

Where do I start?

Talking to children with HIV about their illness

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With thanks to Sarah Adams for her help in the early drafts.

How shall I talk with my child about HIV?

This booklet is for people who care for children with HIV. Many parents and carers are worried about how to talk with their child about illness and HIV. Reading about how other people have tackled the issue may help you think about how you want to deal with it.

There are 4 sections in the leaflet:

- **Should I talk to my child about HIV?**

Why tell your child about HIV?

I'm not sure I feel ready to tell

- **How shall I talk to my child about HIV?**

Who should tell my child about HIV?

Where and when should I talk to my child?

What do I tell my child?

What type of questions will they ask?

How will my child react?

- **Telling my child about other family members who have HIV**

Telling your child about your HIV diagnosis

Telling about brothers and sisters

- **Support**

How can I support my child?

Where can I get help/support for myself?

Should I talk to my child about HIV?

There are lots of good reasons for wanting to talk to your child about HIV.

“It’s a part of his life and preparing him to know about the HIV is part of preparing him for life. I want to tell him step by step”.

Why tell your child about HIV?

- **You want your child to hear about HIV from you** Many parents don’t want their child to find out the truth from someone else, or get misleading information from the TV or other sources.
- **You want to be open and honest** “I never wanted my child to feel they could not trust me by finding out I hadn’t told them the truth sooner”
- **Keeping secrets is hard** Keeping the diagnosis a secret can be very stressful. One mother said “not telling made it so awkward at home”
- **Children often know that something is wrong** If you protect your child by not telling, they may have fears which are worse than the real thing
- **Children can have an amazing ability to deal with truth** You cannot stop them feeling sad, but if you are able to give them information to help them make sense of HIV and what is happening to them, you can offer them support in their sadness.
- **You want to help your child feel more in control** Your child may be more compliant with his or her treatment if they understand why they need it. One parent said: “It was important for him to know about his HIV so that he could be more involved in decisions about his treatments.”
- **You want your child to understand why they have to go to the hospital or have their blood taken.**
- **It’s their right to know** There comes a time when you feel your child has a right to know such an important thing about themselves.
- **Protecting others** “My child has to know so that he can protect others from catching it.”

But I'm not sure I feel ready to tell.....

“However old he is, he’s always going to be my baby, so it’s always going to be hard telling him.”

- You just can't face talking about it yet
- You feel it would be too much for your child to cope with -
You want to wait until they are older and more mature
- You don't know what to say - “I want to say more but I don't know how to”
- You don't know how they will react - Some parents worry about the types of questions that their child may ask or how they will cope.
One parent commented “He'll ask too many questions, like ‘will I die?’ and ‘where did I get it from?’ maybe he'll hate me forever.”
- You worry that your child will tell others - if your child tells people you don't want to know there may be consequences. Unfortunately, there is still a lot of misunderstanding about HIV.
“I don't want to say too much, in case he tells other people. I don't know how they will react to him.”

How shall I talk to my child about HIV?

Who should tell my child about HIV?

Sometimes telling can feel too much for parents.

You might prefer a relative or friend to talk to your child for you, but you need to be sure that they are giving accurate information.

Your doctor, nurse or counsellor may be able to tell your child. Perhaps you'll want to be present when this happens so you know exactly what your child has been told and so that you can be there to support your child after they have been told.

Your child might want to talk about it later when you are at home - remember to ask them if they have any questions later on.

“Tell them what they need to know piece by piece. They don't need to know everything at once.”

Where and when should I talk to my child?

Talking with your child about their illness and telling them about HIV isn't going to happen on just one occasion. Long before you think they're ready to know the name of the condition, you can take opportunities to tell them part of the story, for example when things crop up in books you're reading together, on the television, or when they have to go to the clinic or have blood tests.

Deciding when to tell them about the HIV is difficult. Sometimes carers tell children as young as 6 years old, but most prefer to wait until their child is older. In the end, it's for you to decide. Sometimes, other people may think you should tell before you're ready. Listen to their reasons and try to think about what's best for your child. Think about practical things like what else is going on in their lives. For example, telling a child who is just about to start exams is going to be disruptive.

If you're looking after more than one child with HIV, you'll have to decide whether to tell them together or at different times. Telling them together may mean they can support each other, even though you may be telling the younger one earlier than you planned. If you decided to tell one before the other, decide what to say if they ask about their brothers or sisters.

Here are some practical things to think about when you're planning to tell about HIV.

- Finding somewhere private
- Making sure you won't be interrupted
- Having enough time to talk if your child wants to
- You might want to have other things to do together if your child doesn't want to go on talking
- What you're going to do afterwards
- Who needs to know you've told your child

What do I tell my child?

Most importantly you need to help your child make sense of what is happening to them. You do not have to tell your child everything in one go. Telling your child about HIV can occur over time, step by step. These are some general guidelines:

- Be honest.
- Use words that they will understand.
- Be prepared to answer questions.
- Try not to dwell just on the negative things.
- Let them know who they can talk to about HIV and where to get support.
- Use their experience of illness as a starting point for talking.
- Find out if they already know about HIV from school, books and television.

Talking about HIV will not happen on a daily basis, but you need to have more than one talk about it. It is important to let your child know that illness is **part** of their life, not all of it.

“I think it’s important I bring up the subject of HIV sometimes, so my child doesn’t think it’s always up to him to talk about it.”

Exactly what you say depends on lots of things, including:

- The age of your child
- Their level of maturity
- What they already know
- How much they know about HIV, perhaps what they’ve learned at school
- Their personality
- What illnesses they’ve had
- Whether they’re on treatment
- The health of other people in the family
- Events like moving house, changing school, exams and lots of other things

These are some of the things carers say to their children about HIV.

Up to 6 years

You know I take you to see the doctor/nurse
That's because you're poorly/not very well.

When you get sick, you see the doctor at the clinic.

In the story, the girl goes to the hospital, just like you do sometimes.

You keep getting this cough, so we have to go to the doctor.

Come and take your medicines – they help you stay strong and well.

Remember when you were poorly with that rash? The medicines are to stop you getting ill like that again.

They're going to take some blood today to see if you're OK.

As they get older, maybe from around 7 years, they become more interested in the body.

You're having a blood test today to see if the medicines are working.

One of the reasons you've had illnesses is because something in your blood isn't working as well as it should.

Blood is made up of different cells, so tiny you can't see them without a special instrument. The white cells are the ones which fight off illnesses and infections.

The white cells in your blood don't fight off infections well enough.

The medicines help the white cells work better so you can fight off infections.

The blood tests look at the cells in your blood to see how it is and to see if you need medicines.

Even when you're feeling well, your white cells still need help to fight off illnesses, and that's why you have to go on taking the medicines.

There are different sorts of medicines which you sometimes have to take to make you feel better when you're ill.

At this stage in their understanding, children often like to look at books about the body and about blood. They may also like to do related drawing and colouring.

Most children would be old enough to hear about HIV by the time they go to secondary school.

The reason your white cells don't work properly is because there's something in your blood which is harming the white cells. There isn't a way to get rid of it, but the medicines will help keep the white cells strong.

You were born with the thing in your blood – it's called a virus.

There are different sorts of viruses: this one stays in your body all the time. That's why we have to keep going to clinic and taking the medicines.

The name of the virus you've got is HIV – have you heard much about it?

Sometimes, when a person's white cells can't fight off infections, they do get very ill. This is when it's called AIDS. If the illness is very serious, they may die, but this doesn't necessarily happen. There are lots of medicines and treatments being developed which will keep you well.

Having HIV is important and you have to be careful to take your medicines, but lots of things go on just the same. You can still be happy, have a good job and have relationships just like you would otherwise.

Having HIV is a personal thing which you don't necessarily want to talk to lots of people about until you're ready to. Some other people do know about it so you can talk to them as well as people in the clinic.

HIV isn't passed on by living alongside each other at school or at home (eg sharing cups or cutlery), but it can be passed on through direct contact with blood or by having sex.

By the time your child has reached this level of understanding, they will probably have questions of their own to ask. They will be able to read about HIV in leaflets from the clinic or voluntary organisations. You will need to think about what you want to tell them about other members of the family and about how the illness first came into the family.

What types of questions will they ask?

Your child may have lots of questions or none at all. Sometimes it takes a bit of time for them to absorb the information, so they don't have questions straight away. You need to give time to hear their questions, whether they come immediately or later, perhaps when you're busy with other things.

Remember that as your child gets older, the way they think will change. So even if they haven't asked many questions early on, they may later.

Imagine what sort of questions they might ask and plan how you will reply.

Types of questions they might ask:-

- How did I get it?
- Is there a cure?
- Will I die?
- What will happen to me?
- Have you got it?

How will my child react?

Children are all different. Think about how your child reacts to other things - this may give you some ideas about what to expect. These are some ways in which children may react:

- Go quiet
- Be very matter of fact and accept what you've said
- Ask lots of questions
- Cry
- Be relieved that they can make sense of their experiences
- Want to get on with something else immediately
- Be angry or upset
- Be surprised

You may be worried about how to handle their reaction. Be patient and try to focus on your child and what will be helpful for them.

There may be things which you think it is important to tell them even if they ask no questions, such as who already knows about their illness and who they can talk to for support and information. Just because they are quiet and don't ask questions doesn't mean they don't have any – perhaps they feel frightened to ask. Look out for opportunities to raise the subject again some time in the next few days, so they know they have more chances to talk and ask questions.

Telling my child about other family members who have HIV

Telling your child about your HIV diagnosis

If you're HIV positive too you'll need to tell your child about your diagnosis at some point, although this might be something you're reluctant to do. Of course, your child will be unhappy to hear about your HIV, but they may gain support from the fact too. Your child will probably be aware that you see the doctor when you come to the family clinic, or that you take medicines, and it can be helpful for them to know why. You can help each other remember the medicines and appointments.

Telling your child about your diagnosis may:

- Stop them blaming themselves if you are sick or tired
- Help them understand when something unexpected happens, such as you going into hospital suddenly
- Feel more involved in planning their future
- Feel pleased that you've shared things with them

They may feel scared about what will happen in the future if you get ill, and this is a chance for you to talk to them about your plans and reassure them that although it is scary, you will make plans to make sure they are cared for.

Telling about brothers and sisters

Remember how important brothers and sisters are to each other. They are likely to be curious about each other. When the time is right, helping them talk openly will mean they can share things and support each other.

Support

How can I support my child?

One of the best ways to support your child is by giving them the chance to ask questions if they want to and talk about their concerns and worries. This may happen at any time, but setting aside time to do things alone with them makes it more likely to happen.

“I never ever thought counselling was for me, I just wasn't the type. But when my wife died of AIDS, counselling was helpful in helping me think about how I could cope with my son who was later diagnosed with HIV.”

Talking with you about how they feel about having HIV may be important to your child, but sometimes children need to talk to someone who is not close to them. They may be reluctant to talk to you about some things for fear of upsetting you and it can be easier to talk to someone else. From your point of view, it can be a relief that your child has other people to talk to as well. Teenagers and older children may want to turn to their friends for this sort of support.

It's important that your child knows who they can talk to, so it's helpful for you to think about the likely people both within and outside the family. People who your child might talk to may include a close relative or family friend who knows about the diagnosis. Alternatively, one of the people in the team caring for your child may help.

Local support services and groups for children affected by HIV may be a useful resource in helping you and your child adjust to knowing about HIV in the family and learning ways to cope.

“My support network (doctors, HIV nurse specialist and counsellors) acts as a safety net to support me and my family during the good and the bad times. You know it is always there and that you are not alone to face difficulties. Knowing that helps me get on with normal things.”

When we are faced with extreme difficulties such as HIV, we all need support. It is important to find the right support for you and to use it.

Some of the people who may be able to help:

- A relation
- A close friend
- Other parents who are affected by HIV
- Voluntary organisations for people with HIV and their families
- Health professionals - nurses, doctors, psychologists
- Social workers
- Religious leaders
- Community leaders

