

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:

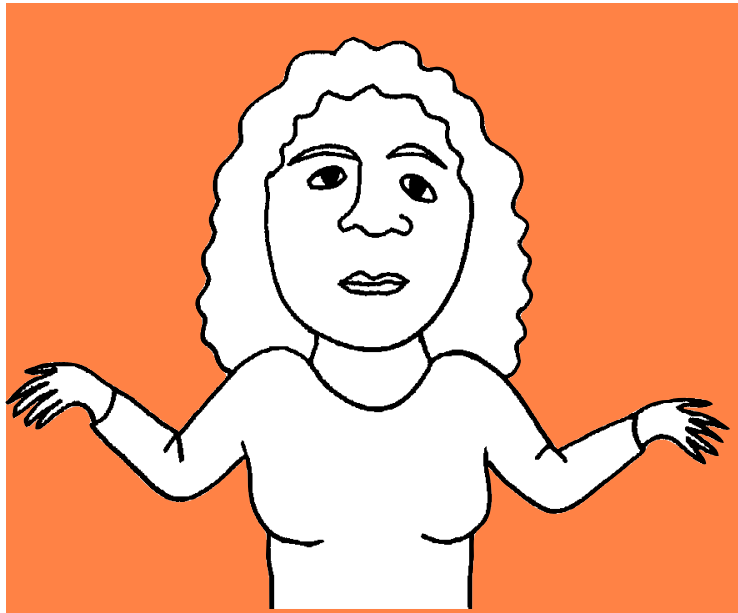
- What happens to me if I get AIDS?
- How long will I live?
- Will it kill me?
- What does it feel like to have AIDS?
- Is there a lot of pain?
- What will my body look like?
- Will I be sent to a hospital?
- What services will help me?

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.

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!