

HERPES

– THE FACTS

How the Facts can help

Genital herpes is caused by herpes simplex virus (one of the most common viruses in mankind) and in most cases causes very 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 it very reassuring to know the facts about the virus and what treatment option is right for you. 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.

TRUE: *Anyone who has ever had sex can get genital herpes. It is not about being clean, dirty, bad or good – it is about being sexually active.*

FALSE: *It is shameful to have genital herpes.*

The Key Facts

- As many as one in three adults has the virus that causes genital herpes.

- Around 80% of people infected with genital herpes don't know they have the virus because they have very mild symptoms or none at all.

- Over 50% of people who have genital herpes get it from people who are entirely unaware that they have it themselves.

- The emotional impact of being diagnosed with genital herpes is often much worse than the condition and it doesn't deserve the upset it causes.

- Oral herpes, also known as cold sores, is commonly transmitted to the genitals through oral genital contact. Up to 50% of genital herpes is caused by the oral cold sore type of herpes simplex.

- There is effective treatment available if symptoms are problematic.

- 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.

- The virus can be passed on when there are no symptoms present.

- 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.

- Daily medication can prevent recurrences and reduce the risk of transmission to partners.

- Having genital herpes is not associated with causing cervical cancer.

Having herpes simplex is normal

Herpes simplex is no different to other herpes viruses: all of us have at least three of them. Most of us have had chickenpox (herpes zoster). Chickenpox can recur as shingles when you get older. Most of us have had herpes simplex 1 or 2, or both. At least 25% of us have cytomegalovirus (HH-5). Nearly all of us are positive for Epstein Barr (HH-4) antibodies, which causes glandular fever. Even if you have not had symptomatic disease, well over 90% of the adult population is infected. And most of us get human herpes virus (HHV) 6 and 7 by the time we are aged two years.

To be infected with a herpes virus is a state of normality, not an abnormality. It happens to all adults, some of us with symptoms and some without. The key thing is not whether you are infected or not, but whether it is causing symptoms or not – and if it is, then what can be done about it.

The Infection

What is genital herpes?

Genital herpes is a common viral infection caused by the herpes simplex virus (HSV). There are two types of the virus, types 1 and 2 (HSV-1 and HSV-2). As well as genital herpes, HSV can infect the mouth and cause cold sores. HSV-1 and HSV-2 lesions look the same and can only be distinguished by laboratory testing.

What is a virus?

Understanding viruses and how they work is the key to understanding genital herpes.

A virus is a very primitive form of life. As an intracellular parasite, a virus cannot live by itself and is entirely dependent on the cellular machinery of the cells it invades.

Viruses and bacteria are the microbial organisms that most commonly cause infection in humans, but bacteria are larger and have their own cellular machinery which enables them to live free of cells and makes them easier to isolate and eliminate.

Viral infections

The herpes virus invades the human body, often through a crack in the skin or through the lining of the mouth and genital area.

Once inside the cells, the virus uses the material in the cell to reproduce itself (known as replication). In this process the cell is destroyed. The disruption of the host cell is responsible for the characteristic signs (blisters, etc) and symptoms (tingling, pain, etc) of herpes infections and the release of thousands of copies of the virus.

Besides entering and taking over cells at the site of infection, particles of the virus enter one of the many sensory nerve fibres which are found all over the body, and proceed to move upward to where the fibre begins near the spinal cord. This is a small cluster of cells known as a sensory ganglion.

In the case of facial herpes, the virus settles in a large nerve centre (ganglion) at the base of the skull, known as the trigeminal ganglion.

In the case of genital herpes, the virus retreats to the sacral ganglion, situated near the tail of the spinal cord.

Once the virus reaches the ganglion, it lives there for the rest of our lives.

Herpes simplex isn't the only virus many of us have living with us. Anyone who has had chickenpox is host to the Varicella zoster virus, another member of the herpes virus family. This virus remains dormant for the rest of our lives; in some people, however, it can leave the nerve ganglia, travel down the nerve fibres and cause shingles. Other chronic viruses include the glandular fever virus (EBV) and cytomegalovirus (CMV), for example.

Once a virus enters our body, whatever the virus, antibodies are produced to fight it. Antibodies are the body's natural form of defence and continue to be produced long after the initial episode.

With genital herpes, antibodies help ensure that recurrences are milder than the first episode. It's interesting to note that it is quite common to find antibodies in people who have never

apparently experienced an episode of genital herpes. Either the initial infection was so mild that the person was unaware that it was taking place, or it was totally without symptoms and therefore unrecognised.

Viral shedding

When the HSV reactivates in the ganglion and travels down the nerve fibres to the skin surface, particles of virus may be 'shed' on the surface of the skin, with or without any signs or symptoms of infection present. This is called viral shedding. Viral shedding also occurs when blistering and/or sores are present.

During these times, HSV may be transmitted to sexual partners. There is no way to tell when the virus is being asymptotically shed on the skin surface and therefore no way to predict when you may be infectious and at risk of transmitting the virus to a sexual partner. However, viral shedding is most prevalent just before, during and immediately after the presence of symptoms. Viral shedding may occur approximately 5% of days per year.

Viral shedding does occur in association with outbreaks of genital herpes and therefore sexual contact should be avoided during these times. Between outbreaks viral shedding may still occur (asymptomatic viral shedding) so, as with any new relationship, it is wise to consider using condoms to reduce the chance of transmission to sexual partners.

How genital herpes is spread

You can get genital herpes by having sexual contact (vaginal, oral or anal sex) with someone who carries HSV. It used to be believed that transmission (passing it on) only occurred if herpes blisters or sores were present. However it is now known that transmission can occur when herpes blisters or sores are not present. This can occur in two situations:

- 1.** People who have recurrent genital herpes (repeated episodes) can transmit the virus between recurrences (through asymptomatic shedding). This occurs on approximately 5% of days per year.

2. There are many people who are exposed to and infected by the virus but never develop any signs or symptoms of the infection. These people carry and may 'shed' the virus from time to time without showing symptoms and in doing so may transmit the infection to their sexual partner if they have sex at that time. Up to 80% of people get HSV from partners who have no signs and symptoms of HSV and are unaware they have the infection.

For more information see 'Transmitting the infection', page 13.

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.

Sites of infection

In women, the genital areas most affected are the vulva and the entrance to the vagina. Sores can sometimes develop on the cervix.

In men, sores are most common on the glans (end of the penis), the foreskin and shaft of the penis. Sometimes, sores can develop on the testicles.

Less commonly, both men and women can experience sores on the anus, buttocks and tops of the thighs.

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.

	HSV-1	HSV-2
Orofacial herpes (cold sores)	✓	✓ (rare)
Genital herpes	✓ (common)	✓
Herpetic dermatitis (rashes or inflamed skin)	✓	✓
Herpetic whitlow (finger infection, usually at the base of a fingernail)	✓	✓
Herpetic keratitis (inflammation of the cornea)	✓	✓
Neonatal HSV (infection of newborns)	✓ (rare)	✓ (rare)

The initial infection

The initial infection that causes symptoms is usually most severe as the body's immune system has not yet come into contact with the virus.

An initial infection can last more than 20 days and it's not uncommon for someone to experience a range of generalised symptoms, such as fever, aches and pains, as well as specific genital symptoms. For others, an initial infection can be mild with minimal symptoms and often is unrecognised and undiagnosed.

The majority of people who acquire genital herpes will not experience any recognisable symptoms. Of those who do experience symptoms (20%), the first indication of infection usually starts between two to twenty days after exposure to the virus. This is referred to as the first or primary episode. The development of symptoms may take longer or be less severe in some people, especially those who have developed resistance to HSV1 from previous cold sore infection.

Symptoms can start with tingling, itching, burning or pain (these are warning symptoms also known as the 'prodrome') followed by the appearance of painful red spots which, within a day or two, evolve through a phase of clear fluid-filled blisters which rapidly turn whitish-yellow.

The blisters burst, leaving painful ulcers which dry, scab over and heal in approximately 10 days.

Sometimes the development of new blisters at the early ulcer stage can prolong the episode. On the other hand, the blister stage may be missed completely and ulcers may appear like cuts or cracks in the skin.

Some women may also notice vaginal discharge.

The severity and range of symptoms differ from person to person. Women frequently experience painful urination, and when this happens, it's important to avoid the problem of urinary retention by drinking plenty of fluids to dilute the urine and thereby reduce pain and stinging. Sitting in a partially-filled bath when urinating also helps.

Both women and men can experience generalised fever, aches and pains, and a depressed run-down feeling.

Recurrences

Some people do not experience symptomatic recurrences, but for those who do, recurrences are usually shorter and less severe than the primary episode. Recurrences are often preceded by warning symptoms (also known as prodromal symptoms) such as tingling, itching, burning or pain.

As with the initial episode, there is a large variation in people's experience of recurrences. Approximately 80% of persons having a first episode caused by HSV-2 will have at least one recurrence, while only 50% of persons with HSV-1 on their genitals will experience a recurrence. Genital herpes caused by HSV-2 recurs on average four to six times per year, while HSV-1 infection occurs less often, only about once per year. A minority will suffer more frequent recurrences.

Recurrences are more likely to recur in the first year or two after acquiring genital herpes, but for many people become less frequent and less severe over time.

Genital herpes can be elusive

In many people, the diagnosis of genital herpes can be hard to establish.

As mentioned earlier, the severity of symptoms can vary greatly from one person to another. An initial episode can, at times, be so mild as to pass unnoticed and a first recurrence may take place some months or even years after the first infection.

Up to 80% of people who have been infected with genital herpes are unaware they have the infection. These people may however transmit HSV to others.

In such cases genital herpes can lead to confusion and bewilderment in people, unable to understand the sudden appearance of infection and apparent transmission from someone else.

What triggers genital herpes?

A recurrence takes place when HSV reactivates in the nerve ganglion at the base of the spinal cord and particles of virus travel along the nerve to the site of the original infection in the skin or mucous membranes (e.g. the skin in or around the genital area). Sometimes, the virus travels down a different nerve causing recurrent symptoms at another site such as the buttocks or thighs.

Although it is not known exactly why the virus reactivates at various times, the cause can be separated into the physical and the psychological.

- **Physical:** Physical factors that have been anecdotally identified differ among people. Being run-down, suffering from another genital infection (compromising the local skin area), menstruation, drinking too much alcohol, exposure of the area to strong sunlight, conditions that weaken the immune system, prolonged periods of stress or depression, are all factors that can trigger an episode. Less commonly, friction or damage to the skin, such as may be caused by lack of lubrication at the time of sexual intercourse, can lead to a recurrence. In summary, anything that lowers your immune system or causes local trauma (damage) can trigger recurrences.
- **Psychological:** Recent studies have demonstrated that periods of prolonged stress may precipitate more frequent recurrences. It is also common to experience stress and anxiety from having recurrences.

Transmitting the infection

People with herpes can be infectious either at the time of symptoms or sometimes when there are no symptoms present.

People who experience an episode of herpes, either oral or genital, should consider themselves infectious from the first symptoms to the healing of the last ulcer.

Oral herpes lesions (cold sores) are also an important source of infection through oral sex and this should be avoided if one partner has an oral cold sore. People worry a great deal about transmitting genital infection, but are less concerned about oral herpes (cold sores). The main way women get genital infection is from cold sores, via oral sex. One is considered to be a nuisance, the other is associated with a degree of stigma. This is unhelpful and both should be considered as a “manageable nuisance”.

People with no obvious lesions can still have infectious virus present at certain times through a process known as “asymptomatic viral shedding”. Asymptomatic viral shedding cannot be predicted but is known to occur on at least 5% of days each year.

Occasionally one partner in a long term relationship may develop symptoms of herpes for the first time. Often this is due to one or both of the partners being carriers of HSV and not knowing it. It does not necessarily imply recent transmission from someone outside the relationship.

By avoiding sex when the signs of herpes are present, and by using condoms with sexual partners between outbreaks, the chance of passing on herpes is reduced. Taking daily oral antivirals, known as suppressive treatment (see page 36), as well as using condoms, makes the chances of passing herpes extremely low.

It is highly unlikely that HSV will be passed on to other people by the sharing of towels or toilet seats. Outside the body the virus cannot survive for more than a few seconds. The virus is killed by the use of soap and water.

Diagnosis

Because people’s experience of genital herpes varies so greatly and because the treatment of each sexually transmitted infection is distinctive and specific, accurate diagnosis is essential.

Accurate diagnosis of genital herpes includes taking a history, doing a physical examination and taking a swab for viral culture.

Diagnosis is easier if early ulcers or blisters containing the fluid necessary for laboratory confirmation are present.

Laboratory confirmation

In order to confirm genital herpes it is necessary to prove the presence of HSV-1 or HSV-2.

The usual procedure is for the doctor to take a swab from the area affected. A sample of the fluid from a blister or from ulcers is taken and sent away for analysis. The test can identify whether the virus infection is caused by HSV-1 or HSV-2.

Because it is possible for a person with genital herpes to have another sexually transmitted infection at the same time, a full genital check for sexually transmitted diseases (STIs) should be made.

Blood tests

Commercial blood tests specific for HSV-1 and 2 antibodies are now available but are not recommended for use in the general population as a routine screen. The time taken to develop antibodies is usually 2 to 6 weeks after infection, but it may be up to 6 months and false positives and false negatives can occur in these tests.

Because of the limitations of a blood test to diagnose herpes, it is recommended you discuss the implications of the test with someone who has experience with requesting them and interpreting the results in light of your particular presentation.

What It Means to Have Genital Herpes

Overall health

Genital herpes is essentially a minor, sometimes recurring, skin infection; 'cold sores' which occur on the genitals rather than the face. It does not cause long-term ill health or affect longevity of life. People who get genital herpes can and do lead perfectly normal lives.

As described earlier, a primary infection can be severe and involve generalised 'flu'-like symptoms. This, combined with the pain and discomfort of the sores and, in some cases, secondary infection, can leave people feeling very run-down. Fortunately, recovery is fast once the herpes has healed.

Sexual relationships

People with recurrent genital herpes may reconsider some aspects of sexual intimacy. For example using non-genital forms of sexual contact when skin blisters or ulcers are present. It also means considering, if, how and when you are going to tell a sexual partner (**see Chapter 2: Genital Herpes and Relationships, page 23**). Many people do not understand what it means to have genital herpes or realise how common it is. Most people react supportively when told and appreciate and respect your honesty. People who choose not to tell a sexual partner risk the burden of fear, guilt and secrecy.

In an ongoing relationship where both partners fully understand the chance of transmission, the use of condoms becomes less relevant.

For people who experience very frequent herpes recurrences, suppressive antiviral therapy, which reduces the frequency of recurrences, can help reduce the impact the herpes recurrences can have on sexual activity and may reduce the risk of transmission.

Fertility

Genital herpes is not hereditary. HSV has no effect on fertility and is not transmitted via men's sperm or women's ova (eggs).

Pregnancy

See Chapter 3: Herpes and Pregnancy, page 42

Women with genital herpes can experience a safe pregnancy and vaginal childbirth. This is especially so when a woman has a diagnosis of genital herpes prior to becoming pregnant. In the situation when the mother already has a history of genital herpes, she will have antibodies circulating in her blood which will protect the baby during the pregnancy and delivery.

Being a parent

Genital herpes in either parent does not affect babies/children and there is little risk of transmission as long as normal hygiene is ensured.

Parents should be aware, however, that HSV can be transmitted from oral cold sores simply by kissing and can cause serious, widespread (disseminated) infection in the newborn. Fortunately, by the time a baby is about six months, the immune system is well able to cope with exposure to the virus. Initial exposure to HSV in babies and young children, after being kissed by someone with a cold sore, can cause gingivostomatitis, an infection of the mouth and gums which goes largely unrecognised and untreated.

Parenting, Children and Genital Herpes – Reassurances

Parents commonly tell us about worries they have about passing on genital herpes to their children in the course of daily life (we are not referring here to pregnancy and childbirth – that’s another topic). Perhaps because there is so little information that addresses parents’ concerns, parents end up devising all sorts of ‘safety strategies’ that are completely unnecessary.

The key message is – loving parents (this category includes grumpy, tired, in-need-of-a-break parents) do not pass on genital herpes to their children through the ‘normal’ intimacies of family life. It’s important that fear of transmission doesn’t get in the way of loving touch and shared experiences.

- Snuggling in bed together is ‘safe’ – the virus isn’t crawling on the sheets from one person to the next.

- Sharing a bath or shower together isn’t a way the virus is passed on – the same is true for spa baths and swimming pools.

- Washing clothes in the same washing machine, even when a person has a recurrence, will not pass on the virus.

- A child brushing against an adult’s upper thighs or abdomen while the adult has a recurrence won’t pass on the virus.

- If an adult uses the toilet or has touched the genital area and forgotten to wash their hands, this omission is not problematic in terms of herpes. The virus is fragile and dies when it leaves living cells.

- Washing with ordinary soap and water is clean enough – there’s no need to use any special hand or toilet seat sanitisers.

- I know children do all sorts of odd things that you can’t anticipate, but even if they put your worn knickers on their head they are not going to contract the virus – relax and laugh with them.

Managing Genital Herpes

Treatment

Genital herpes is manageable. Over the years a number of treatments offering effective relief from symptoms of genital herpes, have been developed.

Simple treatments for the relief of discomfort

The following treatments may alleviate the pain and discomfort of genital sores.

- **Salt baths**, used to wash the genital area, can clean, soothe and dry the sores. Use 1 teaspoon of salt in 600ml of water or a handful in a shallow bath.
- **Pain relievers** include simple analgesics (such as aspirin and paracetamol), ice (which can be soothing if applied directly to the sores) and creams with an anaesthetic component. Creams, however, can slow down drying and should therefore be used sparingly and only for pain relief.
- **Loose underclothes**, preferably cotton (not nylon), can help minimise discomfort and allow healing.

For anyone who is experiencing extreme pain when urinating, sitting in a warm bath or using a pump bottle full of water and spraying water on yourself while urinating can make the process less painful. **It is extremely important to drink plenty of fluids as this dilutes the urine.**

Antiviral therapy

The standard, effective and specific treatment for genital herpes is antiviral therapy, which is usually in tablet form. Antiviral drugs work by stopping HSV from replicating in the body. The antiviral drug only works in body cells where the herpes virus is present, therefore making the drug safe and free from side effects. The treatment only works while you are taking the drug and cannot prevent future outbreaks once you stop taking it.

Antiviral treatments can:

- Shorten the duration of a genital herpes outbreak and help speed healing.
- Reduce the number of outbreaks suffered – or prevent them completely. (See *Chapter 2, page 36*)

Antiviral medications can be used in two ways:

1. To treat outbreaks as they happen – this is known as ‘episodic’ treatment. With episodic treatment, the aim is to shorten the time each outbreak lasts and to relieve symptoms. This works best in persons who experience symptoms some hours before blistering occurs.
2. To prevent or reduce recurrences – this is known as ‘suppressive’ therapy. If your recurrent outbreaks are frequent or severe – or if you find them particularly problematic – your doctor may recommend that you take oral antiviral medication every day to help prevent recurrences happening. Suppressive therapy is taken continuously, i.e. daily, for months or even years.

Suppressive antiviral therapy has also been shown to reduce viral shedding between episodes and therefore may help reduce the risk of transmitting the virus to sexual partners. Recent studies have shown suppressive treatment with Valtrex reduces transmission of symptomatic herpes by 75%.

Oral antivirals currently available in New Zealand are:

1. **Aciclovir**, which is available fully subsidised by prescription. Aciclovir is very safe and effective, even when taken for long periods of time.
2. **Valtrex**, which is available fully subsidised by prescription from your doctor through a Special Authority application, for individuals with problematic recurrent herpes not responding to aciclovir.

Initial or first episode

For people experiencing the initial or primary episode, a course of aciclovir tablets can markedly reduce the duration of the episode and give effective relief from symptoms.

Aciclovir does not eliminate the herpes virus from the body and therefore a course of aciclovir will not provide a “cure”, but assists in the management of the infection.

Recurrences

See Chapter 2, page 36

Many people prefer suppressive therapy for frequent or severe recurrences, or if causing psychological problems, suppressive therapy can be extremely effective and should be considered. For those who experience less frequent recurrences, episodic (three to five day course) therapy may be helpful if taken as soon as prodromal (warning) symptoms indicating a recurrence are experienced. Or some people choose not to take treatment for very mild recurrences.

Topical therapy

Topical antiviral creams are available over the counter but are no longer subsidised on the pharmaceutical schedule and are not recommended as a treatment for first episode or recurrent genital herpes as they are of little benefit.

Counselling

If you have just found out that you have genital herpes, it is likely that you will have a lot of questions.

A diagnosis of genital herpes often comes as a shock. Adequate information about genital herpes and the implications for the future are an important part of the initial treatment.

Seeing a counsellor may be a good idea to discuss any concerns you may have. Counselling offers a way of dealing with your concerns.

Support groups

The experience and support of other people with herpes can be extremely valuable. Herpes support groups exist in some centres. These groups have the objective of providing support and education to people with herpes.

The activities of the herpes' support group include providing advice and literature and arranging seminars, workshops and social gatherings.

"I didn't want to see a counsellor or have contact with a support group when I was diagnosed, but when I finally did call the Helpline and spoke to someone it was the best thing I had done. I felt so much better immediately. I had been so down about it, and this contact helped me deal with and accept it. I realise what a shame it was that I hadn't done this earlier. I highly recommend it." – MJ
