

Just a part of life...

Disclosing to your child

This fact sheet 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.

Telling the kids just gave
them some answers.

— Karen

Some parents have found that not disclosing their HIV status works for them. Doctor's 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.

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.

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.



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- A black silhouette of a pregnant woman standing, facing left. She is wearing a long, flowing dress. The silhouette is positioned on the left side of the page, with a reflection visible below it.
- 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 over 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.

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 understand the information.

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

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

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 '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. Older children may 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 Seaside. 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. However you have found out, it can still be helpful to think about how you would like to approach the issue.

- 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 okay. 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.

I always help my mum
by reminding her to take
her pills.



Routines can also be reassuring

Some children might appreciate being involved in the more routine aspects of your health eg '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.

Children's concerns if undisclosed

If you have not disclosed to your child and they notice you are ill, they might worry about:

- if you have a serious illness
- if they have done something to make you sick
- if you are okay while they are at school.

They might also:

- be fearful of the future
- try hard to please their parents and do things for them
- take on parental roles such as caring for siblings.

Children's concerns will vary depending on their age and the particular family circumstances.

4–7-year-olds might ask themselves:

- is my mum/dad lying down because I'm being bad?
- who's looking after me today?
- why isn't my mum/dad home? Where is she/he?
- why does mum/dad take all those pills?



Meanwhile, 8–12-year-olds might ask:

- what is wrong with my mum/dad?
- will anyone else get sick?
- why is my family different?
- what will happen to me if my mum/dad dies?

A child's concerns after disclosure

If you have chosen to tell your child about your HIV status, their questions and concerns may vary depending on their age and understanding of the illness.

7–12-year-olds may have a lot of questions or concerns.

They might:

- be afraid of getting HIV or AIDS
- need more discussion about how people get HIV and AIDS
- have questions about sex
- worry about their future and who will care for them
- ask 'am I going to die? Are you going to die?'
- ask 'can I still hug and kiss you good night?'

13–18-year-olds have likely heard about HIV and AIDS. This is a good opportunity to educate them on how to protect themselves, as well as to clear up any misconceptions they might have about the illness.

I found honesty and openness the best way to deal and educate my family about these issues.

—Janice

Common questions might be:

- how did you get it?
- are you going to die?
- why didn't you tell me first/earlier?
- have I got it? Can I get it?
- who can I tell about this?
- who can I talk to about my worries?
- how can I help at home and still do what I want to do?
- what will my friends think?
- did you get HIV because you slept with a lot of people?

Older children may also:

- need more information about how HIV is transmitted
- ask more specific questions about how you contracted HIV or AIDS
- react negatively, e.g. become argumentative and engage in high-risk behaviours
- find that schoolwork and grades suffer
- need more information about drugs, safe sex and how to make healthy life choices.

Possible reactions from your child

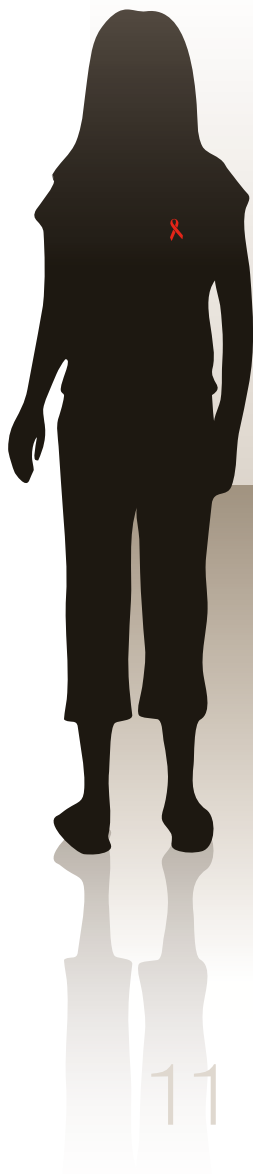
Children react to things differently. Some parents anticipate a child's reactions to be much worse than how they actually respond. It is important to spend time together after the disclosure and let children know that they can share any questions, thoughts or feelings they have.

In addition to asking questions and needing reassurance, children at any age may react to disclosure through nightmares and temper tantrums, or may even become quieter than usual. This could be the time to reach out for support from outside resources and family.

Answering tough questions

Children are curious at every stage of their development. They may ask questions that might be difficult to answer. Try to let the child lead the discussion. This is a good way to gauge how much information to give them. Here are some possible responses to what they might ask:

CHILDS QUESTION	POSSIBLE RESPONSE
Are you going to die?	'I take my medication and it keeps me healthy.'
Who will look after me if you die?	'I am very healthy and I will be with you for a long time.' 'There are many people in your life who love you.'
Can I get it too?	'These are the ways that HIV is transmitted. You don't have it and can't get it from hugging or kissing me'
Who else knows?	'These are the people who know. It is okay for you to talk to these people. This information is private so if you want to talk to someone about it, you can ask these people.'
Is there a cure?	'The medications are very good and keep people with HIV healthy for a long time. Doctors are working to find a cure all the time.'



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.

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.

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.

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

— Jackie

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 Seaside an important source of support, for both their children and themselves. Camp Seaside is a camp for children and families living with HIV and is run by Straight Arrows. 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 counselling 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. For example, www.thebody.com 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.



Benefits of telling

There are many benefits to sharing your status. Disclosure often brings family members closer together, allowing them to talk freely and put an end to secrets. Once children learn about HIV they can ask questions and get answers. Children who know may have the opportunity to join support groups and find friends who are in similar situations.

Meredith: I was surprised. I remember hearing that my mum was kinda sick, but I didn't think it was HIV.

Sandy: I wasn't sure how to bring it up with him. Then the conversation seemed to happen so naturally. He didn't have any questions at first, but I told him that he could always talk to me about things. I'm glad I told him.

Luke: Attending some of my mum's doctor's appointments kept me informed and included as well as the option to discuss questions or concerns with a doctor.

Luke: I chose to only share my family's secret with my close friends and some of my teachers.

Luke: Every family has secrets, family problems and health issues. Nowadays there is less discrimination around.



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). 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:

The National Relay Service (NRS)

The National Relay Service (NRS) provides a phone solution for people who are deaf or have a hearing or speech impairment.

If you have difficulty hearing or speaking on the phone, the NRS makes it easier to stay in touch with family, friends and the outside world. The NRS relays calls at no extra cost.

Contact the NRS Helpdesk:

Telephone: 1800 555 660

SMS: 0416 001 350

www.relayservice.com.au

helpdesk@relayservice.com.au

Victorian contacts

Straight Arrows

Services, support and advocacy for heterosexual people living with HIV, their partners and their families.

Telephone: 03 9863 9414

www.straightarrows.org.au

info@straightarrows.org.au

Positive Women

Support services and advocacy for women living with HIV.

Telephone: 03 9863 8747

www.positivewomen.org.au

info@positivewomen.org.au

Victorian AIDS Council

The VAC aims to improve health, social and emotional wellbeing of the Victorian HIV positive communities.

6 Claremont Street, South Yarra

Telephone: 03 9865 6700

www.vicaids.asn.au

enquiries@vicaids.asn.au

Positive Health/Victorian AIDS Council

Positive Health is a counselling service providing support to people living with and affected by HIV, people with living with hepatitis C and the GLBT community. It chiefly operates out of the Victorian AIDS Council in South Yarra but has outreach services delivered from Footscray and Southbank.

Telephone: 03 9865 6700

Country Awareness Network

CAN provides information, education, support, referrals and advocacy to Victorian rural/regional communities regarding HIV/AIDS, Hepatitis C, other Blood Borne Viruses (BBVs) and Sexually Transmitted Infections (STIs).

Telephone: 03 5443 8355

www.can.org.au

can@can.org.au

Education & Resource Centre (ERC)

The ERC offers a free, confidential information service and education and training programs about HIV/AIDS, Hepatitis and Sexually Transmitted Infections (STIs). A sexual health nurse is available.

Telephone: 03 9076 6993

www.hivhepsti.info

erc@alfred.org.au

Victorian HIV Consultancy

A small multidisciplinary team servicing the continuing care needs of PLWHA, especially those with limited access to mainstream HIV services. This includes rural clients, individuals with a history of disengagement, from mainstream health care, those from culturally and linguistically diverse (CALD) backgrounds and aging PLWHA.

Telephone: 03 9076 3658

Mon–Fri 8.00–4.00pm

Multicultural Health & Support Service

A community service that provides education, information and support on issues of sexual health, HIV/AIDS and blood-borne viruses. They work with migrant and refugee communities as well as health service providers.

Telephone: 03 9342 9720
www.ceh.org.au/mhss
enquiries@ceh.org.au

CALD Service

Provides bilingual support workers who directly assist People living with HIV from Culturally and Linguistically diverse (CALD) backgrounds.

Fairfield House, The Alfred Hospital
Prahran, VIC

Telephone: 03 9076 3942
multiculturalservice@alfred.org.au

People Living with HIV/AIDS Victoria

PLWHA Victoria is the peak body for people living with HIV (PLHIV), providing education, information and representation for all PLHIV in the State of Victoria.

Telephone: 03 9863 8733
www.plwhavictoria.org.au
info@plwhavictoria.org.au

HIV + Sexual Health Connect Line

HIV + Sexual Health Connect Line is a confidential and anonymous Victorian statewide service which provides information and support through referral about HIV and Sexual Health.

Telephone: 1800 038 125
Interpreter: 131 450
www.connectline.com.au

Tasmanian contacts

TasCAHRD

We work to minimise the impact of HIV/AIDS and Hepatitis C in the community. This includes working with people living with HIV/AIDS and/or Hepatitis C and

people who may be at risk of HIV or Hepatitis C. Another part of work is supporting other organisations and services to be better able to respond to HIV and hepatitis issues.

319 Liverpool Street, Hobart

Information and Support Line:
1800 005 900
Telephone: 03 6234 1242
mail@tascahrd.org.au
www.tascahrd.org.au

Sexual Health Services

60 Collins Street, Hobart

Telephone: 03 6233 3557

Women's Health Centre

Lefroy Street, North Hobart

Telephone: 03 6231 3212

Woman's Legal Service

Telephone: 03 6231 9466
or 1800 682 468

National contacts

NAPWA

NAPWA is the national peak organisation representing people living with HIV/AIDS in Australia.

Freecall: 1800 259 666
www.napwa.org.au

For the Kids

Kids Helpline

Kids Helpline is Australia's only free, private and confidential, telephone and online counselling service specifically for young people aged between 5 and 25. 24hrs 7 days a week

Telephone: 1800 55 1800
www.kidshelp.com.au

Let's Talk... Children, families, HIV.

www.kidstalkaids.org

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