



THEIR LIFE

A LEAFLET FOR PARENTS AND CARERS OF YOUNG PEOPLE WHO ARE LIVING WITH HIV.

NCB.org.uk/LifeLinks



This leaflet goes with a series of leaflets called *Your Life*. These offer information on a range of topics for young people who are growing up with HIV. They aim to help young people as they approach adulthood.

So what about the parents and carers of these young people? What do they need to think about?

If that's you, this leaflet provides some information, guidance and tips for you. It covers the following:

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Want to hear parents and young people sharing their experiences? Find videos and audio clips at CHIVA.org.uk and Bodyandsoulcharity.org, or read our leaflets at NCB.org.uk/LifeLinks.

YOUR CHILD IS BECOMING AN ADULT! SOME THINGS TO THINK ABOUT...

Puberty brings **growth and hormone changes**. Young people have to cope with changes in their bodies and often their mood. They will also have feelings about themselves and how they look that can be hard to manage. They may be anxious about other people's views of them.

Adolescence is a key time for developing a **personal identity** – for individuals to understand who they are and where they fit into the world. This can be confusing and also worrying. Young people often feel different **pressures in their lives**, such as exams and the need to prepare for the future.

Friendships and intimate relationships can be really important at this time. Young people may be concerned about fitting in with peer groups. They are also working out their sexual identity.

Your child has HIV too. They may not have known this for very long. They may still find HIV difficult to understand and accept, as many adults do at times. A lot of young people really struggle with taking HIV medication during their teenage years. **HIV can be an additional complication** in the experience of growing up.

Try to remember what it was like for you when you were the age your young person is now. You have valuable experience that can help you to relate to your child.



WHAT IS DIFFERENT HERE AND NOW?

- Considering what life was like for you and how you felt **when you were growing up** may help you to identify with what your child is going through.
- You might also think about **all that is different**. It may be that your child is growing up in a society very different to the one you grew up in. Perhaps you were raised in a different country or culture. Were the expectations of you as a young person much clearer?
- You may see your child having more **freedom, choices or opportunities** than you did. All societies change, and adults worrying about young people's lifestyles and behaviour is not new either! But young people still face many challenges. Whilst they are always influenced by their families in some way, they will also learn and grow as a result of the society they live in. If they are to become well-adjusted adults who live full, happy lives, young people need the chance to work out for themselves who they are and what they want, to make decisions and have a say in what happens to them.
- Wider choices and opportunities can also be a good thing for young people, and helping your child think about these is an important thing for you to do.



LETTING GO

- Young people will seek and gain more independence over time. As a parent or carer you may sometimes find it hard to let go and allow your young person some of the freedom they will want. All parents find the transition of their children becoming adults difficult at times. This is something which happens gradually. As they try to take more **ownership of their own lives and decisions**, young people will still want support and guidance from their parents or carers.
- Young people who have HIV may start seeking **greater control over their health care** and you may feel less involved. Doctors will want to see teenagers on their own as this is important in developing their maturity and confidence to manage their own health. Your child may not tell you about their clinic appointments or CD4 count. They may choose not to take their medication, or may forget.
- This can be very stressful for a parent or carer. If you find this difficult, talk to your child's doctor about your worries. Also it is really helpful to ask your child what input they feel they need from you – **they may still want your help**. Take a look at the parents' pages on CHIVA.org.uk.
- In some families, young people take on **responsibility for looking after the family** and home because parents are unwell. This can be challenging for both parents and their children, and can make letting go especially hard when young people seek independence. If this is a concern for you, seek support from an HIV service or visit YoungCarers.net/parents for information.



WHAT DOES YOUR CHILD NEED FROM YOU AS THEY GROW INTO ADULTHOOD?

Having someone to talk to

Unfortunately the stigma which surrounds HIV can mean it is often not spoken about. If your child didn't know their HIV status in the early part of their childhood you will have spent some years not talking about HIV in front of them. This might be a difficult habit to change. **But talking openly about HIV is probably the most important thing you can do for them.** This gives them the message that it's OK to have HIV – it is after all just a virus.

Children want to feel their parents or carers trust them enough to talk to them about things which are important. If you show them that **you trust them** by discussing HIV, they are more likely to show you that **they trust you**. This also helps bring you closer, building a more open and supportive relationship which will be highly valuable to both of you.

Being able to benefit from your experience

Living with HIV, or in a family affected by HIV, can be challenging. **Passing on the skills and strength you've gained** will give your child a great tool for their own life. If you are HIV positive, have you told friends or a partner? How did you do this and what helped? If your partner has HIV, how did you come to understand it? Young people will want to tell someone about their HIV at some point. Talking to you and learning from your experiences can really assist them with this.

Permission to deal with HIV in their own way

If you have HIV yourself, **have you come to terms with your diagnosis?** This is a big question, but it's important to think about how you feel about your own diagnosis. It will probably affect how you can support your child to accept HIV in their life. Does it worry you if they want to tell a close friend or partner

about their HIV status? This sometimes happens when parents feel anxious about others knowing their own status. Try to talk to someone about these feelings, perhaps a support worker or your nurse or doctor. Visit the parents' pages on CHIVA.org.uk.

Checking in

When was the last time you had a **chat about living with HIV**? Do you catch up with your child about how they're feeling about their health? Do you ask how they're coping with medication and any other concerns they have?

This is really valuable. Try to make sure you regularly check in with your child. You don't have to sit down and have a formal conversation. Often these conversations are more comfortable if you're both relaxed, perhaps watching TV, walking to the shops, or driving in the car. Try to make the conversation friendly and easy-going, without too many questions. Just showing that you are open to conversations about HIV and interested in your child's wellbeing is most helpful.

THE ELEPHANT IN THE ROOM



TALKING ABOUT SEX AND RELATIONSHIPS

What do young people want from parents and carers?

Research with young people has shown that the majority want to talk to a family member about personal issues first, as this is most likely to be someone they know well and trust. We also know that young people who can discuss sex and relationships with parents, carers and professionals are more likely to wait before having sex, and to use contraception when they have sex.

If you can **talk openly to your child about sex and relationships** it can help them to feel confident and comfortable. They're more likely to be able to talk to a partner about feelings and safer sex.



If you know this is a difficult area for you, you are not alone! Get some support and advice, perhaps from a service, and use resources. Here are some suggestions:

- The orange workbook *It's Good2Talk* at PPCLondon.org.uk/uk-family-project is for parents in families living with HIV who want to improve communication with their children.
- The Sex Education Forum website has a list of *Resources for SRE* (sex and relationships education) aimed at parents and carers. Download it at SexEducationForum.org.uk.
- Leaflets, websites and TV programmes can help spark or structure conversations. Try Brook.org.uk for information for young people on sex and relationships.



SUPPORTING YOUNG PEOPLE TO TAKE THEIR HIV TREATMENT

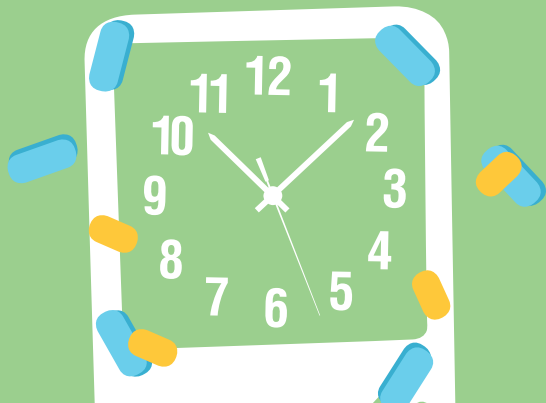
A lot of young people find taking their medication during the teenage years especially difficult. Their lifestyle may be changing. For many young people, medication can be a daily reminder that they have HIV. Sometimes not taking medication means not having to think about being HIV positive.

So what can you do to help?

- Do you take meds? How do you 'model' this to your child? Could you be more open about it? **Making taking meds more normal** can be really useful. Remind your child that many people, including

their peers, take all kinds of medicines for different conditions.

- If you take meds, there have probably been times when you've found it difficult too. **Sharing your understanding** with young people can benefit them. You could take your meds together. If you don't take HIV meds, does your child know anybody else who does?
- Can you **link your child up with other young people with HIV?** One of the most difficult things young people with HIV describe is feeling that they are different and alone in living with HIV. Young people can feel part of a community of young people with HIV, and share experiences, at support groups or camps, or online. Key websites are listed at the back of this leaflet.



CHANGES IN HEALTH CARE

There will be changes to your child's health care as they get older.

- You will probably have been used to being the person the doctors and nurses talk to about your child's health, and being consulted on treatment options. As young people grow up they will have much **more direct say** in their health care and treatment decisions.

- Doctors and nurses are required by law to consult more with young people as they grow up and are seen as 'competent'. This is because young people need to gradually **build their skills in making decisions** about their lives. It's much easier for them to learn these skills over time than to do it suddenly when they legally become adults at 18.
- By the time they are in their mid-teenage years, most young people will be **seen by their doctor on their own** and their health team will be **planning their transfer into adult health care**. You will still have a relationship with your child's doctor but it will be different. You need to work out together how this will work: how you can still get the information you feel you need about your child's health, whilst they also gain the independence and skills they need as they grow up. Planning ahead for your child's transition to adult care from a young age is really helpful as it enables everyone to feel prepared.



WHAT HAPPENS WHEN A YOUNG PERSON LEAVES CHILDREN'S HEALTH SERVICES?

- Young people's care is handed over from their paediatrician to an adult doctor at any time between the ages of about 14 and 18. This will depend on the individual hospital and a young person's readiness. The whole process should be a planned experience, and is known as '**transition**'. Conversations about the eventual move to adult clinic can start around age 13, and you will be part of this conversation. Some clinics may not start this early, but you can always ask questions. The earlier you ask, the more you can be prepared for the changes.
- Young people will move to either a GUM clinic which is a sexual health clinic, or an Infectious Diseases clinic. In either type of clinic, there will be doctors who are HIV specialists, and a team of staff who can offer different support. Adult clinics have very different environments to children's or family clinics. In some areas there are transition clinics which are just for young people. These bridge the gap between children's and adult clinics.
- Transition can be difficult. Young people may have formed strong relationships with the health care team who have looked after them from when they were little. They need to build new relationships and the level of support is likely to be different. Young people's initial experiences of adult care vary. Below, one young person describes a common but temporary feeling when adult services are not yet familiar.

Although I knew the nurses through my mum I still felt as if I literally wanted to run back to the paediatric ward!

WHAT ABOUT PARENTS?



- If you have HIV and receive your health care together with your child at a family clinic, then when your child transfers to adult care, you will also need to **transfer out of the family clinic**, unless you have another child who is still being seen there.
- As with your child, this won't happen suddenly. You'll have **time to discuss this with your health care team**. There may be choices about where you can receive your care (e.g. a GUM or Infectious Diseases clinic). You may stay at your current hospital or it might mean changing to a different hospital.
- Whether you and your young person move to the same clinic is a decision you will both have to make, but remember that in adult care, they will be seen as an adult. Their health information will be their own confidential personal information.
- This may be something that worries you. Talking things through with someone you trust will help. Also remember to **talk to your child** about your feelings and concerns. Building a trusting and open relationship with them will support both of you to manage these changes.

FINAL THOUGHTS

- Accept that there may be some conflict and tensions in your relationship with your child as they grow up. **Change usually involves some conflict.** Try to take a step back if you find yourself getting angry or frustrated. Young people will need a little space to grow and will probably make some mistakes along the way. They may desperately seek independence, or may feel terrified of it. They probably experience both feelings at different times.
- Remember one of the most important things you can be to your child growing up is **someone they trust** to talk to. This might mean doing some work yourself so you feel comfortable talking about HIV, sex, and taking medication. Get help with this if you need it.
- Understand that growing up with HIV from childhood is different from acquiring HIV as an adult. But if you also live with HIV, you have a **unique understanding** of some of what your young person is going through. Being able to share this with them will be very valuable.
- You can still talk to your child's doctor about their health and you can still be informed if there are serious concerns about their health whilst they are legally a child (under 18). However, remember they need to gradually develop **skills to look after their own health** independently, including managing their clinic appointments.

INFORMATION AND SUPPORT AROUND PARENTING AND HIV

- The Parents section at CHIVA.org.uk (Children's HIV Association) has lots of information and advice on topics including communication, medication, sex and the law, transition, schools, fostering and care.
- Look out for the orange booklet *It's Good2Talk* at PPCLondon.org.uk/uk-family-project/ – it's for parents and carers, to help with communication about HIV within the family.
- SheToShe.org is an online resource designed by women with HIV for women living with HIV.

General parenting information

- FamilyLives.org.uk has pages on parenting teenagers with information, guidance, and chat forums for parents and carers. Family Lives also run Parentline, a free and confidential service for information, advice and support about any aspect of parenting or family life. Call 0808 800 2222.
- GOV.UK has information on rights and responsibilities, services and systems under 'Births, deaths, marriages and care'.



- **RelateforParents.org.uk** has free online relationship advice for families, including counselling.

Resources for young people

- **NCB.org.uk/LifeLinks** is a web directory especially for young people with HIV, to direct them to organisations and websites that can help with all aspects of becoming an adult, as well as HIV.
- **CHIVA.org.uk** hosts a secure site for young people with HIV up to age 24, with social networking.
- **Pozitude.co.uk** contains information and young people's stories on a wide range of topics.
- **Bodyandsoulcharity.org** has young people's radio podcasts and comic book and audio stories, such as *This is how we do it*, a collection of personal experiences of HIV treatment.
- **MyHIV.org.uk** is a hub of information and advice from THT on living with HIV for people aged 16+. Online health training, counselling and forums are available. THT also run a free confidential HIV advice line called THT Direct – call 0808 802 1221.

- **TheSite.org** is a good general site with information on all topics for young people.

HIV services for young people and families

- Ask at your clinic or look for the 'Service providers' page at **CHIVA.org.uk** for details of children and families' services in your area. **Aidsmap.com** has a comprehensive directory of UK HIV services.





The leaflets in the *Your Life* series for young people are available from clinics, support services, directly from HIV@ncb.org.uk and to download at NCB.org.uk/LifeLinks. They cover growing up, work, student life, independent living, rights, and sharing information about HIV with others. NCB.org.uk/LifeLinks

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