pass HIV on through sexual contact we will ask you about sexual partners once a year. We understand that for many of you, your relationship history will not change.

Since many people find it a difficult subject to volunteer we will raise the subject once a year as sensitively as possible. Please don't be offended by any questions we ask you. We will ask everybody the same questions so as not to discriminate.

If you have had any new sexual partners we will offer you testing for other sexually transmitted infections which can usually be done without any examination.

You can also choose to be seen at the sexual health clinic for your annual smear (women) or your STI tests (men and women). Please see the section below on the sexual health clinic.

Physical Examination: We will do a full physical examination to ensure everything is "in working order". This will include a look in your mouth, a feel of your glands, listening to your heart and lungs and feeling your tummy. If you have any skin problems you are concerned

about then please alert your doctor. If you have any genital problems then please don't be embarrassed and let your doctor know.

Blood tests

The following tests are recommended for everyone at their annual review. A full explanation of these tests is available at the back of this leaflet.

Full blood count
Urea and electrolytes
Liver function tests
Phosphate
Calcium
Viral load
CD4 count
Hepatitis B serology
Hepatitis C serology
Syphilis serology
Urinalysis

If you also
have hepatitis, there
may be other tests
involved.

What happens at my routine (non-annual review) visits?

We like to see you every 3-4 months to make sure that you are well.

If you are **not on treatment** we will be checking you for signs of a failing immune system. You will have the following tests done:

- Full blood count
- Urea and electrolytes
- Liver function tests
- CD4 count
- Syphilis serology
- We will usually only check your viral load at your annual review as it makes little difference to your care when you are not on treatment.

If you **are on HIV treatment** we will want to know if you have had any problems with your treatment, if you have developed any side effects and if you have been prescribed any new medicines that may interact. You will have the following tests done:

- Full blood count
- Urea and electrolytes
- Liver function tests
- Phosphate (depending on which tablets you take)
- Urinalysis
- Viral load
- Syphilis serology
- We will usually only check your CD4 count at your annual review. As long as your viral load is suppressed, your CD4 count makes little difference to your care.

What can I expect if I have an appointment in the sexual health clinic?

At your annual review appointment you may be offered the opportunity to have your next clinic appointment within the Sexual Health Clinic. At this appointment you will have your HIV care, blood tests and medicines dispensed as normal. You can also have tests for other infections, your smear test (women) and treatment for any infection or genital skin problem. Within the sexual health service there are also sexual health advisers who provide support with disclosure (telling your sexual partners) and contact tracing for previous partners.

Why am I offered condoms every time I come to clinic?

Condoms are essential to help prevent the spread of HIV to someone else. You should never have to pay for condoms. Some people are too embarrassed to ask for condoms. In order to ensure that everyone who needs condoms gets them, the clinic nurse will offer them to everyone at every visit. Please don't be offended by this we will offer them to everyone so we don't discriminate. If there are particular condoms that you prefer (size, style, flavour etc) please ask.

What should I do if I can't make it to an appointment?

If you cannot attend an appointment then please cancel it as soon as possible so that appointment can be given to someone else. You will be given a new appointment.

If you have an appointment and you do not attend then this is referred to as "defaulting". If you cancel your appointment on the day of the appointment then this will also count as a default as it is a wasted appointment. If you default from an appointment we will let your GP know and send you a new appointment. If you default from two consecutive appointments then we will not send you a new appointment and we will write to your GP to let him/her know. We will then expect you to contact us if you wish to make another appointment.

What should I do if my medicines won't last until my next appointment?

We will always try to ensure that you have enough medicines to last until your next appointment. This is usually 3 or 4 months. If you are running out of medications then please contact the specialist nurses who will arrange a further supply. If you have recently missed an appointment you will only be given a one month supply

and a larger supply will be given to you at your next appointment.

What should I do if I think I am pregnant?

Women with HIV can enjoy safe pregnancies and healthy babies if they have monitoring and treatment through their pregnancy. If you have a positive pregnancy test then please contact your midwife or GP at your local practice as soon as you know you are pregnant. Please also contact our specialist nurses who will ensure that you see the right specialists during your pregnancy. If you are unhappy about being pregnant contact your GP or your local Sexual and Reproductive Health Clinic to discuss your options.

If you would like to discuss how you can plan a pregnancy then just ask at your next clinic appointment.

Why does my GP have to know about my HIV?

Your general practitioner should be the centre point for all of your healthcare needs as they are experienced in being able to provide for a broad range of medical conditions. If your GP does not know that you have HIV, he/she is unable to give you the best possible healthcare. In fact, you may come to harm from investigations or treatments they arrange if they are unaware of your infection. HIV specialists are not experienced in all aspects of medicine as your GP is. If your GP thinks that your problem is because of your HIV or your treatment then they can ask us to see you.

Who else needs to know about my HIV?

Not many people need to know about your HIV and we will not tell anyone without your consent or knowledge. It is important that anyone who may have been at risk of either passing the infection to you or contracting the infection from you has the opportunity to be tested. This is so they don't come to harm from HIV and so that they can prevent passing it to anyone else if they are also infected. Our specialist nurses and sexual health advisers can help you with this. We can support you in telling these people yourself or we can do it anonymously for you without giving away any of your personal details.

Your dentist should be made aware of your HIV. People living with HIV are more susceptible to gum problems and other oral conditions and so your dentist can be very helpful. As your dentist is often using sharp instruments in your mouth it is also important they are aware for their own protection. No healthcare facility should discriminate against anyone living with HIV.

What should I do if I think I am having side effects to my HIV medicines?

If you have recently started HIV medicines, the doctor and pharmacist should have explained likely side effects. Most side-effects are short-lived and will gradually get better. It is important not to stop your medicines without discussing it first with an HIV specialist nurse or doctor. Stopping HIV medicines the wrong way can result in the virus becoming resistant. Your HIV doctor or nurse will stop the medicines the right way for each individual drug.

Nausea and vomiting: these side-effects are likely to settle down. Ask your GP or one of the nurses for an anti-sickness tablet. This can be taken about 30mins before your HIV medicines.

Diarrhoea: this side-effect is common and may settle down. You can take anti-diarrhoea tablets to help. If you have been on these tablets for some time and you suddenly develop diarrhoea it is unlikely to be related to the medicines and you should see your GP if it is troublesome or doesn't settle.

Rash: some medicines like nevirapine, efavirenz and abacavir can give you a rash. Please contact a specialist nurse who will arrange for you to see an HIV doctor. Sometimes we will advise that you continue your medicines with some symptom relief. If you also have a fever or signs of liver inflammation we will stop the medicine.

Bad dreams or dizziness: this is common side-effect of efavirenz. It is worst in the first week of taking the medicine and usually settles completely after one month. If it is causing you to have dangerous thoughts then please contact an HIV specialist immediately.

What should I do if I feel unwell?

People living with HIV are at a higher risk of unusual infections and other illnesses. Most people living with HIV however are usually on HIV treatment and have relatively healthy immune systems. If you feel unwell for any reason then you should see your GP in the first instance as it may well be something completely unrelated to your HIV. It is important that your GP knows about your HIV so they can consider it when they make a diagnosis or prescribe any treatment. If your GP is concerned that your illness may be related to your HIV then they can contact an HIV specialist for further advice. We will either give your GP advice over the phone, arrange to see you in the next available clinic or see you urgently depending on the situation.

If you become unwell out-of-hours then contact NHS24 for advice. If it is an emergency then you can call emergency services. There is not

always an HIV specialist available 24 hours a day and in hospital you may be looked after by a specialist in hospital medicine until an HIV physician is available.

What do I do if I would like to transfer my care elsewhere?

If you are moving to another area then it is best for the local HIV team to continue your care. Our HIV specialist nurses can give you contact details of the local services in your new area. Please see us shortly before you leave so we can supply you with enough medicines to last you until you arrange care in your new area. With your consent, your new HIV care provider will contact us to send a summary of your care which will include: date of diagnosis, baseline blood results, details of any HIV treatment and any other illnesses and medicines. If you are still living in Tayside but would like to have your care elsewhere then please discuss this with your nurse or doctor. We would like to support you in continuing to access your care in Tayside and can do this by offering you another clinic in which to be seen; for example in the sexual health clinic or in Perth. If you would still like to move then you can follow the instructions above. However, we would ask that copies of letters from your new clinic be sent to us in case you become unwell and are admitted as an emergency within Tayside.

Research and audit

Ninewells Hospital and Medical School and the University of Dundee have earned an excellent reputation for biomedical research both nationally and internationally. As a department we occasionally take part in research or audit that may be organised through the university or through other agencies such as the British HIV Association or HIV Scotland. We take part in these studies when we believe the results and outcomes are likely to contribute to the health and the care of people living with HIV.

If you are invited to take part in any research project then you will be given written information and will be given the opportunity to decline. There is absolutely no obligation to take part and if you decline this will **in no way** affect the care or treatment you receive within our service.

Audit is a way of making sure that we are “up to scratch” in the way we look after you. Doctors, nurses and medical students frequently undertake audits which involve looking through case notes to make sure that we are meeting the necessary standards that are expected of us. These standards are issued by The British HIV Association, Health Improvement Scotland and NHS Tayside Blood Borne Virus Managed Care Network.

If you are interested in any of the results of these audits then please ask.

Medical Students

Ninewells Hospital and Medical School has responsibility for teaching medical undergraduates from the University of Dundee. In their fourth year they spend a week with the Infection and Immunodeficiency Unit and as part of this attachment they attend an HIV clinic. During this visit they learn valuable lessons that can't always be taught such as how HIV impacts on the different aspects of the lives of real people. The students are always very positive about what they learn from patients.

You can be assured that medical students are bound by the same rules of confidentiality as other hospital staff and are not permitted to divulge any of your information to anyone else.

You are in no way obliged to have a medical student in attendance at your consultation and declining this will ***in no way*** affect the treatment or care you receive within our service. If you do not want a medical student then please let a receptionist or clinic nurse know.

Who else might be involved in my care?

Your care may require that you see one of the following associated professionals for specific support or treatment. These might include:

- Dietician
- Clinical psychologist
- Social services
- Sexual health adviser
- Obstetrician and paediatrics

What are my rights?

You have the right to be treated fairly, with respect and with equality. This means that you cannot be discriminated against because of your HIV status.

You have the right to confidentiality. This means that any personal details linking you to your infection will not be disclosed to a third party without your knowledge and consent. A third party means someone outside of the multi-disciplinary team. In only very exceptional circumstances where we believe there is a serious risk to someone else will we disclose your HIV status and we will always do this with your knowledge. If you would like further information about this then please discuss it with your doctor.

You have the right to a high standard of care which includes a multi-disciplinary team who are properly trained and up-to-date, who communicate well and act professionally. NHS Tayside's HIV service

aspires to meet the standards of care issued by the British HIV Association and Health Improvement Scotland.

You have the right to be fully involved in all decisions regarding your treatment and care.

You have the right to be seen within 30 minutes of your appointment or expect an explanation.

You have the right to make a complaint and receive a written response. Staff can direct you to the appropriate complaints procedure. We welcome this form of feedback in order to better our service.

How can I help?

It is important that you feel able to be honest with those caring for you in order that we can work together with you.

Please turn up for your appointments on time. Tell the clinic if you can't make it, so they can give the appointment to another patient.

Treat all people involved with your care with the same respect you would wish to receive yourself.

If you don't understand anything, ask your doctor to explain it again or in a different way.

It is your responsibility to prevent any further spread of HIV. We will work together with you to ensure that:

- You engage with partner notification and contact tracing
- You have access to condoms in order to practice safer sex all of the time
- You are able to disclose your HIV status to any current or future sexual partners in order that you both can access safer sex and post-exposure prophylaxis if necessary
- You take any HIV medicine correctly to prevent resistance virus

How can I feedback my comments and suggestions?

Complaints, suggestions and feedback are best submitted in writing. This can be done in a number of ways as follows:

“How are we doing”? This is a form you can request from reception staff and is fed directly back to the service manager.

NHS Tayside complaints procedure. This is a formal complaint you

can make via the health board's complaints department. You can request a complaints form from reception staff or you can email the complaints department at complaints.tayside@nhs.net

If you don't wish to make any comments in writing then please speak to a member of staff you feel comfortable discussing the issue with.

Please be assured that making a complaint will not affect the treatment or care you receive from this service.

Where else can I find information?

Patients information leaflets

We have a range of leaflets that are available from the clinic which cover issues such as the HIV infection and disease, treatment and side-effects, pregnancy and women's issues, nutrition, mental health and sexual health. Please ask a doctor, nurse or pharmacist if you are interested in any of these.

Websites

There are many websites which give information for people living with HIV. The content of all websites cannot be always guaranteed to be accurate. Here are a few websites we recommend:

www.aidsmap.com
www.tht.org.uk
www.i-base.info
www.bhiva.org
www.bashh.org
www.waverleycare.org
www.HIVscotland.com
www.healthygayscotland.com
www.sexualhealthtayside.org
www.bbvmcntayside.scot.nhs.uk
www.thebody.com



Support

Information about living with HIV is available from voluntary organisations such as Terrence Higgins Trust and Waverley Care. Your nurse can give you contact details.

What do these tests mean?

Full blood count: This looks at the number of red cells, white cells and platelets circulating in your blood. It tells us about how your bone marrow and how your spleen might be working.

Urea and electrolytes: This looks at some proteins and salts in your blood that are handled by your kidneys. It helps us know how your kidneys are working.

Urinalysis: This is a test done on a sample of urine. It can tell us if there is infection in your urine or if your kidneys are “leaking” blood or protein into your urine.

Liver function tests: These tell us if your liver is inflamed.

Glucose: This tells us whether you might have diabetes. To be truly diagnostic it needs to be taken when you haven't eaten for more than 4 hours.

Lipid profile: This measures your cholesterol. High cholesterol might be related to some of your medicines.

Phosphate: (depending on which tablets you take) This blood salt can be low if you are on tenofovir.

Viral load: measures how much HIV virus is in each millilitre of blood. If you are not on treatment it doesn't give us very much information. If you are on

HIV treatment then it is important that the viral load becomes “undetectable” and stays “undetectable” to prevent the virus becoming resistant to your medicines.

CD4: This is a type of white blood cell that fights viral and fungal infections. HIV destroys this type of cell. A normal CD4 cell count is higher than 500. If your CD4 count is less than 200 then you are in danger of becoming unwell. We monitor your CD4 count and usually start treatment when it is about 350. Sometimes we will recommend it when it is higher for example: if you have kidney damage, if you have hepatitis B or if you are older than 50.

Syphilis serology: Syphilis is a sexually transmitted infection that is more common in people living with HIV and has more serious complications in someone who also has HIV.

Hepatitis B serology: These blood tests can tell us whether you have had hepatitis B before, whether you have it now and whether you are immune to it. This guides our recommendations for vaccination.

Hepatitis C serology: This blood test can tell us whether you have got hepatitis C infection or whether you have had it before.

Useful Contacts

HIV Specialist Nurses
Tel: 01382 496554

Secretary to Consultants
Tel: 01382 496456

East Block Clinic Reception
Ninewells Hospital
Tel: 01382 496561

HIV Pharmacist
Tel: 01382 660111 ext 33281
email: kirsteen.hill@nhs.net



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