

10

This factsheet has come out of a larger project looking at newly diagnosed HIV positive gay men and peer networks.

The material used was derived from a focus group with HIV positive men who attended the After Hours¹ discussion group and a series of one on one interviews. All names have been changed.

These recently diagnosed positive men reflected on the value of accessing and developing peer networks (people who are in the same situation as themselves) and the impact this had on their experience of disclosing their HIV status to others. This factsheet on the role of our HIV positive peers in working out our attitudes towards disclosure reflects the principle that we can learn a lot from listening to and thinking about each other's experiences.

Disclosure is a big issue for people with HIV

For most people with HIV, telling people about our serostatus (who, when, how and why to tell) can be one of the biggest issues we face. And this can be even more the case for those who have been recently diagnosed HIV positive.

Joe: ... for a long time I told virtually no one. (...) I guess judged is sort of the term. Personally I think I have a lot a lot of guilt issues I needed to work through just because in this day and age everyone knows how you get this bug and yet you still allow yourself to get it.

Anthony: [Disclosure is] something that'll inevitably keep coming up, whether we like it or not. It's the number one big issue that you experience as you learn to cope with this disease.

Many people feel that issues around disclosure of HIV status are so important that both HIV positive and HIV negative men should be more aware of them.

Phillip: It's something that you know every gay man should think about, disclosure.

Rob: I think if more people who were HIV negative actually talked about these things, life might be a bit easier.

Your status is your personal information. While for many positive people, HIV can be a source of stigma, it may not necessarily be a particularly visible kind of one.² Therefore there may be times it could seem easier not to bring up the issue. Some of us, however, may feel we have accepted our HIV

the dynamics of
disclosure

to the point where we are not concerned whether people know our status.

Phillip: It's like whether you choose to tell people you're gay or not. There are people around here that might not tell people at work they're gay. It can be a weakness. It can just expose you to prejudice and you think basically I don't have the energy to deal with this prejudice. And so you choose to keep it secret.

Rob: And that's ok too.

Each of us weighs the risks and benefits of what we say and to whom we want to say it, and this includes the context in which we interact, and our decisions will reflect our shared and individual cultures.³

We have some control over the disclosure of our status

We may feel powerless when confronted with an HIV diagnosis and while we will need to come to terms with and accept it, we can make decisions about disclosure and give people access to information about our lives.

Of course, while we might judge that someone is an appropriate or a trustworthy person to be told, and we may try to ensure the conditions in which we tell them are good ones; we can't necessarily always be sure of the outcome. Disclosure is a dynamic process between two people. Just as there are dynamics to relationships and you find they change over time, so too there may be dynamics in the way you do (or don't) disclose your status to other people. Our confidence changes, our knowledge and relationships develop, and so our attitudes to disclosure may well change and develop. Sometimes the

responses we have received to the disclosure of our status can affect our attitudes to future disclosures.

Scott: [...] that's a development thing. Where I'm at six months ago is not going to be where I'm at in six months time.

Attitudes about what kind of information is public and what is private have changed a lot over time. There can also be tensions between our involvement with others and our desire to live our own lives.⁴ It is in this tension where our decisions about disclosure are worked out.

There are no simple answers but, as with many aspects of living with HIV, we are able to learn a lot from each other.

Joining a peer network can be an important first act of disclosure

If disclosing your status is a daunting prospect, doing it first to a group of peers (people in the same situation who are able to relate to your experiences), can be a valuable first step. It can give you the time and space you need to absorb being HIV positive:

Patrick: Disclosure to the group serves as a substitute for disclosure to the wider world so you feel 'alright I have disclosed' and I can discuss it with a range of people who because they're in a similar situation, will be empathetic at least. They'll understand.

Even if you feel you are not ready to tell people like family members and other friends, you may still want a space where you can talk openly about your life and HIV:

Phillip: It's actually easier for me to keep it secret in my everyday life, which is one of my objectives... In a work situation, in a family situation, I'm not really interested in them knowing. I don't want to tell my parents, and I found that a great strain before I did Genesis.⁵ And I knew it wasn't good for me but still I decided I didn't want to tell my family. So it was a big relief for me to meet people where I could be out and HIV.

Just going to a meeting of other HIV positive people can be a significant act of disclosure in itself.

Christopher: I remember when I went to Genesis. It wasn't like I was scared, but it was sort of a strange feeling. I'm actually for the first time in my life in a room where I know everyone's HIV positive and it was like oh ... it's a bit ... what's happening, you know?

An HIV diagnosis can make many people feel isolated, as if no one else seems to be in the same situation. By taking the step to meet with, and therefore disclose to, other HIV positive people you will find, in a very practical way, you are not alone.

Anthony: Genesis for me was funny because at the door I ran into a friend of mine who I didn't actually realize was also positive and he didn't know that I was. And we just looked at each other and just laughed and he went: 'You're here for what I'm here aren't you?'

Why would you disclose?

There are many reasons you may want to disclose your HIV status. One major reason you may have for disclosing your status is to get support:

Sam: To start off with the first things I thought about were: it wasn't so much how the people would react, but who I needed to tell, to be able to have support and not live with this giant secret.

Of course you will not need support all the time. Sometimes just the feeling that you have to keep a secret can be stressful:

Rob: I've told boys and it's been much, much better because it's got it out of the way. Sometimes it turns out they go 'I am too'. That's really good.

And many people also want to challenge stereotypes:

Ivan: For me personally I feel that I can't really whinge about the prejudices that are out there

if I'm not open and honest about my situation. How are people going to learn? How do people actually go 'oh shit. You were like the last person I thought would be' and then they look at it differently. That's what I find.

Disclosing to people in the same situation may be the first step in 'normalising' our experience

An HIV diagnosis might make you feel set apart and different from people around you. Perhaps it's not so surprising that some people express a desire for what they call 'normality': either a normality we think we have lost or one that can be constructed through greater acceptance (on our own part or on the part of others).

This may involve a hope that HIV will become 'less of an issue' in our lives or we become more 'comfortable' with the fact of our new status. We might integrate this change into our lives, or work towards HIV being considered like any other chronic illness:

Andrew: normalising being HIV positive. [Going to After Hours has] definitely had that effect. Or making it seem less of an issue, less of a problem. Making it more bearable to be HIV I suppose.

Joe: The word I keep coming back to for want of a better one is normalised. And I'm not saying it's exclusively through what's happened at the groups, but that's been a big part of it. And it's helped me to actually become more comfortable with it, both at the groups and meeting up with people the same people.

Andrew: My only expectation really was a support network in a way. Or to normalise being positive actually. I guess to make being HIV positive like any illness, like any chronic illness. That's what I mean by normalising it. Like if somebody is diabetic or any chronic illness that people have to live with until the day they die. Because being HIV positive, there's a lot of kind of moral issues hanging around as well. So I thought by being in a group that was positive it would make it seem like it was ordinary, everyday, just another disease.

'Normalisation' may also be about a desire to 'move on.' Certainly HIV can become just another part of life, about which we may think (and worry) less over time. Of course even after it has retreated to the back of our minds it can also quickly return:

Ben: Has everyone noticed that it's become less and less of an issue over time? When I first found out I was thinking about it all day and half the night. Those first few months it's constantly on your mind and now it's slipping further and further back, and one of the reasons that I do still come here is so that I make myself think about it for at least one night a month properly. Like something'll come up and you'll go I've got HIV.

Ivan: I find that every time I have blood tests.

Peer networks can be different from other everyday networks (friends, family and acquaintances)

Most of the men who participated in the interviews and focus groups did draw a distinction between peer networks and established friends. One was not necessarily perceived as better or worse, just different. For some of us it may just seem easier if people do not generally know our HIV status:

Andrew: I want it to sort of shrink and go away as time goes on. And it's easier for that to happen if I feel that it's not generally known. Because I can forget about it quicker than other people can, and I think when they meet me they're going to be remembering I'm positive, a lot of them, whereas I'm not. At the moment, I feel good about just keeping it to myself, and letting it slowly shrink.

Friends may be very supportive but they may need a lot of support themselves:

Martin: They cherish you in some weird way perhaps. They're like 'I'm going to make sure we're in touch all the time now.' A lot of them don't know how to react. Especially if they're straight and don't have any idea about HIV today. They think bowling ball and grim reaper.

Phillip: And you have to give them the support which is the last thing you feel like doing.

You might also wonder whether some friends really understand your experience of dealing with HIV and the new questions and issues you are facing.

Christopher: I've got some very close friends who know that I'm positive. They're straight people and not part of the gay scene and I find that talking to them about HIV is quite difficult simply because they don't understand the situation in many ways.

Martin: How can these people really understand, for example if you're talking about taking treatment or side effects? I think it's something I think you can only really understand if you're actually going through it. And that's why it is important to have these kinds of groups where people have a similar situation, experience.

Scott: I don't bother because some of my friends like to keep things really nice and social and light, and it's like almost like you're supposed to go 'oh hello I'm good thanks.' You're supposed to be alright and fine and that's great. And if you rock the boat they don't want to know.

Rob: If somebody in my life assumes that if I talk about it on any level, however superficial, it's a problem.

People who are less important in our lives may not need to know

Andrew, for example, does not tell acquaintances (but also wonders about that sometimes): I wouldn't be inclined to tell acquaintances because I don't see it's of any benefit to me or to them. But then again in a way I don't necessarily think that's very healthy because it's kind of maintaining the stigma of being positive by not telling every Tom, Dick or Harry that you're positive. 'By the way I'm HIV positive.' But yeah I wouldn't go around telling everybody.

Telling family can depend on the kind of relationship you already have with them:

Phillip: That's often why people don't tell their family, really. You don't want to have to sit down and bloody do social work with them.

Christopher: I don't tell my family because I'd be religiously judged.

Rob: I'd much prefer to tell my family than have them find out because some malicious bitch's mother's bending over the frozen peas counter and saying 'Oh I'm sorry to hear about so and so.' My parents already know.

Even HIV positive friends can be at a different stage of life

Of course, some of your friends may be HIV positive themselves. But if they are, they could be at a different stage of their experience of HIV and feel more resolved about issues which might still be important for you to explore:

Andrew: I had two really close friends who were positive as well. So I didn't really feel the need to go to outsiders as such. The boys who were positive were supportive but they didn't really have much to say after the initial diagnosis.

It was like they didn't want to talk about it very much. Once I got used to it they'd pull back, and being positive was just 'yeah, yeah whatever.'

Peer networks are a kind of prevention (as well as support)

You may not necessarily think that you have any 'problems' you would want to share with other HIV positive people, but peer networks can act as a kind of social capital, and can add some extra ballast to our lives. Developing peer networks may have longer term benefits because as Joe suggests: I don't think anyone's ever going to say one hundred percent that they cope with this disease.

Rob: I think sometimes we really do underestimate the prevention quality of support to stop a crisis from happening.

Martin: I think it's important just to **be** here a lot of the time. I mean I'm just happy to **be** here. It doesn't really matter what's said often or whatever but just feel like you have like a wave of support. It sounds silly but you feel there's a connection there.

Martin also recollects a story he heard in his Genesis group: There were two surviving groups of breast cancer and they'd done a survey. One group, after they'd been diagnosed and had treatment, had gone back to their families and their lives. And the other group had formed a support group. Then they looked at them five or six years later and there was such a high success rate all in that support group. The ones who didn't have the support had a much higher rate of dying, further cancers and so on. It just shows that support is so important, even just from a mental health perspective.

A number of the men in the After Hours network agreed with Martin's observation.

Scott: A couple of times I've turned up to the group not feeling very peaked and had a sense of balance

at the end of it. The group does provide me with a sense of manageability, knowing it's there as a resource, knowing it's there as a space is good. So does that change my attitude? Well, it must do. Even if it's just like taking a valium or something sometimes.

Hearing very different views helps us to make up our own minds

After an HIV diagnosis, the issues we may have thought were all too simple, over time may seem more complicated. Similarly some aspects of living with HIV which seemed so complex might look more straightforward. Research supports the idea that practices evolve and disclosure, like many things in life, is not always as cut and dried as it may seem. Michael Hurley, for example, has observed in *Then and Now, Gay Men and HIV*, certain practices 'are more likely tried on by the same individuals in different contexts, in closely followed moments and with shifting dispositions'.⁶

Martin: I don't do it anymore. At the beginning when I was first diagnosed I thought I had to tell everyone. And then after about a month or two I thought uh-uh I just don't want to tell anyone now because it became this big issue and all the time people start going 'how are you', and I thought 'oh for god's sake, I'm not dying'. And you just wanted life to go on. You realised ok that things were a little bit different [...]

The members of the network expressed a range of opinions about disclosure:

Christopher: I guess that's the big advantage of a group like this too. It empowers you. You can make choices in a better way. You can say well no I'm not going to tell these people or yes it's time for me to tell these people. I've at times heard people express a view here which I personally have not agreed with. But I still think it's good because you see another side of the coin and you're thinking about things from a different perspective and that has changed, helped me to develop ideas and feelings.

Disclosure of HIV status to sexual partners is a particularly significant issue

The 2000 *Male Out Survey* pointed to markedly different attitudes to disclosure of HIV status between HIV positive and HIV negative gay men. Significantly higher numbers of negative men than positive men expected that positive men would disclose their HIV status before sex. In the same survey the majority of negative men surveyed reported that they would avoid having sex with people they thought to be HIV positive.⁷

Scott: I'm over it. I'm over it. I find it very, very wearing and draining to have to talk about being positive for the first time with a person. [...] My negative experiences have been less but I still find it very draining but I do know that my experience is my own doing because I've chosen to disclose to people. I can't really embark on a sexual relationship comfortably unless I tell the person. End of story. But if I wasn't disclosing to sexual partners then I probably wouldn't be so exhausted by disclosing. Because I'm single. I'm living in Sydney. Like hello. And probably if I had a partner and had that space then I probably wouldn't be disclosing very much at all.

What The Law says

The *NSW Public Health Act* says that if you have a sexually transmissible medical condition you must tell your partner before sex. Under the current laws, condoms are not a defence if you do not disclose. People Living With HIV/AIDS (NSW) has advocated, and continues to advocate, that the law reflect the importance of condoms in reducing the risk of HIV transmission.

What about safe sex and disclosure?

Some people questioned how useful disclosure was in negotiating sex and safe sex:

Derek: We only tend to hear one side of it all the time. What we should be telling. We never really investigate the other side like where.. why? Why should you disclose if you're having safe sex? The interviews and group discussion revealed a range of opinions on handling sex and disclosure. Like disclosure in general, disclosure in relation to sex is dynamic and can be influenced by type of partner, location, past experiences, or mood at the time.

Ben: Sex is such a personal thing like... It's probably the most personal thing you do in your life. Even if you're just fucking someone and saying see you later it still is a really personal thing. So you have to come to your own decisions about what you're going to disclose and the way you're going to act. So we've seen the whole spectrum, from people saying 'oh look fuck 'em, you know, if they're not going to look

after themselves I'll just do what I want' then other people saying 'I want to tell everyone.' So you've got that whole spectrum of things. (...) So you have to make your **own** peace with what **you** do when **you're** having sex.

Joe: When I first found out and legally I actually had this obligation to tell everyone I had sex with. I was like 'I've broken the law. I'm not telling them. But if I tell them I'll lose them. But I can't.' Whereas now it's more like 'Ok, I've worked out what I can live with' and it's very much a case of if I'm in a sex on premises venue I'm fairly relaxed about not telling people. Let's face it – if you're going to a venue like that you've got to have at least seen the signs because they're everywhere.

Sometimes people will disclose to you

Phillip: It's nice when people disclose to you. That's for sure. If you're out and you're getting down to it and they say 'excuse me I'm positive.' You say yeah great, you know, love it.

Martin: And do you say anything to them?

Phillip: I just tell them my life story. You know. (Laughter.)

Ben: I've found it nice when people ask and you can say. If people ask obviously I'd say yes. I think it's really good to say yes. 'cause I sit there thinking 'I don't know how I'm going to sort of say it.'

While for some of us it can be helpful if people ask, others, like Phillip, find it intrusive:

Phillip: Well, I think it's rude. It's usually rude in conversation if someone asks you something without volunteering their status themselves. I think it's a bit abrupt. I don't like it. [...] When someone says it to me I think you're being a little bit pushy.

Some people find the Internet an easy place to disclose:

Joe: I would say there are things you can do, for example, cruising for men on Gaydar; I'm very open and honest about it there. You don't see them face to face and you never have to worry about it. Whereas when you're doing it in a face to face situation sometimes it's hard and depends very much on the sort of person you're dealing with.

You can get helpful advice on disclosure and sex from peer networks

While there can be fears about disclosing to a casual partner, anxieties about disclosure can sometimes be worse than the actual experience. And in many cases people can be pleasantly surprised. In *Futures 4*, most respondents (86.5%) had disclosed to close friends. Only 1.5% had not disclosed their status to anyone. 48.8% received a lot of support from close friends. 36.3% of respondents received a lot of support from HIV positive friends.⁸ Whatever your experiences of disclosure might be, sharing strategies and experiences with other positive men can help.

Phillip: The sort of advice we give each other that medical profession or professionals can't give us. Like we can say things that they censor. We can say things about how we deal with sex. How we negotiate sex and how we're positive that is basically good sound advice that helps us which you ain't going to get from any doctor or any nurse or anything.

Scott: I've had a certain validation by listening how to other people and I've gone 'nuh I'm ok with what I do.' I have a fairly high risk strategy in the sense that I tell people that I have sex with. I'll disclose, especially if they're trying to bare back. I have issues with passing it on. End of story on that one. So there's the sense of that validation you get from information you've heard or decisions you've made and that's a great thing to have.

While telling potential partners is a big step, sharing strategies may help

Disclosure to any potential sexual partner can be daunting but choosing the right moment to tell a potential boyfriend where more is at stake can be especially daunting:

Anthony: Every time you actually disclose I find it's easier [...] although there's going to be certain situations where it's always harder like for example when you meet that guy you fall head over heels for and you don't actually tell straight away.

Sam: And yeah it's more, I guess, will they react well, or will they react badly, and then you've also got the further issue: if they react well towards me, and they're happy about the HIV positive thing, would I be happy in a serodiscordant relationship?

Hesitations about joining a peer network are reasonable but then again ...

And finally, we might feel we set ourselves apart if we join a network of HIV positive peers. But as one person observed, if we rule out this kind of networking, could we in fact be subtly accepting stigma and denying the commonalities in our experience of HIV?

Andrew: It was [difficult to come to the group] actually because I'm shy as a person so being in a group at all was quite a brave step for me to take. So it was difficult. And also it felt like in a way being a part of a group was almost like making it seem like, you know, different, apart from everybody else in a way. So in a way it almost felt like creating a stigma by going to a group. Like us and them kind of thing.

But by not going it also says the same thing I suppose. By not going to a group you're kind of admitting that you're different. You know what I'm trying to say?

The men in the After Hours group found that taking the step of meeting with their peers and developing new networks helped them to develop attitudes and approaches to life with HIV, one of the most important, complicated and dynamic of which is disclosure.

For support and information:

- **People Living with HIV/AIDS (NSW) Inc.**
☎ (02) 9361 6011 Freecall 1800 245 677. A non-profit community organisation representing the interests of people living with HIV/AIDS in New South Wales.
- **The AIDS Council of New South Wales (ACON)**
☎ (02) 9206 2000 Freecall 1800 063 060. A health promotion organisation based in the gay, lesbian, bisexual and transgender communities with a central focus on HIV/AIDS.
- **Positive Living Centre (PLC)** ☎ (02) 9699 8756 provides a range of structured programs, special events and social activities as well as peer support and health promotion programs for people living with HIV/AIDS.

Sources

- 1 After Hours is a monthly social discussion group for newly diagnosed gay men, organised by People Living with HIV/AIDS (NSW) and ACON. It is an opportunity for them to meet and talk about experiences of living with HIV in a supportive and confidential environment.
- 2 Goffman, Erving, *Stigma: Notes on a spoiled identity*, NY Prentice Hall 1963 (p.64).
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- 4 *Ibid.*
- 5 Genesis is a weekend workshop for newly diagnosed HIV positive men to meet and share information.
- 6 Hurley M, *Then and Now. Gay men and HIV*, Monograph series no. 46 Australian Research Centre in Sex, Health and Society, Latrobe University, Australia 2003.
- 7 Van de Ven P, Rawstone P, Crawford J, Kippax S, *Facts & Figures. 2000 Male Out Survey* Monograph 2/2001 National Centre in HIV Social Research Faculty of Arts and Social Sciences University of New South Wales.
- 8 Grierson, J, Thorpe R, Saunders M, Pitts M, *HIV Futures 4: State of the [positive] nation*, monograph series number 48. The Australian Research Centre in Sex, Health and Society; Latrobe university, Melbourne, Australia 2004.

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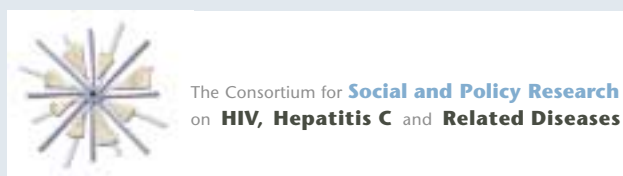


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