



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

(Updated Edition)

positive disclosure



About *Positive Disclosure*

Positive Disclosure has been developed as a guide to help people 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.

Contents

You Have The Power	4
Everyone Is Different	5
The Ups And Downs	6
Why Disclose?	7
Choose Who You Tell Carefully	8
Know Your Rights	9
Be Prepared	10
Supports And Services	11
Support For The People You Tell	12
You Are Not Alone	14
Sharing Thoughts	15
Have You Considered?	16
Services Directory	17





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.

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 obligation²

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 about 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. However you must take all reasonable precautions to prevent transmission³ including practicing safe sex.

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 about your rights contact Positive Life SA or the HIV/AIDS Legal Centre (HALC). See **page 17** for contact details.

“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 stigma 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”

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 stigma 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 for the people you tell can come from you or others including family, friends or organisations.

You don't have to be their only support.

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 you⁴

"[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 ...

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

SERVICES FOR HIV POSITIVE PEOPLE IN S.A.

Positive Life SA (wide variety of services, programs, events, information and support— incl. peer support — for all affected by HIV)
16 Malwa Street,
Glandore, SA 5037
8293 3700 or 1300 854 887
www.hivsa.org.au

HIV Women's Program, Women's Health Statewide (information and support for women affected by HIV, incl. peer support)
64 Pennington Terrace,
North Adelaide, SA 5006
8239 9600 or 1800 182 098

MOSAIC Services, Relationships Australia (counselling and support for people affected by HIV and/or hepatitis)
192 Port Road,
Hindmarsh, SA 5007
8340 2022
www.relationships.org.au

PEACE Multicultural Services, Relationships Australia (HIV and hepatitis service for multicultural community members)
49a Ormond Street,
Hindmarsh, SA 5007
8245 8100
www.relationships.org.au

Cheltenham Place, Centacare Catholic Family Services (residential respite support for people affected by HIV)
8272 8799

Positive Directions, AIDS Council of SA (buddies for socially isolated positive people)
2 Eton Road,
Keswick, SA 5035
8334 1611 or 1800 888 559
www.acsa.org.au

HIV/AIDS Support Services, RDNS (specialist HIV nursing, advice and home-based services)
1300 364 264

Specialist HIV GP's (\$100 prescribers)
Four General Practices in Adelaide include specialist HIV GP's—contact Positive Life SA for details of these practices.

SERVICES FOR HIV POSITIVE PEOPLE AROUND AUSTRALIA

HALC—HIV/AIDS Legal Centre
(02) 9206 2060; 1800 063 060
www.halc.org.au

NAPWA: National Association of People Living With HIV/AIDS Australia
(02) 8568 0300; 1800 259 666
www.napwa.org.au
(check www.napwa.org.au/services for up to date details of services for HIV positive people in other states and territories)

Australian Capital Territory
Positive Living ACT
(02) 6257 4985
www.aidsaction.org.au/plwha

New South Wales
Positive Life NSW
(02) 9206 2177; 1800 245 677
www.positivelife.org.au

Northern Territory
People Living with HIV/AIDS NT
(08) 8941 1711

Queensland
Queensland Positive People
(07) 3013 5555; 1800 636 241 (within Qld)
www.qpp.net.au

Tasmania
TasCAHRD Positive Services
(03) 6234 1242; 1800 005 900
www.tascahrd.org.au/hivcare

Victoria
Living Positive Victoria
(03) 9863 8734
www.livingpositivevictoria.org.au

Western Australia
WA AIDS Council
(08) 9482 0000
www.waids.com.au
HIV/AIDS Peer Advisory Network
www.hapan.org



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. *South Australian Public Health Act 2011*
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.

You can find these resources or more information at:

AIDS Council of South Australia Library,
2 Eton Road, Keswick, SA 5035

Other Useful Sources of Information

Positive Life SA (PLSA)

www.hivsa.org.au

HIV/AIDS Legal Centre (HALC)

www.halc.org.au

National Association of People Living with HIV/AIDS (NAPWHA)

www.napwa.org.au

Australian Federation of AIDS Organisations (AFAO)

www.afao.org.au

Acknowledgments

Community members, service providers and the wider community have contributed greatly to the making of this publication.

The authors wish to thank (the organisations now named) Positive Life SA Inc., HIV Women's Program at Women's Health Statewide and Centacare Catholic Family Services for their contributions and support throughout the original development of this publication.

A special thank you to the community members who were so willing to share their experiences around disclosure, which were invaluable in producing this insightful and honest publication.

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 utilise the services and supports available.

Since the original publication of this resource in 2008, the HIV/AIDS Legal Centre has developed a booklet called *Disclosing Your HIV Status: A guide to some of the legal issues - South Australia*. This comprehensive guide provides more detailed information about the legalities of disclosure in many different situations, and can be used in conjunction with this publication.



Positive Disclosure was developed by Rebecca Ash and Alice Rebellato, as part of a 4th year University of South Australia Occupational Therapy community based project, in collaboration with PLWHA (SA) Inc. and key HIV service providers in South Australia.

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First Printed May 2008. Updated Edition by Positive Life SA (formerly PLWHA-SA) February 2014. SA Health has contributed funds toward this Program.