Changing Lives A resource for Heterosexual people living with HIV/AIDS Chapter 5 • P1

Telling Others

HIV disclosure

I feel even after several years I'm scared I may let it slip I'm HIV positive. Sarah I find it very hard to tell because I don't want people getting scared of me. James

Finding out you are HIV positive is a shock and it takes a lot of time to understand what really has happened to your life. Once you have been told about your HIV status you'll need to decide whether to tell or not tell others about this. Telling others is known as 'HIV disclosure' and is a lifetime issue for most positive people.

Some people who have been HIV positive for many years say that telling others does not get any easier. You will probably think about whether to tell or just keep silent. There is always a fear that comes with telling somebody that you're HIV positive, because you are letting them in on a big secret about your life and you can't be sure how they will react. Telling somebody can feel like being pushed over the edge, because there's no taking it back once you have said 'I'm HIV positive!'.

You may be afraid of being rejected if you disclose and this can be very worrying and upsetting. If it's a close friend you're thinking of telling it's even harder. Some people are still very prejudiced about HIV. It can be especially tough if you feel that your own family may think like this.

Attack of the HIV disclosure monster

A large group of HIV positive heterosexuals from both city and country areas in New South Wales were asked to come up with their top five concerns about telling somebody else they were positive. It's not a surprise that both men and women shared the same worries.

They were in this order:

- I. I can't work out if I can trust this person.
- 2. I haven't worked out what to say yet.
- 3. I can't find the right moment to tell.
- 4. I'm afraid that they'll show me a lot of prejudices.
- 5. They'll want to know how I caught it.



Suit yourself - choosing whether to tell

There are plenty of reasons why you wouldn't want to tell somebody. These could include:

Others may give me a hard time if they know I'm HIV positive. I may be left out of things like parties or outings. My partner doesn't want me to tell anyone. A close friend could gossip and tell people I don't want to know. I don't want to be a downer and seek sympathy. They won't be clever enough to deal with all this. I won't tell to protect my family and friends.

There are also plenty of reasons to tell somebody your HIV status. Things like:

I know this person is special to me. I want some love and support that will help me get through all of this. I just can't keep what is happening to me all to myself. I want to be honest about who I am and stop hiding stuff. Telling will make it easier for me to get help from HIV/AIDS services. I could meet other HIV positive people and make friends. I can be upfront when I have sex and so reduce the risk of somebody else catching this virus. It will make things easier at work and I won't have to cover up every time I have a doctor's appointment.

Not telling - spin a good story!

Not telling means that you have to be prepared to protect yourself. You could be faced with an awkward question from a friend, a relative, a loved one or somebody at work at any time. So prepare yourself for a question from somebody you don't want to tell. Work out a good story about what's happening with your health and don't leave anything to chance.

It takes practice to be good at spinning a good story that works for you! Here are a few tips for answering awkward questions.

- Keep it simple
- Speak confidently
- Make your story something you'll be able to remember and stick to at a later date
- Don't make a big deal of it

Answering curiosity questions

Whether you tell or don't tell, watch out for curiosity questions. A curiosity question is a question someone asks out of curiosity - they have no need to know the answer. And you may have no reason to give them the information. A typical curiosity question is

- Why are you always seeing the doctor?
- What are those tablets for?
- How come you're on the pension?

The biggest curiosity question you will be asked is 'how did you get it?' You must have a variety of answers for this question so you won't be caught unawares. This is also true if you are a negative partner. Someone may ask you out of curiosity how your partner got infected.

Curiosity questions

List down curiosity questions that you worry about.	
Think of some replies.	
Practise your replies. Find somebody you know and trust to practise with. It's even okay to discuss this sort of thing with an HIV/AIDS counsellor.	

Telling - stepping across the line

What if I had safe sex with someone and then got serious - it would be hard telling them then! Lee

I've practised telling him at least fifty times in the mirror. If I had an audition I definitely would get this part. Susan

Telling my family that my partner was positive made us feel very close as a family. I think I needed time myself to get used to the idea. Danny

I do deliveries part time. I told my boss that I'm reliable but my health isn't. He now gets it, and always inquires how well I'm going. Tony

I wasn't being honest about who I was and this caused me to isolate myself. Carlos

It takes time to get to know somebody and trust them, even if you aren't HIV positive or living with someone who is. You may decide not to tell everything straight away. If you've just met somebody for the first time you could wait to see if there's any chemistry between the two of you before you start telling them about your health. Waiting can give you the chance to get to know more about them as you spend time together. When you first meet someone you may think that they can be trusted, but with time you can be more certain. However after knowing them better you may change your mind.

If you decide to cross the line and tell someone that you're living with HIV/AIDS remember that you can't go back. So the best thing you can do is to think about this carefully. Here are some tips.

Preparing to tell

How do you prepare to tell someone? What happens when a relationship reaches the stage when you have to disclose - when you can't keep your HIV status to yourself any longer? You can spend a lot of time worrying about this moment. However there is a sense of freedom when you've disclosed because you can stop worrying about it. So it is important to know why you want to tell and who you are going to tell.

Can I trust this person?

Who in your life do you trust? Make a list of your friends and relatives. Include your own reasons, eg they don't gossip, they care about me, I have been able to trust them in the past with other things.



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Now decide who you ARE going to tell. Think about the time and place for this to happen that's best for you both. Think about how they may reply - what they could ask you. Know what you're going to say in return.

The person I'm telling is:	
The time and place I want this to happen is:	
How do I think they will take it? What are they likely to say? Anticipate their reaction.	
What's the best I can hope for?	
What's the worst thing I may have to deal with?	
If I'm asked how I got infected what will I say? Be prepared. Know how much you want to tell.	

When you disclose to friends and family they usually want to know whether you are getting the best health care and if you're keeping well. They may want to know what support you are getting and who else knows. They could also ask you to give them more information about HIV/AIDS. You can tell them that they are able to speak with an HIV/AIDS counsellor if they want to. Some friends and family members may want you to tell them how you became infected. Decide how you will deal with this if it happens. Good luck!



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