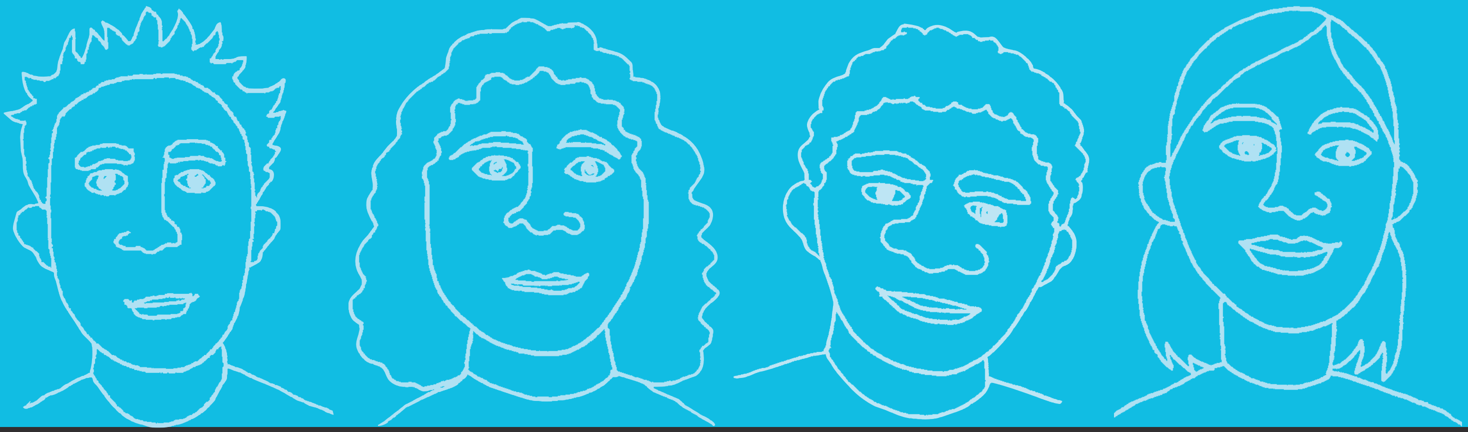
Changing Lives

A resource for heterosexual people living with HIV/AIDS



HIV+ HETEROSEXUALS

helping each other
helping ourselves

Changing Lives

A resource for heterosexual people living with HIV/AIDS

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Contents

Positive Men

Straight men don't catch HIV. Straight people living in the suburbs have a front door, a back door, a labrador and a commodore...not HIV. Matt

Home alone

HIV affects the largest sexually active group - straight men and women. You're not alone, there are other men like you living with the virus in Australia. So, no, it's not only gay men who get HIV! Some men are single, some are in a relationship with a woman, and some are married. Some positive men choose to remain outside of a close relationship. Many have said they have thrived and overcome obstacles that at first seemed overwhelming. However, whether you choose to live in a relationship or on your own it is important that you can meet and talk with other positive people and get support from services.

Are you worried that your love life is now a closed chapter? If you tell a woman you're HIV positive, will she walk away? Bigger still – is it okay to tell and feel that you've done the right thing? What do you say? Where do you look? How do you keep up the hope of finding a partner if you're single? Some men choose to hide their HIV from others, so you can decide what you want to do. It's your choice.

So what's the good news? There are positive men who have met someone to share their life with. Some have even become dads! There is a better future these days because there are new medical treatments to help positive people keep healthy. There are others who can help you make a new start.

Being HIV positive has not been all bad. You need to be positive about the best that you have. Carlos

At first I thought my life had ended, but now I've got a girlfriend and a job and I make the most of every day. Danny

I've recently been diagnosed and want to keep healthy. Kris

Being an HIV positive dad is not much different because I do the same things that any father would do around their children. Mike

Love and the single guy

I've lost track of how I feel about relationships. I don't think I'll ever be able to have another one. It would be a miracle for me to catch any bug...in other words I'm not scoring. Mohammed

You may not go out with women or have sex because you think it's too hard to say how you became infected. Positive men have said that their top three concerns about this are trust, working out what to say and finding the right moment.

Some positive men said 'I think about rejection and lose confidence; I don't know how to approach her for a relationship; I want her but I'm scared of the risk involved; I'm scared that she'll walk away and I'm losing courage; I won't tell her because it's not her business; I think that I'll only attract a curiosity seeker and she'll treat with me with pity'.

Saying how you got it

How do you increase your confidence to deal with awkward questions and situations when somebody is curious about how you got infected? You could suddenly face this question from a friend, a relative, someone you love, a work colleague, a health worker or even a member of the public. You can feel desperate as you use all your wits to protect yourself and the people you love from gossip.

When somebody wants to know how you got infected, always ask yourself:

Who is asking me for this information?
You may decide to give some people more information than others. What you would tell your doctor may be different from what you tell a sexual partner, a friend or a work colleague. You will need to remember the story you tell to each person. Have set answers ready for those difficult questions.

Why is this person asking this question?
Are they just being nosey? What do they really want to know?

What can I say that will be a good answer for them?
Remember, not everybody wants the full story about how you got infected. Develop a comfortable story, working out what you want to say about your diagnosis if the person isn't going to be your friend or you don't like them.

Enter soul mate - telling her

> *I would disclose after a point. I don't know where that point is most of the time though. And that's one of the things that I think makes it difficult. Ricky*

Disclosing your HIV status to someone can be very difficult, especially if it's a new sexual partner. Fear of rejection runs deep and it can make you say to yourself, 'Why risk talking about my status at all with this person? It's not as though she can tell I have HIV by looking at me. I'll just practise safe sex and hope for the best.'

On the other hand, telling her you are HIV positive means she can enter the relationship with full knowledge. This way you can discuss safe sex instead of making up excuses for wearing a condom or for not having sex.

However finding the nerve and choosing the right words isn't easy. Once you tell her that you are positive you can't take it back. Be brave and expect some anger, shock or criticism. Some people will go silent for a while but they rarely walk away. Remember, the person who risks nothing, gains nothing.

Deciding when and how you tell is your choice. Here are a few helpful hints.

- Think ahead how you will describe things. Make time and space to talk.
- Keep it simple. Make it something easy for you to remember. Speak confidently. Don't make a big deal of it. One example is 'I know there's something special about you and me. I think I owe it to you to be honest about myself so we'll always feel safe together. I know we can trust each other, so I'm telling you something really personal about myself. I'm HIV positive.'
- When telling your partner, make it clear that she has the right to know that you're HIV positive. Your honesty about this can help to build trust between you.

- Telling her can be a good way of explaining why you have to use a condom. It's one way of saying you care about her and that she can know there is little or no risk because you always use condoms.
- Practice makes perfect. An HIV/AIDS counsellor can help you work out what you want to say and the best time to tell your story. This has worked well for others, so it's worth trying.
- Don't be the only one she can talk to about it. You can link her up with someone you trust, somebody who already knows you well and can answer any questions she may have. She may want to know something she doesn't want to ask you or tell you about.
- Give her the contact for your nearest HIV/AIDS counsellor or clinic. They will be only too happy to make an appointment for her and give her some help. Counselling is private and confidential. Counsellors and social workers often see new partners on their own. They help answer many questions about living in a relationship with an HIV positive person.
- Join an HIV support group.

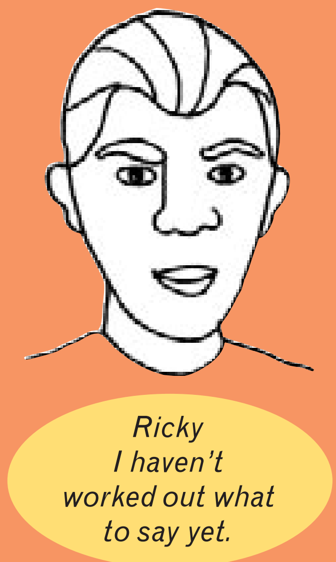
Even if you intend to practise safe sex, as an HIV positive person you are required by law (Public Health Act 1991 in NSW) to tell any person of your HIV positive status and other sexually transmissible infections (STIs), before having sex with them. When the other person has been informed of the risk, they can voluntarily agree to accept the risk. This reflects the legal situation in NSW. Other states' Public Health Act need to be consulted.

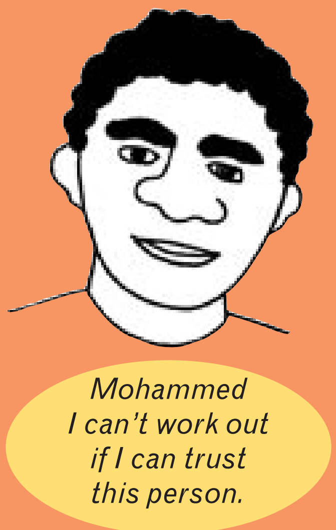
Dealing with rejection

Be prepared for rejection and don't take it personally. Remember it's okay for someone to say 'No' to you when you tell them you're HIV positive. We make judgments about people all the time. Just as you have the right to reject someone's friendship or sexual intimacy they have the right to say 'No' to you.

The lowdown on condoms

A condom is a very thin latex (rubber) sheath that fits over the penis to catch cum before, during, and after you ejaculate. Wearing a condom is the best way to help prevent you from passing on the virus to a negative partner. Using a condom also





protects you from becoming reinfected with other strains of HIV if you're having a sexual relationship with a partner who is also HIV positive.

Although nothing is 100% effective, condoms are very safe and reliable. They come in different sizes, colours and even flavours. Some are flared for a better fit while others have ribbing along the length for extra sensation. There are even condoms that are thinner than latex and are made from polyurethane. They are very strong and transfer body heat for even more stimulation. They are also good for those few people who are allergic to latex. Many HIV/AIDS clinics provide free condoms. Using a condom can also protect you and your partner from sexually transmitted infections.

Get it on!

Saying I want to use a condom

You should wear a condom to reduce the risk of transmitting infections. A new sex partner may ask 'why are you using a condom?' There are a number of possible replies.

- It makes me last longer. That's got to be good for you!
- Let's not risk it. You're too special.
- We'll be more relaxed. It's better for us.
- You can trust me without any worries.
- We can have good sex and stay healthy.
- I'm feeling hot and want to protect you - you can help me put it on.

What if the condom breaks?

Accidents can happen - a condom can break or come off during sex, or you may forget to use one. This doesn't mean your partner will automatically get infected with HIV, but there is a risk. Taking PEP (Post Exposure Prophylaxis), the same sort of medication used to treat HIV positive men and women, for only a short period may give your partner's immune system time to clear up any possible infection. Your partner will have to take PEP immediately after having unprotected sex - within a few hours is best, but it must be no longer than 72 hours. If you're worried that you've exposed your partner to the HIV virus during sex, ring the 24 hour PEP Hotline on 1800 737 669.

Support - the odds are in your favour

Okay, so you don't want HIV to take over your life. You want to stay connected to other people as much as possible and it's hard to travel this bumpy road alone. There are friendly support groups that give you the chance to meet new people. They know what you are going through. Other positive men and women will listen to you and tell you how they are finding new ways to come to terms with their HIV. You can make friends, relax and enjoy companionship and shared experiences. So take time out! Call Pozhet on 1800 812 404 for free, friendly, confidential support and a calendar of events that includes information sessions, country visits, social evenings and seaside retreats.

24 hour PEP Hotline
1800 737 669

Pozhet (freecall)
1800 812 404

Positive Women

> *I come first. There's so much that makes me who I am. I just happen to carry around this unwanted, unasked for virus. Saria*

All walks of life

Positive women are from all walks of life. They are mothers, daughters, sisters, grandmothers, wives and girlfriends of all ages, cultures and religions. Many positive women have children. Some live alone, others live in a relationship with a man or are married and some live with their family.

It takes time to deal with this thing called 'living with HIV'. HIV affects how we feel about ourselves both inside and out. As a woman living with HIV, you may be also caring for your children and family. On some days you may feel that there is no one to support you and that you have to deal with your secret alone.

In Australia, there are women who have been HIV positive for many years and are enjoying good health. They are leading full and happy lives, working, studying and enjoying friendships. Some are in relationships and may even have children. Some have chosen to remain single. With advances in treatments there is every reason for positive women to expect a long-term future. So it is important not to be completely overshadowed by HIV. There are many people who can help you. Here are some of the things other positive women have said.

> *Get on with your life and don't waste the time you have. Margaret*
>
> *Remember there is somebody out there waiting to love you for who you are. Lily*
>
> *HIV has to live with me, I'm not living with it. Julie*

Speaking up

It is important that you have someone to talk with about being HIV positive. Telling is not easy. However, keeping a secret like HIV can lead to stress, anxiety, depression and loneliness, which is bad for your health. Many women find that their partners, family and close friends are very supportive. Talking to other positive women can also be helpful. It can be hard deciding who and when you should tell. This is a decision only you can make. When working out who to tell ask yourself:

- Can I trust this person?
- What am I going to gain by telling them?
- Can they keep this secret?

Sex and the man of your dreams

> *When I found out I had HIV I thought I'd never have sex again. I've been through a lot and now I have a beautiful relationship. I wish I'd had more hope when I first got diagnosed. Hannah*

Can you still have sex? Absolutely! Anyone with HIV can have sex. Being positive may make you think that sex is too hard, especially if you are single. You'll be worried about transmitting the virus, you may find it too scary to tell a new partner that you're positive. Your sexual desire may change over time depending on your health or stress levels. HIV can also affect how you feel about yourself. You may worry about how your body looks. At times you may feel vulnerable and lack confidence. Learning to accept yourself as who you really are takes time and talking to other positive women can help.

So your biggest job may be regaining your confidence and convincing that special man and yourself that you can be around when he goes bald and grey. Go out and have fun! There are positive women who are enjoying sex and having happy, healthy relationships.

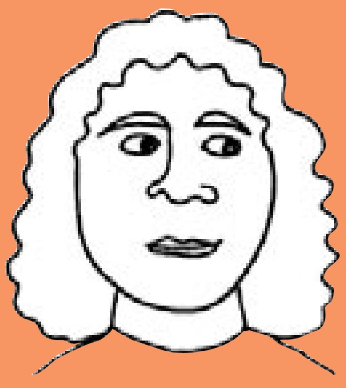
Telling him you're positive

Most positive women find that it's hard to know what to say when they meet someone that they want to have sex with. Some women try to make it as casual as possible - especially if all they want is to have sex. They think that telling him straight away will scare him off and stop the chance of anything developing. Some like to wait for a while.

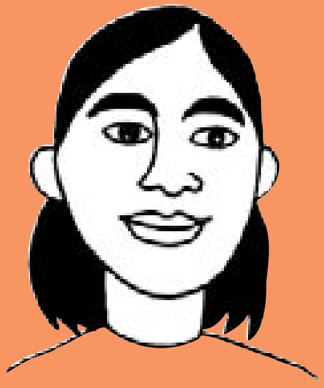
> *I tell a guy upfront. Boom! If he can deal with that he can deal with me. Ruby*
>
> *I often tell a partner that they will be safer with me than with anyone else. Jenny*

The top three concerns about telling mentioned by positive women are not being sure if the person can be trusted, being nervous about his asking how you caught it and his prejudices about HIV/AIDS.

So when is the right time to tell? It is hard to know how he'll react. If he's the wrong type of man for you he'll simply make a quick exit. If he likes you he'll stay, but he'll still be confused and flipped out for a while. So there's never going to be a best time to tell. Each time is going to be different.



Elizabeth
I can't work out if he can be trusted.



Iza
I'm scared that he'll show me a lot of prejudices.

Hannah
He'll want to know how I caught it.

> *It's just as important for me to say what I like sexually as it is to let him know I'm HIV positive. Saria*
>
> *I met someone I really fancy. I plucked up the courage to tell him I was HIV positive. He was cool about it and said it didn't matter. Julie*
>
> *I was a little shy at first but since we've started talking it's brought us much closer together. We're more intimate and our sex life is better. Lily*
>
> *I decided if I were HIV negative, I would still want this guy. Jenny*

Having sex with him may not be easy sometimes. He will need to know that you will not infect him as long as you use condoms. It's also more difficult for a female to infect a male since HIV is less strong in vaginal fluids than in semen and blood.

Even if you intend to practise safe sex, as an HIV positive person you are required by law (Public Health Act 1991 in NSW) to tell any person of your HIV positive status and other sexually transmissible infections (STIs), before having sex with them. When the other person has been informed of the risk, they can voluntarily agree to accept the risk. This reflects the legal situation in NSW. Other states' Public Health Act needs to be consulted.

Dealing with rejection

> *If I don't tell, I worry and feel guilty even if we have safe sex it ends up not being worth it. I'd rather not have sex. Kim*

Sometimes our fear that we will be rejected is greater than our fear of being alone. You don't have to be HIV positive to be rejected or have a bad relationship. Be prepared for rejection. Don't take it personally. Remember that it's okay for people to say 'No' to you, just as you have the right to say 'No' to them.

Make your first move - with a condom!

Are you worried about keeping sex safe? Australia's biggest condom manufacturer says that nearly as many women as men buy and carry condoms. This means that it won't be unusual for you to ask him to put one on. If he asks you why he has to wear a condom you could say:

- It only takes having sex once to get pregnant.
- You'll last longer wearing this.
- If you love me you'll want to protect me.
- I don't want to risk my future simply to prove that I love you.
- I like to have sex and I want us both to stay healthy.

Maybe baby? Pregnancy and children

> *Being HIV positive does not automatically mean that your baby will also have HIV. If you are a positive woman thinking about pregnancy, talk to other positive mums first...your kids often come first and you come second. Kim*

Many women, when they are first told they have HIV, think that this means they will not be able to have children in the future. Around half of the women who are HIV positive in Australia are also mothers. Some of these women had children before they found out they were HIV positive, and some have started a family after learning that they were HIV positive.

With new treatments and better knowledge of the way that HIV works, it is now possible to start a family or have more children. There are a number of choices available for positive women and the partners of positive men.

If you are considering pregnancy, some good resources to start with are the FPA Health/ACON Women and HIV Fact Sheets and the Positive Pregnancy booklet published by the Sydney Children's Hospital. You will need to find a doctor who will support your decision to have a baby and it is useful to talk to other positive women about their experiences.

Stress less – get support

> *The women at my local support group are great. I can relax, be myself and listen to other positive women's wisdom and experience. Margaret*
>
> *I have a few close friends who know. It makes all the difference. Saria*
>
> *My mother and sister help me a lot. Iza*

Many women say their greatest loss since becoming positive is their social life. They want to meet other positive women and positive men and be supported by others like themselves. Joining a support group and being social can make it easier for you to learn things. Other positive people know what you are talking about and going through. You'll make friends, relax and enjoy shared experiences. Support groups also respect your need for confidentiality. They're private and safe. So take time out!

Call Pozhet on 1800 812 404 for free, friendly confidential support and an annual calendar of activities.

Couples

To love somebody

You can never guess who you're going to fall in love with. Many HIV negative men and women have relationships with HIV positive people. The medical term is serodiscordance - that's where one partner is HIV positive and the other is HIV negative. The term is a bit wordy so positive heterosexuals have coined their own word – 'pozneg'. In this pozneg world you may be a husband, wife, long-term partner, boyfriend, girlfriend or casual sex partner.

There are few straight pozneg couples that are public role models for others. Although they deal with the same problems that affect most 'normal' couples, there are issues around HIV that can have a huge impact on their health and daily life. It is often said that HIV is like having a third person in the relationship. There are many feelings and issues that will be faced by each partner individually and together. Here are some things that pozneg couples say they go through that may help you find your way.

We're a positive and negative couple - our relationship needs to be nurtured, because that is all we've got.
Hannah

Is telling make-or-break time?

> *Until you can come out as a heterosexual couple with HIV, you are all things to each other, and that is way too much for any relationship to deal with.*
> *Margaret*
>
> *Telling can be a big issue if one partner wants to tell and the other does not.*
> *Mike*

Some positive partners are afraid that their negative partner will tell other people, even a close friend, that they are HIV positive. This can become a difficult issue especially when the positive partner is ill. The negative partner may also be concerned about revealing their positive partner's HIV status, but sometimes they tell because they can no longer cope with the isolation and silence that comes from being unable to talk openly to anyone.

It's always useful, if you're a pozneg couple, to agree on who can be told and to think way ahead about all of this. Some of the questions you need to answer are:

Why do we want to tell them?

Why do we feel they want to know?

Will they think it's important enough to keep it to themselves?

What are the advantages and disadvantages for each of us?

Are either of us likely to regret that we have told?

Mentalk, womentalk - all about sex

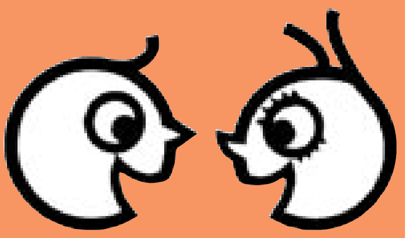
> *The fear of passing on the virus stifled me when we had sex. Liz*
>
> *How will I live with myself if I infect my partner? How can I put it out of my mind? John*
>
> *I don't want to pitch the poison dart, so we don't have much sex. Paul*

Having sex and keeping sex alive are major issues for most pozneg couples.

Some positive partners struggle with fear and guilt around having regular sex with their negative partners. They may fear infecting their partner or may have no sexual desire at all due to periods of illness.

Negative partners may have mixed thoughts about having sex with their positive partner. They may feel rejected if their partner is not keen on having sex, and keep them at a distance. They may also be afraid of catching the virus. This is all part of living with HIV.

Here are questions often asked by pozneg couples:



Positive partner

Can we stay safe by using condoms?

Can we have any real sexual intimacy?

How will I live with myself if I infect my partner?

How do I know if my partner is getting tested regularly?

Would I rather my partner didn't get tested so that I can put it out of my mind?

Negative partner

How do I cope if my partner pressures me to have unsafe sex?

I might want unsafe sex too, but I'm scared of getting infected.

Is withdrawal safe?

If my partner has an undetectable viral load, do we still have to practise safe sex?

How can I ever relax when we're having sex?

How will I and everyone else cope if I get infected?

Should I think about leaving, or about not having sex any more?

Should I get tested more often?

It is important for both of you to know how you can get infected with HIV. Then you can decide together what sexual activities feel safe for you. This is about avoiding things that are too risky, and enjoying and exploring things which are safe, so that you can both relax and feel good about sex. Please read *Sex Matters A-Z, sexual health for heterosexual couples living with HIV/AIDS* to find out what kind of sex is safe.

Some pozneg couples find that talking with an HIV/AIDS counsellor, attending support groups and talking to others can help them learn better ways to have a healthy, active sex life.

What to do if the condom breaks?

Accidents can happen: a condom may break or come off during sex, or you could forget to use one. This doesn't mean a negative partner will automatically get infected with HIV, but there is a risk. Taking PEP (Post Exposure Prophylaxis) the same sort of medication used to treat HIV positive men and women, for only a short period may give a negative partner's immune system time to clear up any possible infection. You have to take PEP immediately after having unprotected sex - within a few hours is best, but it must be no longer than 72 hours. If you're worried that you've been exposed to the HIV virus during sex, ring the 24 hour PEP Hotline on 1800 737 669.

Do we have to cover up and bunker down?

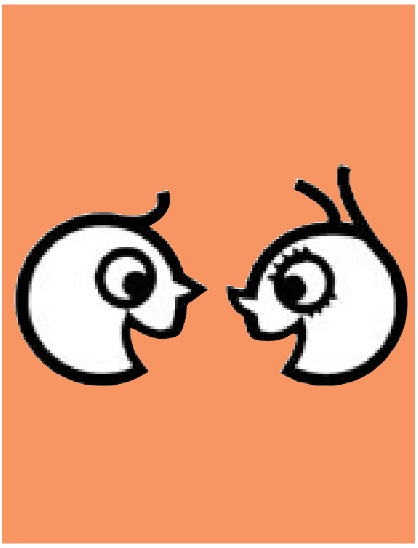
> *Stepping over the line is necessary if you want to start a pozneg relationship.*
> *Carlos*

It may be difficult for you as a couple to conceal that one of you needs regular medical appointments, takes medication or has poor health. It may be better to let close family members and friends know that there is HIV in your life together rather than dealing with the ongoing difficulties of keeping this from them.

But what if they know little or nothing about HIV and are struggling with their own anxieties? They might believe that someone they care about and are close to could die soon. They might worry about whether there is a risk of infection to them. If you're the negative partner they may even feel upset that you have chosen to have a close relationship with somebody who is HIV positive.

Make sure that you think carefully about when and how they learn from you that you are a couple living with HIV and that they get accurate information. This way there is every chance you won't have to keep them at a distance and miss out on an important source of support.

Ask your partner the following questions and then try to come to an agreement on the answers.



Positive partner

How do we enjoy life as a 'normal' couple?

Do we keep it secret or do we tell?

If we tell, will others see us as 'different'?

If we don't tell anyone, will we both end up feeling isolated because we are keeping this big secret?

Negative partner

Should I tell my friends or family that my partner is positive?

Will it be difficult for them to discuss this with me?

Will they know how to treat my positive partner?

Pozneg couples find peace of mind by protecting their HIV status in both their private and social life. In the heterosexual world, telling somebody outside of the home that one of you is HIV positive can be extremely difficult and very confronting.

In sickness and in health

It's only natural for you as a couple to feel anxious about the future. The positive partner may think 'How can I ask my partner to look after me if I am sick, when they've been so good to me? Who will look after me if they leave me?'

The negative partner often thinks 'How will I cope if they get sick? Who will look after and support me when so few people know about our situation? How will I bear being alone if they die?'

Each partner needs time to adjust to living with the virus. It takes practice to talk to each other openly about your feelings, especially about the future. Remember keeping silent is stressful. Talk over your anxieties with each other with love and caring. This will strengthen your relationship.

Getting support

> *My partner is the most isolated. Lets face it, as a positive man I have all the medical services at my feet, I've got somewhere to go. But my partner has very few places to go, if any. Mike*

It's hard to know how people will react if you tell them that you're in a pozneg relationship. But it is important that you reach out and develop a good support network so that you can go and talk to someone about living with HIV, whether they are a family member, a friend, or a health worker. Having someone to talk to outside your relationship will take the pressure off both you and your partner, and will relieve some of the stress of keeping silent.

HIV/AIDS counsellors, social workers and other support workers can all help you to live better with HIV. Both positive and negative partners are welcome to use these services together, or separately.

Finally, there are couples enjoying successful long-term relationships. There's no good reason why an HIV positive person and an HIV negative person can't be in love, support each other and decide to make a go of it!

If you are a couple who are both HIV positive you can get advice from an HIV doctor or a counsellor on managing your sexual health and other treatments issues.

To meet other pozneg couples call Pozhet on Freecall (Aust) 1800 812 404.

Partners

Missing person

As a negative partner of someone with HIV, you'll be sharing the burden of living with the virus. Your HIV positive partner has the immediate health problem, but you are most at risk of stress, being stigmatised and loneliness. You may also be worried about becoming infected. Often you will feel invisible both within and outside your relationship.

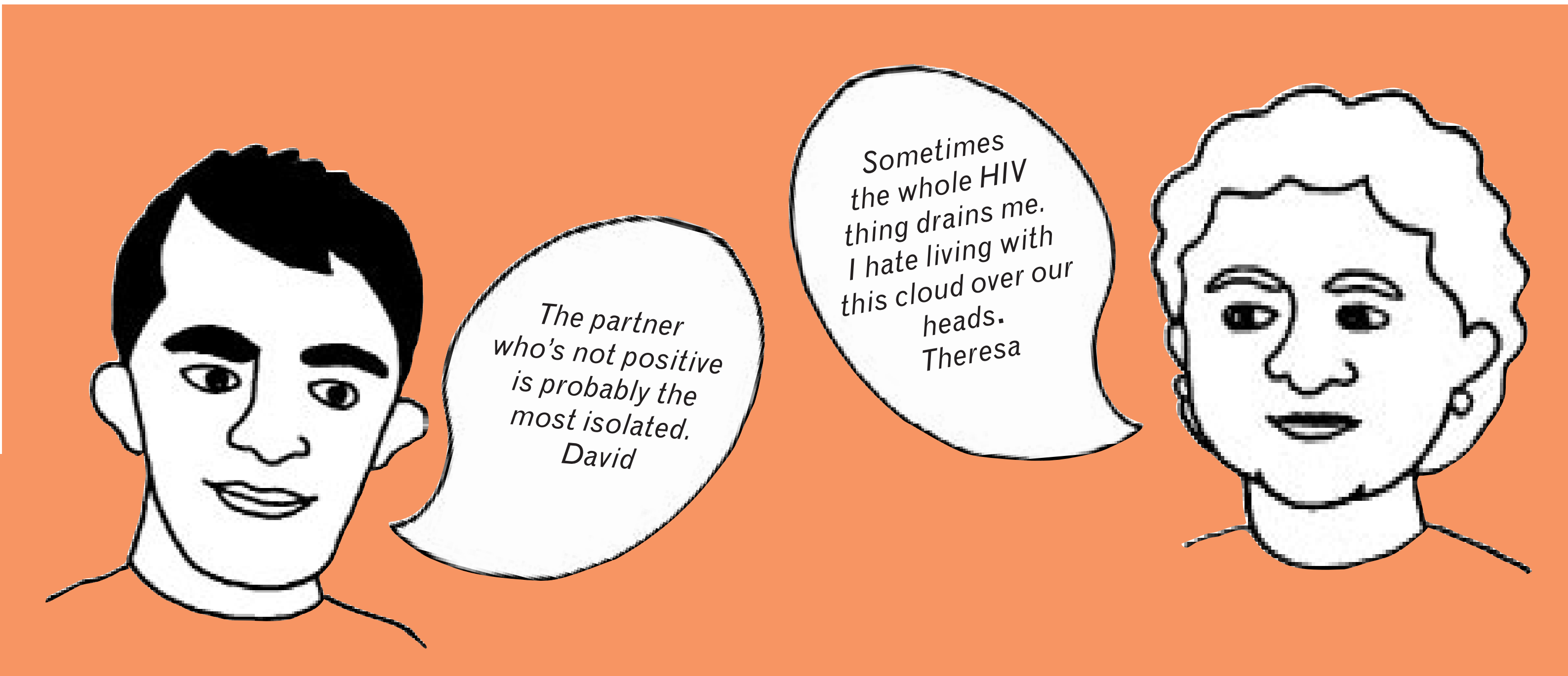
Finding out your partner is positive may open up a whole range of confused feelings in you including shock and anger. Some partners say that coping with HIV on a daily basis is like being in a strange landscape with no signposts, full of suppressed sorrow and ongoing loss.

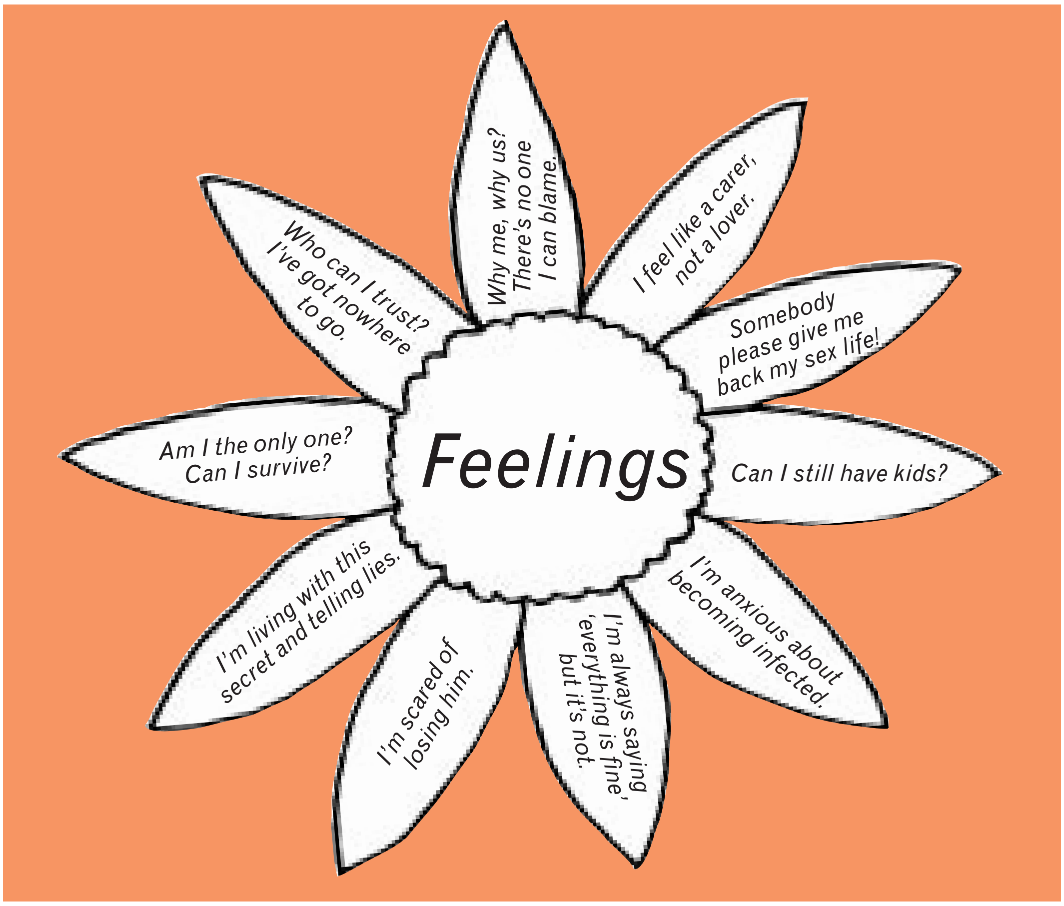
> *I'm angry with my positive partner for being so reckless with his life, and how that affects me and the kids. Jennifer*

As a partner you are likely to have very few, if any, people like yourself to relate to, and you may feel under pressure not to tell. To the outside world, it can look like everything is normal, but you may feel emotionally isolated. Sometimes people who know your partner is positive may think you are positive as well. Your relationship with your immediate family can also change and it could take you some time to work out how you feel and come to terms with your own fears and concerns about having HIV in your life.

There are a wide range of HIV/AIDS services available to you as a negative partner. It's important that you contact these services and let them know if you need help. They will go out of their way to make you feel welcome and give you the support and advice you need. Your needs as a negative person are as important as those of your positive partner.

So what's the good news? It is important to know that there are many negative partners who have worked through these things and have found happiness. They are still sharing their lives and futures with a positive person after many years.





It's understandable if you feel angry about your positive partner's status. Sometimes unrecognised anger and the stress of coping with the virus may press a button inside you when you least expect it. Some negative partners say that they've had to come to terms with whatever caused their partner to get infected in the first place.

Telling others

> *I tell all these brightly coloured lies all the time. Rebecca*
>
> *My friends are divided into two camps. Those who know I live with HIV and make me feel less isolated, and those who are told 'everything's fine!' Jennifer*
>
> *There are tourists who are simply curious, those who truly care, and others who don't want to know. I've made mistakes and told people I shouldn't have. Maria*

Talking about HIV with others can be difficult. There aren't many people outside your relationship as a couple you'll be sharing this with. Even at work your friends are unlikely to sit down together and chat about HIV over a cup of coffee. Some people say that living with HIV is very silencing. They describe themselves as not feeling 'real' when relating to other people. One of the biggest things they are dealing with in their lives is rarely discussed or remains a well-kept secret. So it's important that you are able to talk about HIV with your partner and share the many things you are dealing with.

Many couples make rules to protect themselves from gossip and prying when they talk to other people outside the family. One rule might be that you both don't tell anyone before discussing this together. It's a good idea to work with your partner and decide who can be told and what is said. Some partners may even choose to have friends who will never know about their HIV because they'd rather keep that part of their lives private.

If you tell your family about HIV they may not know at first how to deal with it or how to treat your partner. They may wish you were with someone else who was not HIV positive and can show this in subtle ways. They may also worry about your health, your finances (if your partner gets sick) and your future. It may be difficult for them to discuss all this with you. They may even feel cut off and burdened by their anxieties. Your family can get help from HIV/AIDS counsellors to discuss their concerns.

Enjoying your 'negativity'

I feel like I'm living in a tent and nobody sees me. Jennifer

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

As a negative partner you may forget your own physical, sexual and emotional needs. You may find yourself concentrating on your positive partner's health and their needs, at the expense of your own. Some partners say that they feel like they have 'disappeared' inside the relationship because of this.

Take time out and do things that are just for you. Celebrate your negativity and recognise that it is an important part of your life and your relationship. Talk over your experiences as a negative partner with others in the same situation. Contact an HIV/AIDS counsellor for help on ways to take care of your negative status.

Testing

A doctor said to me 'your negativity is a very important thing, you must protect it!' We have safe sex; I get tested once a year. Maria

The protection comes from keeping safe. David

How can I ever relax when we're having sex? How will everyone cope if I do get infected? Should I think about not having sex? Should I get tested more often? Theresa

How do I cope with the pressure from my partner to have unsafe sex? I might want it too, but I'm scared of getting infected. Rebecca

It's stressful to get a test. I do it when I want to know! Jennifer

As a negative partner, you'll need to find a clinic or a doctor you feel comfortable with if you choose to have regular HIV tests. To feel OK about testing it's also useful to understand how HIV is transmitted. Having a confidential chat with an HIV/AIDS counsellor can be a good way to get the information you need.

It's also important that you decide what kind of support you need before and after getting HIV tests and arrange this each time you go for a test. You will also need to work out with your partner what role they will play and how you can share this together.

Testing can cause anxiety, for both you and your partner, and is a reminder that you are living with HIV/AIDS. Make sure that you have the right support and advice to help you deal with this.

What about me?

> *Being a negative partner takes up so much time there's no time for me. If there is, then I feel guilty and I don't do anything anyway. Maria*

It's normal to get stressed if you are living with someone who is sick or who may get sick in the future. At times it may be hard to find words that express your feelings. You may ask yourself 'who is looking after me?'

If you are feeling stressed, here are some tips that may help.

- Take 30 minutes out each day to do something that is totally about you and nobody else, eg take a bubble bath, listen to your favourite music, read a magazine.
- Go out with a friend
- Join an HIV/AIDS support group and talk to others - it's likely that they feel the same way that you do and may offer some practical ideas.
- Get outdoors and go for a walk. Fresh air and exercise are great for clearing your mind and relieving stress.
- Talk about your HIV experience as a negative partner with an HIV/AIDS counsellor.

Ask yourself what kind of help you can give your positive partner that doesn't add to your stress. You don't have to take care of everything to do with HIV yourself. Remember, there is a wide range of services to help both you and your partner. They include home help, financial assistance, counsellors, social workers and support groups where you can meet other people in a similar situation. So reach out for help... it's out there!

Getting support

> *I'm hoping to make friends with other negative partners. It would be nice to talk to someone who understands. Jennifer*
>
> *You don't spend your whole time keeping up your double life. Rebecca*

Other negative partners living with HIV can be a great source of help, comfort and inspiration. It can be good to hear how other partners live with this virus. Joining a support group with other men and women partners helps you learn useful things, make friends and relax with others who respect your need for confidentiality. An HIV support group is private and safe. Give it a try!

Call Pozhet on 1800 812 404 for free, friendly, confidential support and a calendar of events that includes information sessions, country visits, social evenings and seaside retreats.

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. It is also a legal requirement under the NSW Public Health Act 1991 to tell sexual partners your HIV status even if you intend to practise safe sex.

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:

1. 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.

Choosing good reasons to tell

There are 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.

There are also 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.

Not telling - your cover 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 comfortable with a cover 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

Even if you intend to practise safe sex, don't forget the legal requirement to tell your sexual partner you are HIV positive. (See page 4 of the NSW Public Health Act 1991)

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.

Most trustworthy **The people I trust the most are:**	
Least trustworthy **The people I trust the least are:**	

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!

I've plucked up the will to tell my brother and sister I'm positive because I just wanted somebody who is family to know. Each time I got the same answer back - 'What can I do to help?' and 'Are you okay?' Carlos

My husband supported me telling a best friend at work, so I didn't feel lonely keeping the big secret. When I told her, she hugged me and asked if there was anything she could do. I said - 'yes, just stay my friend'. Olga

Family Matters

The great indoors – the family living with HIV

> *HIV has brought us closer together. The most important part of the day is around the kitchen table for dinner. We make important family decisions with our children. Maria*

Family members are all affected by HIV in addition to the concerns of normal family life. They may experience anxiety, sadness, anger, financial worries and the stress of having to deal with the medical system. In some families there could even be several members who are infected with HIV. They will worry that some day the HIV positive person will get ill and die.

HIV can cause stress and affect the way that families get on with each other. You will have to decide who, if anyone, you will tell about HIV, both within and outside your family. Family routines, like meal times, may need to be changed to fit in with taking pills and preparing different foods. At times, your family will have to cope with testing, illness and medical visits. You may be concerned about other family members becoming infected with HIV because it is in the home.

Every family is different and will need space and time to develop ways of coping with HIV. The family can also be a great source of love and support. Supporting each other by talking about HIV may make you feel closer and increase your sense of wellbeing. For those with HIV, having the support of your family can be vital in coping with infections and remaining healthy. Today it is possible for your family to manage HIV successfully with the help of a variety of services.

What family members have told us about having HIV at home

Parents: Why me? Why my child? I feel lost. I don't know anything about HIV, I've got lots of questions. I'm worried about others finding out. How did they catch it? Where's the cure?

Sisters and brothers: I'm anxious and concerned for all the family. I'm angry with them for being positive. It's hard to keep this secret. I've got lots of questions.

The HIV negative partner: Keeping this secret is a great burden. Do I want to really continue with all of this? What can I do to help my positive partner? I have mixed feelings. Do I have the strength and commitment to survive all this for my positive partner, my children and myself?

The child: I'm scared of losing my mum or dad. I want to be open and honest. I'm scared of getting HIV and being sick. I'm confused about how my mum or dad is being looked after. They don't say much and I feel shut out. I've been told to use my own toothbrush, but I don't know why. I might have to look after them if they get sick. I feel lonely. How do I cope not telling? Who can I talk to?

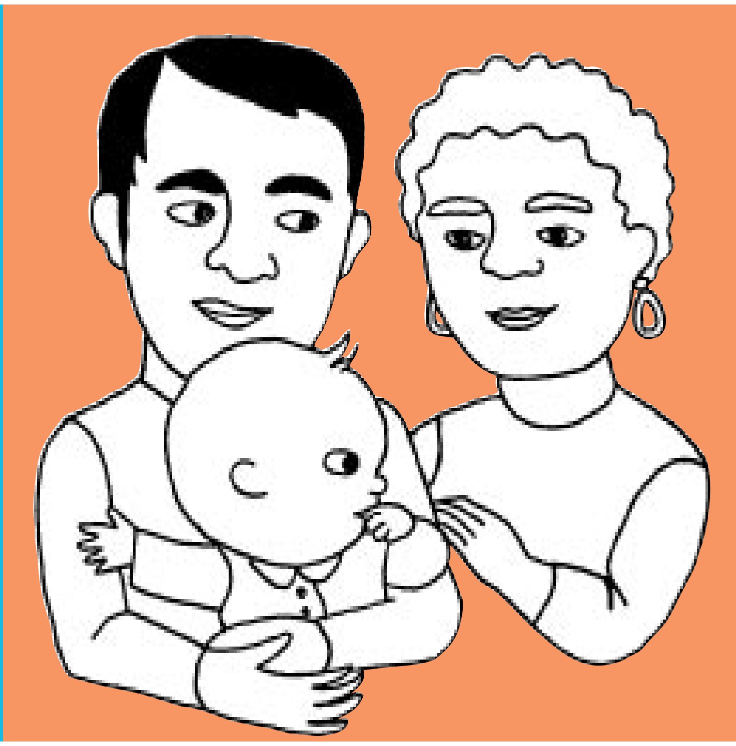
The HIV positive mum & dad: Positive mums and dads have to work extra hard compared with other parents coping with family life. They have to work, look after their family, manage their own health, finances and housework, visit doctors, keep appointments, take medication - all of this even if they're feeling ill. There are many issues that are likely to cause anxiety for a positive mum or dad. They could include:

> I'm trying to come to terms with this. Is this really what has happened? I have to focus on getting on with life. I'll be angry if I get ill. I'm relieved that my family seems to be coping. I'm scared of infecting my partner during sex. I don't want the family to tell anyone I'm positive. I'm living two different lives - one at home and the other at work. I need to tell white lies and it's really important that I get good at it. I'm scared about being rejected by other family members. Should I tell my kids? What if they reject me? I need to tell my parents, but I know they'll only be worried and anxious.

HIV and feeling depressed puts an enormous strain on my family.
John

I just try to do my best. I'm not good at this father thing - actually, yes I am, but it takes a lot of hard work.
Mike

HIV becomes the cause of all problems in the family and gets blamed for everything.
Lily



Telling and the HIV family

I don't want to tell others because of my children. I don't want them to be bullied or ostracised. Theresa

I'm lonely and worried feeling other people will find out and judge my family and me. John

People will wonder how I caught it. Kris

Families are likely to face the stigma that goes with HIV. They may feel ashamed that somebody in their family is infected. They are often anxious about telling others because they may be stigmatised and may not get any support if they 'go public'.

For a family, keeping a secret can be painful, lonely and stressful. Sometimes the family may need to tell a close friend, a relative, an employer, work mates, doctors or health workers. It's important to agree on who, outside the family, will be told.

Once you have worked out who's going to be told and who is not, you will need to agree about this as a family, and stick to it. This will help to avoid any bad feelings in the home.

If your child is HIV positive there's no legal requirement that you must tell their childcare centre or school. Some parents choose to tell the school principal especially if their child is taking medication during school time. It may also be useful to arrange some time for your child to meet other HIV positive children. This can be arranged through your counsellor or social worker.

Talking about HIV with your child

> *It scares me thinking about what will happen to my kids without me. Lily*

It's difficult for any positive mum or positive dad to tell their child that they have a life threatening illness. You will need to decide when the time is right for you and your family to do this. Some people tell when they are first diagnosed and others wait until their children are much older. Others choose not to tell their children at all. If you want to tell your child you can get help from an HIV/AIDS counsellor or social worker to work out what you're going to say.

Before telling your child, you will need to think about what support they will get after being told. Help could come from a close relative, other children of HIV positive parents, or your own support worker. If you decide to tell your child about HIV, here are a few tips that may be helpful:

- Talk truthfully about HIV rather than making up stories.
- Talk simply to your child by using words they understand.
- Don't tell every little thing about HIV in one big hit.
- Do the telling while you are up to it and feeling okay.
- Choose a time when the rest of the family is around so your child can talk to them as well.
- Check that your child understands that it's not okay to tell others outside the home.
- Before telling your child, remember that it is very hard for most children to keep a 'secret' and not tell others.

Can I get infected?

A family member can get anxious if they think that by sharing a house with a positive person there is some risk they can get infected as well. Here's a quick list about sharing stuff with a positive family member:

Sharing stuff in the home	Is it okay?
Cigarettes	Yes
Clothing	Yes
Crockery and cutlery	Yes
Kissing- saliva	Yes
Mosquito bites	Yes
Sheets and pillows	Yes
Shower and bath	Yes
Tears and crying	Yes
Toilets	Yes
Touching, cuddling, hugging	Yes
Towels	Yes
Toothbrush or razors	No Best to use your own

For peace of mind and good hygiene always wash your hands after using the toilet or when preparing food, wear disposable gloves when cleaning up blood and other spilt body fluids, and wash any items with blood on them separately.

Practical things

Tips for coping at home

> *I look after my family. I've succeeded in finding a full time job so I can build my son's future, which gives me all the ammunition to keep going and being optimistic about the future. Mike*

Talking about HIV within your family isn't always going to be easy. You may worry about losing the support of your family and even your children at times and becoming depressed and isolated. There are practical things you can do to make this easier.

The positive family member

- Do family activities together.
- Learn more about your illness.
- Educate your family members about your illness.
- Always try to say things that you feel in a honest way.
- Get counselling to help you along.
- Agree with your family on who can be told about your HIV.
- Don't close doors on your friends and relatives and isolate yourself.
- Join a support group where your partner and family are welcome.

The negative family members

- Talk together as a family about HIV.
- Ask yourself how can I help?
- Don't neglect to look after yourself if you're a negative partner.
- Get some counselling for yourself.
- See where you fit in with your positive family member and don't try and take over the show.
- Don't let the virus take over your life as a family.
- Expect the family to go through good times as well as some bad times with HIV.
- Get in touch with HIV/AIDS services that will help you and your family.
- Attend a support group for partners and family members.

Home alone - getting support

> *I find that I do not want to leave the house. Carlos*
>
> *I worry about losing my job and the house. John*

Life with HIV is getting a lot better for many families since HIV treatments were made available some years ago. HIV for any positive person generally means having good health with periods of infection or illness. As a result your family will have to make changes from time to time to cope with all of this. HIV can throw your family's life into a tailspin at times and it can be hard to plan for the future.

It's natural if you are a parent to worry about your children and their future if anything should happen to you or your partner. Being a good mum and dad means this sort of thing does crop up.

There's help you can get if you're a family member living with an HIV positive person. Help can be both practical and emotional, and includes financial counselling, paying some bills and assistance with benefits and allowances, housing advice, homecare, family support, counselling and peer support. So there's plenty of help available and you needn't live behind closed doors! Call Pozhet on Freecall (Aust) 1800 812 404.

HIV Illness

Will this illness ever end?

HIV is hidden…not like a broken leg. How do you show you're not well? Matt

I'm confused about the future…I try to keep a positive attitude. I feel very well at times, but I'm scared. Danny

There are new treatments that you can take for HIV that are helping many positive men and women in Australia to live longer, active lives. Being positive does not mean you are facing a death sentence, even though at present there is no cure. At the moment you may feel healthy, however you could develop some sort of health problem in the future if your immune system gets too low. You may develop an AIDS-related illness that will have to be treated with medicine either at home or in the hospital.

It's natural to be anxious about getting ill. You may have lots of questions like:

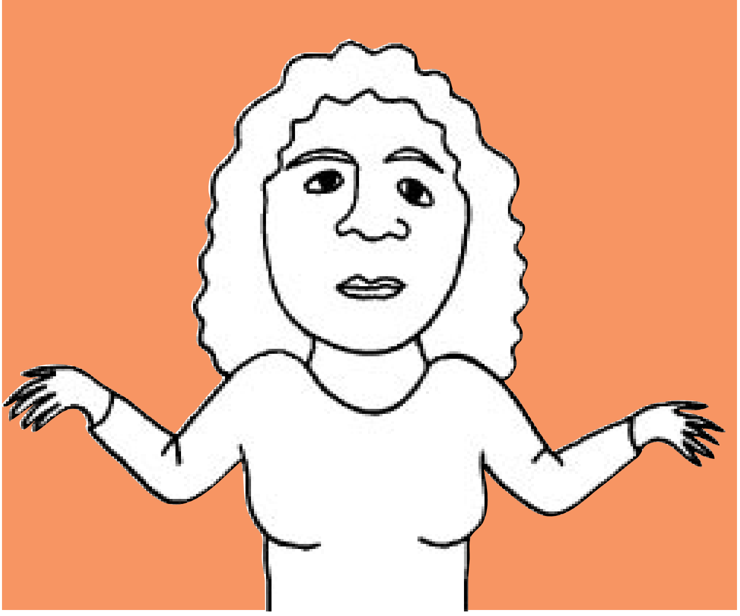
- What happens to me if I get AIDS?
- How long will I live?
- Will it kill me?
- What does it feel like to have AIDS?
- Is there a lot of pain?
- What will my body look like?
- Will I be sent to a hospital?
- What services will help me?

What happens to my body?

Don't let people scare you into thinking that this is the worst thing that can happen to you. You continue to live your life and HIV is just part of it. Saria

I had everything organised to die. Now I've got to work out how to live! Mohammed

Being infected with the virus doesn't mean that you look or feel sick all the time. For the first few years after finding out they're positive most people have big fears about becoming ill. You may be afraid of what will happen to your body. Will you stand out and get noticed by others because you're too thin or feel ugly? Will there be a lot of pain? Who will be told about you? Will you be shunned and separated from others in a hospital? Will your privacy be blown away?



Some people have many years of feeling well without any symptoms. Others have a series of infections and illnesses from the time that they are infected with HIV. If your immune system becomes severely damaged by HIV, you may go on to develop an AIDS defining illness. Many of these illnesses can be prevented or treated. Even after you have AIDS, you may have long periods of feeling well and not being sick at all.

Many positive men and women in Australia have had anxieties about illness at some stage or other and have lived with HIV for well over 20 years. They take new pills, which are called ‘treatments’, to fight the virus, and know others like themselves who now get sick less often. Many people accept that the pills they take won’t kill the virus or be a total cure, but they’re happier having the sense of a better future.

So there’s hope! Many choose to say ‘this virus won’t get me! or there’s nothing I can do about it, so I’ll make the best of my life.’ Life goes on and nothing is going to keep them from taking care of their health.

What does illness feel like?

Illness can be horrible and can make you feel helpless, angry and scared that you have caught HIV all over again. There are many different things that can make you feel sick when your immune system gets too low. Sometimes you may feel unwell from taking HIV pills, but that’s not always the case. Most people taking treatments manage to keep well for most of the time. There are many different symptoms of feeling ill with HIV/AIDS. Each positive person may experience a different type of illness from the next person. Some people will feel constant fatigue and chronic tiredness, others may have anything from mild to moderate diarrhoea, weight loss, taste changes, nausea etc. All these problems are treatable and can be monitored and managed by you on a daily basis with help from your doctor.

Who gets told?

Your HIV is a private matter between you and your doctor and anyone else you choose to tell. You don’t need to tell anyone else, including other doctors or employers. Doctors, nurses and health care providers all know not to tell anyone that you are positive without getting your permission first. However there is a requirement for coded information, that does not identify you by name and address, to be sent to NSW Health from time to time for statistical purposes.

What happens in hospital?

> *I was going to die. Now it's all pointing the other way. I'm going to survive.*
> *That's the big issue now. Kim*

At some time you may be admitted to hospital and have to stay overnight or a bit longer. This may be for treatment to help your immune system recover or because you're feeling sick. Most hospital stays are not for long periods of time.

If you have to go to hospital, it is a good idea to know some things about your own HIV. You will probably need to give information on the following things.

- When you were diagnosed with HIV.
- The history of any HIV related illnesses you may have had.
- Current treatments that you are taking.
- Any new symptoms you may have.
- Any allergies or complications.
- Your doctor's name and contact details.
- Contact details for your main carer, and dependents, if any.
- Who you want to make decisions for you if you can't make them yourself.

Specialist staff in hospitals are expert in HIV/AIDS and will make every effort to help you recover. They have many skills for looking after positive men and women and will treat you kindly and respectfully. You may also be admitted to a ward with other positive patients, which can be comfortable and at times, fun.

Staff will keep your HIV status confidential and will not give any of your visitors information about what's happening to you without your knowing first. You can help by letting staff know what they can tell your family and friends and who they should not give any information to. This type of request is usually recorded in your medical notes.

When you are admitted to a hospital you will see an HIV/AIDS specialist. Other staff you will meet on the ward will be nurses, social workers, dieticians, occupational therapists and physiotherapists who are all trained to work with positive people.

After being in a hospital you may be offered short-term respite care. This means you can go to a place where you can stay for a short time to rest and recover. Sometimes this service is offered because it also gives a chance for your partner or carer to have a rest from looking after you at home.

If you are a negative partner and your partner goes to hospital your confidentiality is respected and you will be able to talk to doctors, nurses and other health workers about you and your partner's needs. Don't forget that an HIV/AIDS counsellor or social worker is a great help at this time.

Tips for the ups and downs of illness

- Make sure that you keep a supply of medicines and easy to prepare food at home.
- Make sure you have plenty of fluids.
- Have a list of names with daytime and evening phone numbers of people who can be counted on to help during an illness eg to heat a meal or pick up your prescriptions.
- Learn what you can and can't do for yourself.
- Know when to ask for help and tell people/carers what you need.
- Try to keep involved in your own care. Ask to be included in decisions.
- Say what makes you feel comfortable.
- Talk about what's happening to you with your partner, a friend or counsellor.
- Invite a friend over. If you're well enough, ask to be taken for a short drive or go to a park and sit in the sun.
- Use your favourite things - music, books and videos etc
- Get out of bed as often as possible - don't be the 'patient' all the time.

Right now you need help!

There are care and support services that can assist you and your carers at home, not only when you are ill but also when you are feeling well. Sometimes you might just want some help. It can be of benefit to both you and your carer to have a break. Help can range from things such as shopping, meals, housework, transport, personal care like bathing and giving injections, to emotional support and support for carers. Look at the Getting Support section for a complete list of contacts.

The last word -
Stay well by monitoring your HIV

One of the ways to help prevent you getting sick is to have regular blood tests. This will keep track of any changes in your immune system, and can help you tackle a problem before it gets nasty. Your doctor can advise you on the best time to start taking treatments that will stop the virus doing too much damage. Most positive people get themselves checked out every three months so they know whether their immune system is improving or declining. Good luck!

Talking Treatments

Taking pills twice a day is a reminder of what I've got! Iza

Treatments have made me feel well again and I've returned to work. Tony

Taking them means that you're not going to die. Margaret

When positive heterosexuals call the Pozhet Freecall line 1800 812 404 they talk about everything to do with living with HIV. On many occasions both men and women have discussed using treatments. Here are some of their frequently asked questions.

Note: Treatments can be called Combination Therapy or HAART (Highly Active Retroviral Therapy). Most HIV positive people call their treatments 'pills' or 'combo'.

Treatments – are they a good thing or a bad thing?

Many people say that the good thing about taking treatments is that it gives them every chance to live a longer healthy life. Treatments have stopped HIV becoming a death sentence for them and they now have the chance to continue with their lives and even start a new relationship or explore new work opportunities. Surveys of positive people on treatments have shown that many are hopeful for a better future, because by taking treatments, fewer people are getting sick. Today HIV is seen as a manageable medical condition.

Some people say that taking treatments is a bad thing because they find it difficult to swallow pills and take blood tests, and they feel anxious most of the time about their blood results. Taking treatments also reminds them that they are HIV positive and sometimes they don't want to think about this. They may also get stressed if they forget to take their pills on time. Some are concerned about the long-term effects of taking treatments and some feel that the side effects from treatments seem to be worse than the HIV itself.

It's a good idea before starting treatments to give yourself enough time to talk about all of this with your doctor, your family, friends, and other HIV positive people in a support group.

How many treatments are available? What if they don't work?

There are more than 15 pills. Their colour, shape and size all vary. They work against HIV in a number of different ways. Most people usually take a combination of three different kinds of pills, but sometimes more are needed. There are even some pills that can be taken once day.

Even if you follow all the rules - take the right amount of pills, eat the right foods - it is still possible that some drugs won't work. This can be because the HIV in your body gets used to the drug you are using and builds up a resistance to it.

You may also have to try several combinations to find out what works best and is easier for you to take. However the more times you change your treatments the less drugs you will have to choose from.

How do I take them and for how long?

Some pills are taken with food and others are taken without food. You usually take pills twice or sometimes three times a day. Taking the right dose at the right time is important. Making sure that you do this will give your treatments a chance to work very well.

Many positive people have come to terms with the idea that they may be taking treatments for a very long time. This is because they do not want the virus to damage their immune system. Some people choose to stop their drugs for short periods of time. If you are thinking of doing this, talk with you doctor about the best way to go about it.

How much do they cost? Where do you get them?

Very few places provide free medicine - usually you have to pay. HIV drugs are subsidised through special arrangements with the Commonwealth government. In a few places the drugs are available for free but generally they cost roughly $20 per prescription (2003 prices). If you are not working or you are on a low income you may be eligible for a Health Care Card which allows you to get the drugs more cheaply.

Your HIV pills are specialist drugs and you need to pick them up at a hospital pharmacy or specialist sexual health centre.

Will treatments stop me from doing things like driving a car, going to work or playing sports?

When you first start taking your treatments you may have some short-term side effects, but in most cases positive people can keep on being active and doing normal things. Some people who have been diagnosed late with an AIDS-related illness, have started treatments and gone on to make a good recovery.

Treatment side effects - what is this?

HIV is a very complicated virus, so the drugs needed to treat it are powerful. Because of this they may cause side effects. Some side effects are things like: diarrhoea, feeling depressed, nausea or having headaches. For some people these can be temporary and may last only a few weeks when they first start new drugs. Some people have on-going side effects while others experience long–term effects which can develop after they have been on treatments for a number of years.

- Over a period of time some people may develop problems, eg body fat changes or high cholesterol, which require them to change pills or have more visits to the doctor.
- On rare occasions it's possible for new drugs to cause potentially serious problems when they are first used, so if you get a rash or any kind of allergic reaction, see a doctor straight away.

Not all treatments are exactly the same and not all people taking a particular drug will have the same side effects. Other people's experiences with treatments are useful to hear about but don't assume what happens to them will happen to you. Some people may have mild side effects while others may have no side effects at all.

Whatever side effects you are experiencing, it's best to find out from your doctor if there are ways to reduce them before you stop the treatments. Don't suffer in silence. It's important to talk with your doctor to see if they can help to reduce or get rid of the side effects. Many side effects can be dealt with so you do not have to 'put up with it'. For example, a simple change of diet can help with diarrhoea. Ask for help! You may need to change your combination therapy, or work out if the side effects are due to your lifestyle or you may need to consider other things that are going on in your life.

What is viral load? Why is it important?

Viral load is the medical term used to describe the amount of HIV present in your bloodstream. This may range from a small amount to a large amount. Knowing how much HIV is present in your blood shows how well your immune system is going to deal with the virus.

You find out what your viral load is by having a simple blood test. The lower your viral load result the better. When it is low it means that the virus is replicating so slowly that there will be little, if any, damage to your CD4/T-cells and your immune system.

Lots of people with HIV say it's important to have an undetectable viral load. This means that the viral load is so low that the test is not able to detect the virus in your blood, but it doesn't mean that you don't have HIV. Current tests can't measure that you have got rid of the virus completely from your body. Undetectable means that HIV is present but in very small amounts.

You don't have to have an undetectable viral load to have an adequate immune system. Some positive people have test results that show low or moderate levels of virus and they are still well.

What are CD4 or T-cells? Why are they important? Will my T-cell count go up when I start taking treatments?

CD4 cells, also called T4 or just T-cells, are a very important part of your immune system. They help to fight infections and keep your immune system healthy. HIV particularly targets, infects and destroys T-cells. The more HIV there is in the blood, the greater the damage that can happen to your T-cells.

Most people starting new treatments for the first time notice some rise in their T-cells within 12 weeks. However it can take up to 12 months before you get the best results. Some positive people's T-cells don't go up as high as others do. Everyone's results are different.

A general guide to T-cell levels is as follows:

- Above 500 T-cells. This is the normal range for adults. More than 500 T-cells means there is little or no immune damage.
- 350 to 500 T-cells. This means that it's not likely you will get sick.
- 250 to 350 T-cells. This means there is some immune damage.
- Less than 250 T-cells. You should be considering starting treatments to keep yourself well.

Viral load and T-cells blood results can change from time to time so you have to look at them over a longer period of time to see how well they are working together. In general, more T-cells are a marker of a stronger immune system but people with low T-cells and low viral load can still manage well.

Remember: One bad result doesn't mean a disaster!

Can I eat normal foods with my treatments?

With HIV you need to get adequate nutrition, eat well and maintain weight. Avoid fad or cleansing diets, which could cause problems and may be harmful.

For treatments to work against HIV in your body you will have to take your drugs at the right time and, if necessary, with or without food, depending on the type of pills. Sometimes HIV drugs cause changes that mean you need to modify your diet, eg if you get high cholesterol your doctor and dietician will help you with this.

Can I use complementary therapies with treatments?

Since they were first diagnosed, many positive people have supplemented their care from their HIV doctors with care and support from a wide range of natural therapy practitioners. Some people still take steps to improve their diet or take herbal medicines or natural therapies while they are taking their treatments.

Be aware that some complementary therapies can interact badly with your treatments. They may affect your blood results and cause problems with the way your treatments work. It's a good idea to tell your doctor what else you are using so that you can get advice on what works well with your treatments.

Can I use other prescription medicines with my treatments?

Yes, mostly. However it's very important to tell your HIV doctor about any other prescription medicines you are using. Your HIV doctor won't always know what other things you have been given from your family doctor. In a few cases there could be a clash between different types of medicines and you could end up with side effects.

What about treatments if I'm pregnant?

It is possible for a positive woman to have a healthy baby using HIV treatments. Treatments can be taken in pregnancy and will dramatically reduce the chance of the baby being HIV positive.

More than 50 HIV positive women have given birth to HIV negative babies in Australia while using treatments with no evidence that the treatments harm babies during childbirth. However, some types of HIV treatments are not used in pregnancy, so speak with your doctor about this first.

Are there other types of drugs you might be taking besides treatments?

Some other drugs used to help positive people are:

- drugs like Bactrim, which is used as a general antibiotic to prevent HIV illness.
- other drugs that are used to treat illnesses and infections when they occur.
- drugs to manage side effects like high cholesterol and diarrhoea.

Who can I talk to about treatments?

Besides talking to an HIV doctor there are several good places you can contact when you are trying to find the answer to a question about using treatments.

☎

Pozhet (Positive Heterosexuals). Freecall (Aust) 1800 812 404

The Treatments and Vitamins information service available through ACON.
Ph (02) 9206 2013 (Sydney) or Freecall 1800 816 518

Your closest dietician, social worker, counsellor or HIV clinic.
Ring: NSW HIV/AIDS Information Line. Ph (02) 9332 9700 (Sydney)
Freecall 1800 451 600

The Treatments & Vitamins
Information Service
02 9206 2013 or
Freecall 1800 816 518

Pozhet Freecall 1800 812 404

NSW HIV/AIDS Information line
02 9332 9700
Freecall 1800 451 600

Tips for Living Well

These are some great tips for living well - from those who know. They were given the thumbs up by straight men and women living with HIV/AIDS at a 'Practical Stuff' workshop in Sydney, run by Pozhet.

1. Make the first move - change your routine

> *Morning ritual - quiet time, no music, go for a walk near the river, feed the birds and sit and take time over breakfast. Rob*

Making the first move means taking control of your health, making your own decisions and developing new ways to manage your HIV that suit you and fit in with your lifestyle. This 'managing HIV' is not just about HIV treatments, viral load tests and CD4 counts. It's about your whole lifestyle, the way you live and the choices you make. And if you're in a rut then change your routine. It could be something simple like putting aside some special time in the day to do some activity that's about you only and for you only.

2. A healthy fix - find a quality doctor

> *My doctor is really a friend, always helpful, and she feels more like family than a doctor. Her advice helped me increase my T-Cells. Ruby*
>
> *I used to accept everything my doctor said and I agreed to do things I knew I couldn't stick to. Now it's different. I have a more honest relationship and say when I can't do something, so we look for other ways that suit me. I am happier with this. Lily*
>
> *I just decided I wanted a new doctor after six years because I wanted to hear a new voice and a new face talking about my health. Mike*

The relationship with your doctor is among the most important relationships you can have over many years. You'll need to visit a doctor for regular check-ups and blood tests and to find out how well your immune system is getting along. So making a visit to the doctor shouldn't feel like a bad experience for you. Most people choose a doctor or specialist with HIV expertise who they feel they can easily talk with and who will listen to them. You'll want to feel confident enough to tell them you're feeling bad as well as feeling good.

3. Make some noise - seek a new opportunity

When I found out I was positive I thought I haven't got much time. Years later I'm still here. There's no reason I can't start doing new things. Matt

There's no shame about seeking help. Danny

I'm learning new things to educate myself. It's how I keep my hope present. Carlos

Okay, so you don't want HIV to take over your life. But you want to get connected to anything that can help as soon as possible. There are hundreds of positive and negative men and women who want to help you with your choices. With well over 300 different HIV/AIDS agencies and service providers in New South Wales all offering different types of support, there's plenty of people to help. They are all listed in *Contacts*, which is the directory of services for people living with HIV/AIDS, which is also available online. You can find medical and complementary therapies to try and there are also new things like cooking, job opportunities, volunteering, lunches and group outings, hobby craft courses and even pet care! And you'll be connecting with like-minded people who live with HIV/AIDS as well. Make some noise and get connected. You can handle it!

4. Fix your spark plugs - be creative around old habits

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

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

Stress can make a mess – get some counselling

You don't have to be in trouble to go to a counsellor. It's a well-tested method for sorting through your feelings and finding better ways to cope with living with the virus. Most counselling sessions are about one hour long. You sit down in private with your counsellor and tell them how you've been going, then you work out different ways to get the best out of the things that have happened to you with HIV. You could talk about your health, a new relationship or things going on with your family. You choose! There are countless positive people and their partners who swear that counselling made all the difference to them in getting on with their lives.

Stress can make a mess out your life. When you're stressed it is more difficult to remember what you are meant to be doing to keep yourself well. Depression is also a very common illness for many HIV positive people. It's different from unhappiness or sadness. Depression is a constant low mood that can last for several weeks or longer, and it's not all in your head. It is very important if you're feeling depressed to tell your doctor, as it's an illness that can recur many times, and it's easily treatable.

Move that bod - exercise

The cheapest way to improve your health is by exercising. Exercise boosts your energy levels, reduces fatigue, can help with some of the changes in your body shape and can make you feel great. A simple thing like a daily walk can do wonders by getting your heart pumping oxygen-rich blood. Any small exercise you do just a few times a week can improve the way you look and feel. Ask your HIV/AIDS physiotherapist to put together a short program of exercise that suits your body type.

Put the EAT back in your grEAT body

Is your daily life one thing after another, so that you don't have time to work out how to eat well? Losing weight can be bad because it makes it more difficult for your body to fight infection and recover. Choosing and eating food that's good for you is an important part of the battle against HIV/AIDS. The hard part is setting up a plan that will help you eat well - something that is right for your lifestyle. How much time do you have to cook a meal? Do you have time to eat in the morning or are you rushing out the door? Do you have to get the kids to school? When do you have to take those pills?

The first step is to talk to an HIV/AIDS dietician or nutritionist who knows about food and HIV. These days they also run cooking classes for positive people to help them prepare tasty meals.

Get the right tools - complementary therapies

There are many complementary therapies offered to HIV positive people that will help to improve your mental, physical and spiritual wellbeing. They include: herbal medicine, massage, Chinese herbs, acupuncture, meditation, yoga, homeopathy, reiki, reflexology, shiatsu etc. The use of vitamin supplements is most popular.

More pills - vitamins, minerals, and nutrients

Studies of nutrient levels in positive people find they can be depleted, increased or unchanged. Positive people should resist thinking that they can fix HIV by just taking handfuls of vitamins. At present there is no convincing evidence that vitamins, minerals, nutrients and herbs can, in themselves, stop an HIV illness. In some cases overdosing on vitamins can damage your immune system. You do, however, need vitamins if you do not eat properly either because of illness or heavy drinking, or you haven't got enough money to spend on food. Most HIV specialists will recommend just a multivitamin and a healthy diet. Vitamins and supplements can be bought at wholesale prices from ACON's Vitamin Service.

Better habits

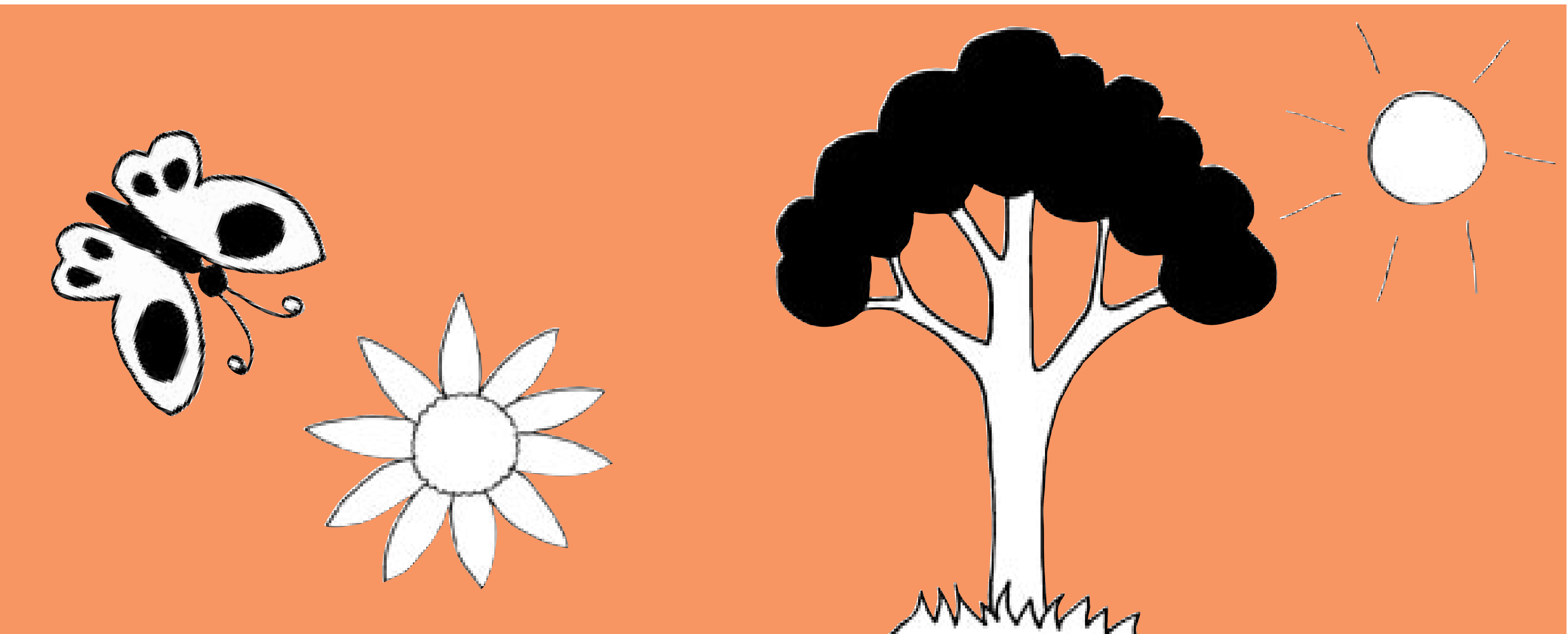
Many positive people wonder whether drinking can speed up the development of AIDS. Moderate drinking isn't harmful but heavy drinking can affect your immune system badly and slow down recovery from infections. If you drink heavily you could also forget to eat good food.

Smoking has two main effects on your immune system. Firstly, it makes it harder for air to move in and out of your lungs and this means that less oxygen is taken to the tissues for use in energy production. Secondly, the carbon monoxide inhaled from cigarette smoke damages almost everything inside you. Any combination of smoking, drinking too much alcohol or coffee, not getting enough sleep and skipping meals will run you down. Giving up isn't easy but you can find ways to be creative around cutting back. There is help. Just ask your doctor, counsellor, social worker, dietician or peer support worker.

Kick yourself a goal!

Making changes and kicking old habits can help you feel good about yourself especially if they're all about changing simple things to improve your health. For example you may decide you'll learn to cook two or three new meals that are packed with goodies or you may decide to get up earlier in the morning and go for a short walk before eating breakfast. Choose whatever you'd like to do.

Give yourself a moment to think about what changes you want to make for yourself in the 'Kicking old habits!' chart on the next page. Then rank them from 1 to 10 in terms of 'very important' to 'not so important'. In the 'How to do it' column write down a few thoughts on how you think you could go about giving yourself a start. Don't forget to give yourself a reward when you've scored that goal!



Kicking old habits!	What changes do you want to make?	How important 1 -10	How to do it?	Reward Yes or No?
Drinking alcohol				
Keeping fit				
Keeping friends				
Love and sex				
Making friends				
My family				
My treatments				
Recreational drugs				
Smoking cigarettes				
Working				
Education				
Getting support				
Having fun				
Money				
New hobbies				
Sleeping				
Spirituality and beliefs				
Stress				
Travel				
Using complementary therapies				

5. The next big thing - there will be a cure

I discovered that negative thoughts affected my physical and mental health. Ruby

I'm focusing on how much longer people are staying well. Tony

I've been positive for 20 years and have decided I will grow old. I've even read an article on ageing. Margaret

Having a low viral load does not lead to a full recovery of your immune system. You probably won't be able to get back to a perfect immune system for a while yet but if you take treatments at the right time you can have a pretty good immune system that will get you by for some years to come.

HIV is now a manageable infection and people who are HIV positive can all be cautiously optimistic that there is a better future ahead. If you believe the next big thing will be a cure then who says you can't be right! So never, ever give up!

Getting Support

There's lots of services and support to help you but you have to go looking for it. It takes lots of persistence and asking questions, to really find out what you need to know. Saria

Don't be afraid to use as many services as you can to get your life back to normal. You'll meet amazing people who will welcome you with friendship, support, confidentiality and hope. John

Like everyone, positive heterosexuals and their partners can be intelligent, funny, sensitive and attractive. Being straight and positive doesn't mean you have to hide yourself indoors. You can make a little effort and be rewarded by meeting other men and women like yourself who live with the virus.

These days it's not unusual for positive straight men and women to regularly use a wide range of HIV services. Don't be afraid to explain that you're not gay. It isn't such a big deal! You may have to cope with an occasional rejection but overall people, both straight and gay, will want to meet you, help you and spend time with you.

Okay, so now you've made up your mind to stop staying indoors and letting HIV get you down. You're going to get it together and stop feeling lonely by making new friends and finding services that can help you.

Which services would be good to try? We've chosen a list of the ones that are most popular. Make contact for the support that can get you where you want to go.

Finding your nearest HIV/AIDS doctor and clinic

NSW HIV/AIDS Information Line
For the closest help to where you live. Find an HIV/AIDS doctor, clinic, counsellor or social worker.
(02) 9332 9700
1800 451 600 (Freecall)
TTY (02) 9332 4268

Sexual Health Clinics
For your nearest clinic to see a doctor, nurse or social worker, look under **S** in the White Pages.

Meeting others like yourself

Positive Heterosexuals - Pozhet
Positive men, positive women, their partners and family members
A social events calendar includes workshops, retreats, support groups, country visits and phone counselling.
1800 812 404 (Freecall Australia)
www.pozhet.org.au

Women's HIV and Health Promotion (ACON)
HIV positive women's support
(02) 9206 2015
1800 063 060 (Freecall)

Multicultural HIV/AIDS and Hepatitis C Service
Bilingual/bicultural co-workers - for people from a non-English speaking background
(02) 9515 3098
1800 108 098 (Freecall)
www.multiculturalhivhepc.net

Ankali
One-to-one emotional and social support for positive men and women, their partners, family and friends
(02) 9332 9742
1800 451 600 (Freecall)

Children & HIV, family support

Paediatric HIV/AIDS Unit
Paediatric HIV Social Worker at Sydney Children's Hospital
(02) 9382 1851

ACON Family Support Officer
Help for families where a parent or child has HIV
(02) 9206 2079

FPA Health
For contraception, pregnancy counselling, breast checks and pap smears
(02) 9716 6099

FPA Healthline
Answers your questions about reproductive and sexual health
1300 65 88 86 (NSW and NT for the cost of a local call)

Financial help and counselling

BGF - Bobby Goldsmith Foundation
For direct financial help and counselling, supported housing, employment support to men and women disadvantaged by HIV/AIDS
(02) 9283 8666
1800 651 011 (Freecall)
www.bgf.org.au

Friendly HIV/AIDS organisations

Positive Central
Counselling, physiotherapy, occupational therapy, nutrition and referrals for positive people, their partners and family living or working within the central Sydney area
(02) 9395 0444

Western Suburbs Haven
Social support, cheap groceries, lunch, workshops, Internet access and respite care in Sydney's Greater West. Support events for positive heterosexuals
(02) 9672 3600

Positive Living Centre
One-stop access point for daytime social activities for positive people wanting new skills, interests and work opportunities
(02) 9699 8756

North AIDS
North Sydney day centre, lunch and social activities
(02) 9929 4288

PLWHA (NSW)
Referrals and Contact Directory. Contact your local PLWHA centre
(02) 9361 6011
1800 245 677 (Freecall)

Tree of Hope
Emotional support - spiritual - pastoral care. Hospital and home visits on request for plwha and families
Sister Margaret Mines
(02) 9698 3161

Free advice

HIV/AIDS Treatments
Treatments Officer ACON
Free advice on treatments and vitamins
(02) 9206 2013
1800 816 518 (Freecall)

Legal advice
HIV/AIDS Legal Centre (HALC)
Free legal advice for legal problems related to HIV/AIDS
(02) 9206 2060
1800 063 060 (Freecall)

Hep C Helpline
Hepatitis C Council of NSW
Information and support
(02) 9332 1599
1800 803 990 (Freecall)

NSW Users and AIDS Association (NUAA)
Services for past and current injecting drug users
(02) 8354 7300
1800 644 413 (Freecall)

Aboriginal and Torres Strait Islander Support Services
There are Aboriginal sexual health workers in all areas of NSW. Contact your local Aboriginal Medical Service under **A** in the White Pages or contact your local sexual health service under **S** in the White Pages.

Food – when the larder is empty

Luncheon Club Larder
Free lunch and groceries for people on pensions
(02) 8399 3220

Food Distribution Network
Delivery of market price fruit and vegetables for people on pensions
(02) 9699 1614

Foodshare
Low-cost food once per month in return for volunteer help
(02) 9310 2722

Housing – finding somewhere to live

ACON Housing
(02) 9206 2039
1800 063 060 (Freecall)

BGF Supported Housing
(02) 9283 8666
1800 651 011 (Freecall)

Home care and support

CSN - Community Support Network
Help with transport and homecare - cooking, shopping, cleaning etc
(02) 9206 2031
1800 063 060 (Freecall)

Jobs & employment for positive people

Positive Employment Service
Help if you are looking for some sort of change in your work direction
(02) 9283 8666
1800 651 011 (Freecall)

Options Employment Service
Employment and training service. Intensive one-to-one help to get a job, study or retrain. Darlinghurst, Chatswood, Parramatta, Katoomba and Strathfield
1800 784 667 (Freecall)

Complementary therapies

The Sanctuary
Free shiatsu massage, social activities and cooking programs
(02) 9519 6142

ACON Vitamin Service
Quality vitamins and nutritional supplements at near wholesale prices
Independent advice on treatments and vitamins
(02) 9206 2013
1800 816 518 (Freecall)

Free HIV magazines and journals

Pozhet Connections Program
The latest HIV/AIDS magazines and newsletters for positive heterosexuals
1800 812 404 (Freecall Australia)

Useful websites - Australia and overseas

Positive Heterosexuals (Pozhet)	www.pozhet.org.au
People Living with HIV/AIDS (NSW) Inc	www.plwha.org.au
AIDS Council of NSW (ACON)	www.acon.org.au
Australian Federation of AIDS Organisations (AFAO)	www.afao.org.au
Positive Women (Victoria)	www.positivewomen.org.au
Straight Arrows (Victoria)	www.straightarrows.org.au
The Body - Information for positive people	www.thebody.com
National Association of People With HIV/AIDS (NAPWA)	www.napwa.org.au
Terrence Higgins Trust	www.tht.org.uk

Hetero chat rooms

www.positiveconnections.org
www.heterochat.org
www.hivstraight.com

Copies of
Changing Lives and Sex Matters A-Z
are available from Pozhet
1800 812 404 (Freecall Australia)
www.pozhet.org.au

Changing Lives

A resource for heterosexual people living with HIV/AIDS

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Developed by the Heterosexual HIV/AIDS Service
Central Sydney Area Health Service

Funded by NSW Health

Positive Heterosexuals (Pozhet) is a statewide peer support and education program for heterosexual men and women living with HIV/AIDS and their partners, families and friends.

Call 1800 812 404 for free, friendly, confidential support and a calendar of events that include information workshops, country visits, social evenings and seaside retreats.