

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

So you are HIV positive and are thinking about telling a friend, sexual partner or family member that you have HIV?

#### **WHAT MIGHT YOU NEED TO THINK ABOUT?**

Why might I want to tell someone in my life that I have HIV and what things do I need to be prepared for?

Page 3

What about my family?

Page 4

How can I plan to tell someone and what might happen after I tell?

Page 5-6

I want to tell my sexual

partner – when might I do it? Page 9

What if the condom came off or broke, or we didn't use one?

page 10

What does the law say about sex for people with HIV?

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 adults with HIV from 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 vellow boxes.





# WHY MIGHT I WANT TO TELL SOMEONE IN MY LIFE THAT I HAVE HIV?

- It feels good to know that people close to you accept you as you are.
- The person can understand more of you, and may be able to support you.
- You can both trust each other more if you're open, which can make you closer.
- Telling any sexual partners shows that you have considered their feelings and how they might be affected if you used a condom and it broke.

# WHAT THINGS MIGHT I NEED TO BE PREPARED FOR?

- The person you tell may not be understanding and may reject you – you need to be ready for this, just in case.
- Once you've given someone that information, you can't get it back. The person may tell someone.

Whether telling is right for you will depend on both of you and the situation.



### WHAT ABOUT MY FAMILY?

You may wish to talk to a family member who doesn't know that you have HIV. Parents or carers may have previously decided who to tell about your diagnosis.

Or maybe you want to tell someone else that you have HIV, but worry that you'll be disclosing personal information about your mum, other family members, or partner if they also have HIV. Remember:

- you have a right to make decisions about what you tell people about yourself, to decide when you feel you can trust people, and to get support with issues that affect your life, including HIV
- you also have a responsibility to respect the confidentiality of people close to you. The HIV status of a family member or partner is that person's own information. Just as you will want to decide who knows your personal information, it's right that they are able to make decisions about who knows their information

You may need support to work out how to balance these considerations. You can choose to tell people that you have HIV, whilst respecting other people's privacy.

Visit CHIVA.org.uk parents' pages if you want advice on talking to children about HIV.



## HOW CAN I PLAN TO TELL SOMEONE?

It's really important to think this through carefully first. Ask yourself:

- How well you know this person and what your relationship is like?
- Why, where and how you want to tell him or her?
- How you'll feel and what you'll do if the person doesn't react how you hoped, or tells other people?
- Have you been able to trust this person with private information before

- Does this person know much about HIV? What is his or her attitude towards HIV?
- How did you feel when you found out you had HIV?
   Can it help you understand what someone close to you might feel after you tell him or her?

Think about where you can get support. Can your nurse, doctor or someone from a support group help?

It may also help to talk to other people who have dealt with these issues. You can do this through a support group, at clinic, on the secure website made by CHIVA.org.uk if you're under 24, or on the forums at MyHIV.org.uk if you're over 16.



## WHAT MIGHT HAPPEN AFTER I TELL?

Often a relationship improves after a person opens up about their HIV status, but it can take time. At first, your friend, partner or family member may:

- feel unnecessarily worried about getting HIV themselves
- need to take a test if they have been at risk, which they may find stressful
- worry that you must be unwell or depressed even if you feel fine
- ask you lots of questions
- listen and be supportive
- be angry or confused about why you didn't tell them before.

You can help the person learn about HIV and deal with their own feelings. Look at your favourite HIV websites or leaflets, or **HIVaware.org.uk**, together. You could also arrange for him or her to meet or speak to your doctor, nurse or support worker.

Violence and threats are **never** acceptable. If somebody's reaction makes you feel unsafe, call the police on 999 or one of the helplines at the back of this leaflet.

My friend went out with a person who was HIV positive and the way he disclosed to her scared her. She called me in tears. When I planned to see her the next day I had a motive to disclose. Many things went through my mind including, would she tell anyone?

We were walking home from our summer job and I just came out with it and said, 'I am HIV positive just like your boyfriend, that's how I know him, but you shouldn't feel weird around me because it's only a little part of me. When we get to my house we will look on the website I helped to make. It has a shed load of information.' She and I looked on the website and talked. She understood and didn't really get bothered and to this day she has kept my secret. That's what I call a real friend.

Come with a nice approach, like, 'Listen, here's the situation. Here's my background story. Back it up a bit with some research and information. Not everyone's going to understand. It's not their fault, it's just that it's not taught or explained anywhere. So if you teach someone, if you explain what HIV is – not necessarily out with yourself, but if you say you watched something on TV or you're studying it at college – you can get like a little understanding of how they'll react when you do disclose. Try to break it down. Eventually they'll understand.



### THE SEX BIT...

If you're having sex, or thinking about it, there are a number of things to think about besides HIV, such as sexuality, being ready, healthy relationships, sexual health and pregnancy.



Parents, friends, healthcare workers, support workers, youth workers and teachers can also be good people to talk to about these issues. **Brook.org.uk** has lots of useful information.

It's normal for men and women of any age, HIV positive or HIV negative, to feel at times:

- in a rush to have sex
- scared to have sex, uninterested in sex or even physically unable to have sex
- happy with their sex lives, or with not having sex.

Everyone is different, but HIV doesn't need to prevent you from having safe and satisfying sexual relationships when you're ready.

It's quite possible for people with HIV to have children without the children getting HIV. Ask your healthcare team about it, or look at MyHIV.org.uk or Pozitude.co.uk.

A while before you have sex
This is probably the least complicated time.

Just before or during sex
Best avoided – your partner may panic.

When you've had sex already
It's not too late. How your partner reacts may depend
on how close you are and whether you've used a
condom every time. It may help to explain why you
didn't tell them before

Whenever you choose to tell your partner, planning will help you to feel more comfortable and handle the conversation better.

A young peer mentor with HIV says: Disclosing to your partner is one of the most nerve-wracking feelings ever if you don't have the right things in place at the time. Young people all seem to say, 'I can't tell my partner. I'm going to break up with him or break up with her.' I'm like, 'Why?' 'Well, because they're going to run away.' I say, 'But you haven't tried yet, have you?'



# WHAT IF THE CONDOM CAME OFF OR BROKE, OR WE DIDN'T USE ONE?

Your partner might need PEP – medicine that a person who has been exposed to HIV can take to reduce the risk of contracting HIV. Find out more on the secure site for young people at CHIVA.org.uk. You can see step-by-step advice on how to get PEP at NCB.org.uk/LifeLinks.

PEP is not a substitute for using condoms, and it's not an easy option. For PEP to work, your partner must start taking it as soon as possible, within 72 hours of unsafe sex, and must continue for one month. It also has some unpleasant side effects.

For your partner to get PEP, they'll need to know straight away that you have HIV and that they are at risk of infection. If you can contact your HIV clinic within a few hours of having sex, your clinic will arrange to see your partner. Otherwise, your partner will need to visit a sexual health (GUM) clinic or the Accident & Emergency department in a hospital.

- If a condom breaks, there is a risk of other sexually transmitted infections (STIs) for both of you, and pregnancy for women if condoms are the only contraception used.
- Your HIV clinic can tell you about PEP, emergency contraception and STI screening. You can also find sexual health information and local services at NHS.uk.



# WHAT DOES THE LAW SAY ABOUT SEX FOR PEOPLE WITH HIV?

A small number of people in the UK have been prosecuted in court for 'recklessly' transmitting HIV to another person. This is called 'criminalisation of HIV transmission'

In England, Wales, or Northern Ireland, for someone to be convicted of 'reckless transmission' the court would need to prove that:

- The person making the accusation has HIV, and definitely got it from the person who is being accused
- The person who is being accused knew they had HIV when they had sex with the other person, and they knew how HIV is transmitted
- They didn't tell the other person they had HIV and they didn't use a condom.

Accusations may be investigated by the police, though the vast majority of them never end up in court.



In Scotland, the law is different. Visit **LifewithHIV.org.uk** or call THT Direct for up-to-date information. If there's a chance you'll have sex whilst abroad, remember to check the law in that country.

Criminalisation can sound scary, but what you should remember is everybody, whatever their HIV status, has a **right** to sex with consenting partners. People with HIV are having great sexual relationships, and safer sex is important for **everyone**.

- Use condoms to protect your partner against HIV
   (and to protect both of you against other infections and unplanned pregnancy).
- Know about PEP in case a condom breaks.
   Remember, if this happens, contact your HIV clinic or go with your partner to a sexual health clinic or Accident & Emergency.
- If you're in a relationship, think about telling your partner you have HIV if you haven't already done so.
   Sex is better with somebody who likes and accepts you as you are!

 Your doctor, nurse or support worker, as well as organisations and websites listed in this leaflet, can help you plan and manage sex and disclosure, and explain the law.

NCB.org.uk/LifeLinks has step-by-step advice on dealing with concerns about the law and on accessing PEP. You can also call THT Direct on 0808 802 1221. THT knows the law around HIV and has provided important help for people with HIV who have had issues with this

I had bad experiences of disclosing to partners in the past because I didn't know how to do it. They'd be freaked out because I went in all guns blazing and crying. That person didn't know me well enough. I thought, 'I'm never going to disclose to anyone again'. But I've got a partner now. We've been together six years and I told him about my HIV status three years in. I did want to tell him years before, and every other day, I was like, 'OK, now's the time.'

I became comfortable with myself and my status. I read up online and I got tips. I thought, 'I've hidden it for three years, he's going to go mental.' But he understood because he knew me first. He didn't react in any bad way. He actually said, 'Yeah, I knew because of your meds.'

I took my medication secretly. I don't understand how he found out. I always said it was pneumonia. I thought he must have been dumb! When I said, 'I've got something to tell you,' – no one should ever start a sentence like that because it makes someone defensive automatically – he thought it was something really bad. He thought I'd cheated!

We put ourselves down, put ourselves in a box before we even know how the person will react. He saw me panicking, not being myself, saw I wasn't completely happy. I got irritated, like, 'Why didn't you put me out of my misery?' He said, 'I was waiting for you to do it.' That's fair enough – he can't force me to tell him. But we're good now. He does research and asks me questions and we're good.



### WHERE CAN I GET HELP?\*

- 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+
- NHS.uk health advice and local services online or by calling 0845 46 47
- ChildLine.org.uk phone (0800 1111), email and online advice and counselling for any problem
- Samaritans.org Phone 08457 90 90 90 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

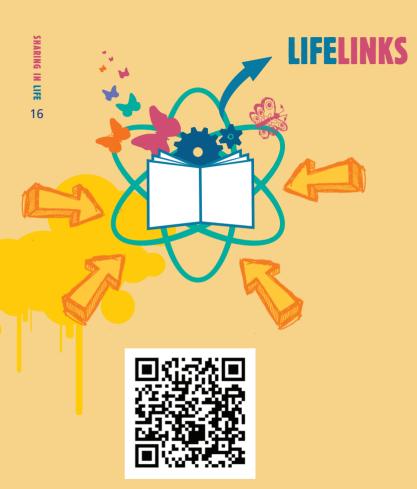
#### Information, advice and networking for young people

- 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
- \* All numbers except Samaritans and NHS are free from landlines and most UK mobiles. At the time of writing, all lines are open 24 hours except THT Direct and Men's Advice Line. See websites for details.

### Information for young people on family, friendships, sex and relationships

- TheSite.org all topics for young people
- Brook.org.uk sex, sexuality, relationships and pregnancy
- fryp.org.uk sex and relationships information for young people of faith
- TheHideOut.org.uk family and relationship violence and abuse
- YGM.org.uk for young gay and bisexual men
- Bullying.co.uk bullying





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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