



LIFE LOOKING

FORWARD

**STAYING SAFE, WELL AND HAPPY
ON THE WAY TO ADULTHOOD:**

A GUIDE FOR YOUNG PEOPLE WITH HIV

[NCB.org.uk/LifeLinks](https://www.ncb.org.uk/LifeLinks)



So you're growing up with HIV?

WHAT MIGHT YOU NEED TO THINK ABOUT?

How can I look after myself, feel well and safe, and do normal stuff young people do? page 3

How can I cope with family issues? page 8

Can I have my own family? page 9

What is transition and how do I deal with it? page 11

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 people 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.

LOOKING AFTER YOURSELF

It's important for all young people to treat their bodies with care, to feel well and stay well in the long-term. For young people with long-term health conditions like HIV, it's especially important, and has many benefits.

Look at the next page for ideas on how to stay healthy and happy. These are suggestions, but your HIV team can give you personal advice on your health. You can also talk to them if you're having any problems.

- Get tips on diet, exercise, sleep, sex, relationships, treatment, emotional wellbeing and drugs and alcohol at MyHIV.org.uk or Pozitude.co.uk
- Try using **iDiary Meds** if you have trouble remembering to take your medication – it's a discreet phone app designed by young people with HIV
- Visit FoodChain.org.uk to see how diet can help with general health and any symptoms and side effects.



Diet	Exercise	Sleep	HIV treatment	Careful choices
<p>Try to eat a mix of different coloured foods – you get a good range of nutrients. Eat fresh fruit and veg every day.</p>	<p>Exercise can improve muscle tone, body shape, mood, sleep, energy and more! Aim for at least 3 exercise sessions a week.</p>	<p>Aim for 8 hours sleep a night. If you get enough sleep regularly your body and brain function at their best.</p>	<p>Take your meds at the same time as another daily activity you do, like brushing your teeth.</p>	<p>Do you feel happy, supported and appreciated by people in your life? If not, they may not be relationships you want to continue.</p>
<p>It's important to drink plenty of water. If you have nausea or diarrhoea, drinking fluid can also help.</p>	<p>Set goals you can achieve and don't be disheartened by off days. Websites and apps can help you track your progress.</p>	<p>If you can't sleep, speak to your doctor/nurse – you may have treatment side effects, anxiety or depression.</p>	<p>Ask your nurse about ways to make taking medicine easier, like pillboxes, reminders and charts.</p>	<p>Everyone takes risks in life. But you have to weigh up the risks and whether you want to face the consequences.</p>
<p>Prepare food with friends or family members to make it more enjoyable.</p>	<p>Take it slowly and exercise with friends or try a team sport if you feel unmotivated.</p>	<p>Avoid caffeine, eating, smoking, exercise or alcohol just before bedtime.</p>	<p>Don't forget to reward yourself when you're doing well with your treatment.</p>	<p>Carry condoms in your wallet or bag, and make sure you know how to use them.</p>

WHAT DOES MAKING 'CAREFUL CHOICES' MEAN?



Think about the situations or decisions that may pose risks to your wellbeing, like:

- smoking tobacco, and also weed – when you have HIV, smoking increases the risk of getting certain infections and HIV-related illnesses
- drinking alcohol or taking drugs and medicines (including fitness drugs and herbal remedies)
- having unprotected sex, or sex you don't want
- violent or abusive behaviour and relationships.

For example, lots of young people and adults get drunk – this can be good fun, but it can make you more likely to do or say things you regret, or have sex without a condom. Think about the need to balance having fun with the need to remain in control and able to make safe choices.

If you plan a night out, think about how you will remember to take your medication. If you vomit within an hour of taking them you need to take them again. Also be aware that some recreational drugs may interact with your HIV medication.

You can get advice from your nurse/doctor or through **THT Direct** by calling 0808 802 1221.

FEELING WELL

Growing up can be a stressful time for anyone – HIV adds some extra complications. Maintaining your physical health has big benefits for your mood and self-esteem. You can also look after yourself emotionally.

Don't hold it all in – talk about issues or read or listen to stories from other young people with HIV (there are over 1,000 in the UK so you're not alone). You can contact young people with HIV aged up to 24 on the secure site through **CHIVA.org.uk** or adults aged 16+ at **MyHIV.org.uk**.

- If you find talking difficult, try writing down your feelings, or drawing or creating something. People find many different ways of expressing themselves.
- Try to focus on the things in your life that you enjoy. Be aware of the things and people who make you feel good and try to increase the time you spend with them.



- If you are feeling very down, want to be alone, cry a lot or lack energy, you could be depressed. Depression is very common and there is a lot you can do to recover. Take a look at **YoungMinds.org.uk** for information on depression and other mental health issues. Try to talk to someone about how you're feeling. Many people find counselling helps them deal with all sorts of difficulties – your nurse or doctor should be able to arrange this for you.

Be aware of your drinking and do it in moderation – that's not specific to whether you have HIV or not: everyone should do it in moderation. It's important that everyone looks after themselves, eats well, doesn't drink too much. It's just that it can matter more if you are HIV positive.

Everyone needs to protect themselves in sex. If you're protected – using a condom – do what you're doing and have a good time! This applies to everyone. It's just that if you don't use a condom and you have HIV, you put yourself at risk of transmitting HIV.

Try to limit stress as much as possible as it's important for us.

Be aware that certain medication can make you vulnerable to things like depression. Sometimes you don't realise it. It can come on because of the different pressures and stress you are facing. Monitor your health and take stock of how you are mentally and physically.

If you do get depressed you should tell your doctor. It might be an effect of your medication and they might be able to change it.

FAMILY

For some young people with HIV, family is their main source of support. A parent, carer or sibling may know you better than anyone, and may have experience of living with HIV themselves. This is great. Still, it's normal for young people to have rocky periods with family members. Some common issues are:

- Not feeling able to talk about personal things like HIV with family
- Feeling that family members are from another planet
- Getting enough space but also enough support
- Sacrificing your own needs and wishes to put family members first.

Try discussing any concerns at home or with someone else you trust. If things have been really difficult or you don't feel safe, you may have, or need, a social worker to help with family matters or support you to live away from family. You can also contact ChildLine for advice or a chat: call them on 0800 1111 or email/instant message – go to [ChildLine.org.uk](https://www.childline.org.uk).

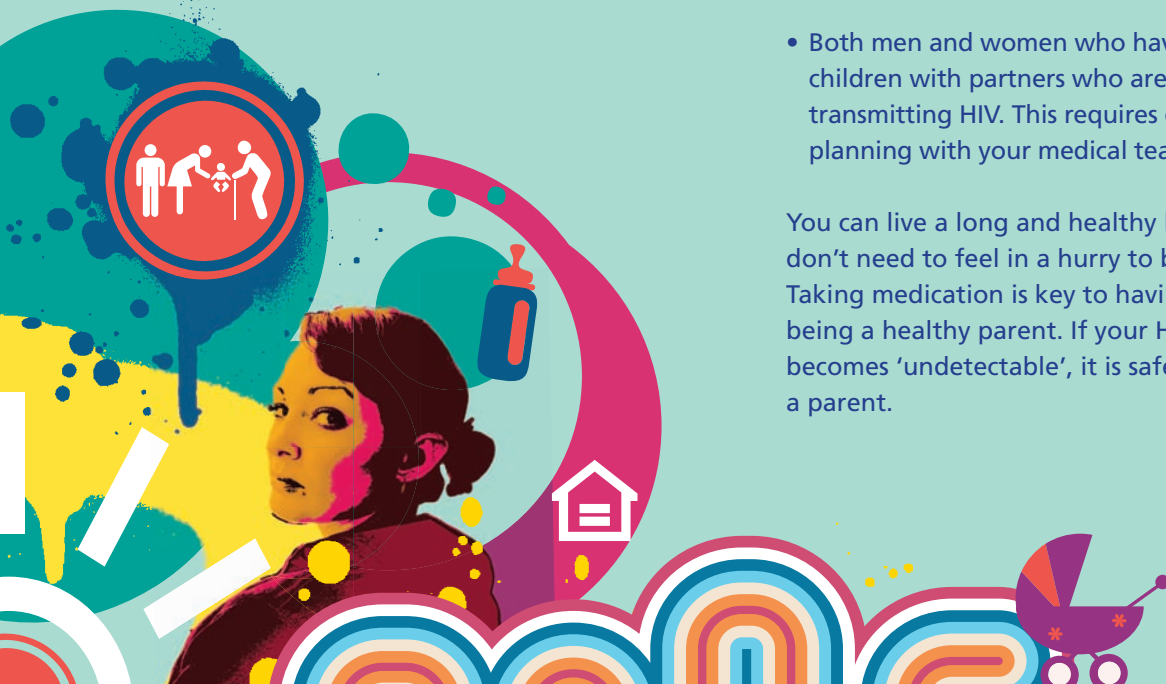


CAN I HAVE MY OWN FAMILY?

Absolutely! Having HIV does not stop you from being a parent and, importantly, you are very likely to be able to have a child who doesn't have HIV.

- Every year, over 1,000 babies are born in the UK to women who know they are HIV positive – almost all of these babies are not infected with HIV, because protective measures like taking medicines can reduce the risk of the baby getting HIV to less than 1 in 100
- Both men and women who have HIV can have children with partners who are HIV negative without transmitting HIV. This requires discussion and planning with your medical team.

You can live a long and healthy life with HIV, so you don't need to feel in a hurry to become a parent. Taking medication is key to having children and being a healthy parent. If your HIV is suppressed and becomes 'undetectable', it is safer for you to become a parent.



You can get the latest information from your HIV clinic or at **MyHIV.org.uk**. If you want to start a family or are expecting a baby, make sure you keep in touch with your HIV team. They can also give you advice on which types of contraception are safe for people with HIV to use.

I want to have loads of kids! Without a doubt. But I think, at the time that I got disclosed to, I had this sense of guilt, like, 'There's no way I can do that. How about if I pass on HIV to my child?'

That was then. This is now. The treatment that's around now is amazing.

At first, when you find out you've got HIV, you just think everything's stopped. It's learning more about it, doing your own research and asking your doctors, asking the right people around you. What are the procedures now? What can I do? What can't I do? There's loads of websites.

I have no worries about it any more. I did, for a good few years. It's obviously to do with your partner as well. You've got to find the right partner. You've got to learn when to disclose, how to disclose, who to disclose to.

Some young people feel like, 'I might as well have a baby now, because I don't know what's going to happen later,' or, 'No, I'm never going to do anything now.' They're on treatment but they don't even understand how effective their treatment is for them in the future. On the other side, some stay away from relationships like, 'I can't tell a girl, she'll run away from me'. It's just getting the right guidance, and reading the right information.

WHAT IS TRANSITION AND HOW DO I DEAL WITH IT?

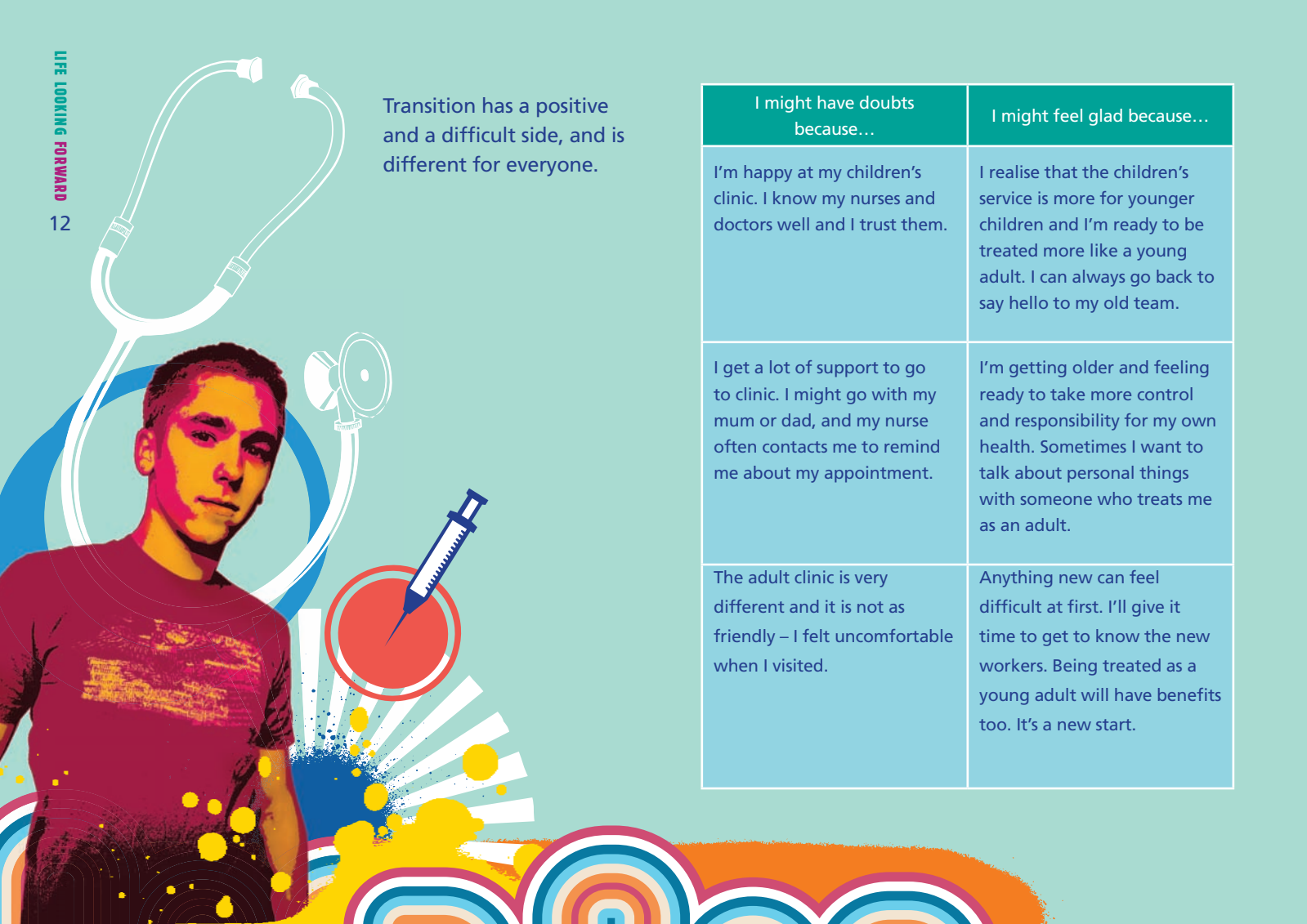
You may have been going to an HIV clinic as long as you can remember, or you may have only started going recently. Either way, all young people with HIV eventually start using adult services – it's like moving from school to college. Moving from a children's service to an adult one is called **transition** and it should happen in a gradual, planned way.

It's important you feel comfortable with this. There are lots of things your HIV team may do to help, including slowly introducing you to the adult clinic.

There are different types of adult HIV clinic, and some especially for young people. You may have a choice of clinics. Ask your doctor or nurse about clinics you might go to and how they are different from your current clinic.

You may go through other transitions too, like leaving school or leaving care. If you go to a support group, you might find that you stop going as often, or you become a leader for younger members. Your support worker can discuss this with you.





Transition has a positive and a difficult side, and is different for everyone.

I might have doubts because...	I might feel glad because...
<p>I'm happy at my children's clinic. I know my nurses and doctors well and I trust them.</p>	<p>I realise that the children's service is more for younger children and I'm ready to be treated more like a young adult. I can always go back to say hello to my old team.</p>
<p>I get a lot of support to go to clinic. I might go with my mum or dad, and my nurse often contacts me to remind me about my appointment.</p>	<p>I'm getting older and feeling ready to take more control and responsibility for my own health. Sometimes I want to talk about personal things with someone who treats me as an adult.</p>
<p>The adult clinic is very different and it is not as friendly – I felt uncomfortable when I visited.</p>	<p>Anything new can feel difficult at first. I'll give it time to get to know the new workers. Being treated as a young adult will have benefits too. It's a new start.</p>

WHAT CAN I DO IF I'M STRUGGLING WITH TRANSITION?

- **Don't give up on it or stop going to clinic.** This is about **you** and **your** health.
- Tell the team at the adult and children's clinic that you're finding it difficult. If you need more support or changes in your clinic appointments, try to identify this and tell them what will help.
- Talk to someone about how you're feeling – like a family member, support worker, or other young people with HIV or different long-term conditions. Some clinics have peer mentors, or perhaps a close friend or partner can go to adult clinic with you the first couple of times.

I was so used to my doctor in paediatrics that it was just like, 'I'm not going.' And going to the new clinic without my mum was scary. My best friend, who knows about my status, came with me for the first couple of appointments, but then I was like, 'I don't really need you any more'.

When you go into the transition stage, staff talk more about sex and I was like 'Ooh! Lucky Mum's not here.' At the time I was dealing with college, boyfriends and whatever, and the new clinic had all this information. I'd seen a couple of the doctors from paediatrics who were there, which was comforting. Eventually I was all right. I'd got my own little place, sort of like a little home for me.

WHERE CAN I GET HELP?*

- **ChildLine.org.uk** – Phone, email and online advice and counselling for any problem. Call 0800 1111 (free from landlines and most mobiles).
- **Samaritans.org** – Phone 08457 90 90 90 (call costs vary) or email jo@samaritans.org for someone to talk to if you're in emotional distress
- If you feel unsafe with a family member or your partner, call **ChildLine**, the **National Domestic Violence Helpline** for women on 0808 2000 247 or the **Men's Advice Line** on 0808 801 0327

HIV information, advice and networking

- **THT Direct** – call 0808 802 1221 (free from landlines and most mobiles, check MyHIV.org.uk for opening times) for help relating to HIV or visit **MyHIV.org.uk**, which includes a forum for people aged 16+
- **CHIVA.org.uk** (Children's HIV Association) – includes secure site for young people with HIV aged 24 and under, with social networking, as well as information for parents/carers
- **Pozitude.co.uk** – includes forum and Your Stories
- **Bodyandsoulcharity.org** - includes young people's radio podcasts, comic books and audio stories
- **LifewithHIV.org.uk** – find local support services
- **FoodChain.org.uk** – how to use nutrition to feel well and stay healthy with HIV

* At the time of writing, All numbers except Samaritans (see website) are free from landlines and most UK mobiles. Several are open 24 hours.

OTHER LINKS

- **TheSite.org** – anything and everything for young people
- **TalktoFrank.com** – for advice on drugs and alcohol (phone line 0800 77 66 00)
- **NHS.uk** – advice about health and local health services
- **TheHideOut.org.uk** – family and relationship abuse
- **Brook.org.uk** – sex, sexuality, relationships and pregnancy
- **YoungMinds.org.uk** – mental health
- **Thewhocarestrust.org.uk/who-cares-town** – for young people in care

- **YoungCarers.net** – for young carers
- **RD4U.org.uk** – for young people who have been bereaved

There may be lots of issues that you want to find out about or get help with at different times. Turn over to find out about **LifeLinks...**



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!

Published by the National Children's Bureau.
Registered Charity Number 258825.
8 Wakley Street,
London EC1V 7QE. Tel: 020 7843 6000.
© NCB, June 2012

NCB is grateful to the Department of Health for funding the *Your Life* leaflet series. NCB would also like to thank all the young people, professionals and organisations who have contributed to these resources. The *Your Life* leaflets are designed by www.rawshock.co.uk. Order by email: HIV@ncb.org.uk

