



**A guide for helping you through the
process of disclosing HIV status**

positive disclosure



About *Positive Disclosure*

Positive Disclosure has been developed as a guide to help through the process of disclosing HIV status.

This publication contains the lived experiences and thoughts of eighteen community members living with HIV, who have had various experiences of disclosure.

Community members contributed to the development of this guide. Surveys, questionnaires and interviews were used to gain information, thoughts and personal experiences around the disclosure of HIV status.

The quotes highlighted throughout the book are those of community members living with or closely affected by HIV, in South Australia. They offer a unique and invaluable insight into the disclosure experience.

Disclosure is a complex and multilayered process and a personal decision. No conclusion is made on whether disclosure is the right or wrong thing to do. There is no attempt to dictate how it should be done. **The choice is yours.**

What is disclosure?

Disclosure is communicating personal health information about yourself to another person.¹

Disclosure is a process rather than a one off event. Often further discussion around HIV can occur after disclosing your status.

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You Have The Power

You Have The Power

HIV does not have to take over your life.
It is you who has the power.

Choose **who** you tell...

When to tell...

How much to tell...

The choice is **yours**.

“it should always be my choice first and foremost”



Everyone Is Different

Every relationship in your life is unique, in the way you communicate, express your feelings, what you share and how you interact with each other.

Everyone will disclose differently.

Everyone will react differently.

There is no right or wrong way to disclose or to react.

Your experience is your own.

“it is never simple and depends on who you are disclosing to”

“it is up to each individual to decide what works for them”



The Ups And Downs

You may experience a variety of emotions.

Disclosure can bring up feelings of...

Regret
Rejection
Fear
Isolation

It can also offer feelings of...

Relief
Happiness
Freedom
Belonging
Support

It is not uncommon to experience many different emotions throughout the disclosure process.

“[I] have experienced the whole spectrum from violence, rejection, judgment, isolation [to feeling] loved, supported”

“each time was different and still always difficult...and places you in a vulnerable position where emotions are often raw or just under the surface”

Why Disclose?

Before you disclose:

Think about **why** you want to tell.

Knowing **why** can affect who, what and how much you tell.

Your reasons for disclosing will vary for different people.

Reasons for disclosing your HIV status...

- support from others
- access to services
- medical reasons
- legal reasons
- honesty in a relationship
- felt moral obligation ²

Write it down!

Writing down your thoughts, feelings, hopes and fears around disclosure can be helpful in clarifying **why** you want to disclose.

“I don’t want to be disclosing looking for sympathy and empathy but so [that] people are able to understand what I need to do to stay healthy”

“I didn’t want to hide it anymore...if you keep hiding it–it’s going to stay hidden. It’s not going to become aware in the community”



Choose Who You Tell Carefully

First tell the people you trust most.

They may offer **support** when telling others.

Choose someone who you feel **comfortable** discussing personal issues with.

Set boundaries for the person you are telling on who they can or cannot discuss your HIV status with.

Tell people you can **trust** and who will **respect** you and your decisions.

“I only tell people who are close to me”

“if they don’t need to know, don’t tell them”

It is against the law to discriminate against people because they are HIV positive.

In South Australia you do not legally have to disclose your HIV status as long as you always practice safe sex and take the appropriate precautions to prevent further transmission.³

However, you may legally have to disclose for...

- insurance
- travel purposes
- medical reasons

Know your rights!

Across Australia each state has different laws around disclosure. For further information on these laws or any other queries contact your local HIV service provider, details on available services can be found on **page 17**.

“people don’t need to know I have HIV if I don’t have sex with them”



Be Prepared

When discussing your HIV status with someone, it is likely there will be questions.

Be prepared for what may come up in discussion or what may be helpful to explain. Discussion can help to improve their understanding of HIV.

Know the facts...

- what is HIV?
- how is it transmitted?
- risk factors for contracting HIV
- treatment options
- difference between HIV and AIDS
- your rights and legalities

There are educational resources and services available to help.

Be prepared to...

- know the facts
- answer questions
- dispel myths
- challenge stigmas and discrimination

“like with every condition I get, I do my own research”

“if they ask you a specific question you need to know a specific answer”

Supports And Services

Disclosure can be a complex process and you don't have to do it alone.

Support services and peer networks are available. Support can help with the decisions on why, what, when, who, how and where to tell.

Services can include...

- counsellors
- support workers
- support groups
- discussion groups
- social gatherings
- books
- pamphlets
- articles
- chat rooms
- internet

To access these supports and services and for more information refer to **page 17**.



Support For The

The person you disclose to may need support around understanding HIV and coping with the news.

Support may involve...

- helping them to understand HIV
- answering questions
- providing emotional support
- educating them on the virus
- decreasing or dispelling myths

Educating the person you are telling can be empowering and can allow the person to better understand HIV and the impact it has on your life.

Educating others can help to...

- dispel the myths surrounding HIV
- decrease the stigmas associated with HIV
- increase the acceptance and understanding of HIV within the community

Remember there is much more to you than HIV.

“there were negative moments where I didn’t know what was going to happen... there was a little bit of stress after. But then people came back with the information I gave them and felt more comfortable”

People You Tell



Support can come from you or others including family, friends or organisations.

You don't have to do it all.

Linking them with support other than yourself can be helpful by...

- decreasing the burden placed on you to provide emotional and educational support
- giving them time and space to absorb the information
- providing them with the opportunity to ask questions and discuss aspects of HIV which they may not feel comfortable talking about with you ⁴

"[Have] printed information to hand them that they can read after in their own time or when the shock factor [has] gone down, this may be many months later. Others may want to know everything and that can be a burden on you the positive person so contact names or business cards are good"





You Are Not Alone

You Are Not Alone

Remember you are not the only one in this situation.

Other people can offer invaluable insight and support throughout the process of disclosure around their experiences, challenges and encouraging moments.

It can be helpful having someone there to...

Listen to you

Support you

Offer advice

Voice your fears to

Share your hopes with

There are opportunities to discuss your experiences and thoughts with other people living with HIV.

“meeting and hearing other positive people’s experiences is what made the difference to me around disclosing and taking that big step....now it is always the personal stories or testimonies that make a difference”

Community members share their thoughts about disclosing ...

“I feel bad reactions say more about the other person than myself”

“be honest with yourself, be comfortable with the person [you are] disclosing to, ask them to respect your confidentiality”

“you must be comfortable with yourself first”

“I own my own virus”

“some people cannot be trusted with this information so you don't tell them”

“I believe that to live an authentic life you must be true to yourself”

“be sure of the need to disclose, why you are disclosing, where you are comfortable to talk that's neutral ground”

Have You Considered...

Have You Considered...

Disclosure...

Is a complex and multi-layered process. The following can be used as a guide to help you think about disclosing.

Who

- Who are you going to tell?
- Who can help you?

Where

- Where will you disclose?
- A place which is: comfortable, private, emotionally safe.

What

- What support do you need?
- What support do they need?
- What supports are available?
- Know what you want to say and how much to say.

Why

- Why do you want to tell them?
- Do they need to know?

How

- How are they likely to react?
- How can you prepare yourself?

Services Directory

SOUTH AUSTRALIAN HIV SERVICES

Positive Life SA

16 Malwa Street, Glandore, SA 5037
8293 3700
www.hivsa.org.au

HIV Women's Project at Women's Health Statewide (Children, Youth & Women's Health Service)

64 Pennington Terrace,
North Adelaide, SA 5006
8239 9600
1800 182 098
www.whs.sa.gov.au/project_hiv.php

ACSA: AIDS Council of South Australia

2 Eton Road,
Keswick, SA 5035
8334 1611
1800 888 559
www.acsa.org.au

MOSAIC: Relationships Australia (SA) Inc

55 Hutt Street, Adelaide, SA 5000
8223 4566
www.relationships.com.au

P.E.A.C.E: Relationships Australia (SA) Inc. (multicultural HIV and Hep C Service)

49a Orsmand Street, Hindmarsh, SA 5007
8245 8100
www.relationships.com.au

O'Brien Street Clinic

17 O'Brien Street, Adelaide, SA 5000
8231 4026

AROUND AUSTRALIA

AFAO: Australian Federation of AIDS Organisation

(02) 9557 9399
www.afaao.org.au

NAPWA: National Association of People Living With HIV/AIDS Australia

1800 259 666
www.napwa.org.au

Australian Capital Territory

PLWHA/ACT
(02) 6257 4985

New South Wales

Positive Life NSW
(02) 9361 6011
1800 245 677

Northern Territory

PLWHA/NT
(08) 8941 1711

Queensland

Queensland Positive People
1800 636 241

Tasmania

Tasmanian Council for AIDS & Related Diseases (TASCARD)
(03) 6224 1034

Victoria

PLWHA Victoria
(03) 9865 6772

Western Australia

HIV/AIDS Peer Advisory Network (HAPAN)
(08) 9482 0000



Resources Used

1. Arnold, EM, Flannery, D, Rice, E & Rotheram-Borus, MJ 2008, 'HIV Disclosure Among Adults Living With HIV', *AIDS Care*, vol 20, no. 1, pp.80-92.
2. Godreck, B 2003, *The First Year – HIV: An Essential First Guide for the Newly Diagnosed*, Marlowe Company, New York.
3. Cameron, S, Edler, D, Machon, K & Plus, D (eds) 2006, *HIV/AIDS and Your Rights*, 6th edn, Australian Federation of AIDS Organisations, viewed 15 April 2008, <http://www.afao.org.au/library_docs/policy/HIV_Yr_rights07.pdf>.
4. Heterosexual HIV/AIDS Service 2004, *Changing Lives: A Resource for Heterosexual People Living with HIV/AIDS*, Central Sydney Area Health Service, NSW Health, New South Wales.

All the above resources are available at:

Darling House Community Library
AIDS Council of South Australia,
64 Fullarton Rd, Norwood.

Other Useful Sources of Information

Australian Federation of AIDS Organisation
www.afao.org.au

National Association of People Living with HIV/AIDS, Australia
www.napwa.org.au

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Disclaimer:

The views put forward in this publication are those solely of the authors and contributors. This publication is in no way intended to be an exact step-by-step guide to disclosure as everyone's situation is unique, and we encourage you to utilize the services and supports available.



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