



INDEPENDENT LIFE

LEAVING HOME AND STANDING
ON YOUR OWN TWO FEET:

A GUIDE FOR PEOPLE WITH HIV IN THEIR TEENS AND EARLY ADULthood

NCB.org.uk/LifeLinks



So you're thinking about leaving home to live independently, or have already left, and you have HIV?

WHAT MIGHT YOU NEED TO KNOW?

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This leaflet is a starting point to answering these questions, and will direct you to support and further information. Download other leaflets on life for young adults with HIV from [NCB.org.uk/LifeLinks](https://www.ncb.org.uk/LifeLinks) or get them from clinics or support services.

Want to hear from other young people with HIV? Look out for the yellow boxes.

DO I HAVE TO CHANGE MY HOSPITAL OR GP IF I MOVE TO ANOTHER AREA?

- You may find it more convenient to change hospitals, but you don't have to do this straight away. Talk to your doctor or health team about where you plan to move. You can work out a plan together and they can make arrangements for your transfer to a new clinic, or arrange for your care to be shared between two clinics, depending on what is best for you.
- If you are leaving home temporarily (e.g. to study) you may want to keep getting your HIV health care at the same hospital, but register with a GP locally. See what one young person who went to uni said below.
- GPs can help with a wide range of health issues. If they know that you have HIV, they can understand your health better and also help if you need emergency care.
- Remember, moving to a different area doesn't mean you have to move clinic, but if you do and it doesn't go too well for any reason, you can always still contact your old health team and see if they can help you sort it out.

It's good to have links with a local GP to make sure you have health support in place near you.



HOW CAN I FIND SOMEWHERE TO LIVE?

If you need somewhere to live, you could:

- Rent as a private tenant – you might rent a room in a shared flat or house
- See if you're eligible for social housing (council or housing association accommodation) which is cheaper, though there can be very long waiting lists
- Register as homeless if you don't have a secure home (being homeless doesn't just mean sleeping on the streets) – if you're found to be homeless, your local council must provide you with emergency accommodation.

TheSite.org and **Shelter.org.uk** have loads of information on housing options, rights and issues. Shelter provides legal advice and has a helpline: 0808 800 4444.



HOW CAN I COPE WITH LIVING IN SHARED ACCOMMODATION?

Many young adults share flats or houses with friends or people they've found or been placed with. Living with people means you get to know them quite well and may have more intense ups and downs. You might go into each other's rooms and know each other's whereabouts.

Remember, HIV can't be transmitted through shared household living, so you don't **have** to tell anyone you live with, or a housing provider, that you have HIV. But you may **choose** to.

- If you decide to tell a housemate (or someone else in your personal life) that you have HIV, you are likely to want them to keep this confidential unless you have chosen for your HIV status to be openly known. You'll need to feel you can trust a person – it's easier to judge this if you know them well than if you've met recently. Avoid rushing into telling.

- Be prepared to answer questions, and also suggest they look at **HIVaware.org.uk** or another website you like. People's fears about HIV are often based on not understanding it.

It's up to you who you tell. I did tell people – I told people I was close to and I felt I could trust. It can help if you're stressed, it can help if there is someone you can talk to and who knows you. It can make you feel more comfortable.

Read young people's tips on telling on the websites listed in this leaflet.

WHAT IF I'M STRUGGLING AFTER I LEAVE HOME?

- If you feel lonely, try joining a local club or class, contact your nearest HIV support organisation (find it at LifewithHIV.org.uk), or talk to support workers or other professionals you trust.
- If you feel HIV is making you isolated, you can talk to other people with HIV securely online – go to CHIVA.org.uk to speak to young people aged up to 24 or MyHIV.org.uk to contact adults and people aged 16+
- Keep in touch with friends and family who make you feel supported
- Use the websites at the end of this leaflet to learn how to take care of yourself and build your skills for independent living.

I NEED HELP WITH EVERYDAY LIVING...

There are adult social workers based in disability teams in Social Services who can help and support people who they assess as having sufficient needs. If you think that applies to you, get in touch with your local Social Services department, which you can access through the main council telephone number.

AskSARA.org.uk is an interactive tool to help find ways of making daily living easier.



HOW MIGHT HIV AFFECT GETTING A JOB AND WORKING?

- There are thousands of job options, and only a tiny number that are not open to people with HIV at the time of writing: mainly surgeon, dentist, or roles in the armed forces.

For almost all jobs, you don't **have** to tell your employer you have HIV. But you might **choose** to (for example, if you need adjustments like time off for hospital visits). For jobs in healthcare, there are some restrictions on working without testing for, or declaring, HIV.

If you do want to tell your employer (or a service), the law says that your **consent** (permission) is required before employers can share personal information. You're also protected from discrimination relating to HIV by law. See LifewithHIV.org.uk for legal rights.

Use the websites in this leaflet to learn more about work, or visit NCB.org.uk/LifeLinks where you can also find the **Working Life** leaflet, plus a confidentiality agreement by CHIVA, which you may wish to use or adapt.



WHERE CAN I FIND WORK OPPORTUNITIES?

- Newspapers, job search websites, recruitment agencies, or employers
- With help from your local JobCentre Plus (find it at [GOV.UK](https://www.gov.uk)) or a careers adviser at [NationalCareersService.direct.gov.uk](https://www.nationalcareersservice.direct.gov.uk)
- Through learning on the job ([Apprenticeships.org.uk](https://www.apprenticeships.org.uk)) or volunteering ([Do-it.org](https://www.do-it.org)).

WHAT KIND OF WELFARE BENEFITS MIGHT I BE ABLE TO GET?

You may be able to get some money towards your living costs. Benefits are changing, but currently include:

- **Housing benefit**, which can help pay your rent in private or social housing if you are not working, or working limited hours and earning less than a certain amount. You apply to receive this benefit from your local authority.



- **JSA or Jobseekers Allowance** can be claimed by people who are aged 18 and over, who are seeking work. There are special circumstances under which you can claim JSA if you are 16 or 17. Contact your local Jobcentre Plus office (find it through the Employment pages on **GOV.UK**) to learn more about JSA.
- **ESA is Employment and Support Allowance** for people who can't apply for JSA because they have limited capacity for work due to illness or disability. You can apply for this benefit on the phone: 0800 0556 688 (open 8am-6pm; charges apply to some mobile networks).
- **Income support** – to receive this benefit you have to be working fewer than 16 hours a week, and be able to show that there are valid reasons you can't work more hours. Your local Jobcentre Plus office can advise you.
- **Working tax credit** is for people who work at least 16 hours a week and are on a low income. You can get extra payments if you have a disability that meets set criteria.
- **Disability benefits** – you can apply for financial help towards care or help getting around because of a disability. These benefits are currently changing.
- If you have a child, you can get **child benefit** and may also be able to get **child tax credits**.

Get all the latest information on benefits and tax credits straight from the government at **GOV.UK** For explanations written for young people, go to **TheSite.org**.

You may be able to get other financial support for your education. Speak to your school, college, or a training provider. To learn about finance for uni students, go to **Push.co.uk**.



Trying to apply for benefits and council tax and sorting out your rent and getting grants and loans and whatever from here, there and everywhere – it's irritating. But once you get the hang of it, you get your independence. Like, 'Oh, I can do it on my own now!' Because before I was ringing up my sisters and my mum. Once you've done it a few times, you get used to it.

I moved out when I was sixteen. The council put me in a hostel that was just awful, it was grotty, and I had no fridge. At the time, I was on treatment that needed a fridge. The fridge was in the kitchen, shared, and I didn't want to show everyone my medication. But my doctor gave me the best support. She wrote me letter after letter.

I asked them to talk about HIV, but the doctors can say it's a long-term condition if you don't want to disclose. Eventually they moved me out to another hostel but it was my own space.

Young people who are looking to move out need to know their rights because you don't want to be sharing a space with someone that's going to make you feel uncomfortable. You want to be able to have your medication in the right place and if you are feeling unwell, to know you can have a good night's rest.

WHERE CAN I GET HELP?

- **THT Direct** – call 0808 802 1221 for help relating to HIV or visit **MyHIV.org.uk**.
- **Shelter** – call 0808 800 4444 for housing advice or visit **Shelter.org.uk**.
- **CitizensAdvice.org.uk** – advice on a wide range of issues online, over the phone or in person
- **GOV.UK** – services, rights and benefits plus links to your local council
- Learn about rights and HIV at **LifewithHIV.org.uk** and find local support services.

These phone lines are not open 24/7. At the time of writing, calls to the Citizen's Advice Bureau are charged; THT and Shelter are free from landlines and most UK mobiles.

HIV information, advice and networking for young people

- **CHIVA.org.uk** (Children's HIV Association) – includes secure site for young people with HIV aged 24 and under, with social networking
- **Pozitude.co.uk** – includes forum and Your Stories
- **Bodyandsoulcharity.org** – includes young people's radio podcasts and comic book and audio stories

Information for young people on independent living

- **TheSite.org** – finding housing, housing issues, housemates, bills, money, benefits, work, studying, and more...

LIFELINKS



LifeLinks is a web directory to help you find information and support on all aspects of becoming an adult, as well as HIV. It contains other leaflets like this, links and helpline numbers as well as step-by-step advice for certain situations.

Visit **NCB.org.uk/LifeLinks** or scan this QR code with a phone app and it will take you straight there... Remember to save the link!

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