

the facts

*a simple guide to
managing genital herpes*

To go straight to our website
click on the link below

thefacts.com.au

Contents

How the facts can help	3
The key facts	4
What is genital herpes?	5
Symptoms	6
First episode	7
Recurrences	8
Trigger factors	8
Identifying the virus	9
Confusing symptoms	9
Relieving pain and discomfort	10
Controlling the symptoms	11
How genital herpes is passed on	12
Protecting relationships	13
Being gay and having herpes	14
Fertility and pregnancy	15
Some key terms	15
Extra information and support	16

How the facts can help

Genital herpes is a common virus that, in most cases, causes relatively mild symptoms or none at all. Even when the symptoms are more severe, they are simple to treat and can usually be very well controlled.

The trouble is that most people's perceptions of the virus are based on the wide range of myths about it rather than the facts.

As a result, being diagnosed with genital herpes can often be both confusing and confronting.

This booklet is designed to help you clear up the confusion and start taking positive steps to get your life back to normal.

If you've just found out you have genital herpes, we hope you'll find the facts about the virus and what treatment option is right for you very reassuring. The information in here should also help if you're dealing with a specific issue like managing herpes during pregnancy, or if it's your partner who has herpes.

You can read it straight through or use individual sections for reference. If you have any additional questions you'd like answered, you'll find a list of resources and support groups inside the back cover that may also help.

If you have herpes, there are simple and effective steps you can take to minimise the risk of passing the virus onto your partner during sex.



The key facts

- About 1 in 8 of us has the virus that causes genital herpes.
- Women are twice as likely to have the virus as men.
- Around 80% of people infected with genital herpes don't know they have the virus.
- The way people who are diagnosed with genital herpes feel about it usually affects them more than the actual symptoms. But most of the worry or anger is based on misunderstandings.
- The symptoms of genital herpes vary enormously. It can show up as blisters or sores, but it can also just produce a mild rash. And whatever symptoms do appear may be on the thighs, back, fingers and of course the genitals.
- There is no cure for herpes, but effective antiviral treatment is available once a doctor has diagnosed the infection.
- Because most people with the virus have very mild symptoms or none at all, they often don't realise they are infected.
- The virus is usually passed on when there are no visible symptoms.
- Most people who infect others don't realise they are even putting their partners at risk.
- Using condoms reduces the risk of passing on the virus but doesn't completely eliminate it.
- Simple daily treatment can help to prevent potential outbreaks and reduce the impact of any that do occur.

What is genital herpes?

Genital herpes is the second most common sexually transmitted infection (STI). It's caused by the herpes simplex virus – the same virus that can cause facial cold sores.

The herpes simplex virus is just one of several herpes viruses, including the chickenpox virus. All the different types are stored in the body for life.

There are two types of herpes simplex that can cause genital herpes:

- Type 1 (HSV-1) is carried by around 80% of the population and in the past has mostly caused cold sores;
- Type 2 (HSV-2) affects 12.5% (1 in 8) of the population and is generally associated with genital herpes.

Now, partly because oral sex is more common, the traditional distinctions between the two strains are breaking down and both types appear orally and genitally.

The good news is that, when it comes to treatment, both strains respond well to antiviral therapy.

HSV-1	Orofacial herpes (cold sores) Neonatal HSV (infection of newborns) Herpetic dermatitis (rashes or inflamed skin) Herpetic whitlow (finger infection usually at the base of a fingernail) Herpetic keratitis (inflammation of the cornea) Herpetic encephalitis (inflammation of the brain tissue)
HSV-2	Orofacial herpes (cold sores) Neonatal HSV (infection of newborns) Herpetic dermatitis (rashes or inflamed skin) Herpetic whitlow (finger infection usually at the base of a fingernail)

The most serious of these other conditions are neonatal herpes and herpetic encephalitis, both of which are relatively rare but can be deadly. The causes of herpetic encephalitis are not fully understood, but having genital herpes doesn't seem to make you more or less likely to develop it.

Symptoms

The virus affects different people in different ways, and can affect the same person differently over time. Most people infected with genital herpes have mild symptoms or none at all, but some symptoms are very severe.

The first time symptoms appear is usually the most severe outbreak. If you have symptoms, you are most likely to go on having occasional outbreaks, but they will probably become less and less severe as time goes on.

The classic symptoms of genital herpes, are cold sore-like blisters that burst and leave painful ulcers, then take about 10 days to dry out, scab over and heal.

But in at least half the cases where symptoms are noticed, they are still hard to identify. They may be very mild (which is a good thing, of course, but can add to the confusion) and may not be on or even near the genitals.

Many people don't realise they are having herpes outbreaks until they understand the full range of possible symptoms. When their partners are diagnosed with more obvious symptoms, for instance, it suddenly becomes clear that what they thought was recurrent thrush was really a series of herpes outbreaks.

Possible warning signs before symptoms appear:

Tingling, itching, aching.

Possible symptoms:

Blisters that burst and become painful ulcers, tiny sores, small cracks in the skin, localised chafing, vague redness, a distinct rash.

Possible areas where symptoms can appear:

Anywhere on the genitals (including within the vulva and vagina and under the foreskin), anywhere else on the groin, in and around the anus (if the infection was passed on by anal intercourse), on the buttocks and/or lower back, on the thighs, behind the knees or on the backs of the fingers. (The dermatomes map in this booklet shows how the symptoms can be distributed.)

First episode

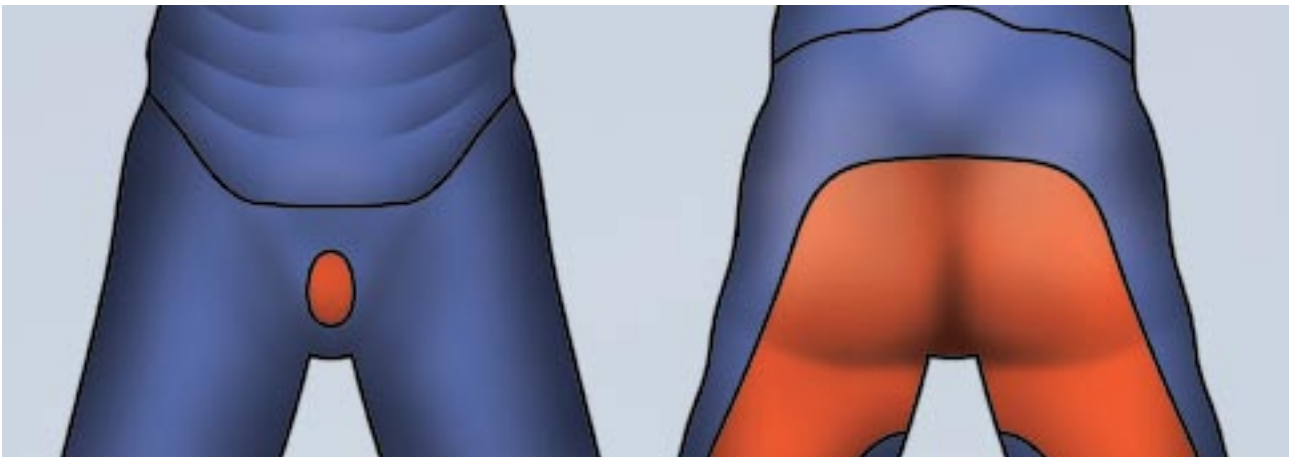
The first time you experience the effects of genital herpes (also known as a primary outbreak) the symptoms are likely to hit you harder than they ever will again. They may also be quite different from the ones that appear in future outbreaks.

For some people, the first episode can be more like a bout of flu than a localised outbreak of sores. It can include generalised symptoms like fever, aches and pains and swollen lymph nodes.

Whether or not you have flu-like symptoms, you are likely to have specific genital symptoms as well. Overall, the symptoms may last for as long as 20 days.

If you've had a severe first outbreak of symptoms, you can be reasonably confident that they will never be as bad again (even if you don't take tablets to control them).

If your first symptoms were very mild, further outbreaks may become barely noticeable. This is because once your body has dealt with the first flare-up of the virus, it can produce antibodies that fight the virus each time it is reactivated and reduce its impact.



■ Areas where lesions can occur

This diagram shows how quite large areas of the skin surface (called dermatomes) are linked by sensory nerve fibres to a single spinal nerve root. The first time your herpes symptoms appear they'll probably be on or near the spot where you were infected, but after that they may emerge in other places within the same dermatome.

Recurrences

Almost everyone who's had genital herpes symptoms will experience symptoms at least once more. The overall average number of outbreaks for people with HSV-2 is about four a year, but just as the symptoms themselves can take many forms, the frequency and nature of recurrences is varied.

In extreme cases, symptoms can reappear as the first ulcers are still healing. A more typical pattern is that you may get 6–10 recurrences in the first year, and less in the years after that.

But almost anything goes. Some people wait years for a recurrence; many others have regular outbreaks of such minor symptoms that they don't notice them. Symptoms may rotate from site to site, appearing on the genitals, then on one thigh, then in the small of the back, then reappearing in the original spot.

The good news is that, in most cases, antiviral therapy can greatly reduce the number of times symptoms reappear and make them less severe on the few occasions they do come back.

Trigger factors

Some people who have multiple outbreaks of herpes symptoms are able to identify a trigger factor that sets them off, while others are usually caught by surprise.

There's no doubt that herpes can be reactivated by specific factors: it's well established that strong sunlight can set off an outbreak of cold sores, for instance.

In the case of genital herpes, there is a long list of suspected trigger factors. Many women connect outbreaks with their menstrual cycle, and other people cite causes as particular as having vigorous sex (probably because friction causes skin damage that sets off the symptoms) or as general as being physically run-down or stressed.

Even if you can establish a pattern to the reappearance of your symptoms, you may not necessarily be able to eliminate the trigger factors.

Stress is one of the most common triggers people mention, but it's usually hard to work out whether the stress is causing the symptoms or the threat of symptoms appearing is causing the stress. If you're in that situation, it's a good idea to discuss treatment options with your doctor and consider using daily tablets to minimise the chance of further outbreaks.

Identifying the virus

One of the reasons so many people don't realise they have genital herpes is that its symptoms can easily be mistaken for the signs of some other STI or fungal infection.

The only way to be certain that you have genital herpes is to see a doctor while you have symptoms. The doctor will take a swab from the affected area and have it microbiologically tested.

Although you can be prescribed antiviral treatment for herpes before the test results are known, a positive result is needed before your doctor can provide repeat prescriptions.

In the past, blood tests were often used to confirm a diagnosis of genital herpes. That was fine when almost all cases were caused

by HSV-2, but a positive blood test no longer provides enough information.

Microbiological testing of a swab is a better indication, especially using the PCR (polymerase chain reaction) technique. But although PCR can detect the virus even when only a few molecules of its DNA are present, even this type of test is not foolproof. The swab may simply fail to pick up any virus, so a negative result doesn't absolutely guarantee that you don't have genital herpes. If in doubt, speak to your doctor about your concerns.

Confusing symptoms

If you're confused by genital symptoms, you're by no means alone. As this comparison shows, very similar signs can indicate quite different problems – and this table only lists the most common symptoms and causes.

Genital symptom	Possible cause
Pain when urinating	Genital herpes, balanitis, gonorrhoea, thrush, NSU.
Redness or a rash	Genital herpes, chlamydia, gonorrhoea, pubic lice, scabies, syphilis, thrush.
Blisters or ulcers	Genital herpes, chancroid, CMV, Crohn's disease, syphilis.
Itchiness	Genital herpes, genital warts, pubic lice, scabies, thrush.
Vaginal discharge	Genital herpes, bacterial vaginosis, chlamydia, genital warts, gonorrhoea, thrush, trichomoniasis.

Relieving pain and discomfort

Broadly speaking, the treatment of genital herpes can be divided into two categories: practical measures and medicines you can use to relieve the pain and discomfort symptoms can cause, and antiviral drugs you can take to prevent symptoms developing or to speed up their healing.

Just as symptoms vary from one person to another, so do the practical measures that people find helpful. If you have painful symptoms, here are a few of the things you can try.

Aspirin and paracetamol

Aspirin and paracetamol should help ease aching pain (and any fever if you have a high temperature), but you may find applying ice directly to the sores provides more immediate relief.

Pain-relieving creams

Creams that contain anaesthetic can also help, but they tend to slow down the drying out and healing of the sores – so the short-term gain may be offset by longer lasting pain.

Salt baths

Washing the affected area with salt water may speed up the healing of sores as well as easing discomfort. Use a teaspoon of salt in 600ml of water, or a handful in a shallow bath.

Cool baths

Some people find it very painful to urinate when they have sores. One way to make it less uncomfortable is to sit in a cool bath to pee. If you think drinking less, so you pee less often, will help, you're wrong. The urine becomes more concentrated and stings even more.

Warm showers

Most people with painful sores find it soothing to run warm water over them. If you're one of them, try having a warm shower every few hours when outbreaks are at their most uncomfortable.

Loose underwear

Loose-fitting underwear, preferably cotton rather than nylon, will be more comfortable and allow faster healing.

Controlling the symptoms

The antiviral treatment your doctor can prescribe doesn't just relieve the pain of sores; it blocks the multiplication of the virus. That blocking action can be used in two different ways.

Suppressive therapy

Most people who experience genital herpes symptoms prefer taking daily tablets to help prevent further outbreaks (they can be reduced by as much as 90%) and make the few episodes that do still occur less severe.

As well as blocking the development of symptoms, daily treatment can greatly reduce the risk of passing the virus on. Research has shown that people taking daily antiviral tablets and practising safe sex can halve the risk of giving their partners the virus.

This approach, known as suppressive therapy, can be used to suppress the activity of the virus for years at a time.

Another option is using suppressive therapy just long enough to protect yourself while you're coping with a potentially stressful event like sitting exams, moving house or getting married. Because they can have emotional triggers, outbreaks are actually more likely to occur when they're 'just what you don't need'. At times like that, tactical use of short-term suppressive therapy can be very helpful.

Episodic therapy

The other way of using antiviral therapy is to start taking it as an outbreak begins in order to stop sores developing. For patients who get warning signs, this should be as soon as they feel the tingling or itching that indicates other symptoms will soon appear.

The earlier treatment starts, the more effective it will be. In many cases, sores still develop, but are less severe and heal more quickly than they otherwise would have.

In the past, this 'episodic therapy' was the only way tablets could be prescribed. It still suits some patients, but research has shown that most patients who have tried both methods prefer the convenience and effectiveness of suppressive therapy.

One of the drawbacks of treating each episode as it happens is that there's nothing to stop viral shedding going on between outbreaks and causing new infections because people have unprotected sex while there are no symptoms present.

If you need antiviral therapy, it's a good idea to discuss both options with your doctor.

How genital herpes is passed on

New genital herpes infections usually start with sexual contact.

Heat and moisture help the virus survive moving from one body to another, so infection is much more likely to occur during sex than through people just brushing against each other or other forms of contact.

The virus can be passed on by anyone who has the active herpes virus on the surface of their skin.

That doesn't necessarily mean there are symptoms present. In fact, we know that the virus is most often passed on when there are no symptoms – and remember that 80% of people who have the virus are unaware they are infected.

As well as not having symptoms, the person carrying the virus may not have genital herpes. In many cases, the herpes virus is on the face and infection occurs during oral sex.

Given how common the virus is and how hard it is to detect, it's hardly surprising that thousands more Australians become infected with genital herpes every year.

While practising safe sex is an important protective measure against all STIs, people with genital herpes have the extra advantage of being able to use daily antiviral tablets to further reduce the risk of passing on genital herpes.



Protecting relationships

For many people who find out they have genital herpes, the greatest worry is the effect the virus will have on their relationships.

It's probably true that all couples are affected in some way by a diagnosis of genital herpes, but the change is not necessarily for the worse. While some relationships are damaged, others are made stronger by the need for honesty and trust the virus creates.

Telling your partner

It's only natural to be nervous about telling someone else you have genital herpes, but strong long-term relationships are usually built on honesty and trust – and having herpes is not something you can easily conceal from a regular sexual partner.

Exactly how you tackle the subject is up to you, but here are a few general principles you may find helpful:

- timing is important, and you can control it. Carefully choose the time and place to make your partner as receptive as possible;
- be prepared. As well as working out what you want to say, you may like to print out some information for your partner to read. There is a list of helpful websites inside this booklet; and
- accentuate the positive. Most people are scared by the thought of genital herpes without knowing much about it. Emphasise things that make it seem less scary: for example, there are plenty of things you can do to protect your partner (especially once he or she knows you have the virus).

Practical protection

Telling your partner is the first step towards protecting him or her against infection.

Next, your partner should see a doctor and be tested for the virus.

If the tests show that your partner doesn't have herpes, there are several simple precautions you can take to help reduce the risk of passing the virus on:

- don't have sex (including oral and anal sex) if you have any herpes symptoms – even just the tingling or itching that shows other symptoms are about to develop. You are almost certain to have the virus on the skin surface whenever you have symptoms, but it may not be confined to the places where the symptoms are visible;
- always use condoms when you have sex. They're not 100% effective, but they provide some protection against all STIs. Remember that you can have the virus on your skin even when there are no symptoms; and
- if you take daily antiviral tablets, you will be less likely to have the active virus on the skin surface at any time.

Being gay and having herpes

Obviously the herpes virus doesn't care what sort of sexual activity is creating the right conditions for infection, but different sexual practices create different risks.

Gay women are slightly less likely to become infected than heterosexual women, but for those who do, the impact of the virus is exactly the same.

In the past genital herpes was much more prevalent among gay men than in heterosexuals. That's no longer the case, partly because more heterosexual couples are having oral sex and becoming infected that way. However, infection through anal sex remains more common among gay men.

It has also been shown that having the herpes virus makes men more susceptible to infection with HIV.

The good news is that there is less stigma attached to all STIs in the gay community, that safer sex practices are widely accepted, and that there is a range of sexual health services specifically aimed at gay men and women. You can find contact details for some of those services on the websites listed at the back of this booklet.



Fertility and pregnancy

Genital herpes has no effect on a couple's chances of conceiving a child, but there are risks associated with herpes and pregnancy.

There is a small chance that the herpes simplex virus can be passed on to babies during birth: about 20% of all pregnant women have genital herpes, but only around 8 in every 100,000 newborn babies are affected by the virus.

However, the few cases of neonatal herpes that do occur can be life-threatening.

The risk of infecting your baby can be minimised by taking some simple precautions, so it's important that if you become pregnant, you tell your doctor and obstetrician that you have the virus.

It's even more important that women who don't have the virus make every effort not to get infected during pregnancy. The virus may be more active and the symptoms more severe in the first stages of infection, and therefore put the baby at greater risk. Studies have shown that the use of antiviral treatment can be taken during pregnancy to reduce the risk of outbreaks. Seek advice from your doctor.

As long as the medical team are aware of the situation, they can assess the need for protective measures such as having a caesarean section.

Some key terms

Antiviral treatment: use of medication that aims to reduce outbreaks and symptoms of genital herpes.

Episodic therapy: taking antiviral tablets when symptoms appear.

HSV: herpes simplex virus, the virus that causes both genital herpes and oral-facial herpes, or cold sores. The two main types are HSV-1 and HSV-2.

Outbreak: reappearance of symptoms.

Safe sex: the idea of safe sex (also known as safer sex) is to enjoy sex while minimising risk of sexually transmitted disease. This includes men wearing condoms during penetrative sex.

STIs: sexually transmitted infections.

Suppressive therapy: daily treatment with antiviral tablets to prevent herpes symptoms reappearing.

Transmission: passing the virus on.

Viral shedding: a period during which the virus is active and on the skin surface, even if there are no symptoms.

Extra information and support

There is so much misinformation about genital herpes, and it is such an emotionally charged issue, that it's important to have access to reliable information and advice. If you want to find out more about genital herpes and get an insight into other people's experiences of managing the virus, you may like to visit some of these websites or contact your nearest support group.

Websites

www.thefacts.com.au

The website designed to complement this booklet with additional information, a list of medical clinics with particular expertise in sexual health and a downloadable questionnaire to help you discuss herpes with your doctor.

www.ahmf.com.au

The Australian Herpes Management Forum was set up by a group of specialists to improve the awareness, diagnosis and management of the virus in Australia. This site has plenty of facts and figures as well as expert advice.

www.health.nsw.gov.au/sexual health/

A very supportive guide with a good range of information on other STIs as well. You may need to check other government sites for support services in your area.

www.herpesalliance.org

An international guide to patient support groups, plus a basic guide to the virus and its management.

www.ihmf.com

This international equivalent of the AHMF site is mainly designed for healthcare professionals, but it does provide a good overview of recent herpes research around the world.

Support groups

Brisbane HRC Group

PO Box 5429, Alexandra Hills,
Brisbane QLD 4161, Tel: 0415 991 954

Melbourne Herpes

Self Help Group (MHSHG)

PO Box. 1044H, Melbourne VIC 3001,
www.vicnet.net.au/~mhshg

Perth Support Group

W.I.S.H Building, 335-337 Pier Street,
East Perth WA 6004,
www.geocities.com/perthgroup

Sydney Support Group

P.O. Box 2162, Carlingford Court,
Sydney NSW 2118, Tel: (02) 9294 6738,
www.geocities.com/sydneygroup/

Sydney HELP

Sydney Sexual Health Centre, APO Box 1614,
Sydney NSW 2001, Tel: (02) 9382 7440

Living sphere

A website where people living with the herpes virus gather to share information, resources, personal stories and experiences.

www.livingsphere.com

Proudly sponsored by:



GlaxoSmithKline Australia Pty. Ltd. ABN 47 100 162 481
1061 Mountain Highway, Boronia, Victoria 3155.
www.gsk.com.au PC:060765 GW7211/H&T