




Life, Loving and HIV

a heterosexual's guide to serodiscordant relationships

A sunset over the ocean with a dark red horizontal band containing text. The sky is filled with soft, orange and yellow clouds, and the ocean below is calm with gentle waves. A dark red horizontal band is overlaid on the image, containing white text. The text is a quote from Gabriel, who is HIV negative, expressing a desire for a normal relationship.

**“Basically I love the woman...
and I just want to have a normal relationship.
And that’s it.”**

— Gabriel, hiv negative

This booklet was developed by Pozhet (Heterosexual HIV Service, SLHD), pozhet.org.au with input from the following partners:

Positive Life NSW

Multicultural HIV and Hepatitis Service SLHD

National Centre in HIV Social Research UNSW

Clinic 16 NSLHD

ACON Women and Families Project

Community HIV Team SESLHD

HARP Health Promotion Team SLHD

Social Work Dept HNELHD

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Monograph 1/2009 Sydney: National Centre in HIV Social Research, the University of New South Wales.

Persson, A., Barton, D. and Richards, W. (2006) Men and Women Living Heterosexually with HIV: The Straightpoz Study Volume 1.

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Life, loving and HIV

Many people are living well with HIV, working and enjoying their lives, and many of them are in relationships with people who don't have HIV. These are known as serodiscordant relationships, pos/neg relationships, or magnetic couples.

With the right information and support a serodiscordant relationship can be a happy, healthy experience and a great source of joy, love and learning.

If you have HIV and you're thinking about being sexual again or starting a relationship, this booklet is for you. If you don't have HIV and someone you like or love does, read on as this information may help you.

This booklet features the voices of HIV positive and HIV negative men and women talking about their lives together. They talk about starting relationships, bringing up the subject of HIV with someone new, supporting each other and living with HIV. It also has useful tips and facts that may help you take the first steps on your journey in love and life.

We know HIV is now a manageable health condition. With medication, a person with HIV can live a long, healthy life. Relationships are an important part of life, so don't let HIV stop you from having love and great sex in your life.

Relationships and intimacy

A great relationship is not just about sex, it's about the connection between two (or more) people. It's the things you do together, the support, the laughter and friendship. All relationships have challenges, and having HIV can bring a few more. It's normal to fear intimacy and rejection, especially if you're HIV positive, and the fear of infection is also understandable. However, there is good news.

There is now general agreement among HIV scientists and researchers that proper use of HIV medication can significantly reduce transmission of HIV.

In 2008 Swiss HIV experts produced the Swiss Consensus Statement which stated that a person with HIV has a negligible risk of transmitting HIV during sex under the following conditions:

- They have had an undetectable viral load for at least six months
- They take effective medication and are regularly monitored by their HIV doctor
- They have no other sexually transmitted infections (STIs)

A later study in 2011, HPTN052, concluded that HIV medication, when taken as prescribed and without missing any doses, is 96% effective in preventing HIV transmission.

So it's all pointing to the fact that you can have a healthy, enjoyable sex life with HIV and significantly reduce the risk of transmission to your partner.

The following stories outline some of the ways people think about sex with HIV, and manage the challenges...

I love sex, it's good for you.

— Paulo, *hiv positive*

Well, you theoretically negotiate sex. And everybody knows what's going on. And you're very informed. And you decide beforehand what you're going to do and what you aren't gonna do.

— Olivia, *hiv positive*

We practice unsafe sex, but it's something that she has a full understanding of what we do. I don't always feel comfortable doing it. She seems to be prepared to accept that risk. She knows of the risk. She's been to information sessions and I think is very well informed. She's done a fair bit of reading.

— Cory, *hiv positive*

I think he worries about it heaps more than me, which he shouldn't...I'm a big girl; I make my own decisions.

— Alice, *hiv negative*

My sex life these days is basically, every now and then I go to the parlours, you know. And I'm honest there, you know, well, honest in the sense of a condom. But it's a touch thing with me, you know?

— Victor, *hiv positive*

We were together for such a long time with me being positive unknown and he didn't get it, so I knew the risk was very low.

— Dianne, *hiv positive*

He, too, has elected not to have protected sex because of my good health... that's his decision... So it's a wonderful thing for me to have that acceptance.

— Donna, *hiv positive*

I've been with guys who have made an informed decision about not using condoms, and, because I'm on treatments and I don't believe I'm a risk to them, I've agreed. Actually I made them get tested for sexually transmitted infections first!

— Mary, *hiv positive*

Your risk of transmitting HIV is significantly reduced only if:

- You have had an undetectable viral load for 6 months or more
- You never miss a treatment dose
- You have no sexually transmitted infections (STIs)
- You are regularly monitored by your HIV doctor

Remember that condoms protect against sexually transmitted infections (STIs) and HIV

If you use them properly and have an undetectable viral load, your risk of HIV transmission is next to zero

HIV treatments

HIV treatments are usually well tolerated, they can keep you well and healthy, and significantly reduce the risk of HIV transmission to your partner.

Take care of your health by staying in regular contact with your HIV doctor, whether you're on treatments or not.

Here are some things people have told us about their experiences with treatments...

Taking medication doesn't bother me... I'm the kind of person, if I have to take medication I'll take it. To me it's not a hassle... it's part of my life.

— Ratu, hiv positive

It was a big deal when I first went on them. Like it was a huge hurdle for me to get over thinking 'God I have to take these things every day'... But now it's just kind of normal.

— Olivia, hiv positive

They put me on HIV medication and that seemed to work quite well. Very quickly my viral load went down, remained undetectable and very slowly my CD4s went up. I get excited now when I do my bloods!

— Dianne, hiv positive

I think I've very much accepted the fact that I probably will have to take medication for the rest of my life... I've been taking the treatment for so long now it's just become a part of my life and it doesn't affect me.

— Carlos, hiv positive

I do everything I can to keep him stable and comfortable and resourced, strong to do that. Because our lives and our happiness depends upon his ability to do that.

— Maria, hiv negative

He's highly compliant. He's got perfect compliance... He's not shambolic; he's highly disciplined around it, which is fabulous from my point of view because I haven't got to worry about it... I think I would go mad if I was with someone who was all over the shop with their treatments.

— Maria, hiv negative



Taking HIV medication (treatments) is good for your health, and it significantly reduces your risk of transmitting HIV to your partner

Disclosure... talking about HIV for the first time

You've met someone you like... when should you tell them you have HIV? What do you say? And how will they respond?

Many people say that telling someone they are HIV positive is the hardest thing to do.

All their great qualities tend to fade into the background as they fear that all the other person will see is HIV. This is why it's so important to take your time, be prepared, and be realistic. HIV is not who you are.

The following is a real story of meeting someone new...

"I guess I went through a stage where I was quite depressed so my self-esteem was sort of rock-bottom and I felt pretty horrible about myself and everything else...

so I wouldn't have been capable of having a relationship really during that period... I really had to feel like I was okay and that there was always hope and whatever, 'cause there's always the possibility of getting the flick... Yeah, so I guess I had to work on that for some time so that, if that did happen, that would be okay and I wouldn't crumble.

As it turned out, I ended up marrying him!

Yes, so I asked him out for dinner and he went "okay" and I went "Oh, my God!" I was actually a bit terrified. I sort of looked at him too and I thought "My God, he is so fit!"

And I thought "Who am I kidding?" But anyway I thought "Oh, what the hell?" Yeah, so

we went out and I picked him up and he had a box of chocolates with him. Yeah, we went out for dinner... and then we went home and he made a move and I told him.

He was getting fairly randy and... I just kind of stopped him mid-kiss and said "I just need to tell you something". And he said "What? What is it? Is everything okay?" And I'm like "Well, we'll see". And I told him and he was like "What? You gotta be kidding!" and I'm like "It's not something you joke about." He was quite shocked and I can't even remember how much information he wanted, but he knew what I was talking about and then he just sort of went "Okay" and then he carried on. I was like "Oh, okay!?"

It was probably the best reaction you could hope for." — Olivia, hiv positive

Olivia's story touches on the complex process she went through to disclose her HIV status and start a new relationship.

If you're thinking of being in a relationship it can be helpful to talk with a social worker or counsellor. Talking about some of the feelings, hopes and fears you might have can help you take the next step.

Some things others have found helpful...

How well do I know this person?
Can I trust them?

Maybe I'll try sussing them out first.
Are they generally open minded?

Do they treat people with empathy and respect?
Do they care about me?

Will I tell on the first date, or wait until we get to know each other?

Why am I telling?
(I don't have to unless I want to have sex)

I could be prepared. I could have information about HIV to give them

Am I ready for questions, like 'How did you get it?'

It might be good to choose a time and place where we won't be disturbed

I can talk it through beforehand with a close friend or counsellor

Sometimes people I tell will need time
I might need to be patient



Do we tell other people?

How did you get it?



I'd rather not say right now. Maybe later on when we get to know each other better.

When you're a couple with HIV you might make some decisions about who to tell. Will you tell friends and family, or not?

Making these decisions takes understanding and communication. Talking openly together or visiting a counsellor or social worker can help you make the right decisions.

It feels as though HIV still provokes a lot of fear in people. As such, my partner and I do not believe that it is worth disclosing to family or friends. At the end of the day, it is only one aspect of our lives and who we are both as individuals and as a family.

— James, *hiv negative*

Telling can be a big issue if one partner wants to tell and the other does not.

— Mike, *hiv positive*

Telling my family that my partner was positive made us feel very close as a family.

— Danny, *hiv negative*

Sex and the law in NSW

Under the NSW Public Health Act 2010, people with HIV are required to tell a sexual partner they have HIV before having sex.

Note: In Australia each state has its own laws. Make sure you understand the law in your state.



The following stories show how people manage HIV disclosure

Some get scared, others think about the evidence about treatments (HIV medication), some practice telling, while others only tell if the relationship is serious...

I find it very hard to tell because I don't want people getting scared of me.

— Jim, hiv positive

When my partner and I first started dating she suggested she might be HIV positive, and wanted to know how I felt about it. I knew enough to know that there was nothing for me to fear in us getting to know each other better, and that if she was, it was not the end of the world. I did my best to assure her that whatever the outcome, we were in this together. We now have two healthy young children, my partner takes very good care of herself, and there is no reason to believe that we can't have a long, happy and healthy life together.

— James, hiv negative

Telling is hard but it's worth it. It is a lot easier than 20 years ago, but there's still stigma. We can now think about our future, we know we're not going to die. When you're on treatments it's 99.9% it's not going to be transmitted, but I guess it still could. I don't want to pass it on, the anxiety still lingers, but the risk is almost non-existent with treatments.

— Jayson, hiv positive

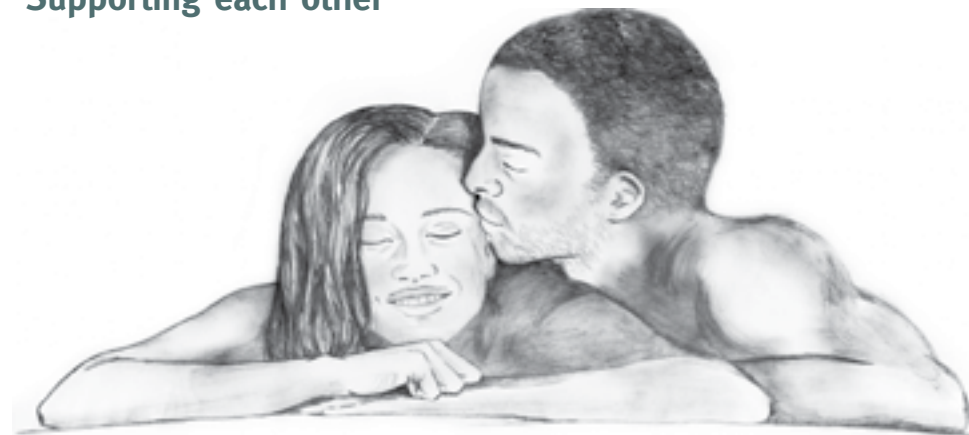
I've practised telling him at least fifty times in the mirror. If I had an audition I definitely would get this part.

— Susan, hiv positive

Be confident and keep it simple. With treatments you can live a healthy life and your risk to sexual partners is minimal (as long as you take your medication as prescribed, have no STIs and are regularly monitored by your HIV doctor)



Supporting each other



So you've gone on a few dates, maybe you've had a few nights together... is this just a casual thing, or could it be something more serious?

Whatever your relationship is, looking after your own health and supporting each other can make life smoother.

Counselling has helped me work through lots of issues. It's great to have someone who listens and understands.

— Maria, hiv negative

Supporting each other involves communication, love and understanding.

Remember there are counsellors, social workers and other support workers who can help you through tough times.

You don't have to keep problems to yourself and struggle alone.

The greatest difficulty in getting care and support is me asking for it!

— Mike, hiv positive

Sometimes living with HIV can be difficult and getting support can give you some breathing space... See Useful Contacts on page 16 for a list of services you can contact for support



Every couple has their own way of communicating about HIV...

I said to him, 'Well, okay, now I know, what do we do about it? What impact is that going to have on me, my kids, and how do we deal with this? I know we can't cure it, we can't fight it, but how do we live with it?' I go to all his doctors' visits with him.

— *Claire, hiv negative*

He looks after me like I've never been looked after by anybody. And my well-being and my safety and my happiness is more important to him than anything else in the world.

— *Maria, hiv negative*

For a long, long time, oh, probably a good twelve months, he kept saying, 'I'm waiting for the bubble to burst. I'm waiting for you to change your mind and call it off.' And it took a long time for him to accept that. He couldn't believe that I could accept it so easily and stand by him.

— *Claire, hiv negative*

I think it would be good if he asked more questions, sometimes I wonder if he has a really good understanding of stuff, and I want him to be really well informed.

— *Olivia, hiv positive*

We go on with life like there's nothing wrong. I never bring it up. I don't know why I haven't brought it up. It's never an issue at all. We just live our life. But for me, because I love her, I don't really give a damn, it's never an issue. But, you know, if she wants to talk about it, she can talk about it. But I don't want to bring it up.

— *Jason, hiv negative*

My last partner, my sixteen-year partner, didn't want to know anything. He was accepting—but didn't want to know about it. If I got sick, he went to bed. He didn't react very well at all to it, which was a burden for me. In actual fact, I would prefer to have been on my own than to carry him in the relationship.

— *Donna, hiv positive*

She has this thing about not wanting to burden anyone, even me. She just tries to struggle on alone with it. I said, "You know, you've got to talk to me about this stuff."

— *Gabriel, hiv negative*

It's extremely important to have a bit of normalcy. You don't normally wake up and talk about HIV so we don't really talk about it.

— *Anthony, hiv negative*

With improvements in HIV treatments it is now possible to have a baby without passing HIV onto your baby or partner. For more information speak to your doctor



HIV can be a positive in your life, it's all about your attitude...

One has got to be mentally tough because this disease is not only physical...The mental side of it plays a whole big part, yeah. That's one very big lesson I've learnt out of all this. It's not only medication alone. It's the mental side of it that is very important.

— *Ratu, hiv positive*

I think he's healthier than me... He's got more endurance than me, heaps more energy... He's been through a hell of a lot and I don't think anything can break him.

— *Alice, hiv negative*

My relationship has actually got stronger since finding out about my status and it was fearful for both of us at first. He said as a HIV-negative man he felt that it had no affect on our relationship, he only had to educate himself, face the facts, shock and pain of what happened and move on with his life, our life as a couple.

— *Dianne, hiv positive*

I can either let this thing control me or I can control it. And I've always been one to say, "No I'm in control". Like I'm not gonna let this thing ruin my life.

— *Lydia, hiv positive*

What's important is remaining negative while having a good sex life, helping my husband stay healthy, having a good sense of the absurd and keeping our secret.

— *Jacqui, hiv negative*

When I found out about the HIV my attitude was, OK, what are we gonna do about it?.. The only thing I can do is make sure you're eating properly, that you're resting, that you're not overworked, stressed and all the rest of it. I can't do anything with drugs; that's the doctor's job, but I can help with the lifestyle.

— *Claire, hiv negative*

Tips for fun and safety

Kissing, touching, hugging, licking and rubbing are safe

Condoms remain the best way to protect yourself and your partner from HIV transmission

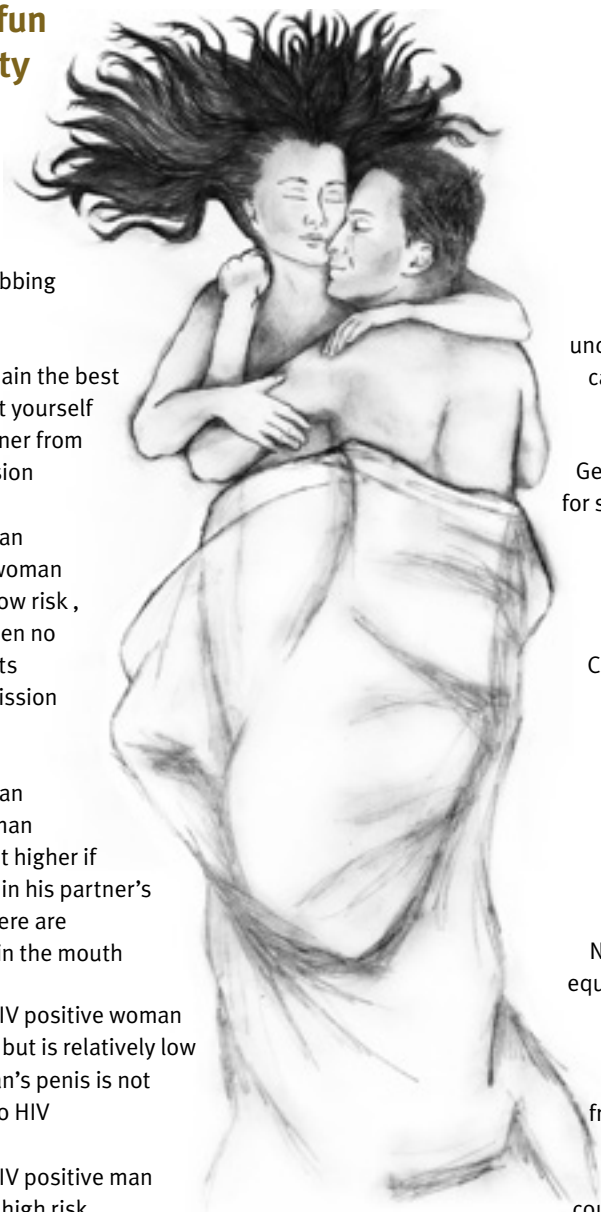
Oral sex with an HIV positive woman is extremely low risk, there have been no reliable reports of HIV transmission this way

Oral sex with an HIV positive man is low risk, but higher if he ejaculates in his partner's mouth and there are cuts or sores in the mouth

Sex with an HIV positive woman carries a risk, but is relatively low because a man's penis is not as receptive to HIV

Sex with an HIV positive man is considered high risk

Receptive anal sex with an HIV positive man is the highest risk for HIV



Sex with a person with HIV who is on treatments with an undetectable viral load carries a minimal risk of HIV transmission

Get tested and treated for sexually transmitted infections. They can increase the risk of HIV transmission

Circumcision reduces a man's risk of getting HIV

If you have sex with multiple partners use a new condom with each person

Never share injecting equipment. Always use sterile equipment.

You cannot get HIV from household items, toilets, showers, cups, sneezing, coughing, saliva, urine, sweat, faeces, shaking hands, mosquitoes or laundry

Testing

If you are having sex with someone who has HIV you may want to get tested regularly. Often the test gives peace of mind and lets you know that what you are doing is working. The person with HIV should have regular tests to ensure their viral load is undetectable. Regular testing and treatment for STIs is important, especially if you have sex with other people. Testing should be completely confidential and you have a right to privacy. See *Useful Contacts* (pg16)

Slip up?

If you're worried about being exposed to HIV there is something you can do.

PEP (post exposure prophylaxis) is a course of HIV medication taken as soon as possible after exposure to HIV, but no later than 72 hours. It must be taken for four weeks. Call the PEP Hotline on 1800 737 669 to assess your risk. Only hospital emergency departments, sexual health centres and HIV specialists can prescribe PEP.

The future

The future looks bright for people with HIV and their partners. Love, sex and relationships are all part of a healthy, happy life so don't let HIV stop you from living yours to the full.

Advances in HIV science and treatment mean the future is yours, so make the most of it.

Useful contacts

Pozhet (Heterosexual HIV Service)

Support, information, referrals and events for heterosexuals with HIV
Freecall: **1800 812 404**
Email: pozhet@pozhet.org.au
Website: pozhet.org.au

Positive Life NSW

A community-based organisation for people with HIV
Phone: **(02) 9206 2177**
Freecall: **1800 245 677**
Website: positivelife.org.au

Multicultural HIV and Hepatitis Service

Information and support for individuals and communities from culturally diverse backgrounds
Phone: **(02) 9515 1234**
Freecall: **1800 108 098**
Website: mhahs.org.au

Bobby Goldsmith Foundation (BGF)

Practical, emotional and financial support
Phone: **(02) 9283 8666**
Freecall: **1800 651 011**
Website: bgf.org.au

ACON (NSW)

Information and support for people with HIV, Vitamin service, counselling
Phone: **(02) 9206 2000**
Freecall: **1800 063 060**
Website: acon.org.au/hiv

Women Partners of Bisexual Men Service (NSW)

Counselling, support and information
Phone: **(02) 9560 3011**
Website: lwchc.org.au/womenpartners

HIV Legal Centre Inc (HALC)

HIV related legal matters
Phone: **(02) 9206 2060**
Freecall: **1800 063 060**
Website: halc.org.au

Relationships Australia

Relationship Counselling
Phone: **1300 364 277**
Website: relationships.com.au

Sexual Health Infoline

Sexual health information and referrals
Freecall: **1800 451 624**

PEP (Post Exposure Prophylaxis) Hotline

(24 hrs, NSW)
Call immediately if you think you might have been at risk of exposure to HIV transmission. Trained staff will advise you what to do next
Freecall: **1800 737 669 (1800 PEP NOW)**

Australian websites

National Association of People With HIV Australia napwha.org.au

Australian Federation of AIDS Organisations afao.org.au

Straight Arrows (VIC) straightarrows.org.au

International websites

NAM aidsmap (UK) aidsmap.com

Positive Women (NZ) positivewomen.co.nz

The Body (US) thebody.com

HIV/Aids Tribe (US) hivaidstribе.com

Always check the date when a site was last updated and check to see who produced the site so you can be sure they are professional and scientific

