

THE FACTS

A guide for people with Herpes Simplex



www.herpes.org.nz

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This pamphlet was written in partnership with people with herpes, for people with herpes.

Some Key Terms

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

Asymptomatic shedding: When the virus is shed from the skin with no symptoms present.

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, with or without symptoms.

<u>Winning the war in your mind.</u> 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.

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.
- 75% 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 2 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 is very 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 asymptomatically 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:

- 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. (Remember it is quite possible your partner may
 already carry one or both of the herpes simplex viruses. Once
 an individual has the virus they cannot be re-infected.)
- 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 10.

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)	V	✓ (rare)
Genital herpes	✓ (common)	~
Herpetic dermatitis (rashes or inflamed skin)	~	~
Herpetic whitlow (finger infection, usually at the base of a fingernail)	~	V
Herpetic keratitis (inflammation of the cornea)	~	V
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 2–20 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 HSV-1 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 people having a first episode caused by HSV-2 will have at least one recurrence, while only 50% of people with HSV-1 on their genitals will experience a recurrence. Genital herpes caused by HSV-2 recurs on average 4–6 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 29), as well as using condoms, makes the chances of passing on 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 laboratory testing.

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 HSV-2 antibodies are now available but are not recommended for use in the general population as a routine screen. There are many reasons that a blood test to diagnose herpes is not recommended as a routine test. The blood test has many limitations and doesn't necessarily provide information that is helpful in management of the infection. The time taken to develop antibodies is usually 2–6 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 Section 2: Herpes and Relationships, page 18). 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.

In a long-term monogamous relationship, when one person gets herpes and the other person is not symptomatic, it is most likely both parties have the virus, so practising safe sex is not necessary as they cannot re-infect each other.

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 Section 3: Herpes and Pregnancy, page 34

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 6 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

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- 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 Section 2, page 29)

Antiviral medications can be used in two ways:

- 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 valaciclovir reduces transmission of symptomatic herpes by 75%. Valaciclovir tablets are the recommended treatment for herpes in New Zealand.

 Valaciclovir, which is available fully subsidised by prescription, is very safe and effective, even when taken for long periods of time.

• Initial or first episode

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

Valaciclovir does not eliminate the herpes virus from the body and therefore a course of valaciclovir will not provide a "cure", but assists in the management of the infection.

Recurrences

See Section 2, page 29

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** therapy – valaciclovir 500mg twice daily for 3 days – may be helpful if taken as soon as prodromal (warning) symptoms indicate a recurrence. Ask your doctor to provide a prescription of 50 x 500mg tablets so you can self-initiate treatment at onset of symptoms.

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. Talking to a specialist nurse counsellor may be helpful. Counselling offers a way of dealing with any concerns you may have (Herpes Helpline: phone **0508 11 12 13** tollfree from a landline or 09 433 6526 from a mobile).

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 groups include providing advice and literature and social gatherings. Here is a link to a support group in Auckland www.meetup.com/Auckland-H-Friends

"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

HERPES AND RELATIONSHIPS

Discussing Genital Herpes with Your Partner

Many people do not feel comfortable talking about sexuality and sexual health issues. This booklet will help you explore ways of feeling more confident in discussing herpes in the context of a sexual relationship.

Cold sores on the mouth and genital herpes are medically the same condition. The significant difference arises from the stigma that tends to accompany an infection that is associated with being sexually transmitted.

Most people find that their partners are both supportive and understanding. It is a common assumption to initially think that a person may base their judgement of you on the fact you have genital herpes. However, for most this is a minor skin infection. People fear the possibility of rejection but the reality of this is that it rarely happens.

Because fear of rejection is a concern, it leads some to question why they should risk talking about herpes. Accordingly, some people choose not to tell. Instead they abstain during outbreaks, practice safe sex at other times, and hope for the best.

This strategy may have more disadvantages than advantages. First of all, you spend a lot of time and energy worrying that your partner is going to get herpes. It's much harder to tell someone if they just found out they're infected. For most people, the anxiety over not telling is worse than the telling itself.

On the other hand, telling your partner and allowing them to enter into the relationship with full knowledge of your infection, will provide an opportunity for them to learn about and not fear genital herpes. This is because, when you have an outbreak, you can discuss it with a partner instead of making excuses for why you can't have sex. Excuses create distance between partners and often lead to misunderstanding and guesswork.

Your partner might interpret your excuses in ways more detrimental to the relationship than an honest discussion about genital herpes would be.

If you are able to discuss the situation openly and honestly, you can find imaginative ways to be 'safely' sexually intimate.

And remember, your partner may already have one or both strains of HSV; just because they have never had symptoms doesn't mean they don't have it.

Genital herpes is extremely common, with up to one in three adults who are sexually active having genital herpes, although approximately 80% remain unaware that they are infected.

Inaccurate and stigmatising articles and advertising have contributed to many of us having negative herpes-related beliefs that make it difficult to convince ourselves that others would want to be with us. It's important to recognise these beliefs and consciously change them. Accepting the fact that you have herpes and are still the same person you were before will make it easier to have a fulfilling relationship.

Getting the facts

The more emotionally charged an issue, the more important it is to find out the facts. Most people know little or nothing about herpes. Frequently, what knowledge they have is coloured by myth and misconception. Having the correct information not only makes it easier for your partner, it makes it easier for you.

Following are some of the basic facts about herpes that might be important points to tell a partner.

There is a lot more information about herpes. Have educational materials on hand for your partner to read. Be prepared to answer their questions.

- Most people who have genital herpes do not know they've got it. The absence of symptoms does not mean a person has not got genital herpes.
- Herpes simplex virus (HSV) most often shows up as small blisters or sores on either the mouth (cold sore or fever blisters) or the genitals.
- HSV can be passed on when one person has virus present on the skin and another person makes direct skin-to-skin contact with live virus.
- Virus is likely to be present on the skin from the first sign
 of prodrome (tingling or itching where the outbreak
 usually occurs) until the sores have completely healed
 and new skin is present.

- There are likely to be certain days when active virus might be on the skin even though there are no obvious signs or symptoms.
- Always using latex condoms can reduce the risk of transmitting the virus by approximately 50%.
- Herpes is very frequently transmitted by infected persons who don't know they are infected. Since they have not been diagnosed, they are unaware that they may be contagious from time to time.
- There is effective oral antiviral treatment for people with problematic genital herpes.

Preparing to tell your partner

What you say and how you say it is going to depend on your own personal style.

Your attitude will influence how this news is received. Psychologists have observed that people tend to behave the way you expect them to behave, and expecting rejection increases the chances of an unhappy outcome.

A straightforward and positive conversation about herpes issues is the best approach and may be helped by forward planning.

How long should you know someone before you tell them?

If it appears the two of you could end up in bed on the first date, that's probably a good time.

Ideally, though, it's best to give it a few dates before telling. Allow the relationship to develop a little. It's going to be easier if the two of you enjoy a degree of comfort and trust in each other's company. It's probably better to wait until you know and trust each other.

There are good and bad times to bring up this topic. Some of the more inappropriate moments include the crowded bar or party scene, travel en route to a romantic weekend, or a talk when you've just finished having sex. Talking just prior to love-making is not a good idea either.

Bring up the issue when you are not already 'in the mood' for sexual intimacy, when you're feeling good about yourself, and when you both have an opportunity to have a discussion.

The discussion could take place anywhere you feel safe and comfortable. Some people turn off the TV, take the phone off the hook, and broach the subject over a guiet dinner at home.

Others prefer a more open place, like walking in the park, so that their partner will feel free to go home afterwards to mull things over. This allows both people to work off a little nervous energy at the same time.

No matter where you choose to have the discussion, it's important to allow for the fact that one or both of you might get emotional.

Try to be natural and spontaneous. If you find yourself whispering, mumbling, or looking at the floor, stop for a moment and try to speak calmly and clearly. Look your partner in the face. Your delivery affects your message. If you are obviously upset, the person you're speaking with might perceive the situation as being much worse than it is.

Conversation starters

The following opening statements represent a variety of nonthreatening ways to prompt discussion. They are not intended to be regarded as scripts.

- "I have something I'd like to discuss with you. Have you
 ever had a cold sore? The reason I ask is that cold sores
 are caused by a type of virus. Herpes simplex virus. I have
 the virus. Only instead of getting a sore on my mouth,
 I get one in my genital area."
- "When two people get along as well as we do, I think we owe it to each other to be totally honest. I'd like to talk about our sexual histories."
- "I really enjoy being with you, and I'm glad that we're becoming more intimate. I think it's important that we talk about sex. Can we talk now?"
- "We're both responsible adults who want to do what's best for each other and ourselves. Let's talk about safe sex."
- "I feel that I can trust you and I'd like to tell you something personal. Last year, I found out that I had contracted genital herpes."

Try not to be melodramatic. This is not a confession or a lecture, simply the sharing of information between two people. Avoid negative words and keep the dialogue simple and factual: "I found out two years ago that I have herpes. Luckily it's both treatable and manageable. Could we talk about what this means for us?"

"When I finally told my partner I had genital herpes, he was relieved, he thought it was something much worse..." – AH

Look for logical opportunities to bring up the subject. This way it seems more natural, there's no time to get nervous, and you're not making it into a bigger deal than it is. With more and more singles talking about 'safe sex' and HIV/AIDS, these opportunities come up fairly frequently. You might even be surprised to learn that your partner has been equally concerned about telling you that they have genital herpes or another sexual infection. In fact, the probability of this is reasonably high, given the statistics on HSV.

Realistic and unrealistic expectations

People may just need a little time to assimilate the information. This is where having good written information helps. Consider giving them reading material or referring them to a sexual health clinic, the Herpes Helpline **0508 11 12 13** tollfree from a landline or 09 433 6526 from a mobile, or the herpes website **www.herpes.org.nz**, to verify the information you've given them.

Whatever the reaction, try to be flexible. Remember that it took you time to adjust as well.

Negative reactions are often no more than the result of misinformation. In some cases, they are brought on when a person fears that you're asking them to commit to a relationship, instead of just informing them of the situation. If your partner decides not to pursue a relationship with you simply because you have herpes, it's better to find out now. It takes a lot more than the occasional aggravation of herpes to destroy a sound relationship.

Some people react negatively no matter what you say or how you say it. Others might focus more energy on herpes than on the relationship. These people are the exception, not the rule. This is not a reflection on you. You are not responsible for their reaction. If your partner is unable to accept the facts, encourage them to speak with a medical expert or counsellor.

The majority of people will react well. They will respect the trust you demonstrate in sharing a personal confidence with them. With the proper approach and information, herpes can be put into perspective: an irritating, sometimes recurrent skin condition – no more, no less.

Regarding the relationship overall, know that you can have the same level of intimacy and sexual activity that any couple can. It is true that in an intimate sexual relationship with a person who has herpes (oral or genital), the risk of contracting herpes will not be zero, but while there is a possibility of contracting herpes this is a possibility for any sexually active person. And the person may unwittingly already have been exposed to the herpes virus in a previous relationship.

All relationships face challenges, most far tougher than herpes. Good relationships stand and fall on far more important issues – including communication, respect and trust.

Whether or not this relationship works out, you have enlightened someone with your education and experience, correcting some of the myths about herpes that cause so much harm. You have removed the shroud of silence that makes it so difficult for others to speak. And you have confronted a personal issue in your life with courage and consideration.

"The first time I told someone I had genital herpes in the early stages of a relationship, he said: 'You want to know something... I have too.' ... I couldn't believe it... all that worry... we had to laugh." – JM

What It Means for Partners

Your partner has genital herpes. Your support is very important in helping you and your partner to understand what this means. When your partner goes back to the doctor, you may wish to go too, so that you can find out more about the infection. In the meantime, here are answers to some guestions you may have.

What is genital herpes?

Genital herpes is a common infection generally transmitted through sexual contact. It is caused by one of two members of a family of viruses which also include the viruses causing chickenpox and shingles, and glandular fever.

Usually, genital herpes is caused by infection with herpes simplex virus type 2 (HSV-2), and studies suggest that in some countries, one in five people are infected with this virus. Genital herpes can also be caused by HSV-1, the virus which usually causes cold sores on the lips and face, through oral-genital contact.

Genital herpes, for most people, is an occasionally recurrent, sometimes painful condition for which effective treatment is now available. Generally, it is not life-threatening and has no long-term repercussions on one's general physical health. Anyone who is sexually active is at risk of catching genital herpes, regardless of their gender, race or social class.

How has my partner caught genital herpes?

Genital herpes can be transmitted through direct contact with an infected blister or sore, usually through sexual contact. It can also be transmitted when there are no symptoms present. HSV-2 infection is usually passed on during vaginal or anal sex. HSV-1 is usually transmitted by oral sex (mouth-to-genital contact).

If your partner has only just been diagnosed as having genital herpes, this does not necessarily mean that they have been unfaithful to you, or sexually promiscuous in the past.

Your partner may have caught genital herpes from you. It is possible that you carry the virus without knowing that you have it, since up to 80% of people who have been infected with HSV-2 have either no symptoms or such mild symptoms they are unaware they have the virus. So it is very easy for you to have unwittingly transmitted the infection to your partner. The symptoms of the infection vary greatly between individuals – it might be totally unnoticeable in you, but cause severe blistering in your partner.

Since the genital herpes virus can be transmitted through oral sex as well as genital-to-genital sex, it is also possible that your partner caught the virus from a cold sore on your mouth or face. Remember, it is possible you can pass the virus on even if you didn't have a cold sore present at the time of contact.

Alternatively, your partner may have contracted the virus from a previous sexual partner, perhaps even several years ago. The virus can remain inactive in the body for long periods, so this may be the first time it has caused symptoms.

What are the symptoms?

If your partner is having a first episode of genital herpes, they are likely to feel generally unwell and have fever, headache, and general bone and muscle aches, as well as irritation in the genitals. This may last for several days, during or after which reddened areas may appear on the genitals. These may develop into painful blisters. The blisters then burst, generally to leave sores which gradually heal, usually without scarring.

The severity of this first episode varies between individuals, but for some people it may be severe and last for up to 3 weeks if not treated

These symptoms should quickly resolve with treatment. The doctor should have given your partner a course of antiviral treatment. This is an effective medicine which, although it does not cure genital herpes, can speed recovery and reduce the severity of the episode. There are also other steps which your partner can take to relieve the pain.

However, for many people who have genital herpes, the physical symptoms are far outweighed by the emotional stress relating to the diagnosis. There are many misconceptions about genital herpes, including the belief that it is associated with promiscuity, and these have given it a reputation which may cause your partner to feel angry and shocked by the diagnosis.

Anxiety, guilt, loss of assertiveness and fear of rejection are also common emotions.

Your support can be very important in helping your partner to deal with these feelings and to minimise the effect of genital herpes on their life.

How do I know if I have genital herpes?

Most people who have genital herpes don't know because they have either no symptoms or such mild infrequent symptoms, it goes unrecognised. Diagnosis is made from having laboratory confirmation from swabs taken from clinical symptoms of an active episode.

If I don't have symptoms, are there any tests to find out if I have HSV?

There are commercially available blood tests that can distinguish between herpes simplex virus type 1 (HSV-1) and herpes simplex virus type 2 (HSV-2) antibodies. The time taken to develop antibodies is usually 2–6 weeks after infection, but can be up to 6 months. It is also important to know that false positives and false negatives are common in these tests and they do not identify the site of the infection. These tests are not recommended in the general population for trying to establish if you have herpes or not

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 them. If you think you might be showing signs of the infection, consult your doctor.

Do the symptoms return?

The symptoms of genital herpes may reappear from time to time. This is because once the virus is acquired, it stays permanently in the body. Most of the time it remains inactive, but every so often it may reactivate and cause another outbreak.

Each individual is different – some people never have a recurrence; others may have recurrences several times a year. However, recurrent outbreaks are usually shorter and less severe than the first episode.

Certain events or situations can trigger recurrences, and you may be able to help your partner avoid or reduce the trigger factors, which may include stress at work or home, fatigue, ill health, loss of sleep, friction due to sexual intercourse, and menstruation in women.

If your partner has frequent or severe episodes of genital herpes, or if the recurrent outbreaks are causing a lot of anxiety for your partner, then they may benefit from suppressive therapy (taking oral antiviral tablets continuously), which prevents or reduces recurrences.

What can we do to reduce my chances of getting the infection?

If you take the necessary precautions, the chances of getting the virus from your partner are reduced. Genital herpes does not mean abstinence from sex or a reduced enjoyment of sex.

The risk of transmitting the virus can be reduced about 50% if you use condoms. The continued use of condoms in a long-term relationship is a personal decision that only the couple can make.

Most find that as the importance of the HSV infection in their relationship is seen in perspective, that condom use becomes less relevant if this is the only reason condoms are being used.

However, most couples choose to avoid genital skin-to-skin contact during an active episode of herpes because this is when the virus is most readily transmitted. This period includes the time from when your partner first has warning signs of an outbreak, such as a tingling or burning in the genitals, until the last of the sores has healed. Also, sexual activity prolongs the healing of the episode.

Transmission risk is increased if there are any breaks in the skin. For example, if you have thrush or small abrasions from sexual intercourse, often due to insufficient lubrication. It can be helpful to use a lubricant specifically for sexual intercourse and avoid sex if you have thrush. Sexual lubricant is helpful right at the start of sexual activity.

Sores in other areas – such as the buttocks and thighs – can be just as contagious as those in the genital area, and care should be taken to avoid direct contact with such sores during sex.

At other times, there is still a small risk of transmitting the infection through a process known as asymptomatic shedding, even if your partner is showing no signs of genital herpes. This risk can be reduced significantly if a person with herpes takes suppressive oral antiviral treatment.

If you or your partner has a cold sore, it is advisable to avoid oral sex as this can spread the virus to the genitals.

You cannot catch genital herpes by sharing cups, towels or bath water, or from toilet seats. Even during an outbreak, it is only skin-to-skin contact with the parts of your partner's body which have the sores which you need to avoid. You can still cuddle, share a bed, or kiss.

Where can I get more information and advice?

After you have read this booklet and discussed genital herpes with your partner, you might have specific questions or concerns. You can ring the Herpes Helpline **0508 11 12 13** tollfree from a landline or 09 433 6526 from a mobile, or your doctor or your partner's doctor should be able to answer such questions or recommend other experts who can provide advice and support.

Sexual health clinics also provide confidential free treatment, management and information.

The NZHF website **www.herpes.org.nz** has more information.

Controlling Recurrent Genital Herpes: The use of oral antivirals in herpes management

The following section gives you in-depth information about the use of oral antivirals. Valaciclovir/aciclovir have been used for this indication for a number of years now and found to be highly effective in controlling recurrences.

Some people with genital herpes have identified factors which may influence frequency or severity of recurrences. Factors such as stress, diet and lifestyle may be worth considering when looking at ways of managing herpes in your life. Each case is individual and what works for one may not work for another.

Frequent or severe recurrences of genital herpes infection may interfere with normal work and social activities, and cause disruption to your sex life. However, there are steps which you can take to reduce outbreaks and help bring the virus under control. This section explains what you can do and answers some other questions that you may have about living with genital herpes.

Individuals will find their own method of what works best for them and it is important you have a doctor who works with you and leaves you in control of the process once you have all the information.

Recurrences

Once you have acquired the herpes simplex virus (HSV-2) it remains permanently resident in your body, living in a structure called the dorsal root ganglion, which is part of the nervous tissue located near to the base of the spinal column. It spreads down the nerve to break out on the skin from time to time. Most of the time it is inactive, but every so often something happens to reactivate it, which causes the symptoms you recognise. Sometimes the virus can reactivate and be shed without recognisable symptoms (asymptomatic shedding).

It is not known exactly why the virus becomes active again. Some people recognise certain trigger factors which contribute to an outbreak. These may include friction due to sexual intercourse, ill health, stress, fatigue, depression, loss of sleep, direct sunlight and menstruation.

Many people find that as the years go by the number and severity of their recurrences naturally diminish. There may be several reasons for this, for example, changes in lifestyle, in the body's immune system, in the virus itself, or in your ability to cope with the trigger factors.

Education and counselling will often help an individual cope with recurrences. People who make contact with a support group often describe this as being a turning point in their coping with genital herpes in their life.

What is 'suppressive therapy'?

Suppressive therapy involves taking an oral antiviral drug every day for prolonged periods. It interferes with the virus reproductive cycle and so prevents or dramatically reduces the number of recurrences. When recurrences do occur, they are usually less severe and shorter lasting.

If you find the frequency of your outbreaks unacceptable, or if you are finding it difficult to cope emotionally with having recurrences of genital herpes, tell your doctor and discuss the use of suppressive therapy.

How effective is suppressive therapy?

Studies have proven that continuous suppressive antiviral therapy can dramatically reduce the frequency of outbreaks, or prevent them altogether, and reduces the risk of transmission by 50%.

For example, a very large study found that people who had an average of over 12 occurrences a year, could reduce the frequency of their outbreaks to less than two a year after one year of continuous suppressive therapy.

The study also showed that if recurrences do occur during suppressive therapy, they are usually less severe and shorter lasting.

Who is suppressive therapy suitable for?

Suppressive antiviral therapy is suitable for you if one of the following applies to you:

- · You are having frequent recurrences.
- You have less frequent but particularly severe or longlasting outbreaks.
- You find recurrences of genital herpes are making you depressed, anxious or withdrawn, or the emotional upset caused to you by genital herpes is disrupting your social activities or sex life. Such feelings can themselves bring on a recurrence and so you can easily get into a vicious cycle.

- Taking suppressive therapy, perhaps only for a short time, can help you break the cycle and give you a sense of control over the infection.
- You experience severe pain (neuralgia) due to recurrent episodes.
- You have only a few recurrences but they always occur during specific situations, for example, when you have exams or go on holiday. You may wish to start suppressive therapy before you go on holiday and continue on it until you return, thereby reducing the chance of a recurrence.
- You want a worry-free period when getting into a new relationship and are working through when and how to tell – suppressive therapy also decreases the risk of transmission to a partner.
- You know that stress is a trigger factor for your recurrences, and you are going through a stressful period, for example a new job or a recent death in the family.
- You want to avoid a situation which would be spoilt by a recurrence, for example if you are going on your honeymoon.
- You have another illness which triggers a recurrence of herpes – a course of suppressive therapy may be appropriate until the condition triggering the outbreak has resolved.

How do I take suppressive therapy?

- Valaciclovir is now the recommended treatment for suppressive therapy in New Zealand. It is the new generation antiviral with better absorption than aciclovir.
- Valaciclovir tablets 500mg taken once a day. If you start
 suppressive therapy it is important to take it at the same time
 every day without missing out days or taking it haphazardly.
 If you continue to get symptoms on the 500mg dose then the
 doctor needs to increase the dose to 1000mg daily.

How long will I need to take the treatment?

Many people who use suppressive therapy say that they get so used to taking the tablets or capsules they are happy to continue with the treatment.

If you choose suppressive therapy, you do not have to stay on it permanently. If you prefer, you can take it until you feel in control of the infection, but this is usually a period of 6–12 months initially. Your doctor may suggest you stop the suppressive therapy for several months after you have taken suppressive therapy for some time, in order to assess how active your genital herpes remains. If you are still having problems with recurrences, you and your doctor may then decide that you should start suppressive therapy again.

Is it safe to take the treatment for a long time?

Valaciclovir has been reported to cause no serious side-effects, even after years of use. A few people taking suppressive therapy do experience minor side-effects such as headache, nausea and diarrhoea. If you have a problem, discuss this with your doctor.

Research to date shows that people with normal immune systems who are on oral antivirals for a long period do not develop virus resistance or clinical breakthrough. Also, there is little interaction with other drugs, e.g. the contraceptive pill is unaffected by valaciclovir or aciclovir.

Will suppressive therapy make it easier to live with genital herpes?

Suppressive therapy may give marked improvement to your emotional well-being. Many people find the fact that they can control the infection gives a boost to their sense of well-being and self-confidence. Even if only taken for a few months, suppressive therapy can help you to come to terms with emotions caused by recurrent genital herpes, including depression and anxiety.

However, suppressive therapy is only part of it. There are benefits gained from expert counselling from your doctor or nurse, or by speaking to a specialist nurse counsellor on the Herpes Helpline **0508 11 12 13** tollfree from a landline or 09 433 6526 from a mobile. Make sure that you continue to talk to a health professional you are comfortable with, at least until you feel completely at ease with having genital herpes and in command of the infection.

Are any other treatments effective against genital herpes?

The antiviral drug aciclovir was the first therapy that had been shown conclusively to be effective in treating genital herpes. Newer generation antiviral drugs (valaciclovir) are now available, which work in a similar way to aciclovir, are more effective and require less frequent dosing to treat or suppress the recurrence.

Recent studies using an HSV-2 vaccine are showing some promise in both prevention and transmission of HSV-2. However, these are still in the developmental research stage and will not be available commercially for some years.

Many people find that having a healthy diet, eating regularly and getting enough sleep are helpful in preventing recurrences.

I didn't want to take any drugs, so I tried natural therapies. These didn't work. I now take valaciclovir 500mg daily and have not had any outbreaks since. If your outbreaks are frequent, I really recommend it."

— MK

Can genital herpes harm babies, either during or after pregnancy?

Having genital herpes does not affect your ability to have a baby. Overall, the incidence of neonatal herpes (babies up to 28 days old infected by herpes) is very rare. However, when it does occur it is potentially very harmful to the baby. It is therefore important to tell your doctor or midwife if you or your partner have had a history of genital herpes. They will then be able to provide information, reassurance and optimal management.

Recurrent episodes of genital herpes during pregnancy are not harmful to the fetus. If you have genital herpes at the time when your baby is due, there is a small risk that the baby could become infected at delivery as it passes down the birth canal. This risk is most substantial for mothers who are having their first ever episode of genital herpes near to or during delivery. However, if you are simply having a recurrence of genital herpes, then the chances of your baby becoming infected at delivery are low as the baby is protected by antibodies circulating in the mother's blood.

Is it safe to take drug treatment for genital herpes during pregnancy?

As with any drug therapies, oral antiviral tablets are not routinely recommended for use during pregnancy. Valaciclovir/aciclovir have been used for treating genital herpes for over 40 years and as with any drug, a register has been kept to report any adverse side effects for women who have taken it during pregnancy. To date there have been no adverse side effects reported for either the baby or the mother.

Due to the potential seriousness of a primary episode of genital herpes for the baby and the relative safety of valaciclovir/aciclovir, it is now recommended that valaciclovir/aciclovir are used for treating a first episode of genital herpes or severe recurrent herpes in the last trimester of pregnancy. It is believed that the benefit of using valaciclovir/aciclovir, by reducing the risk of transmission of herpes to the baby, outweighs the risk of not using it.

See Section 3: Herpes and Pregnancy, page 34

Episodic treatment

Episodic treatment is taking a short course of valaciclovir at the onset of a recurrence. Those who have less frequent recurrences may find episodic treatment useful. It works best if treatment is taken as soon as warning signs of an impending recurrence (such as neuralgic pain and/or tingling or buzzing sensation in the skin), occur. If taken soon enough, it may stop ulcers developing (known as aborting the lesion). It helps to have valaciclovir available beforehand. If you want to use episodic treatment, ask your doctor to prescribe a supply for you, so you can start the treatment as soon as you feel the symptoms start. As soon as you get the 'warning' signs of a herpes recurrence, take valaciclovir 500mg twice daily for 3 days.

This approach will not have any effect on asymptomatic viral shedding and hence its effect on reducing transmission is unclear and not likely to be very significant.

This approach is useful, however, for people who have infrequent attacks or for when people are stopping continuous suppressive therapy.

General practitioners are able to prescribe oral antivirals for suppressing herpes. Prescriptions can be filled at retail pharmacies.

HERPES AND PREGNANCY

General Information about Herpes and Pregnancy

As an expectant parent eagerly awaiting the birth of your new baby, you are probably taking a number of steps to ensure your baby's health. One step many experts recommend is that you become informed about herpes simplex virus (HSV). This common virus is usually a mild infection in adults. But in infants, HSV can cause a rare, but serious, illness.

What is herpes simplex virus?

HSV can cause sores near the mouth (oral herpes or "cold sores"), or sores on the genitals (genital herpes). HSV-1 is the usual cause of oral herpes, and HSV-2 is the usual cause of genital herpes. But either type of HSV can infect either part of the body. Either type can infect a baby.

How common is herpes simplex?

Approximately 80% of New Zealand adults have oral herpes and 20% have genital herpes. These figures are based on New Zealand studies and studies from countries with similar population groups to New Zealand. You can get genital herpes if you have sexual contact with a partner who is infected, or if a partner who has an active cold sore performs oral sex on you. Most people with HSV don't know they are infected because they have no symptoms, or symptoms too mild to notice.

How can herpes simplex spread to an infant?

- Herpes simplex is most often spread to an infant during birth if the mother has HSV in the birth canal during delivery.
- HSV can also be spread to the baby if he or she is kissed by someone with an active cold sore.
- In rare instances, HSV may be spread by touch, if someone touches an active cold sore and then immediately touches the baby.

How can herpes harm a baby?

HSV can cause neonatal herpes (babies up to 28 days old, infected by herpes), a rare but life-threatening disease. Neonatal herpes can cause eye or throat infections, damage to the central nervous system, mental retardation, or death. Medication may help prevent or reduce lasting damage if it is given early.

How many babies get neonatal herpes?

Less than 0.1% of babies born in the United States each year get neonatal herpes. The limited information from Australasia suggests the incidence is even lower in Australia and New Zealand (4/100,000 live births in Australia). By contrast, some 20-25% of pregnant women have genital herpes. This means that the great majority of women with genital herpes give birth to healthy happy babies.

Which babies are most at risk?

Babies are most at risk from neonatal herpes if the mother contracts genital HSV for the first time late in pregnancy. This is because a newly infected mother does not have antibodies against the virus, so there is no natural protection for the baby during birth. In addition, a new herpes infection is frequently active, so there is a real chance that the virus will be present in the birth canal during delivery.

What about pregnant women who have a history of genital herpes?

Women who acquire genital herpes before they become pregnant have a very low risk (less than 1%) of transmitting the virus to their babies. This is because their immune system makes antibodies that are passed to the baby through the placenta. Even if HSV is active in the birth canal during delivery, the antibodies help protect the baby. In addition, if a mother knows she has genital herpes, her doctor can take steps to protect the baby.

Protecting the Baby: Women with genital herpes

If you are pregnant and you have genital herpes, you may be concerned about the risk of spreading the infection to your baby. Be reassured that the risk is extremely small – especially if you have had herpes for some time. The following steps can help make the risk even smaller:

- Talk with your obstetrician or midwife. Make sure they know you have genital herpes.
- At the time of labour, check yourself for any symptoms in the genital area – sores, itching, tingling or tenderness.
 Your health care provider will also examine you with a strong light to detect any signs of an outbreak.
- The choices regarding an active outbreak at the time of delivery should ideally be discussed with your obstetrician early in the pregnancy. The choices are to proceed with a vaginal delivery (avoiding routine use of instruments) or have a caesarian section. The risk of transmission with vaginal delivery is low (less than 3%) and needs to be weighed against the risk of caesarian section to the mother. Other factors that might affect your delivery need to be considered too before a decision can be made.
- Ask your Lead Maternity Carer (LMC) not to break the bag of waters around the baby unless necessary. The bag of waters may help protect the baby against any virus in the birth canal.
- Ask your LMC not to use fetal scalp monitor (scalp electrodes) during labour to monitor the baby's heart rate unless medically necessary. This instrument makes tiny punctures in the baby's scalp, which may allow herpes virus to enter. In most cases, an external monitor can be used instead.
- Ask that a vacuum or forceps not be used during delivery unless medically necessary. These instruments can also cause breaks in the baby's scalp, allowing virus to enter.

- After birth, watch the baby closely for about four weeks.
 Symptoms of neonatal herpes include blisters on the skin, fever, tiredness, irritability, or lack of appetite.
 While these can be several mild illnesses, don't wait to see if your baby will get better. Take them to the pediatrician at once. Be sure to tell the pediatrician you have genital herpes.
- The odds are strongly in favour of you having a healthy baby.

Protecting the Baby: Women who don't have genital herpes

The greatest risk of neonatal herpes is to babies whose mothers contract a genital infection late in pregnancy. While this is a rare occurrence, it does happen, and can cause a serious, even lifethreatening, illness for the baby. The best way you can protect your baby is to know the facts about HSV and how to protect yourself. The first step may be finding out whether you already carry the virus. If you have a partner who knows they have genital herpes and you don't know whether you have it, you need to discuss this with your doctor.

How can I get tested for genital HSV?

If you have symptoms, the best test is for a swab to be sent for laboratory confirmation and typing. To perform this test, your health care provider must take a sample from an outbreak while it is active, preferably on the first day. Test results are available in a few days.

If you don't have symptoms, a blood test can tell you whether you carry HSV-2, the type of herpes that usually infects the genital tract. A blood test may also tell you whether you have HSV-1, but in many cases this simply means you have oral herpes.

The most accurate blood test is the Western blot, not currently available in New Zealand.

Ask your doctor about these tests as they differ regionally and some tests are not accurate. Also the doctor needs to be aware how to interpret the test in light of the clinical presentation.

How can I make sure I don't get genital HSV?

If you test negative for genital herpes, the following steps can help protect you from getting an infection during pregnancy:

- If your partner has genital herpes, abstain from sex during active outbreaks. Between outbreaks, use a condom from start to finish every time you have sexual contact, even if your partner has no symptoms. (HSV can spread when no symptoms are present.) Consider abstaining from sex during the last trimester.
- If you don't know whether your partner has genital HSV, you may wish to ask your partner to be tested. If your partner has genital or oral HSV, there is a very real chance that you may acquire it unless you take steps to prevent transmission.
- Do not let your partner perform oral sex on you if your partner has an active cold sore (oral herpes). This can give you genital herpes.

What if I contract genital HSV during late pregnancy?

If you experience genital symptoms, or believe you have been exposed to genital HSV, tell your obstetrician or midwife at once. However, be aware that herpes can lie dormant for several years. What appears to be a new infection is usually an old one that is causing symptoms for the first time. Talk with your provider about the best way to protect your baby. If a pregnant woman gets a new genital HSV infection during the last 6 weeks of pregnancy, a caesarean delivery is recommended, even if no outbreak is present, as there is a greater than 50% risk of neonatal HSV.

How can I protect my baby after birth?

A baby can get neonatal herpes in the first 8 weeks after birth. Such infections are almost always caused by a kiss from an adult who has a cold sore. To protect your baby, don't kiss them when you have a cold sore, and ask others not to. If you have a cold sore, wash your hands before touching the baby.

For Partners of Pregnant Women

If your partner is pregnant, and she does not have genital HSV, you can help ensure that the baby remains safe from the infection. Remember, approximately 20% of sexually active adults have genital HSV, and most do not have symptoms. If you find that you have the virus, follow these guidelines to protect your partner during the pregnancy:

- Use condoms from start to finish every time you have sexual contact, even if you have no symptoms. HSV can be spread even when no symptoms are present.
- If you have genital outbreaks, abstain from sex until the outbreak has completely healed.
- Talk with your health care provider about taking antiviral medication to suppress outbreaks and to reduce the risk of transmission between outbreaks.
- Consider abstaining from intercourse during the last trimester. Explore alternatives such as touching, kissing, fantasising, and massage.
- If you have cold sores (usually caused by HSV-1), avoid performing oral sex on your partner when a cold sore is present.
- Your partner needs to tell her doctor if you have genital herpes so that all the issues can be discussed.

The best way to protect your baby from neonatal herpes is to prevent contracting genital HSV during late pregnancy, especially during the last 6 weeks.

FACIAL HERPES

What is Facial Herpes?

Facial herpes is very common and is also known as cold sores, fever blisters, sun blisters, oro-facial herpes, herpes labialis and herpes febrilis. Facial herpes is characterised by groups of fluid-filled blisters that appear on red swollen areas of the skin or on the mucous membranes. A burning sensation is often present just before the skin lesions develop. The areas can be tender and painful. The blisters heal without scarring but they have a tendency to return.

These episodes are caused by a very common virus infection known as herpes simplex virus (HSV), of which there are two types:

- 1. HSV-1, the most common type, which usually causes facial herpes.
- 2. HSV-2, which usually causes genital herpes.

Although cross infection can occur it is more common from the face-to-genitals route (causing genital HSV-1) than from the genitals to the facial area.

How Do You Catch It?

Facial herpes is spread by close physical contact between an infected person and somebody who was previously uninfected. Infection is most commonly acquired during infancy or childhood as a result of contact with relatives (for example kissing or hugging). The source does not always have typical facial herpes symptoms at the time of transmission. For instance, virus is often shed from the lips before blisters appear and it is also possible to shed infectious virus particles without noticeable symptoms.

Most people will have come into contact with the virus between the ages of 3–5, but only one in three of these will have a first episode with symptoms.

What Does the Virus Do?

The HSV virus invades the cells of the epidermis, the outer layer of the skin, causing fluid-filled blisters to appear. The virus travels from the epidermis along the nerve paths to the trigeminal ganglion, a bundle of nerves close to the inner ear, where it lies

hidden until it is reactivated. Potential triggers include a fever (for example, a common cold), UV radiation (exposure to sunlight), extreme tiredness or lowered immune function

The initial infection

When a person is infected with herpes for the first time, the episode is called a *primary infection*. The primary infection can progress in different ways. Some people only have very mild symptoms or none at all but others can experience considerable discomfort. Sores can develop inside the mouth as well as outside it and this is commonly called *gingivostomatitis*. Initially, this can take the form of painful sores affecting the mouth, gum, throat and lips, which may last for more than 14 days if left untreated. Gingivostomatitis should be treated with antiviral medicine. Most patients also require painkillers or even local anaesthetics, applied direct to the site, to ease the discomfort so that they can eat and drink.

This first outbreak starts 1–3 weeks after the virus has invaded the skin and subsides within a few weeks.

Recurrences

The virus remains hidden in the nerves for the rest of the person's life and becomes active again from time to time. Some people have few or no outbreaks while others have regular recurrences. They seem to become less frequent with age.

An outbreak has four stages:

- 1. A tingling feeling in the skin.
- 2. Slight swelling and then development of a number of fluid-filled blisters, which are often painful.
- 3. The blisters burst and form clusters, leaving fluid-filled sores.
- 4. The sores eventually dry, scab over and heal without scarring after 8 to 10 days.

The virus can spread until the sores are completely covered by scabs and the infection will usually be external.

Sites of infection

Most commonly, herpes simplex affects the lips or nasal region, causing cold sores. Recurrences may affect the eye region or even involve the eye itself. Eye infection with HSV is also known by several other names, including: herpes keratitis, herpes conjunctivitis and herpes stromal keratitis. Deep infection of the eye is very rare, but can cause a syndrome called acute retinal necrosis. In children, the virus can infect the mouth and throat. The infection may be accompanied by a fever and general aches and pains.

What triggers facial herpes?

The factors which can trigger outbreaks differ from person to person. Menstruation, trauma, fever, exposure to sunlight, extreme weather conditions or anything that lowers the immune system, such as a cold, flu or general illness, can cause reappearance in some people. In others, there is no definite cause.

Transmitting facial herpes

People who experience an episode of herpes, either facial or genital, should consider themselves infectious from the start of the episode to the healing of the last ulcer. During this time the virus can be transmitted to other people and in rare cases, can be transferred to other areas of the body. Increasingly, genital herpes (genital HSV-1) is being caused by face-to-genital transmission. Remember, most of us acquire facial herpes in the first 5 years of our lives.

To help prevent transmission, you should avoid:

- Kissing anyone or sharing drinking utensils when you have a cold sore present.
- Having oral sex when you or your partner have facial or genital sores.
- Sharing towels and face flannels.
- Using saliva to wet contact lenses if you have sores around your mouth.

Precautions

Hygiene is important for people infected with this virus. Try to avoid direct contact with the sores but if this does occur, wash your hands with soap and water and dry thoroughly. Avoid picking at the sores as this can spread the virus to other parts of the body or result in a bacterial infection of the sores. Avoid the use of harsh detergents on the skin.

The body's defences can be strengthened by a healthy lifestyle. Try to eat a varied diet, exercise regularly and get enough sleep. Using a sunblock may help to prevent a recurrence in some cases.

How to diagnose facial herpes

Accurate diagnosis of facial herpes is made most easily and accurately at the time of an active herpes infection. A combination of the patient's medical history and the appearance of the sores will usually be sufficient to identify facial herpes. A swab of the lesion or a specialised blood test can be used to confirm it

Possible complications

The sores may become infected by bacteria. If the condition spreads to the eyes, in severe cases, it can damage vision.

In patients who suffer from atopic dermatitis, in rare cases, the cold sores can spread to larger parts of the body.

Massive cold sores can be a sign that another disease, pneumonia or HIV, for example, has weakened the body's defences.

Treatment

Facial herpes may be treated, and sometimes even prevented, with an antiviral drug, valaciclovir, which is available as tablets (you need a doctor's prescription). There are also over-the-counter cold sore treatments your pharmacist can advise you about. Painkillers and a pain relieving mouthwash may also ease the symptoms. The treatment should be started as soon as the first symptoms appear. Each episode can be treated with tablets or cream to speed the healing process. If episodes are very frequent or problematic, taking antiviral tablets daily may help prevent outbreaks.

Andrea says: "One thing I would like to reinforce: Please do not define yourself as 'someone with herpes'. Everyone has a disease or some health issue (some of which are so much worse than herpes), at some point. Herpes may be one of them, but it is not the end of the world and does not define who you are. I see it as a skin problem and we have a role to play in not dramatising the infection. There is effective treatment and herpes is not life-threatening."

Conclusion

- Herpes is not the end of the world and does not define who you are. It is "cold sores" – no more, no less.
- Herpes is a skin problem, not a life-threatening infection, and is manageable and treatable.
- Having accurate up-to-date information is key to understanding and coming to terms with having herpes.
- Knowledge is power and over time it allows feelings about the virus to be integrated and normalised.
- Getting herpes in perspective and winning the war in your mind neutralises the 'stigma' attached to a diagnosis.

For further information

We recommend you read **Herpes Myth vs Facts** on **www.herpes.org.nz**, or email **info@herpes.org.nz** to have a copy posted.

If you want further information regarding herpes treatment, or herpes support groups, you can:

- See your own doctor
- See a doctor at your local sexual health clinic
- Ring the Herpes Helpline 0508 11 12 13 tollfree from a landline or 09 433 6526 from a mobile
- Visit the herpes website <u>www.herpes.org.nz</u>

"Ringing the Herpes Helpline was the most useful thing I did."

– MJ

Find out more at

www.herpes.org.nz

For further information ring
Herpes Helpline **0508 11 12 13** tollfree from a landline
or 09 433 6526 from a mobile

New Zealand Herpes Foundation

Sexually Transmitted Infections Education Foundation

Copies of this booklet are available from: STIEF, PO Box 2437, Shortland St, Auckland 1140, New Zealand Email: <u>info@herpes.org.nz</u> www.herpes.org.nz

Helpline Tollfree 0508 11 12 13 Phone: 09 433 6526



View our consumer website with information about sexual health and all sexually transmitted infections:

www.justthefacts.co.nz

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