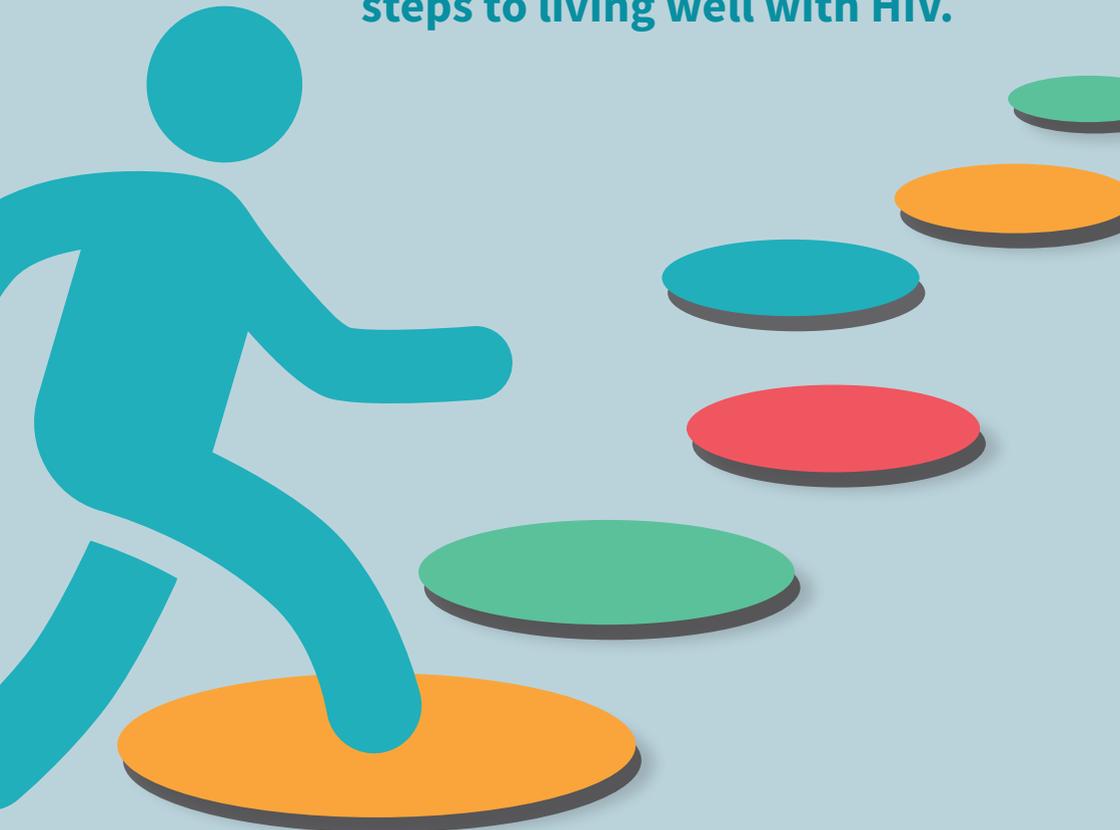


The *Stepping Stones* living with HIV

An information booklet on the
steps to living well with HIV.



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Have you recently found out you have HIV? Have you moved to Suffolk and need some information on the support available to you locally?

Do you have lots of questions?

Being diagnosed with HIV can be difficult and overwhelming, but with the right treatment and support many people will live long and healthy lives. This booklet aims to give you the information you need in simple, easy to follow steps.

We have used the experiences of health care professionals, and people living with HIV, to cover the main things we think you may need to consider after receiving a diagnosis.

Remember, you don't need to process everything now. Take your time, you can come back to the information as and when you need it.



Receiving a diagnosis of HIV

Finding out you are HIV positive can be hard to accept and you may be experiencing a range of emotions. Although you may not feel like it now, it is positive that you now know your HIV status, as you can start taking the steps which will help you to maintain good health.

Getting a diagnosis of HIV can make you feel like you are alone, but in 2019 it was estimated that over 98,000 people were living with HIV and were seen for HIV care in the UK . 98% of these people are now on effective treatment which helps them to stay free of illness and prevents them from passing on the infection to others.

It is normal for it to take a while for the news to sink in and it is important that you work through this at your own pace. You may want to know everything there is about HIV or may not want to know nothing at all right now. Just knowing some of the basics may help, you don't need to become an expert overnight, so let's take one step at a time.





Step 1:

**Getting the
right treatment**

What is HIV and AIDS?

HIV stands for Human Immunodeficiency Virus. It is a condition which damages the cells of your immune system. The immune system is your body's defence against diseases, so when HIV enters your body it can weaken your ability to fight infections.

When you have HIV, making sure you are on the right HIV medication, and taking it regularly, helps to keep the virus under control and helps your immune system to stay healthy and fight off infection. In fact, most people who take the effective treatments and monitor their health live long and relatively healthy lives.

AIDs stands for Acquired Immune Deficiency Syndrome. This is the most advanced stage of HIV and means your immune system can no longer fight infections. With an early diagnosis and treatment, this can be prevented.

Someone with AIDs has both HIV and at least one of a specific list of AIDs defining diseases such as pneumonia and/or some types of cancers. This is why it is important to get tested early and monitor your health to make sure you are accessing treatment that will prevent the risk of developing AIDs.

 *Delivering HIV care is such a positive experience and a real privilege. Advances in medication means that my patients remain well and we get to know each other well - I was discussing this with one of my patients recently as we have now known each other for 25 years A cause for celebration!* 

Dr Edwards, iCaSH Suffolk

Treatment

You may have just been given information about CD4 counts, viral load and names of medications – all of which might sound a little confusing right now. This section aims to give you a basic understanding of what some of these terms mean, as well as signposting you to useful information which can help you understand more about what treatment involves, and what it means for you.



Contact the sexual health services in Suffolk by visiting www.icash.nhs.uk or by calling 0300 300 3030

What do I need to know?

Although HIV treatment does not cure HIV, it can reduce the amount of virus in your body. With less of the virus in your body, it is less able to damage the cells of your immune system (the body's defence against diseases). The aim of treatment is to keep the virus undetectable. It is usually recommended that treatment is started straight away to minimise the risk of getting ill.

The first step is to talk to someone who specialises in HIV at your local sexual health clinic. They will be able to guide you on what treatment is good for you based on blood test results, your symptoms and lifestyle.

Usually treatment is a combination of medications known as antiretroviral drugs. You may have come across the terms ART or HAART. ART stands for 'Antiretroviral Therapy' and HAART stands for 'Highly Active Antiretroviral Therapy'. These are treatments for people living with HIV. There are over 25 anti-HIV drugs now available. Each one works in a different way to stop the HIV virus multiplying in your body. The HIV team at your local sexual health clinic will go through this with you. They should also provide you with more detailed information about the different types of drugs and what may work best for you.

You may notice from time to time the colour of the packaging of your medication may change. This isn't something to worry about. Your clinic may buy drugs from different manufacturers meaning the packaging is slightly different, but the medication inside will be made of the same ingredients. If you are concerned, please see your pharmacist or local sexual health clinic and they will be able to go through this with you in more detail.



Contact the sexual health services in Suffolk by visiting www.icash.nhs.uk or by calling 0300 300 3030

So what is my CD4 count?

Most of the information about HIV and your health comes from something called your CD4 count (sometimes called T cells, or T-lymphocytes). CD4 cells are a type of white blood cell that play an important part in your immune system which protects the body against germs and viruses. Everyone has CD4 cells and your CD4 count is a measure of how many are in your blood. This will tell you how healthy your immune system is and gives you an idea of how HIV has affected your immune system.

The CD4 count is usually given as a number. This number can be anything between 1-1500 and it may go up and down depending on things like exercise, lack of sleep or smoking. If you are HIV positive, this means that your CD4 count may be lower than normal. A 'normal' or healthy CD4 count is usually between 500-1500. If it is below 200 then you are at a much greater risk of getting ill. If it does dip below 200, your doctor or HIV specialist will go over treatment options with you to avoid you getting sick.

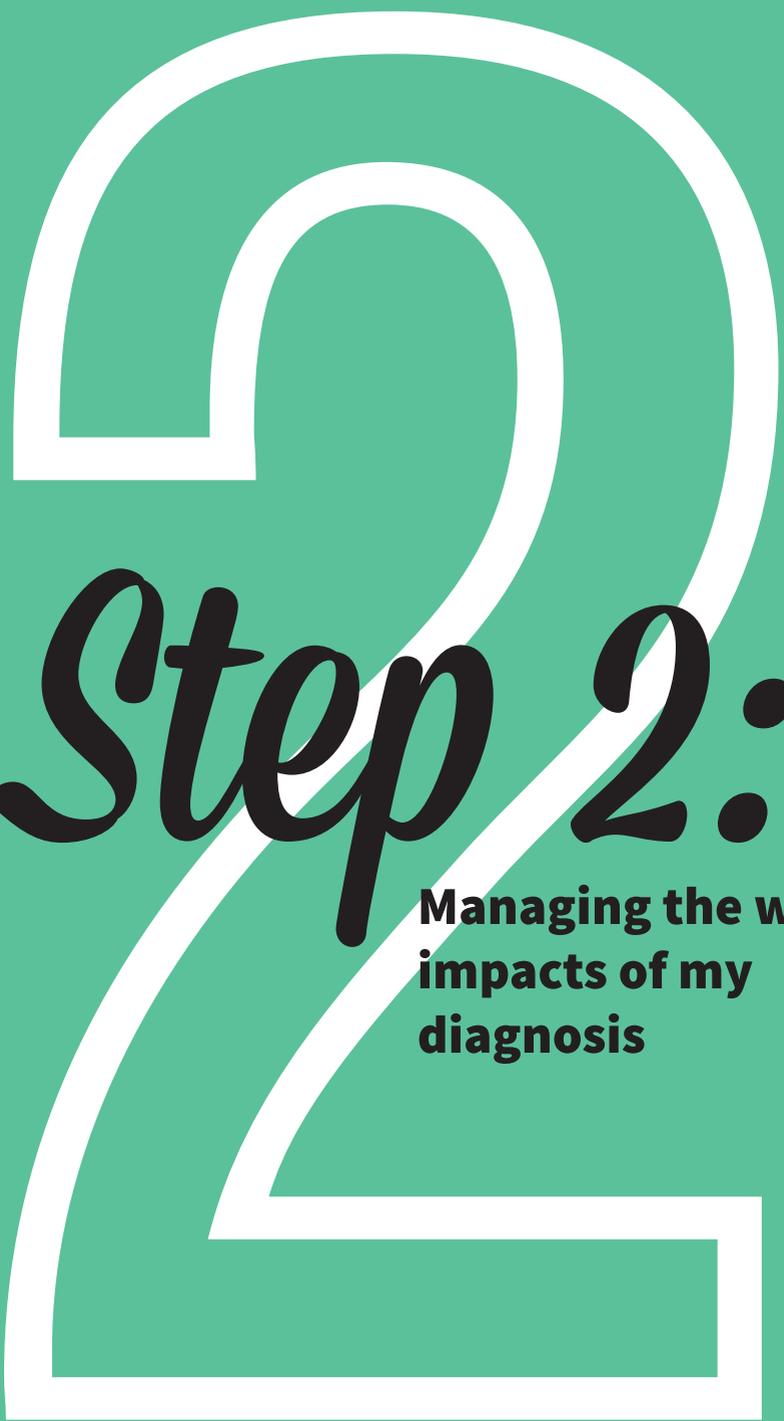


So, what is a viral load?

The viral load is the amount of HIV measured in your body. The HIV team at your local sexual health clinic will be able to find this out by taking a sample of blood. This is a test that will be carried out regularly and used to monitor your health. Having a higher viral load means that HIV may also be in other bodily fluid such as vaginal fluid or semen which increases the likelihood of it being passed on to others. Once you start treatment, your viral load will fall and will become undetectable (which means your CD4 count usually increases). If your treatment is successful, you will eventually have an undetectable viral load. This should happen within 12 weeks, and often happens very quickly. Unfortunately, it doesn't mean you are cured, but it does mean that things are under control. But that's good news! With an undetectable viral load, you are significantly less likely to pass on the virus to others, and you are more likely to remain healthy and avoid illness.

How important is it that I stay on top of treatment and have check-ups?

VERY IMPORTANT! Usually, people who have an HIV diagnosis take between 1-4 pills a day. It is really important that these are taken at the right time every day to keep your CD4 count up and prevent you from getting ill. Adapting to taking medication every day can be difficult but finding a good routine that works for you is key to managing HIV. Normally, your doctor will check your viral load before your treatment, at; 1, 3 and 6-month check points. Once you have an undetectable viral load, your doctor will then discuss how often you will need to see them. If you take all your treatment, then you should see the best results. However, if you are having trouble with this, it is best to talk to one of the HIV team at your local sexual health clinic. The team will be able to give you advice and have more detailed information which can help you with understanding and managing your treatment.



Step 2:

**Managing the wider
impacts of my
diagnosis**

How do I go about telling someone I have HIV?

Stigma is one of the main reasons HIV is not talked about. Stigma is when someone views you in a negative way because they believe you have a personal trait which is negative or undesirable. When HIV was first detected in the UK, a lot of ideas and negative feelings were developed about HIV, leading people to believe things about HIV that were not true. Today, people have a better understanding of HIV, but unfortunately stigma does still exist. No-one should have to feel like they are on their own. Talking to someone you feel close to and feel you can trust can really help.

There is no easy way to tell someone you are HIV positive – but it does get easier with practice.

Sometimes, talking in general about HIV gives you the chance to know how open this person will be to discussion. You might get a positive response if that person knows about HIV, has had previous partners or family that are HIV positive, or they might even be positive themselves.

Before you make these decisions, it is useful to consider the reasons for telling someone, how they will react, how you will deal with a negative reaction and whether they will keep it confidential. Some useful tips on how to do this are provided by an organisation called 'Aidsmap', and can be found by:

1. Going to their web page which is www.aidsmap.com
2. Searching '**deciding whether to tell people you are living with HIV**'



 *I prefer to keep my information about my diagnosis to a limited number of people... people I know, and know I can trust and that everything we discuss is kept confidential* 

Suffolk resident, living with HIV for 10+ years

Who should know about my HIV status?

You may have questions such as who do I have to tell? How do I tell them? How do I tell my partner? Does my employer or GP have to know? Will a doctor or nurse tell any of my family?

These questions can become overwhelming, but it is important to remember that this is your diagnosis, no-one else's, and so the decision should be yours.

Partner and former partners

Telling your partner or a potential partner about your HIV status can be daunting. Although it may be a hard thing to do, it is important to tell your current sexual partner and any sexual partners you have had previously so they can get checked and treated if need be. It is okay to feel angry, upset or embarrassed about the thought of discussing HIV with current or previous partners. The important thing is telling them at a time that is right for you, and in a way that you feel comfortable.

There are a few things you can do to help you get in the space to tell your partner. The first is to discuss it with a professional or peer who is knowledgeable about HIV. This can either be someone at your sexual health clinic, or through organisations such as Terrence Higgins Trust. The people at these organisations will have loads of experience working with people who are living with HIV and will be able to talk you through it. You may also want to hear other's stories of how they have told people about their diagnosis. You can do this by accessing peer support forums or visit sites such as **National Aids Trust - Real Life Stories**

Peer support

Terrence Higgins Trust:
My Community Forum

The Tribe HIV AIDS support
Group

Positively UK Peer Support

**JUST SEARCH THESE PAGES ON THE
INTERNET FOR MORE INFORMATION**

GPs

To keep it short, it's a good idea to tell your GP you have HIV. Your GP cannot offer the best or most appropriate care to you if they are not aware of your diagnosis and the treatment you are on. This could lead to your GP providing medication for other conditions which may react badly with your HIV treatment, and this could be harmful, so it is important that they know. It is useful to keep in mind that legally, GP's must keep your medical records confidential. No-one else will see these documents unless involved in your care. If you are still unsure about telling your GP and have a few more questions, you can visit the **Aidsmap: Telling healthcare workers you are living HIV** webpage - this has a section on telling your GP.



Exposure-prone procedures' are invasive procedures where there is a risk of direct contact to the patient's open tissue (under the skin) if the health worker has an injury.

Employer

There are pros and cons to telling your employer and it is useful for you to understand these so you can make an informed decision about whether and when to tell them. The cons may be the worry that your confidentiality will be breached and others in the workplace may find out about your diagnosis. This could put you at risk of experiencing discrimination. However, remember that you are protected under the Equality Act 2010, so if you are refused a service or receive less favourable treatment because of your HIV diagnosis, you do have your rights.

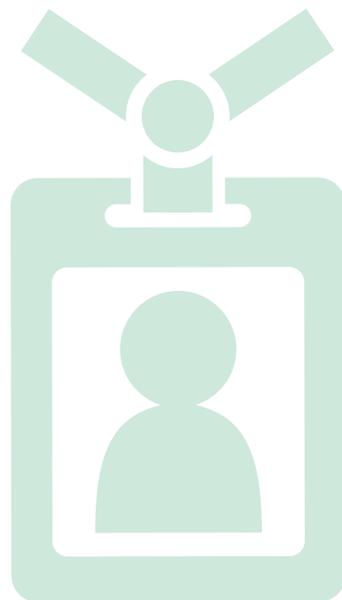
The pros are that if your employer knows, they may be able to make reasonable adjustments which allow you to access support. For example, allowing you the time for medical appointments. Whether you decide to disclose your HIV status or not, it is worth understanding your rights and the laws which protect you by searching HIV: The Equality Act and the workplace in your web browser.

Side note: if you work in healthcare, are HIV positive, and perform exposure-prone procedures, there is guidance which tells you the steps you must follow to disclose your HIV status. If you are still unsure about telling your employer there is an online advice booklet which can be accessed by following the following link:

National Aids Trust Online Guides

Dentist

It is against the law for dentists to refuse to treat people living with HIV. You shouldn't worry about going to a dentist as there is no risk of transmission through general dental treatment if standard hygiene procedures are followed. Similarly to your GP, there is no obligation for you to tell your dentist about your HIV status, however they may need to check for gum-related problems and if you require any medication, it is useful for them to know to ensure that it doesn't clash with your HIV medications.



I need help with...

You may be starting to think about how HIV is going to impact on your daily life, work, benefits or housing. This section will use the experiences of others who are living with HIV to provide you with useful information on how to find support if you experience difficulty with money or benefits, housing, relationships or your general wellbeing.

...Benefits

You may be feeling worried about having time off work or how this diagnosis affects your benefits. The benefits system is complex, and what you are eligible for will depend on your individual needs. This means that the level of support you get might be different to someone else who has a diagnosis of HIV.

HIV does not automatically make you eligible for benefits, but it is important to know what benefits you qualify for, as this can help you with managing day-to-day life whilst living with HIV.

If you are living with HIV and have to stop working or reduce how much you work, you may want to look into seeking the following types of support:

- Universal credit
- New Style Employment and Support Allowance (ESA)
- Personal Independence Payment (PIP)

Please note: universal credit is new single benefit which is being introduced across the UK, which replaces old benefits such as working tax and child tax credits.

We have pulled together information on each of these benefits below, including eligibility, how to apply, and what to do if you are having difficulty applying.

To get help with your application, you can visit your local Job Centre Plus, Citizen's advice office, or ring HMRC (Tax office) on **0345 300 3900**.

If you get stuck and need help with your universal credit claim, there is a universal credit helpline which you can access by calling **0800 328 5644**. You can also get help from the 'help to claim' advisers at the citizens advice service by calling 0800 144 8444 or visiting their website <https://www.citizensadvice.org.uk/helptoclaim/>

Universal Credit

Universal credit is a single benefit which has replaced and combined six previous benefits: Income support, income-based jobseekers' allowance (JSA), housing benefit, income-related Employment and Support Allowance (ESA), child tax credit and working tax credit.

You may be able to get universal credit if:

- You are on a low income or out of work.
- You have £16,000 or less in savings (this includes your partner's savings if you have a partner)
- you are over the age of 18 (there are some exceptions if you are 16 or 17)
- You are under the state pension age.
- You are living in the UK.

Universal credit is paid monthly and is there to **help with your living costs if you are on a low income, out of work or you cannot work**. Your Universal Credit payment is currently made up of a standard allowance of around £344 per month if you are single and under the age of 25, and £411.51 per month if you are single and over the age of 25 (there are different allowances if you have a partner). You can also receive extra payments if you have additional support needs. For example, if you:

1. have children.
2. have a disability or health condition which prevents you from working.
3. need help paying your rent.

How much you get will depend on your earnings and circumstances and is different for everyone. The standard allowances shown above may also change slightly over time. For this reason, you will need to visit the gov.uk website and search 'Universal Credit' for the most up to date payment amounts and more information on how to apply and what you may be eligible for.

The full website is: <https://www.gov.uk/how-to-claim-universal-credit>

If you get stuck and need help with your universal credit claim, there is a universal credit helpline which you can access by calling 0800 328 5644. You can also get help from the 'help to claim' advisers at the citizens advice service by calling 0800 144 8444 or visiting their website <https://www.citizensadvice.org.uk/helptoclaim/>

New Style Employment and Support Allowance (ESA)

ESA is a benefit for people who are unable to work due to a long-term illness or disability. Not everyone living with HIV will need to claim ESA, but it is useful to know whether you are eligible as it can:

1. Help with living costs if you are unable to work.
2. Support you to get back into work if you are able to.

You can apply for ESA if you are under the state pension age and have a disability or health condition that affects how much you can work.

How much you get will depend on what stage your application is at, as well as things like your age and whether you are able to get back into work. You will need to go through an assessment process to decide how much you will get, and this may take up to 13 weeks to be completed. During this time, you will be paid a sum of money called an 'assessment rate'.

After you have been assessed. If you are deemed to be entitled to ESA, you will be placed into one of 2 groups. If you are assessed as being able to undertake activities such work preparation, you will be put in the work-related activity group, you'll be put into the work-related activity group. Otherwise, you will be put into the support group.

Currently, ESA is paid every 2 weeks and the current rates for each group are:

- up to £74.70 a week if you're age 25+ in the assessment phase, or in the work-related activity group.
- up to £114.10 a week if you're in the support group.

However, make sure you check the 'What you'll get' page on the government website to find the most up to date rates as they can change!

Note: you will not be able to apply for ESA if you already receive statutory sick pay or job seekers allowance. You also need to have worked before as an employee or been self-employed and have paid enough National Insurance contributions or credits over the past 2 or 3 years.

You can check your state pension age at <https://www.gov.uk/state-pension-age>

Statutory Sick Pay is what your employer must pay if you have a job but can't work because of your illness. This can be paid for up to 28 weeks. For up-to-date information on allowances, please check the national government page on Statutory Sick Pay

Make sure you visit the [ESA Eligibility Page](#) for more information on the types of ESA you may be entitled to before you apply. To do this, just search 'Employment and Support Allowance' on the www.gov.uk webpage and click on the tab that says 'eligibility'.

You can apply for ESA online by visiting the 'How to Claim' page, or if you are unable to apply online you can call 0800 328 5644 (and choose option 3). After you apply, the Department for Work and Pensions will make an appointment to talk to you.



Personal Independence Payment (PIP)

Personal Independence Payment (PIP) can help you with some of the extra costs of living if you have long-term ill-health or a disability. The PIP benefit has recently replaced the Disability Living Allowance (DLA) for most adults.

You can receive PIP whether you are in or out of work. The amount you get depends on how your condition affects you, not the condition itself. For this reason, you will be assessed by a health professional to work out the level of help you can get. Your rate will also be regularly reviewed to make sure you are getting the right support.

To be eligible for the PIP you must be 16 years of age or over, not reached state pension age, and you must have a physical or mental health condition where you:

- Have had difficulties with daily living or getting around (or both) for 3 months.
- Expect these difficulties to continue for at least 9 months.

Personal Independence Payment (PIP) is made up of 2 parts - a daily living part and a mobility part. Whether you get one or both of these and how much you'll get depends on how severely your condition affects you. The weekly rate for the daily living part of PIP is either £60.00 or £89.60. The weekly rate for the mobility part of PIP is either £23.70 or £62.55.

Mobility difficulties

You may get the mobility part of PIP if you need help moving about or going out.

To find out more about PIP, including up to date information on allowances, please search 'Personal Independence Payment' on www.gov.uk.

To claim PIP, you would have to ring the Department for Work and Pensions on 0800 917 2222, or ask for the form via post by sending a request in letter format to:

Personal Independence Payment New Claims,
Post Handling Site B,
Wolverhampton ,
WV99 1AH.

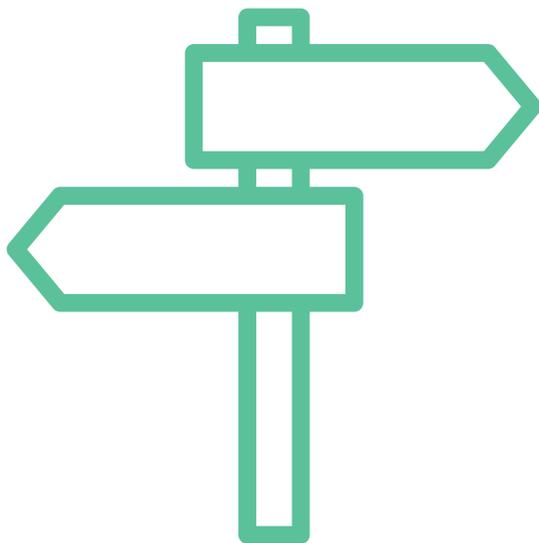
Daily living difficulties

You may get the daily living part of PIP if you find it difficult to undertake daily activities such as:

- Preparing or eating food
- Washing or bathing
- Using the toilet
- Dressing and undressing
- Reading and communicating
- Managing your medication or treatment
- Making decisions about money
- Engaging with other people

Once you have received the form you will have one month to return it. Fill in the form using the notes that come with it to help you. Return the form to the address on the form. The form will be assessed and you will be invited for a meeting or a professional advisor will talk to your health and/or social worker. If successful, a formal letter will be sent to you about your entitlement.

A claimant commitment is a record of responsibilities you have accepted in return of receiving this benefit.



Contacts

Ipswich & District Citizens Advice

19 Tower Street
Ipswich
Suffolk
IP1 3BE
01473 219 777

Jobcentre plus - Ipswich

St Felix House
Silent Street
Ipswich
IP1 1TF
Public phone: 0800 169 0190

Mid Suffolk Citizens Advice Bureau

5 Milton Road South,
Stowmarket
IP14 1EZ
Phone: 01449 676280

Citizens Advice Bureau

90 Risbygate Street,
Bury St Edmunds
IP33 3AA
Phone: 0300 330 1151

Newmarket Citizens Advice Bureau

Foley Gate Wellington St,
Newmarket
CB8 0HY
Phone: 01638 665999

North East Suffolk Citizens Advice Bureau

St. Margaret's House Gordon Rd,
Lowestoft
NR32 1JQ
Phone: 01502 518510

Citizens Advice Bureau

Belle Vue Newton Road,
Sudbury
CO10 2RG
Phone: 01787 374671

Citizens Advice

Haverhill House Lower Downs Slade,
Haverhill
CB9 9HB
Phone: 03003301151

Citizens Advice Bureau

12 New Market,
Beccles
NR34 9HB
Phone: 01502 717715

Job centre Plus

Rishton House
Clapham Road Town Centre,
Lowestoft
NR32 1RW
0845 604 3719

Job centre Plus

21 Borehamgate,
King St,
Sudbury
CO10 2EG
0845 604 3719

Jobcentre Plus

St Andrews Street North,
Bury St Edmunds
IP33 1TT
0345 604 3719

Jobcentre Plus

49 Ipswich Street,
Stowmarket
IP14 1AH
0345 604 3719

To find local benefits services click here; Turn2Us Advice and Service Finder

Free benefit calculators can be found here;

- Entitledto Website: Benefits calculator
- Turn2Us Website: Benefits calculator

You can find out more information on the national government page on Benefit Calculators

For more information on benefits you can visit;

- Housing Benefit Overview
- Terrence Higgins Trust: Living Well with HIV Support pages
- Citizens Advice benefits advice
- Aidsmap information on HIV and money
- National Aids Trust: ESA and WCA guide

For local information on benefits you can visit the district borough websites:

- Babergh and Mid Suffolk: Benefits Information and Advice
- East Suffolk: Benefits Information and Advice
- Ipswich: Benefits Information and Advice
- West Suffolk: Benefits Information and Advice

I need help with housing...

A house should feel like a home and should be somewhere that you feel safe and secure. When living with HIV, a stable housing environment makes it easier to stick to your treatment and can help with managing any side effects or health risks. This makes it important to know what support is available to help you with your housing needs.

You may be worried about housing due to your finances, or maybe your current housing is unsuitable due to it being crowded or poorly maintained. We have included some information and key contacts below to help you if you are worried about any of these things.

Social Housing

You can apply for a home through your local council. This is called 'social housing'. If your application is accepted, you'll go on to a waiting list of people who need a council home. Your council will then prioritise applications based on who needs a home most urgently.

Your local council will have its own rules on who can apply and who has priority for homes - this is called an 'allocation scheme'. You can find your local council by searching for the <https://www.gov.uk/find-local-council> website. All you have to do is enter your postcode.

The citizens advice service says that you'll probably need to:

- be on a low income or not have a large amount of savings.
- have lived in the area for a number of years, or have a job or family there - this is called a 'local connection'.

Not all councils need you to have a local connection. If you're thinking about moving to a different area, it's worth checking the council's website to see if you can apply.

Please bear in mind that there is currently a shortage of affordable accommodation in the UK, and while this can vary from area to area it can still be difficult to secure decent and affordable accommodation. This shortage includes private rented accommodation and social housing.

Find out if you are a priority for housing...

You're more likely to get a council home if you've been given priority by your council's allocation scheme.

This could be if you're:

- legally homeless or the council has a duty to find you accommodation if you're homeless - check what help the council should give you
- moving because of a disability or serious, long-term health condition
- moving to a different area because of 'hardship' - this could be to get medical treatment, because you're in danger or to take up a new job
- in a home that's overcrowded or in poor condition

It's likely to take some time to get an offer - even if you get priority in your area. In areas with long waiting lists, you might not be offered a home at all so keep your options open. Other options are to look for a home yourself or stay where you are. You can also look at renting from a private landlord.

If you think you haven't been given enough priority, you can ask your council to review their decision. Check your council's allocation scheme to see who's given priority in your area.



Getting a Mortgage

There should be no issues in obtaining a mortgage, unless this is an endowment mortgage; however, these tend to be something of the past. The difficulties tend to be with getting life insurance to cover the loan, but there are specialist life policies available if you have HIV. It is useful to note that this is not something you have to do. If your income drops due to ill-health and you cannot make full payment, it might be worth speaking to Citizens Advice or Shelter about your options.

Housing Related Support

If you are in rented or mortgaged accommodation and are experiencing difficulties with your housing, you may be able to get help from a support worker and other agencies to help you solve your housing issues. This includes if you are:

- at risk of being evicted
- behind with paying your rent or mortgage.
- struggling with budgeting, paying bills, or finding it hard to manage your home.
- at risk of losing your home for any other reason

You may also be able to be placed in supported accommodation if you have extra support needs, or access emergency accommodation for the night if you find yourself in an emergency with nowhere to stay.

To find out more about the above support you will need to search for 'Homelessness and housing support' on the www.suffolk.gov.uk website.

Key contacts

Some links that might be helpful to you are;

Citizens Advice: Housing Information

Shelter: Advice and Support on Housing

IHAG – Ipswich Housing Action Group

Suffolk Housing

Suffolk County Council: Apply for housing related support - 01473 265696 or email hrsaccess@suffolk.gov.uk

Just search these websites on your web browser.

Healthy relationship, practising safer sex and moving forward

After receiving a diagnosis of HIV, you may feel differently about your relationship, sex and about yourself. For some, feeling this way can affect the way you interact with your partner and may affect your sexual performance. The first step is to recognise you may be feeling this way, and that feeling this way is normal. You may want to talk to a GP or the HIV specialist about how you feel, however it is important to remember that you are not the only person that has felt like this. You may also experience physical issues and again, it may be good if you discuss this with your GP or HIV clinic team. They will be able to advise you on things you can do to help you and your relationship.

There are some online resources and stories that may be helpful to you when processing these feelings and experiences;

- **Aidsmap:** HIV and Sexual Health
- **National Aids Trust** - Real Life Stories
- **Terrence Higgins Trust:**
Living with HIV - Sex and Relationships

**JUST SEARCH THESE
PAGES ON YOUR WEB
BROWSER**

No matter how you may be feeling about current or future relationships, it is important to know that there is advice and support out there.

Those who are HIV positive can have a relationship with those that are HIV negative, however it is important to practice safe sex and make sure you are taking your treatment to minimise the risk of passing HIV on to them.



Step 3:

**What can I do to
keep myself healthy
with HIV?**

Now knowing the basics of what HIV is, it is important to know how to keep yourself healthy.

It may take some time to build a healthy routine, but that's okay. This section will help you think through the steps you can take to maintain a healthy body and good mental health and wellbeing.

Lifestyle choices

There are many things you can do to improve your general health and reduce the risk of getting sick. Most of these involve making healthy choices.



Smoking

Someone with HIV is more vulnerable than others to the harmful effects of smoking. Smoking causes a quarter of cancers and two out of five heart attacks that occur in people living with HIV. It has been shown that smokers who have HIV treatment and an undetectable viral load are more likely to become ill from a smoking-related illness rather than by an HIV-related illness.

Giving up smoking can be hard, yet it is important to maintain good health. Even one cigarette a day is harmful. To find local support for smoking, you can visit your GP, contact OneLife Suffolk to speak to a stop smoking advisor or visit NHS SmokeFree to gain more advice. They can help talk through different techniques for quitting smoking and will give you information about medications such as Champix, and nicotine replacement therapy such as patches which can help. However, it is important to note that you will need to talk to your HIV doctor if you are considering any stop smoking medications to make sure they are safe to use alongside your HIV treatment.



Eat a balanced diet

Eating a balanced diet is important for everyone. It means trying to have a variety of foods. It is encouraged that those with HIV try and maintain a balanced diet to reduce the risk of common health problems such as heart disease, obesity, diabetes and hypertension. Making sure you have the right amount of vitamins and minerals is also vital for maintaining a strong immune system.

It can be hard to keep a balanced diet, and it is important not to avoid attending social events or allowing yourself to enjoy the foods you love. It just means you have to be more careful and try to make healthy informed choices most of the time to reduce the risk of developing health conditions. To find support on what is considered a healthy diet search for The EatWell Guide online. If you feel like you need support with your weight you can contact your GP and OneLife Suffolk.

OneLife Suffolk

Inspire Suffolk Centre,
Lindbergh Road,
Ipswich IP3 9QX
01473 718193



Physical activity

Regular exercise can reduce the risk of common health conditions and can help maintain strength and reduce stress. Adults should aim to get 150 minutes (2 and a half hours) of exercise a week. It is encouraged that people living with HIV also up their exercise as it helps maintain the strength and stamina for day to day activities as well as boosting your immune system.

Similar to with keeping a balanced diet, it can be hard to maintain an active daily routine. Trying to increase your activity a little bit each day (if you don't already) can make a big difference to anyone's health, the same way as it would with someone not living with HIV. If you have a condition that might impact your ability to do any form of exercise, it might be worth speaking to a specialist or your GP about this. Advice is also available on the OneYou app which can be downloaded from NHS Better Health website.



Reducing the intake of drugs and alcohol

Long-term drinking or drug use can cause serious health implications for anyone. It can be associated with conditions such as hypertension (high blood pressure), heart disease, and can affect the liver which is needed to process medications. It is also important to remember that under the influence of alcohol or drugs, you may also forget to take your HIV treatment, and this could harm your health.

Guidelines show that in the UK men and women should drink no more than 14 units per week. This is the equivalent of 6 pints of beer or 10 small glasses of wine a week. There are some tools online from the OneYou website about alcohol intake which may help you make sure you have healthy drinking habits which can be found here - NHS OneYou: Drink Less . If you feel like you are suffering from addiction and need support, we have a Recovery Network in Suffolk – Turning Point – which offers a range of services and support which can help you.

TurningPoint

Ipswich Hub
Sanderson House
17-19 Museum Street
Ipswich
IP1 1HE
Tel: 01473 220 240

Lowestoft Hub
Woodbury House,
Mill Road,
Lowestoft
NR33 0PP
Tel: 01502 531 138

Bury St Edmunds Hub
2 Looms Lane
Bury St Edmunds
IP33 1HE
Tel: 01284766554

Emotional wellbeing and staying connected

Emotional wellbeing and staying connected

It is important that you try to stay connected with other people to avoid becoming isolated following a diagnosis of HIV. This will help with your day to day mood and is good for your emotional wellbeing. You may be feeling quite down about your diagnosis and still trying to come to terms with it all. This is perfectly normal. Staying connected with friends and family and having regular contact with people can be good for your mental health. It doesn't matter if you are not ready to tell people about your diagnosis yet, this should be done in your own time and in a way that works for you. Staying connected can be done in different ways such as face to face, online, phone calls, or even a video call via skype. It is important to remember to keep the communication lines open if possible, even if you do not disclose your HIV status.

You may want to look at our five ways to wellbeing Suffolk campaign for some useful tips on how to stay emotionally well.

Telling people about your diagnosis and staying connected are two separate matters. Staying connected refers to being socially engaged, meeting new people, trying new activities, and learning new skills. This can help stimulate your mind and provide some time to focus on the things you enjoy. This can be done in your own time but getting involved in social activities and keeping your brain active may help you as you adapt to living with HIV.

Telling people is slightly different to staying connected. This is more about having the conversations about your diagnosis. You may be in two minds about telling people or be worried about who to tell and how. We realise that this is an important question you may have so please refer to section 2.3 which aims to help with this.

As well as staying connected, it is also good to keep your brain active and this can involve anything you enjoy that stimulates your brain, e.g. Reading, quizzes, as well as trying new skills or maybe trying a new sport or social club in your local area.

If you feel like you are struggling with your mental health, you can contact the Suffolk Wellbeing Service on 0300 123 1781 to speak to a member of the team or speak your GP.

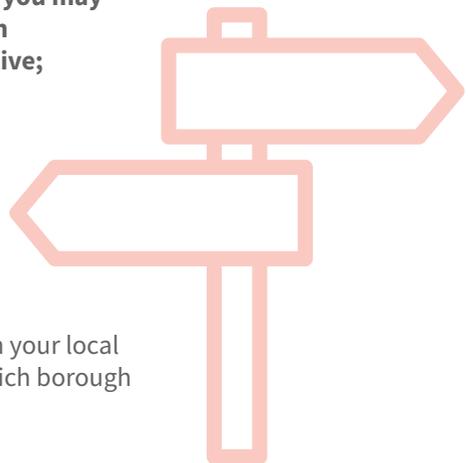
Some national websites may help;

- **Rise above** - <https://riseabove.org.uk/tag/relationships/> – advice about relationships amongst other topics for young people
- **THT direct line** - <https://www.tht.org.uk/our-services/phone-and-post/tht-direct-helpline> or ring 0808 802 1221 – for advice support and information 10am to 8pm Monday to Friday
- **MyHIV forum** - <https://www.tht.org.uk/our-services/online-services/myhiv-forum> - free, welcoming and safe place to meet other people living with HIV.
- **NAT life stories** - <https://www.nat.org.uk/real-life-stories> - Explore what is like for people living with HIV through the eyes of those who have been affected

Local services that may interest you...

Here are some local services which you may want to check out or get involved in to stay connected and mentally active;

- Library services
- Museums
- Local Sports clubs or your local Park run
- InfoLink
- Healthy Suffolk website
- For local activity services look on your local district council website e.g. Ipswich borough council.



Top tips going forward

Now you have the stepping stones to living healthily with your diagnosis. Don't forget that the support doesn't stop here. There is plenty more information out there and different places you can get support. We have come up with some top tips for you and things that are important to keep in mind as you move forward on your journey;

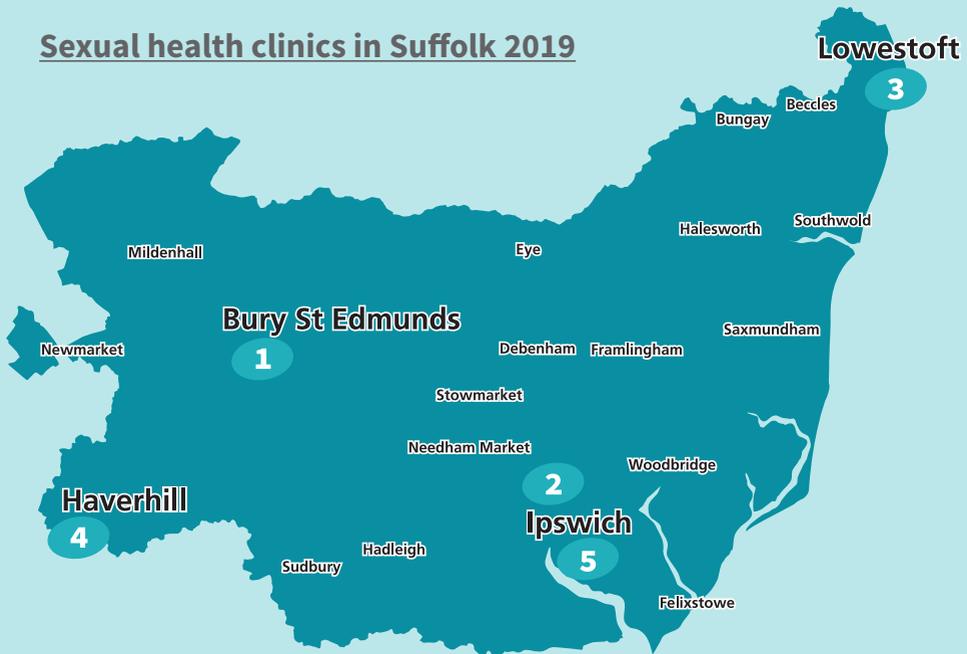
1. Stay connected – it is easy to become isolated following a diagnosis of HIV, so it is important you try to stay connected with your friends and family and avoid trying to deal with everything alone
2. Talk to professionals – many people who live with HIV have said that it has really helped to talk through their worries with a professional
3. Know your rights – there is legislation which can protect you and provide additional support when living with a long-term condition such as HIV. It is important you can understand this legislation so you know your rights and are making the most of the support available
4. Take your time – this is your diagnosis and you are in control over when you tell people and who you tell

Myths about HIV

- HIV is just a young person's illness – incorrect! HIV affects people of all ages
- If I change treatment I can't switch back – this depends on the reason e.g. if you become drug resistant (the current medication you are taking is not working anymore) or because of side effects. It is best to speak to the team at your local sexual health clinic
- HIV has a cure – there is no current cure for HIV however with effective management you can keep it controlled
- I can't work if I have HIV -incorrect! Effective treatment can mean people can keep the virus under control and people can work like everyone else
- I can't have children – incorrect! There are options available if you are wishing to start a family and steps are available to ensure that HIV is not passed on to your partner or the child.
- I can catch HIV through normal social contact – incorrect! You cannot get HIV from kissing, hugging, normal social contact, or sharing household equipment such as cutlery or bed linen.

Sexual health services and support Suffolk

Sexual health clinics in Suffolk 2019



- 1** Abbey View Clinic, 9/10 Churchyard, Bury St Edmunds, IP33 1RX
- 2** Orwell Clinic, Lindbergh Road, Ipswich, IP3 9FA
- 3** 6 Regent Road, Lowestoft, NR32 1PA
- 4** Health Clinic, Camps Road, Haverhill, CB9 8HF
- 5** Terrence Higgins Trust 10-12 Orwell Place, Ipswich, IP4 1BB.

Visit **The Healthy Suffolk website** for more up to date information on services and support available

Notes

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