THE CHIVA STANDARDS OF CARE 2025

YOUR GUIDE

Chiva GROWING TOGETHER FOR HEALTH AND HAPPINESS

THE CHIVA STANDARDS OF CARE 2025

1. HOW TO STOP HIV BEING PASSED ON DURING PREGNANCY AND BIRTH
2. HOW CHILDREN WITH HIV SHOULD BE CARED FOR
3. WHO SHOULD BE INVOLVED IN HIV CARE
4. WHO ELSE CAN BE INVOLVED TO PROVIDE SUPPORT
5. HELP WITH TAKING HIV MEDICATION
6. HOW TO TALK ABOUT HIV
7. HOW TO TALK ABOUT SEX AND RELATIONSHIPS
8. MOVING ON TO AN ADULT CLINIC
9. TESTING FOR HIV IN CHILDREN AND YOUNG PEOPLE
10. GETTING INVOLVED AND GIVING FEEDBACK
11. COLLECTING DATA ABOUT HIV

ABOUT THIS GUIDE

WHAT ARE THE CHIVA STANDARDS?

A Standard explains how care should be given. It helps healthcare professionals to understand what is expected of them, and it helps people using a service know how they should be cared for. It is also used to make sure clinics and hospitals are working properly by giving them a list of things they should be doing.

The aim of the Standards is to make sure that services providing care for children and young people living with HIV can meet all their needs in the best way possible. They ensure equal care across the UK.

WHO ARE THEY FOR?

The Chiva Standards of Care apply to care of pregnant people with HIV, and for babies from birth, through childhood, until a young person reaches age 25. At this point, they will usually be in adult care.

This guide is for children, young people, and their families to understand what the Chiva standards mean for them.

KEY POINTS FOR YOUNG PEOPLE

Sometimes it might seem like the information on the page is written for your family or caregivers. That’s why, on most pages, there is a section that will help you understand what the Standard means for you.

HOW TO STOP HIV BEING PASSED ON DURING PREGNANCY AND BIRTH

In the UK, HIV tests should be offered to everybody who is pregnant. If somebody doesn't want to take an HIV test, they should be given support to understand why it's best for them and their baby. If they don't have an HIV test while pregnant, then their baby should be offered an HIV test when they're born.

If a pregnant person is diagnosed with HIV, they should be seen by the HIV team at the hospital within two weeks, so that they can get care and treatment.

It's important that a birth plan is written, and that the pregnant person is given a copy in case of emergencies.

It's also important to discuss feeding options (breastfeeding and bottle feeding) during pregnancy.

All babies born to people living with HIV will be given medication once they are born.

After the first three or four negative HIV tests it's likely that the baby does not have HIV. However, they will be monitored until they are around 18 to 24 months old. At this time, a negative HIV test means that HIV definitely hasn't been passed on to the baby.

A baby that is confirmed as living with HIV will be seen by the children's (paediatric) HIV service as soon as possible.

HOW CHILDREN WITH HIV SHOULD BE CARED FOR

All children and young people living with HIV should be seen at a Lead Paediatric HIV Centre or Special Interest Paediatric HIV Centre.

Children and young people who have been newly diagnosed (or who have just arrived in the UK and were previously diagnosed with HIV abroad) should be seen at an HIV centre, ideally within two weeks.

You can find out where these centres are on the **Chiva website**

However, babies newly diagnosed should be seen more quickly and treated as urgent, as should children who are having symptoms of ill health which may be due to their HIV.

All children and young people living with HIV should take antiretroviral therapy (ART), even if they feel well.

Their medication should be reviewed once a year to check if there are any better options for them. For example, this could be a medication that has fewer side effects.

They should also have HIV clinic appointments at least every three to six months to make sure their medication is working and to talk about any issues with their physical or emotional wellbeing.

If a child, young person, or their family needs extra support to understand and take part in their appointment, they should be given it.

A health action plan or health passport might be helpful.

KEY POINTS FOR YOUNG PEOPLE

If you have been diagnosed with HIV you should be seen quickly by a children’s HIV team.

At the HIV clinic you will be given medicine. It’s important to take your medicine even if you don’t feel unwell.

You should go to the HIV clinic two to three times a year (or more) based on your age and needs.

You should be given help if you or your family have trouble talking to the team at the HIV clinic.

2

3

WHO SHOULD BE INVOLVED IN HIV CARE

A multidisciplinary team (sometimes shortened to ‘MDT’) is needed to make sure children and young people can get the support they need.

This team should include people who deal with different parts of their care, such as doctors, nurses, dietitians, and psychologists. The team should help support emotional wellbeing, as well as physical health.

For example, children and young people should speak to somebody about their mental health within the first two months of starting at an HIV clinic.

The clinic team should meet regularly to talk about how the children and young people that come to their HIV clinic are doing. Every child or young person should have a full review once a year.

If it’s possible, clinics should try and make it so that parents and children can be seen within the same visit.

There should also always be a children’s doctor who is an expert in children with HIV available to help any child or young person who needs urgent HIV care. This might be in person or over the phone. This includes at night or on the weekends.

Information should be provided about charities like Chiva, which are available to give services, support, and practical help to children, young people, and their families.

Young people aged between 11 and 17 should be told about the Chiva support camp that happens every year, and why it’s a good idea to come along.

KEY POINTS FOR YOUNG PEOPLE

There are lots of different people at the HIV clinic who can help you and they should be thinking about all aspects of your health and wellbeing, not just whether you are taking your medicines.

Somebody should speak to you about your mental health within the first two months of going to the HIV clinic.

Your HIV clinic should try and make it so that you and your family have your HIV appointments around the same time.

If you’re between 11 and 17 years old, you should be told about the Chiva support camp that happens every year, and why it’s a good idea to come along.

WHO ELSE CAN BE INVOLVED TO PROVIDE SUPPORT

Children, young people, and their families should be offered help from lots of different people. This can include the children's HIV clinic team, a social worker, teachers or nurses at their school, and people who work for charities like Chiva. Families should be told how these people can help them.

Everyone working with children and young people should do their best to keep them safe.

Not everyone needs to know if a child or young person is living with HIV. Usually, families will need to give consent (say it's OK) before someone is told. Sometimes a young person might be able to give consent themselves, if they're old enough.

Rarely, someone might need to be told a child or young person is living with HIV, even if their family haven't given consent. This is only if the young person will be at risk of harm if the person isn't told.

It's a good idea for GPs (family doctors) and other healthcare professionals to know a child's HIV status. The hospital HIV team should help families to share this information. They should also help families who want to tell the child's school about their HIV diagnosis.

Peer support can be really helpful. It's when people living with HIV and their families have the chance to share their thoughts and feelings about living with HIV with others who share this experience.

All children and young people living with HIV should be given the chance to try peer support. This might be through Chiva or another charity.

KEY POINTS FOR YOUNG PEOPLE

You should be offered help from lots of different people, and all these people should do their best to keep you safe.

Not everyone needs to know you are living with HIV, and usually you or your family will be asked if it's OK for someone to share your HIV status with someone else outside of the HIV clinic team.

Your clinic team can help you and your family tell your GP that you are living with HIV. They can also help if you and your family want to tell your school.

You should be given the chance to try something called 'peer support'. This means having the chance to meet other children and young people who are also living with HIV, which many young people find really helpful.

5

HELP WITH TAKING HIV MEDICATION

It’s really important to take HIV medication in the way the doctor or nurse says, but this can be tough sometimes. Children and young people with HIV should be given support to take their medication by the team at their HIV clinic.

Someone at the HIV clinic should give children, young people, and their families information about ART. This should include what HIV medication is, why it’s important, and any side effects it might have. This information should be given in a way that is easy for everybody to understand.

Children and young people should be able to talk about their medication and any problems they are having with it with their HIV team. Their medication should also be reviewed regularly.

Clinics should make sure they know about anything that might make it harder for a child to take medication. Families should also be told how they can get advice about medication problems at any time.

Peer support can help some people take their medication. Organisations such as Chiva can help with this.

A child might need extra support if they are just starting treatment, if they are changing the way they take their medicine (for example, from liquids to tablets), if they have to change the type of medication they take, and during their teenage years.

There should be a plan in place in case things get difficult, such as a parent being unwell, having new side effects, or facing housing issues.

KEY POINTS FOR YOUNG PEOPLE

You should be supported to take your medication by the team at your HIV clinic.

The team at the HIV clinic should help you understand why you need to take your medication and how to do it.

The team at the HIV clinic should review the medication you are taking regularly to make sure it is the best one for you at that time.

They should give you extra help at times when it’s harder to stick to your routine.

Peer support (talking to other children and young people living with HIV) can help some people to take their medication.

HOW TO TALK ABOUT HIV

Children should know about their health condition. Naming HIV should happen while a child is in primary school and it's better if it's done before the age of nine.

Families should talk about naming HIV with the HIV clinic.

There should be someone in the HIV team that helps with naming HIV. Other services, such as Chiva, can also help with this.

Everyone at the HIV clinic should talk to children, young people, and their families about HIV in an honest and open way.

When talking about HIV, the words 'virus' or 'HIV' should be used. Other words such as 'bug', 'germ', 'goodies', 'baddies', and 'battles' should be avoided.

Children and young people should have support to share their HIV status with other people if they want to. They should also be encouraged to talk about HIV at home.

How well a child understands their HIV should be written down in their medical notes.

If families don't want to talk about HIV with their child, they should discuss why this is with the team at the HIV clinic.

KEY POINTS FOR YOUNG PEOPLE

You should be told about HIV in a way that makes sense to you.

Everyone at the HIV clinic should talk to you about HIV in an honest and open way.

If you want to tell other people that you are living with HIV, your clinic team can help you do this.

6

HOW TO TALK ABOUT SEX AND RELATIONSHIPS

Young people living with HIV should get care that helps them have good sexual health. It should be taught and talked about in a way that works for them.

They should be given the chance to talk about sexual health without a family member present, and they should have access to a sexual health clinic.

Young people should be taught about:

- sexual health
- reproductive health
- contraception
- ways to avoid passing on HIV
- the meaning of U=U
- PEP and PrEP and how to access them
- how to protect themselves and others from acquiring STIs
- consent, including how to give and get consent, and how to say no
- any laws that relate to sex and HIV.

They should also be given free condoms or information about where to get them.

HIV clinics should start talking about sexual health before the young person starts puberty.

7

KEY POINTS FOR YOUNG PEOPLE

At your HIV clinic you should learn about sexual health, including information about contraception and consent.

You should have the chance to talk about sexual health without your family member being in the room.

You should be given free condoms or information about where to get them.

MOVING ON TO AN ADULT CLINIC

Young people should have a care plan that helps them move on to adult services. This plan should consider things such as their medical and emotional needs. It should also be age appropriate.

Talking about moving on to adult services should start in primary school. This helps to prepare children for the change.

Something called a ‘paediatric discharge summary’ should be made. This lists all of the information about the young person that might be useful for the adult HIV clinic to know. Young people and their families should be offered a copy to have at home.

The children’s HIV clinic should check that the young person is going to their adult HIV clinic appointments for at least a year after they move on.

Some young people might need more support than others, for example, if they are going through a difficult time in their home life. Some young people will need support up until they are 25 years old, or older.

KEY POINTS FOR YOUNG PEOPLE

You should have a care plan that helps you move on to adult services in a way that works for you.

A ‘paediatric discharge summary’ is a list of all the information that might be useful for the adult HIV clinic to know. You should be offered a copy to have at home.

The children’s HIV clinic should check on how you are getting on at the adult HIV clinic for at least a year after you move.

Your children’s HIV clinic might decide it’s best that they keep supporting you for a bit longer if you are finding it difficult.

TESTING FOR HIV IN CHILDREN AND YOUNG PEOPLE

All babies, children, and young people who see a healthcare professional, such as a doctor or nurse, should be offered an HIV test when it’s indicated (the healthcare professional thinks it’s a good idea to do one).

It's important that all children born to a mother (or birthing parent) living with HIV are assessed to see if it's possible that they may also have HIV.

They may require a test, depending on their age and when their mother (or birthing parent) acquired HIV.

Babies less than a year old that might be at risk should be tested urgently.

Families should be told how testing works, including the different tests given to babies and toddlers.

If a child tests positive for HIV, then it might mean their mother (or birthing parent) is also living with HIV. Support for families whose child tests positive for HIV should be given by the children’s HIV team.

Children and young people should also be included in schemes that increase HIV testing. This helps avoid a late diagnosis.

9

GETTING INVOLVED AND GIVING FEEDBACK

All children's HIV services should be welcoming, inclusive, accessible, and non-judgmental. They should help children and young people to understand their treatment and care.

Children and young people should have the chance to shape their HIV services. Clinics should ask for their feedback and use this to decide how the clinic is run. They should also have the chance to take part in trials and help make policies.

Peer support and peer-based learning can give young people living with HIV a chance to share their experiences and understand HIV better.

KEY POINTS FOR YOUNG PEOPLE

HIV services should be welcoming, inclusive, accessible, and non-judgmental.

You should be asked for your feedback and be able to get involved with ways to make the service better.

You should be told about peer support and how to take part in it.

10

COLLECTING DATA ABOUT HIV

Places that provide care for children and young people living with HIV have to give data to certain organisations. For example, data about how HIV affects children is collected by the the Children's HIV and AIDS Reporting System.

This national data helps to improve health care. All information collected is anonymous so that no child or young person can be identified.

Clinics also have to complete audits on the Chiva Standards of Care. These audits check how well the service is doing at meeting the Standards in this booklet.

11

For more information about HIV, and to see the full version of the Chiva standards for professionals, visit the Chiva website:

WWW.CHIVA.ORG.UK/ CLINICAL-GUIDELINES

GLOSSARY

Adult services: Clinics where adults get their HIV care.

Antiretroviral therapy (ART): Medicine that keeps HIV at low levels in the body and helps you to stay healthy.

Being diagnosed: Being told you have a condition, such as HIV, by a doctor or nurse.

Contraception: Ways to avoid getting pregnant or risk being exposed to sexually transmitted infections (STIs) if you're having sex.

Dietitian: Someone trained to talk to you about food and help you to eat well.

Giving consent: When you are helped to understand something that will happen before agreeing to it.

Multidisciplinary team (MDT): A group of health professionals who work together to help take care of people at a hospital or clinic.

Paediatric discharge summary: A written document that contains information about you and your health.

Paediatric HIV team: A group of people, including doctors and nurses, who are trained to take care of children and young people living with HIV.

Peer support: Having the chance to meet other children and young people who are also living with HIV.

Psychologist: Someone trained to help you with your feelings and emotions.

Sexual health: Staying healthy and feeling good when it comes to sex and relationships.

Side effect: The unwanted way a medicine might make you feel.

Social worker: Someone who helps families to improve their wellbeing and solve problems they may be having.

Standard: Explains how care should be given.

Symptoms: Feeling unwell because of an illness

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