

# It's Good2talk



**Sharing your diagnosis with your children**

**This booklet draws on our research with parents with HIV, and affected by HIV, and the knowledge and experience of professionals. We aim to guide you through some of the main issues of thinking through to telling your child about your HIV diagnosis. It is very common for parents to worry about how, when and what to tell their children.**

**Your nurse, health advisor or support worker are here to help you. If your child is tested HIV positive there will be a paediatric team in your area to give you the best care and support you and your family need.<sup>1</sup>**

**This booklet is not designed to use with children.**

**9 out of 10 women did not regret telling their children. They told because they wanted the child to hear it from them and felt the child had a right to know.<sup>2</sup>**



<sup>1</sup> For professionals, the guidance used for children with HIV is Diane Melvin, Sheila Donaghy and Magda Conway (2009) 'Talking to children and their health Diagnosis' This can be found at [www.chiva.org.uk](http://www.chiva.org.uk)

<sup>2</sup> (R.Ostrom Delaney, J.M Serovish and J-Y Lim reasons for and against maternal HIV disclosure) AIDS Care vol no 7 August 2008 876-880

## Talking to your children – making the decision



What parents say...

### On the one hand

I am not ready.

I will be rejected by them.

They will feel burdened, they will feel ashamed.

It will be upsetting for them, they won't be able to handle the news.

They will tell other people.

I do not normally talk to my children about these matters.

I don't know what to say.

They will ask me difficult questions.

My partner does not know or speak of it.

They are not infected, they do not need to know.

## On the other hand

I can reassure them that there is health and life after diagnosis, especially with medication. It's not the end of the world.

They will find out accidentally or they will hear of it from someone else, they will get angry, blame me and lose trust.

I may tell them in a bad way during an argument.

I have raised them to be honest and truthful.

They will feel trusted.

I think they know anyway, I will tell them so they need not worry.

We will be closer as a family.

The child will be able to help if something happens and know what to do.

I won't need to hide my medication.

## What do I think?



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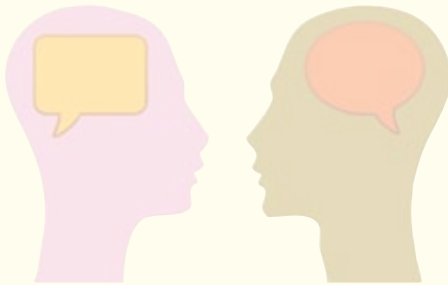
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## What age is best?

There is no 'right' or 'perfect' age. Each child and situation is different.

Research with families living with HIV shows often children are aware something is wrong and feel confusion and anxiety.<sup>3</sup> When they are young you can give yourself time to think it through before the issues become pressing. It is better to start preparing yourself and your child when they are in primary school. Teenage children often have a stronger reaction.

**If I could advise any parent in my parents' situation, I would say please tell your children earlier, don't wait till they are mid teenagers or older" - young man, affected by HIV**



**Get yourself ready to share**

If you do not normally talk to your children about difficult subjects you may need some more support; is there an aunty, uncle, friend, support worker, health advisor or nurse who you can trust to talk this through with you?

**"you have to accept what is happening, your diagnosis, then you are ready to communicate" - parent, with HIV**

<sup>3</sup>D.A. Murphy HIV Positive Mothers' Disclosure of their serostatus to their young children: A review Clinical Child Psychology Psychiatry 2008 Jan 13 (1) 105-122

Do you know anyone in the same situation as you? Sharing your diagnosis with someone you trust can make it easier to share again. Ask your health advisor or find an organisation that can put you in touch with someone you can talk to and support you.

Take home 'Sharing something important with your child'. It's a small booklet produced by PPC, which will help to think it through. It does not mention HIV.

Talking isn't always easy! But it's important to think how you communicate within your family. Be aware of what makes you feel comfortable. Ask yourself – am I comfortable with talking about sex and sexual health?

Having an open and honest relationship with your child is hard work sometimes. Prepare yourself by thinking about the questions you don't want them to ask and practice your answers. This will help your child get the answers about HIV, safe sex, family, positive relationships and life in general. It will also help them cope better after learning about your HIV diagnosis.

How is your relationship with your partner? Can you talk openly to them about your diagnosis? Will they support you sharing your diagnosis with your child?



**"I would, as a parent talk about what I feel and I would ask them the same. I would be more open to my children" - young man, affected by HIV**

## What do I say?

Some ideas from other parents and professionals

*When and how do I start?*

Use opportunities that come in every day life; topics that come up at school or on telly, questions they may have about your health, appointments or medication.

When you see the children start asking a lot of questions about your health, appointments or medication.

Let the children know that there is an important topic you want to discuss with them.

Use clear and straightforward language.

*What is HIV?*

It is a virus that affects your immune system.

It is a sickness like any other sickness.

It's an illness that's in some people's blood.

An infection of the human blood cell by a virus, it can't be cured but medicine can stop it causing too much trouble.

*How did you get it?*

Be honest

You can get it from unprotected sex, from your mother when you are born, from breast milk, from blood.

*Will you die?*

If it is found early and you are given special medicine you can hopefully live a long and happy life.

We will all die at sometime. We all need to lead a healthy life and live well. The doctor helps me do that with the medicine he gives me. I will take really good care of myself.

*Why was I not told before?*

I wanted to think it through first.

I wanted to find the right time.

It felt like a big burden to put on you.

I didn't think you were ready.

*Who can I tell?*

Who do you want to tell?

You can talk to me any time in private.

You can talk to \_\_\_\_\_ in private.

You don't need to tell everybody.

*How does HIV affect your daily life?*

I can do all daily activities like everyone else but sometimes I feel tired and unwell.



If you are going to have your child tested for HIV

*How do I explain the HIV test I want them to have?*

I have a virus in my blood and just want to know if you have the same thing.

To make sure you don't have any infections which can affect your health, like HIV or hepatitis.

Explain about your own status and the importance of medicine.

**“Keep it simple, answer what is right for them. You will gain confidence the more you deal with these situations. Get support from elsewhere” - mother with HIV**

## **What to do if they find out?**

Sometimes your child will find out about your diagnosis themselves (they will get an idea when they see you taking medication or going to the hospital) or by accident.

**“Sometimes i fear for them to know before i am ready to tell” - mother with HIV**

It is a good idea to plan for this happening, even if you intend to tell them yourself soon.

The earlier you respond to this situation the better.

## **Check out what they think they know or have found out.**

Be honest and straight forward. Explain to them some of the reasons you have not told them so far and why you did not feel ready.

Get yourself some support if you can to help you deal with this, and find a support group for children and young people to meet people and friends like them to talk to and share experiences.

## **After you have told them or they have found out**

### **Expect a reaction**

Your children are likely to show a reaction, for example, they might..



**a) Be upset and show anger.**

**b) Say nothing and be quiet and withdrawn.**

**c) Be worried, concerned and show a need for comfort.**

Take opportunities to talk about it and help them understand. They might ask how you are and check you have taken your medication. Many children will feel some level of anxiety about their parent being ill and will want to ensure you are taking your medicine and following the doctor's orders. Keep the conversation going and keeping them informed about your health will make them feel involved and empowered to support you.

**"If I was a parent, and I thought about what could be done different, I would say talk, talk, talk" - Young woman, affected by HIV**

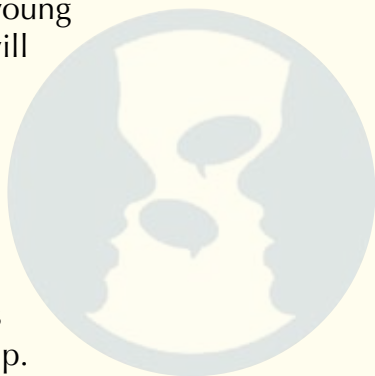


Do not worry if your child does not want to discuss it further with you. This is normal, but it does not mean they are not worried. They may have delayed reaction. They may not want to talk to you now but they will want to talk about it at some point.

Agree to talk to them again in a day or so, may be even arrange a time so you are both prepared. Always offer them the opportunity to talk in the future.

**Identify a 'safe' person or people they can talk to.**

Most young people will gain a great deal from being in a group with other young people in similar situations. You will be able to reassure them that you are happy for them to talk openly in this group. Make contact with organisations that can provide this. Your clinic can also help you find them. Other young people do not feel comfortable talking things through or want to be part of a group. Talk to the service co-ordinator in the organisation to see if they have other services that may be suitable.



**"Children are quite good at keeping things private" - father, with HIV**



## Try and find some support for yourself and your child

Contact [please insert a sticker of your local HIV support service]

or NAM 020 7735 5351 [info@nam.org.uk](mailto:info@nam.org.uk) for advice on support available to you in your area, and visit [www.chiva.co.uk](http://www.chiva.co.uk) for more information on telling your child about HIV and other parenting matters.

**“There was suddenly a bridge that was built ...there was always that distance between us. So now it brought us closer; I do not agree with parents who do not want the child to know because you’d be surprised that the child knows or that it will make sense...” – mother with HIV.**

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**UK Family Project**



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