

# HIV HEALTH SERIES

## Just a part of life: disclosing to your child

**This factsheet looks at why and how you might disclose your HIV status to your child. It also shares some of the views and experiences of parents who have not yet disclosed.**

Every family's situation is different, with different considerations and circumstances to weigh up. As one parent says: "You know your child and family better than anyone else."

At the same time, it can be helpful to read about other people's experiences. We hope they will give you some ideas to support the decisions you would like to make for you and your child.

### **To tell or not to tell**

You may have not disclosed to your child because:

- You are keeping well and your HIV is manageable.
- You want your child to have a happy childhood, without the distractions of adult concerns or having to keep family secrets.
- You may also worry your child could experience discrimination, if others know about your HIV status.
- You might feel your child is too young and you'd prefer to wait until they are older.
- The family is going through a lot of change.

**James:** If we weren't where we are with medications, we would have had to have told her. But we asked ourselves: is it really necessary? I think they should have a chance to focus on having a happy childhood, their schooling and being a teenager.

Some parents have found that not disclosing their HIV status works for them. Doctors' appointments can take place when children are at school. HIV treatments can be taken after children have gone to bed. People may also take a whole range of tablets from allergy tablets to vitamins. Some parents simply disclose they have a health condition, for which they need to take tablets and see the doctor on a regular basis.

If you are sick, however, they may worry and it can become important to keep your child informed.

**Helene:** Is it better to disclose now when I'm healthy? If I did get sick it wouldn't be such a shock to her.

### Some parents choose to tell earlier rather than later

Think about why you might want to disclose. Many parents disclose to their child because:

- You can then give them the right information and offer them some reassurance about your health.
- You don't have to worry about watching what you say in front of them, or them finding out in an inappropriate way.
- By having a more open discussion with them, you can give them more support.
- They may feel trusted and included in decision-making.
- Some parents find it difficult juggling appointments or accessing services when their children don't know.
- You might feel you have more control of what happens to the information, with the opportunity to explain to them that it is personal, and needs to be kept within the family.
- Adolescence is already a time when a young person deals with a lot of change. If they were younger when they were told, they may have had some extra time to process the information.

"WE'VE EXPLAINED THAT I'VE GOT SOMETHING IN MY BLOOD THAT MAKES ME TIRED, AND MAKES ME SICK SOMETIMES, AND I'VE GOT PILLS FOR IT." — LINDA

"TELLING THE KIDS JUST GAVE THEM SOME ANSWERS." — KAREN

**Karen:** I had to tell them. I was quite sick when I was diagnosed and we didn't know why I was sick. I had to start on medication. Telling the kids just gave them some answers.

**Tim:** I told them because I had their best interests at heart. I didn't want them to find out the wrong way.

**Linda:** You're giving them some credit for being able to assimilate the information.

Many parents report that once they've told their children, it's a weight off their shoulders, and becomes another aspect of daily life.

### Some parents disclose gradually

Many parents have found it better to introduce the topic of HIV gradually. You might not even mention HIV at first, but talk about what it means in practical terms. If the disclosure is gradual and ongoing, it gives children the opportunity to process information and ask questions later.

- You can develop their knowledge by talking about what a virus is, and how the immune system works, the need to take tablets and go regularly for check ups to the doctor
- You can talk about the health issues calmly and reasonably, without necessarily using the HIV label initially. As we know from our own experience, once we hear the word HIV, it can be hard to hear anything else.
- You can use language appropriate for their age, and check they understand what you mean when you talk to them about your health.
- You can also discuss HIV generally when it comes up on the TV news, or in the newspaper as a way of normalising it. Children will probably have studied it at school.
- Being sick when you're diagnosed can feel stressful for some parents. But even in these situations you may still be able to disclose gradually.

**Linda:** I haven't told them explicitly yet. I don't think they need all the facts right now. We go to Camp Good Time. They've been around talk of it. They've seen me ill. We've explained that I've got something in my blood that makes me tired, and makes me sick sometimes, and I've got pills for it.

**Jennie:** I've told my little girl I've got bad blood – a problem with my blood. And she comes along to the clinic with me.

**Ben:** I'm thinking over time I'll give her little bits of info. I find they only ask as much as they can handle. As soon as you give them too much information they'll go off and do something else. If they're not ready, then it's unnecessary for them to have all the details. They might dwell on things if I go into too much depth.

- It's also fine if they don't have a lot of questions for you. You can still take the lead and offer them information.

**Jackie:** After my daughter found out, I thought 'Great, now she's going to ask all these questions.' A month later all she asked was "Am I positive?" I told her no, that she'd been tested. And she said: "Are you sure?" Once she knew she wasn't and believed me, it was never a big issue.

**Tim:** My son only brings it up in passing. But I take the lead and usually volunteer the information. I can see when there's a question there.

## Being prepared can make it easier

Being prepared might make the process less stressful. It may seem easier for parents who have been diagnosed who then later choose to have children to be prepared. But however you have found out, it can still be helpful to think about how you would like to approach the issue.

"IF I WAS GOING TO TELL MY CHILDREN,  
I'D REACH OUT TO OTHER POSITIVE WOMEN."  
— NICOLE

"I DON'T THINK THERE'S A RIGHT OR WRONG AGE.  
EVERY CHILD IS DIFFERENT." — JACKIE

- Educate yourself about HIV, how it works, and where to find support.
- Talk to your partner, and to other parents who have already been through this process.
- Write a list of the things you'd like your child to know. You can also ask them what they know already.
- Be prepared for the question about your personal history: Older children may be more likely to ask the question: "How did you get it?" Think about what you're comfortable telling them.
- Disclose to them in a private, calm and familiar place, and not when you're angry or frustrated with them.
- Think about what additional support your child might need, and who they will be able to talk to (apart from yourself).

**Nicole:** If I was going to tell my children, I'd reach out to other positive women. It would be good to hear how other women have done it.

**Jackie:** Usually people need to go and tell someone else.

## Be reassuring

Your attitude will have an effect on theirs. Reassure them, that you are taking care of yourself, and your doctor is well informed. As adults, we usually take it for granted that we have a certain level of knowledge about things. But we may need to spell it out to our children that we are going to be ok. This can also be an ongoing process.

**Emma:** Don't make too big a deal of it. Let them know it's just a part of life – something we deal with.

## Routines can also be reassuring

Some children might appreciate being involved in the more routine aspects of your health – for example, “I must remember to take my tablets before bed,” or “Remind me to pick up a script next week at the doctors.” This could help to normalise the situation for some children.

## Possible questions your children may ask

- How did you get it?
- Are you going to die?
- Why didn't tell me first?
- Why didn't tell me earlier?
- Have I got it? Or can I get it?
- Who else has it?
- Who else knows?
- Who can I tell?

## It can help to have someone with you when you disclose

When you are ready to talk about it, you might want to disclose on your own or as a couple. If you're disclosing to the children as a couple, think about what you're comfortable talking about. You don't want them to feel you're still “hiding something.”

You could also talk to them with a friend or a social worker. They may be able to help explain some of the facts about HIV. Your child may feel awkward asking you some questions. Even after you've told your child, it could still be helpful for them to talk to a health professional such as a counsellor or social worker.

If you'd like help disclosing, ask yourself who would be the best person to help you.

“THE NEXT BIG ISSUE WAS WHO SHE COULD DISCLOSE TO. SHE CHOSE ONLY TO TELL HER TWO BEST GIRLFRIENDS WHO HAVE BEEN REALLY SUPPORTIVE.” — JACKIE

“I THINK IF PEOPLE GET GOOD SUPPORT FROM THEIR DOCTOR OR SOCIAL WORKER THEY DON'T NEED TO TELL FRIENDS OR FAMILY.” — KAREN

## Every child is different

Some parents have decided to tell one child and waited before telling another child in the same family. This might be because a child is younger, or one of their children may have other issues in their life they are dealing with.

Just make it clear that the other child doesn't know, and give the child who has been told some justification for this decision. You might even ask the older child if they would like to be a part of that process when the time comes. Be aware that the child who doesn't know could feel disappointed or not trusted with the information, when they do find out. You may need to explain to them the reasons you took this decision.

- Talk to primary school aged children in simple terms with simple language.
- Each family situation is different. Some parents prefer to wait until early adolescence to tell their children – sometimes thinking about whether their child will be able to keep the information private and also thinking about their level of understanding.
- Adolescents will probably have a better understanding than younger children of how HIV is transmitted, and they may ask you how you got it.

**Jackie:** I don't think there's a right or wrong age. Every child is different.

**Tim:** My oldest son has no trouble talking about anything, but he is harder to read. My younger son is different. I can read him better. What works with one, doesn't work with the other. I know if I told my oldest boy earlier he would have worried.

**Peter:** I went through things more with my oldest boy, but because of the age of my other children, less so with them.

## Be prepared: Think about someone else your child can talk to

It can be important for children to get support from someone who's not a parent, and this can be especially the case for teenagers.

- Possible sources of support for children could include other family members, grandparents, uncles and aunts, or a close family friend if they already know.
- Many parents find Camp Good Time an important source of support, for both their children and themselves. Camp Good Time is the national camp for children and families living with HIV and is run by the Sydney Children's Hospital. Many other states will also have similar family camps and family days. Disclosing to friends at camp can mean there is less need to disclose to people in their everyday circle of friends.
- Some children have told a best friend who has been supportive. But be aware that this kind of information can be a lot for a young friend to carry.

**Jackie:** The next big issue was who she could disclose to. She chose only to tell her two best girlfriends who have been really supportive.

**Alex:** You don't want them to tell just anyone, because the kickback can be huge, if people don't react well.

**Alex:** I told my daughter's friend's mother, so she knew it was ok and I'd given my daughter permission to disclose.

**Karen:** Both my daughters have told friends who have told others. I think if people get good support from their doctor or social worker they don't need to tell friends or family.

**Jackie:** We found the family camp was invaluable. The first year my son went, the kids sat up for hours talking to each other, after we had gone to bed. That did more than what years of counseling could have done.

**Jackie:** Before that camp, he thought he was the only one in Australia with positive parents, and here were six or seven other kids who were similar ages and also had parents living with HIV.

## The internet can be a useful tool

**Jackie:** Young people use the internet more than any other age group for support.

There are good websites on HIV. For example **www.kidshealth.org** is a US-based site. The information is accurate and there is a kids', teens' and parents' section. You can look at the site together with your child, and this can be a more reassuring way to look at the issues around HIV. It can also be less confronting sitting next to each other (rather than facing each other) and talking about what you're finding on the computer. Other general HIV websites can also be very informative. **www.thebody.com** for example has a number of fact sheets on basic questions.

We would recommend that parents check out sites first to make sure you're comfortable with them.

## What about their school?

This decision is also yours. There are no legal obligations to disclose to your child's school. To help you make this decision, think about whether it is in the best interests of the family, and how you might protect them from potential discrimination from parents or children.

- If you feel it is important to tell the school so they understand if you need time for doctor's appointments etc, you could tell them you have a chronic health issue, without necessarily disclosing it's HIV.
- If you decide to disclose to the school, clearly set limits on who can be told and inform the school that they are obliged to protect your privacy and confidentiality.
- You can also ask a service (such as the Sydney Children's Hospital, ACON or Positive Life) to be involved with the disclosure. They can also give the school information on such things as legal issues. They can tell the staff, for example, how the law prevents them from telling anyone else.

**Jackie:** I didn't want to tell the school because of the risk of judgment. I know there are advantages and disadvantages. I know some people have told the teacher. But then they ask do I have to do this each year to every teacher?

## Finally, there is no right or wrong time or way

**Alex:** It's each parent's choice. It depends on what level your child is at. It also depends where you're at with your HIV.

You know them best. Planning, forethought and support are helpful (and do think about a friend or service who may be able to help you). However at the end of the day, trust yourself that you will do what you think is best at the right time for you and your family.

**Caroline:** Children are resilient, can accept the truth, and will love you. They have a huge capacity for love and understanding.

## For further support and information

- **Sydney Children's Hospital Paediatric HIV Service** The Paediatric HIV Service at Sydney Children's Hospital works with children, families and pregnant women living with HIV.  
Ph (02) 9382 1851 (Social Worker)  
Ph (02) 9382 1654 (Clinical Nurse Consultant)
- **Camp Good Time** the national camp for children and families living with HIV. Children are supervised by volunteers and spend their time participating in a range of fun activities, whilst parents participate in a workshop program. Ph (02) 9382 1851 (Social Worker at Sydney Children's Hospital) or visit [www.sch.edu.au/departments/hiv](http://www.sch.edu.au/departments/hiv)
- **Poz Het** for positive heterosexual men and women, their partners and family members. Services include peer support, workshops, social activities and retreats, and free phone counselling.  
Ph (02) 9395 0444, 1800 812 404 (NSW only) or visit [www.pozhet.org.au](http://www.pozhet.org.au)
- **ACON Women and Families' Project**  
The Family Support Worker offers support, information, referrals, advocacy and connects families with existing services where appropriate.  
Ph (02) 9206 2000 Family Support Worker or email [family@acon.org.au](mailto:family@acon.org.au)

- **Multicultural HIV/AIDS and Hepatitis C Service** Bilingual/bicultural co-workers providing emotional support, advocacy and information to people with HIV from diverse cultural backgrounds.  
Ph (02) 9515 5030, 1800 108 098 (regional NSW) or visit [www.multiculturalhivhepc.net.au](http://www.multiculturalhivhepc.net.au)
- **Positive Life NSW** A community organisation representing the interests of people with HIV in New South Wales. Information, educational resources, referral, *Talkabout* magazine, Speakers' Bureau.  
Ph (02) 9361 6011, 1800 245 677 (NSW only) or visit [www.positivelife.org.au](http://www.positivelife.org.au)
- **Counsellors** Counselling can be helpful for either yourself or your children. Talk to your GP about a referral. You can also look for counsellors at [www.positivelife.org.au](http://www.positivelife.org.au). Click on the 'Contacts Directory', Ph (02) 9361 6011, 1800 245 677 (NSW only). **For services in states and territories other than NSW Contact your local AIDS Council or PLWHA organisation.**  
If you would like these contact details call Positive Life NSW. Ph (02) 9361 6011

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