

The Herpes Handbook

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Herpes Viruses

Viruses cause herpes infections. A virus is an organism that invades cells, and while it is there, disrupts the normal activities of the cell. There are eight human herpes viruses. They include herpes simplex 1 (HSV 1), herpes simplex 2 (HSV 2), cytomegalovirus (CMV), varicella-zoster virus (VZV), Epstein-Barr virus (EBV), human herpes virus 6 (HHV 6), human herpes virus 7 (HHV 7) and human herpes virus 8 (HHV 8).

HSV 1 is the virus usually associated with cold sores or fever blisters that occur on the lips, nose, chin and other parts of the

face. Most HSV 1 infections are contracted during the childhood years, and many infections go completely unnoticed, as the symptoms can be minor or not apparent. About 56% of adults in the US between the ages of 14 and 49 display evidence of an HSV 1 infection when their blood is tested for HSV 1 antibodies. This percent is declining over time, perhaps as more people recognize that “herpes” causes cold sores and more care is taken not to kiss others when cold sores are present. However, HSV 1 is increasingly the cause of genital herpes infections, as oral-genital contact becomes a more routine part of sexual expression. In fact, more than $\frac{3}{4}$ of all new genital herpes infections in college students are HSV 1, not HSV 2.

HSV 2 is the virus usually associated with genital herpes infections. About 16% of people in the US between the ages of 14 and 49 show evidence of HSV 2 infection when their blood is tested by a test that accurately distinguishes between HSV 1 and 2.

Varicella-zoster (VZV) is the virus responsible for chicken pox, and also for shingles or herpes zoster. After a person recovers from the outbreak of chicken pox sores, the virus remains in the body in the nerve cells. At some point in the future, the virus can again travel to the surface of the skin and cause the condition called shingles. The symptoms of shingles include painful blistering sores on one side of the body only. The shingles rash can go from the back to the front or vice versa, but it always stops at the very center of the body and rarely crosses the midline. It can appear anywhere, but most often shows up on the chest, back, or face. In older people, especially, shingles can be an extremely unpleasant ordeal. Even after the blisters are gone, the pain can remain for months. This is called post herpetic neuralgia. Although shingles blisters can look like HSV 1 or 2, it is not the same thing, and an experienced professional combined with good lab testing can determine which is which. But sometimes the two (simplex and zoster) get mixed up. One way to tell the difference is that simplex recurs but zoster infrequently does. Only about 5% of people who get zoster ever recur a second time. And of those, almost no one recurs again unless they are immunocompromised in some way. There is a vaccine that will boost immunity and decrease the chances of getting shingles in older adults. It is called Zostavax and is FDA approved for adults age 60 and over. A second shingles vaccine should be released in 2018. Vaccines reduce the risk of having shingles by about 50%.

Epstein-Barr virus is the most common cause of mononucleosis.

Cytomegalovirus infections in healthy adults usually go unnoticed. Most adults show evidence on blood tests of having

been infected with cytomegalovirus. However, if a mother contracts CMV when she is pregnant, it can cause serious problems in the unborn baby. Cytomegalovirus is also a problem for people whose immune systems are not functioning properly, like those with HIV or AIDS.

Human herpes virus type 6 causes roseola in children. Human herpes virus type 7 also causes a rash in slightly older children.

Human herpes virus type 8 causes Kaposi's sarcoma (KS), an infection seen mostly in AIDS patients but occasionally in other populations.

If you have further questions about VZV, CMV, KS or EBV, you may wish to contact your clinician. The rest of this book will be discussing only the herpes simplex viruses. When the word "herpes" is used, it will refer to genital herpes infections, unless otherwise stated.

Symptoms

Genital herpes infections are classified as being in one of three categories: primary, initial (or non-primary first episode), or recurrent.

A PRIMARY outbreak is defined as one that occurs in a person who has no prior antibody to herpes simplex virus. This means that they have never had either HSV 1 or HSV 2. Symptoms in these people are sometimes more severe. However, the majority of people experiencing a true primary outbreak have symptoms that they do not recognize as herpes or have no symptoms at all. For now, let's talk about people who do have symptoms with their primary outbreak. They may have whole body involvement - headache, aching joints, tiredness, fever, pain in the legs, and flu-like symptoms. The lymph nodes in the groin are often enlarged and tender and may feel like large peas under the surface of the skin. When lymph nodes enlarge, it should be seen as a good thing in this situation. It means that the immune system is mounting an aggressive response to the herpes infection. Lesions or sores may also appear in the throat or mouth if they have both given oral sex to and had intercourse with the person who infected them. Genital symptoms may include sores (often on both sides of the genitals), painful urination, itching, and a discharge from the penis or vagina. The sores begin as blisters, then break open

and form ulcers in the skin. Women often do not notice lesions in the blister stage on the labia. Crusts or scabs form and eventually fall off. Lesions on the inner labia do not form crusts, but instead, new skin simply fills in the sores. Women will usually have lesions on the cervix as well, and men may have them inside the penis, hence the discharge described above, which occurs due to infected cells being sloughed off from those areas. Some women with primary herpes infections also get a yeast infection in the vaginal area, making the itching and discharge more bothersome. Sometimes, people may have difficulty initiating a stream of urine or a bowel movement. If this goes on for any significant period of time, it is important to involve a clinician in that problem. Frequently, a new crop of herpes lesions will appear 5-7 days after the first batch is seen, more frequently if antiviral therapy is not taken quickly. The typical primary outbreak lasts from 2-4 weeks in those people who recognize symptoms.

NON-PRIMARY (or initial) first episode infections occur when a person has been infected with HSV 1 and newly acquires HSV 2. The existing antibody to HSV 1 keeps the HSV 2 infection largely under control, and HSV 2 symptoms may be missed completely. However, the antibodies to HSV 1 do not keep someone from getting HSV 2. So a person could have a history of cold sores caused by HSV 1 (or have been infected without knowing or remembering), and still acquire genital herpes caused by HSV 2. The symptoms for non-primary first episode infections are less severe than the primary infection and most go unnoticed. The sores will usually cover a smaller area. The whole-body symptoms described above are less likely to occur. The time to recovery is generally shorter. It is important to note that most people falling into this category have outbreaks that are minor enough to go unnoticed; it is now known that as much as 80-90% of first time genital outbreaks are unrecognized and many of those unrecognized infections occur in people who already have HSV 1 and acquire HSV 2.

RECURRENT infection occurs in people who have had a previous HSV infection at or near the same site on the body. For people with genital herpes, that includes having outbreaks anywhere in the "boxer shorts" area. The same group of nerves supplies the genitals, thighs, lower abdomen, rectum and buttocks. A person need not have had sexual contact in any part of that area to have outbreaks there. For example, one need not have had anal sex to have an outbreak around the anus. Sometimes outbreaks occur in the same place every time they appear, but sometimes outbreaks move to a different location. It should be noted that when outbreaks show up in a new location in the boxer shorts area, it isn't because the infected person has spread the virus themselves. The virus has just "chosen" to travel along a different nerve to get to the surface of the skin. During recurrent outbreaks, most people do not experience the whole-body symptoms like headache, fever, etc.

The sores cover a still smaller area and many people do not experience pain with their outbreaks. The average recurrence lasts about 2-10 days. Fifteen to 30 percent of women have virus present on the cervix during recurrences. Bear in mind that these are averages, and outbreaks can vary a great deal, even in the same person. A person could have genital herpes for 30 years, not know it, and then have their first recognized recurrence. When they finally do have an outbreak they recognize, it can cause unnecessary havoc in relationship when issues of fidelity arise.

A WORD ABOUT ORAL HERPES: Because oral herpes can be transmitted to a sexual partner through giving oral sex and is then, technically, a sexually transmitted infection, it is appropriate that it be discussed briefly in this book. However, it should be noted that the vast majority of oral infections (cold sores and fever blisters) are not sexually transmitted. Oral herpes is often acquired in childhood, and is frequently the result of an adult with a cold sore kissing a child or an infected child in day care kissing an uninfected child. Many acquisitions are totally without symptoms. However, adults who get an oral first infection can have symptoms that are both dramatic and painful. Blisters can develop around the mouth, in the mouth, and on other places on the face. The lymph nodes in the neck and head may enlarge and become very tender. Like genital herpes, the infected person may feel like they have the flu. Often, people infected with oral HSV 1 have recurrences that occur on the border between the lip and the face. These are commonly known as cold sores or fever blisters. Herpes does not cause canker sores, which occur inside the mouth. When a cold sore is present, one should not be the giver of oral sex to someone else. Like genital herpes, there is a risk of giving off (or shedding) the oral herpes virus without symptoms present. Though herpes outbreaks rarely occur inside the mouth, shedding of herpes virus can occur from inside the oral cavity. Often, people are concerned about kissing their children at all if they have ever had a cold sore. The kind of kiss an adult appropriately gives a child when no cold sore is present does not transmit HSV 1 to a child. The kind of kiss one would give a lover, on the other hand, might.

HSV 1 now causes about a third of first time genital outbreaks. At the first outbreak, there is no difference between how type 1 and type 2 behave. However, if a person has been infected with type 1 genitally, they are far less likely to have recurrences. The recurrence rate for genital HSV 1 infection is about one outbreak every other year vs. HSV 2 genital infection that recurs 4-6 times per year. It is very important that when herpes lab tests are done, (either blood or swab tests), they are typed (HSV 1 or 2). As you can see, the two simplex viruses behave quite differently in the genital area. It is also important to know the viral type because a person who has HSV 1 genitally can still acquire HSV 2 genitally (the reverse almost never happens). In addition, HSV 1 genital infection can happen in a relationship where neither person has ever had

another sexual partner if the couple engages in oral sex. Also, if a person who has oral herpes caused by HSV 1 has intercourse with someone who has genital HSV 1 infection, transmission to a new location on the body is highly unlikely.

About half the people with genital herpes experience something known as prodrome. Prodrome is a set of symptoms that occur before an actual outbreak is present. Itching, tingling, a crawling-under-the-skin feeling, pain down the back of the leg or in the buttocks, may all be signs of a recurrence on the way. Some people get the prodromal signs but no recurrence. This is called an "aborted" outbreak. Over time, a pattern may emerge that will help predict the onset of a herpes outbreak. The virus can certainly be transmitted during prodrome, so at that point, one should stop sexual contact with the infected area, be it mouth or genitals. It may be beneficial to keep a calendar of prodrome and outbreaks for a while to see how well one can predict a recurrence. Developing an awareness of prodromal symptoms is one way to try to reduce the chances of transmitting virus to another person.

"Triggering mechanisms" are those things that seem to be associated with the onset of an outbreak. Menstruation, sunlight, pregnancy, birth control pills, diet, friction (which includes prolonged or vigorous intercourse, oral sex or masturbation), stress, illness, and heat have all been identified as **possible** triggering mechanisms. Again, keeping a calendar of events associated with outbreaks may help to identify one's own triggering mechanisms, if indeed there are any. It is worth noting that only one study has shown that stress has any relationship to recurrences. Several other studies have not confirmed this connection. Stressing out about having stress is not useful.

People who have genital HSV 2 have an average of 4-6 outbreaks per year. This varies greatly from person to person, with some people having as many outbreaks as one per month to others having outbreaks once every five years. About 20% of people with HSV 2 have 10 or more outbreaks per year. Men generally have about one more outbreak per year than women. The first year of having herpes may not be a good measure of things to come; people usually have more outbreaks in this first year than they do subsequently as their immune system becomes more attuned to the virus. Giving off the virus without symptoms is also more common during the first 1-6 months of having herpes than it is after that. There is another drop off of viral shedding after two years have passed since first infection.

Diagnosing Herpes

Genital herpes can be challenging to diagnose, but an accurate diagnosis is the cornerstone for everything that follows and is absolutely essential. Methods for diagnosis are changing rapidly, so be prepared for some ambiguity and misinformation about the process for a while. And don't settle for something less than great. You don't need to, and you'll be glad that you persevered in getting the best possible answers. Many clinicians are unaware of the best ways to diagnose herpes, so you may need to be the one who leads the way and asks for the correct testing. This might feel inappropriate to you, leading the way instead of your clinician, but sometimes, one must be in charge of their health care in spite of awkwardness.

There are three ways in which the diagnosis of herpes can be made. They include physical examination, swab tests, and blood antibody tests. With all three techniques, a careful medical and sexual history adds to accuracy.

Physical Examination

This is one of the most frequently used (and least reliable) diagnostic methods. A physician, nurse practitioner, physician's assistant or RN trained in STD evaluation usually does the exam. First, she/he will complete a verbal health history related to the course of the illness. The examiner will need to know what sexual practices the patient participates in (oral sex, vaginal intercourse, anal sex) in order to know which areas to check for symptoms. This may feel awkward to patients, but it is useful to remember that people who work in this field are virtually unshockable. It is essential that all information requested be provided as honestly and completely as possible. Next, he/she will look for symptoms associated with genital herpes. For women, this may include a pelvic examination of the internal reproductive organs. If there are many painful lesions, the clinician may elect to eliminate the internal part of the exam until the patient is more comfortable and this is just as it should be. During a typical female exam, the external genitalia, vagina, and cervix will be inspected for lesions and unusual discharge. In men, the penis and scrotum will be examined for sores. Both men and women will also be checked for signs of infection in or around the rectum, on the thighs and buttocks, in the pubic hair area, and in and around the mouth.

Lymph nodes in the groin will be checked for enlargement and tenderness. **If lesions are not present, a physical exam will not provide an accurate diagnosis, to diagnose or rule out herpes infection.** Per the advice of the Centers for Disease Control, laboratory tests should be done to confirm the opinion of the clinician. Studies have shown that clinicians call things herpes that are not herpes, up to 20% of the time. Insist on lab testing in addition to an exam. Always. If the clinician tells you they've seen enough herpes to know and they don't need a lab test, insist anyway and ask for typing of the virus. More about that later.

SWAB TESTS

Viral Culture

For culture, a swab is rubbed vigorously across an area of skin that looks abnormal. Then the cells that are gathered on the swab and the swab itself are put into a liquid to take the specimen to the laboratory. The swab should be made of synthetic material, like Dacron, never cotton, and the shaft of the swab should be plastic, never wood. It may be necessary to gently open a lesion to recover enough material to get a good sample. In the lab, healthy animal cells are combined with the patient sample. A laboratory technician then observes the culture for changes that typically appear when herpes is present. If these changes occur, then the test is declared positive, meaning that the herpes virus is present in the sample. Typing should then be done on sample to see if the patient has HSV 1 or 2. If the changes do not occur, then the sample is declared negative, which means there was insufficient virus or no virus present in the sample to make the animal cell changes. It does not necessarily mean that the person doesn't have herpes. If the test is negative, it could be because the sample was gathered too late in the outbreak, the culture was handled inappropriately in the medical office or the lab, too long was taken to get the sample to the lab, or that the sores were too well healed to yield virus. One study found a 76% FALSE NEGATIVE result for cultures, as compared to the better test, polymerase chain reaction (PCR). That means that 76% of the time when a culture came back negative, the person really had herpes after all. All negative cultures should be followed up with an accurate blood test three to four months from possible exposure to see if the person really has herpes or not. False positive cultures are extremely rare. If a culture is positive, then a person should be convinced that they do have herpes. The traditional culture can take 7-14 days to grow. There are new tests on the market that give a quicker answer, some as quickly as 18 hours.

PCR (Polymerase Chain Reaction)

This test is also done by gathering a sample from an abnormal area of skin. However, this test is much more sensitive than culture; i.e., more true cases of herpes are picked up when using this test. Simply put, the test takes a tiny section of virus and amplifies it many times so it can be seen and subsequently typed. This test is routinely available through the larger laboratories, like Quest and LabCorp, but smaller labs may not yet have the test and available, and it may be more expensive. It is, however, up to four times more sensitive than culture, and should be used whenever possible for diagnosing herpes from a swabbed sample. In addition, samples tested by PCR instead of culture are much more stable, less likely to be influenced by transport issues or length of time taken to get samples to the lab. In time, culture will likely be replaced completely by PCR. Only PCR should be used to type spinal fluid and babies with suspected herpes infections. If you are really trying to sort out if you have herpes or not and antibody tests are not giving you a clear answer, you might wish to have PCR swabs at home to gather a sample at the very first appearance of symptoms, and then you can drop the sample off at the clinician's office or lab for processing.

Tzanck Preparation

This test is sometimes used in STD clinics and dermatology offices for a quick diagnosis, or may be used for an initial diagnosis while the culture or PCR is being run. For this test, cells from the base of a lesion are collected on a swab, placed on a glass slide, stained with a special stain, and examined under the microscope. Cells infected with herpes virus appear as very large cells with many centers (also known as multinucleated giant cells). Infected cells pick up the stain in a different way than uninfected cells. This test is not as desirable as culture or PCR because other herpes viruses may cause a Tzanck to look positive as well and a Tzanck smear cannot be typed (HSV 1 or 2), but a positive Tzanck, read by an experienced lab person, combined with a good physical exam can be useful.

A negative Tzanck is not definitive. Tzanck stains pick up only about 30% of the actual herpes cases. As with cultures, if a negative result is obtained, it should be followed in three to four months from possible exposure with an accurate blood test to determine if herpes infection has actually occurred.

Pap Smear

A Pap smear is a process similar to the Tzanck test, but a different staining technique is used. However, Pap smears tend to be available in more laboratories than Tzanck preparations. The Pap smear also picks up less than 30% of the actual positive cases. There is a new test that has shown up in a few laboratories where herpes PCR is included in a pap smear, along with gonorrhea and Chlamydia testing. It is important to understand what is happening with this combined test. The test is looking to see if herpes virus is present at the time the Pap smear is taken. If the test is negative for herpes that does not mean someone doesn't have herpes; it simply means that there was no virus there at the time the sample was gathered. Unlike gonorrhea or Chlamydia, herpes virus isn't present every day in the genital area when someone is infected. There can certainly be confusion about the meaning of a negative "silver pap" as these combinations may be called. The only way to know about herpes infection in the asymptomatic person is to look for antibody to virus, not the virus itself.

BLOOD TESTS

Herpes blood tests look for antibody to herpes virus, not the virus itself, and a truly positive antibody test means that someone is infected with herpes and is infectious to others. There is no such thing as a blood test being positive because of "exposure". It is a little like being pregnant - you are or you are not, there is nothing in between. Pregnancy tests are not positive only because someone has been exposed to semen! Likewise, herpes antibody tests are not positive only because someone has been exposed to the herpes virus. Antibody is made up of proteins made in response to a virus, and sometimes it can take a while to be made by an individual. So it is important to wait long enough from exposure until testing to make sure the test is accurate. The ideal time is probably 3 months or 12 weeks from exposure. Old style blood tests (called crude antigen tests) could detect antibody to herpes simplex in general but were exceedingly poor at differentiating accurately between HSV 1 and 2. So if a person had either cold sore virus or genital herpes, the blood test would be positive for herpes antibody. These old style tests are not good because they imply that they can tell the difference between HSV 1 and 2 but really cannot. So a person could be told they have HSV 2 (almost always genital herpes) when really they have HSV 1 (still most often cold sore virus). This inability to distinguish between the two viruses is called cross reactivity. The new tests, called type specific serologic tests (or TSST) do distinguish between HSV 1 and 2 with a high degree of certainty. The accurate tests all measure a kind of antibody called IgG. They are based on the detection of an immune response that is

specific to HSV 1 or HSV 2. IgG herpes simplex blood tests do not pick up antibody from other herpes viruses, such as chicken pox.

A type specific IgG blood test may also help sort out new from old infection. Let's say someone develops a lesion in the genital area. A swab is taken, and the result shows HSV 2. At the same visit, a blood sample is drawn. The antibody test is negative for HSV 2. This is likely a first infection – there is virus present on the skin, but not enough time has passed for antibody to the virus to be made.

IgM (a different kind of antibody) tests do not accurately distinguish between the types of virus nor can they accurately tell a new infection from an old one. IgM tests also may pick up other herpes viruses, like chicken pox or mono virus. IgM tests for herpes should be avoided completely until better ones are available. Many clinicians don't realize that the IgM test is not good for diagnosing people, and tell people, based on an IgM test, that they have herpes. And not only that, they tell them have new herpes infection because IgM, with other viruses, comes up early in infection. But with herpes, IgG and IgM come up around the same time. The IgM can be generated years after first infection and will be detectable periodically. There are also commonly false positives on the IgM test. A person might have an IgM test and four months later, still be IgG negative. The IgG is the only test you ever want for herpes, never ever IgM.

So who should have blood tests for herpes? This is still somewhat controversial, but here is a partial list of people who might want to get a blood test for herpes:

1. Anyone who has had a sexual partner in the past and wonders if they got herpes without developing symptoms.
2. Someone who has been diagnosed with herpes by visual exam alone and wants confirmation of the diagnosis or wants to know if they have HSV 1 or HSV 2.
3. Someone who has had repeatedly (or singly) negative herpes PCR or cultures from suspicious skin changes.
4. Someone who has had repeated urinary tract infections but never grows out a bacteria on a urine culture. They may have herpes lesions in the urethra (herpetic urethritis).

5. Anyone who wants to get screened for sexually transmitted diseases. STD screens most often do not include a herpes test. You need to ask if herpes testing is included, and if not, request that it be added to a full STD screen. It is the most prevalent STD in the US today.

There are now several type specific, gG based, serologic tests available. I'll discuss those most commonly used.

Western Blot

The oldest of these, the Western Blot, was developed at the University of Washington by Dr. Rhoda Ashley Morrow, and in the US, is still done only there for the public to access. It is very accurate. Samples can be sent to their laboratory from any place in the United States. Again, see the UW website address at the back of the booklet. However, the Western Blot is not necessarily a good screening test because it will detect a positive result a little later in infection than some of the commonly used IgG tests that use the ELISA method. It is, however, an excellent confirmatory test.

IgG antibody tests

The HerpeSelect IgG for Herpes Simplex 1 and 2 comes in two different test formats: The EIA (or ELISA) and the Immunoblot. Both accurately distinguish between HSV 1 and 2, and are very sensitive and specific for herpes. Captia is another ELISA style test that can distinguish HSV 1 from HSV 2. And there are many other brands as well of type specific antibody tests.

These are the tests a clinician would optimally get when they send blood to a national reference lab and request a type specific serology.

The antibody tests for HSV 2 have a sensitivity of about 92% (out of every 100 cases of herpes, the test will pick up 92 of them. Since this disease can be quite troubling to those diagnosed, we would like to be able to identify who is "tripping" this test artificially and who is more likely to have an accurate test result, so that not even three out of 100 people get an inaccurate diagnosis of herpes. The ELISA test yields a number value called an index value. Recent research has shown

that most of the false positive HSV 2 results occur in people who have an index value of 1.1 to 3.5 (low positive) on the ELISA test, though we have seen people with an index value >5 be falsely positive. The lab report does not indicate a low positive range. It will identify everyone with an index value of 1.1 or over as positive. The closer your index value is to 1.1, the more likely it is to be a false positive. The closer the value is to 3.5, the more likely it is to confirm. It is up to you to find out your index value on your herpes antibody test and request confirmatory testing if your index value falls between 1.1 and 3.5. If you have obtained a lab value in the low positive range, the Centers for Disease Control recommends that you have your lab test confirmed with a second test. The second test should ideally be western blot but the in-office Biokit may also be used effectively as a confirmatory test. There are other tests out there, but for now, I am not convinced that any other test has the reliability of western blot.

The other problem with the IgG test is that it misses about 30% of HSV 1 infections. As more and more cases of genital herpes are caused by HSV 1, this poor performance can be problematic. The good news is that 100% of people in our most recent research study who tested positive for HSV 1 at index values over 3.0 were confirmed by western blot, so with that index value knowledge, test interpretation can be done more easily

False positives in people who have values over 3.5 are rare but I have seen them in people with index values as high as 5.07.

Biokit

The Biokit test looks for antibody to HSV 2 only. It is an in-office test, and has good sensitivity and specificity. A finger stick collects blood, and the test takes about 5 minutes to run. It must be done in a laboratory that has been nationally certified, which most clinician's offices are not.

It is important to remember that timing with antibody testing is everything. Let's say that a person has sex with a new partner, and three weeks later they get a blood antibody test for herpes. The test value comes back at 2.2. This would normally suggest confirmation is needed, because the value is between 1.1 and 3.5. However, in this case, the test value could be low because they are still in the process of making antibody – they are moving from 0 to >5 . The blood was drawn too soon for a completely accurate test. If they have the blood redrawn when 3-4 months have passed since their sexual

exposure, the result might be 7. However, if, four months later, the value were still 2.2, then confirmation would be a good idea because adequate time has passed to produce complete antibody. Actual lab test numbers and a sexual history need to both be taken into account when interpreting lab values. These issues can be discussed with your clinician for greater understanding.

Sometimes getting a blood test for herpes can be difficult. Some clinicians still don't know about the new blood tests, and may tell patients that there is no way to diagnose herpes unless they are having symptoms. Sometimes the wrong test is still ordered, either crude antigen tests or IgM tests. Sometimes people feel odd about asking for this test. If you are having difficulty getting one of the new type specific blood tests for herpes, skip the hassle and use one of the websites where you can order your own test. They are listed in the back of this booklet.

Some General Suggestions about Diagnosis

If you have questions about the tests that have been run on your behalf, or any part of the exam, ask your clinician. The more you understand about what is going on, the less anxiety you will feel in the long run. The high level of anxiety at the diagnostic visit may make it hard to think of the right questions to ask. If that happens to you, make a list of what you want to know, call back and ask your questions. You will find that your clinician will have more time for your questions if you set up an appointment to go in for a brief consultation.

Transmission

Genital herpes is transmitted from one person to another through sexual contact. Sexual contact includes intercourse, oral-genital contact and rubbing the genitals together without clothing in between (sometimes known as "outercourse").

When someone has a cold sore on their mouth or simply an oral infection with no sores present, and is the giver of oral sex to someone else, the virus can be spread from the mouth to the genitals. The receiver of the oral sex might then get genital herpes type 1. The virus type doesn't change (that is, it doesn't change from type I to type II because it is in the genital area), but the cold sore virus will simply live, and possibly recur, in the area of the genitals. Cold sores have been around for a

long, long time, and some people find it hard to accept that these can indeed be the source of genital herpes infections. But as oral sex becomes more common, the incidence of getting genital herpes in this way is increasing. Anal intercourse can also transmit the virus to the rectal area, though remember, many people who get herpes outbreaks around the rectum and the buttocks have not had anal sex.

Adults and children can (but rarely do) transmit the virus from one part of their body to another. This phenomenon is called autoinoculation. Autoinoculation almost always occurs during the first outbreak when the immune system has not yet produced a competent immune response to the herpes. Autoinoculation is quite uncommon, or many more children would have genital herpes as a result of touching their cold sores and then touching their genitals, as children seem to do. One specific area of concern is the transmission of the virus from the mouth to the eyes. If someone has a cold sore, it is important that they wash their hands carefully between touching a sore and rubbing their eyes. Saliva should not be used to wet contact lenses. HSV 1, not HSV 2, causes the majority of ocular HSV. However, having said all of that, the group of nerves that innervates the mouth and lips also supplies nerves to the eye so it is possible to have herpes of the eye simply because the virus from oral herpes travels along the eye nerve.

One of the hardest pieces of news to hear about herpes is that there is a chance that the virus can be transmitted when there are no apparent lesions. Women can have virus on their cervix with no sores on the outside of their body. Men can have the virus present inside of the urethra with no external sores. Virus can be given off from the genital skin of both men and women with no sores, through microscopic breaks in the skin. This is called asymptomatic shedding of the virus; giving off the virus from the body with no apparent symptoms. The more sensitive our virus detection methods become, the more viral shedding we can identify. Shedding rates vary, based on location of virus and type of virus. The chart below is a guideline about how often shedding happens.

HSV 2 genital	15-30% of days evaluated
HSV 1 genital	3-5% of days evaluated

HSV 1 oral	25% of days evaluated
HSV 2 oral	1% of days evaluated

We know that up to 70% of new cases of herpes are transmitted from someone showing no apparent symptoms at the time they infect their partner. Research has shown that asymptomatic shedding occurs more frequently during the first year of having herpes than it does subsequently. This information may present difficult emotional concerns about sexuality, and, unfortunately, there are no guarantees for fail-safe methods of dealing with this thorny issue. It is probably true that many people who have herpes **do** have symptomatic episodes when they give off virus but do not recognize them as herpes symptoms. We have thought for so long that all herpes is remarkable - that we would know for sure if an outbreak were occurring. But now we know that isn't the case, and that herpes has multiple faces, many of them not easily recognized. The truth is that most genital herpes is mild and really easy to miss.

People don't get genital herpes from an inanimate object such as a hot tub or swimming pool. Generally, the chemicals present in hot tubs and swimming pools easily kill the virus. We do recommend, however, that during an outbreak, one not share their towel with another person. Towels stay wet and warm for a while, and the virus could conceivably live for a very short time in that environment. Warm water and soap will easily kill the vulnerable virus on surfaces and clothing. Some studies have shown that the virus can live for a short time outside of the body, but there are no documented cases of someone contracting herpes from an inanimate object with the possible exception of sex toys. .

People often want to know what the chances are of getting herpes from another person. Overall, the risk is about 10% per year that an infected male would transmit HSV 2 to an uninfected female. That is, if 100 infected men were having one-on-one sex with 100 uninfected women, about 10 women would get infected per year. If the situation were reversed, about 4 uninfected men would get herpes in a year from infected women. Unfortunately, we do not have good studies on same gender couple transmission rates.

The studies that gave us those numbers were based on the following criteria:

- 1) No sex during outbreaks,
- 2) No daily antiviral medication and
- 3) No regular use of condoms.
- 4) The people involved know that one of the people has genital herpes.

But there is a caveat here. When people enroll in trials to study transmission, they didn't just meet and decide to do a study together. Most often, they have been in their relationships for a year or two, maybe much longer. Most herpes is transmitted in the first three months of a relationship so when couples are enrolled in these trials, they have already come through the period in their relationship where transmission is most likely. They are, in essence, herpes survivors. So these transmission statistics should be viewed in that light.

A study completed in the summer of 2002 evaluated whether antiviral therapy, taken daily, could reduce the risk of transmission of HSV 2 in healthy, heterosexual adults over the age of 18, from an infected partner to an uninfected one. The person with herpes took either valacyclovir 500 mg daily or placebo. The study followed the couples for a total of 8 months, drawing the blood of the uninfected partner monthly to look for infection. The study found that the taking of valacyclovir daily reduced transmission by 48% over placebo (or sugar pill).

We know that condoms also reduce the risk of transmission. When men use condoms with every single intercourse, transmission is reduced by 96% to an uninfected female. Condoms used by uninfected men while having sex with infected women reduce the risk of transmission by 30-50%

When both condoms and antiviral therapy are used, transmission rates can be greatly reduced. Even then, there is a small chance that transmission can occur. Taking antiviral therapy and using condoms does not alleviate the need to tell prospective partners about genital herpes.

Treatment

There have been many attempts to find a successful cure for herpes, but to date, no permanent cure has been found. However, great progress has been made on treating the disease, and research is constantly being conducted on all aspects of the infection.

Antiviral Therapy

In 1985, the first oral antiviral medications became available for general use. There are now three antivirals available in the US: acyclovir, valacyclovir (brand name Valtrex) and famciclovir (brand name Famvir). All three drugs work equally well when taken as directed. There may, however, be convenience advantages for medicines requiring less frequent dosing. The antivirals may be taken in one of three ways: first episode treatment, episodic therapy (the taking of medication with outbreaks only), and suppressive therapy (taking medicine every day). The first two uses of the drug attempt to shorten the length and severity of a specific outbreak. Taking medication with outbreaks, either first or future ones, has not been shown to impact future recurrence rates of herpes.

The third use of the drug, for suppression of outbreaks (i.e., to prevent outbreaks from coming), is recommended for anyone who has frequent outbreaks, who are bothered by their outbreaks, or who has an uninfected partner and wishes to reduce the risk of infecting them. Studies with these drugs have found that 80-90% of the people who take the drug for suppression have greatly reduced frequency of outbreaks or do not have outbreaks while taking the drug. The virus is still present in the body, and after the drug is stopped, the outbreaks and shedding come back to a regular level. While the risk of asymptomatic shedding may be greatly reduced by this medicine, it is not stopped altogether. It takes about five days for daily antiviral therapy to be functioning at peak efficiency.

An antiviral medication works something like this: the drug presents itself to the herpes virus as a chemical element that the virus needs to reproduce itself. But it is really just a phony, and when the virus tries to reproduce after it takes up the medicine, it can't. It doesn't die off completely, but it doesn't reproduce effectively either.

None of the antivirals have been proven safe for use in pregnant women, but data is being gathered about the use of antivirals in pregnancy and most clinicians use the medicines suppressively in the last month of pregnancy to try to prevent outbreaks and/or shedding near the time of delivery. If a woman should become pregnant while taking antiviral medication,

she should discontinue its use and consult her clinician but there is likely no real urgency about that.

acyclovir (generic)

This anti-viral medication was first FDA approved as a topical treatment for first-time outbreaks in 1982. The topical form of the medicine was shown to shorten the first outbreak very slightly, but had no effect on recurrent disease, and the topical form has no place in the treatment of recurrent genital herpes.

Oral acyclovir is indicated for use in one of three ways:

First time outbreaks: 400 mg three times a day for 7-10 days.

Recurrences: 400 mg three times a day for 5 days or 800 mg three times a day for two days.

Suppression: 400 mg twice a day, every day.

Acyclovir is also available for intravenous use in babies and adults for whom more aggressive treatment is necessary. It is available in a liquid form for people who have difficulty swallowing pills.

valacyclovir (generic)

This FDA approved medicine, whose brand name is Valtrex, may be used for first outbreaks, recurrent outbreaks and suppression. It is also approved to reduce transmission of genital herpes from an infected person to an uninfected one. Valacyclovir and famciclovir are both effective for treatment outbreaks for a single day.

First time outbreaks: 1000 mg twice a day for ten days.

Recurrent outbreaks: 2 grams, twice in a day, 12 hours apart, for one day. Or 500 mg twice a day for three days.

Suppression: Either 500 mg or 1000 mg once a day. I usually start patients with 500 mg and see how it goes. If there are frequent breakthroughs, it can be increased to 1000 mg (1 gram) once a day or 500 mg twice a day. Doses are taken every day.

famciclovir (generic)

This antiviral medication has been FDA approved for recurrent disease and suppression. The FDA has not approved famciclovir for first episode treatment, though the CDC does describe a dosing regimen for this purpose and it works just fine:

First time outbreaks: 250 mg three times a day for ten days.

Recurrent outbreaks: famciclovir 1000 mg orally twice daily for 1 day

Suppression: 250 mg twice a day every day.

Treatments That Need Further Testing To Determine Their Effectiveness In Treating Genital Herpes

Resiquimod - an immune modulator, whose sister drug, imiquimod or Aldara, has shown good success in treating genital warts. One study showed some limited benefit while using resiquimod for treating genital herpes.

Therapeutic vaccines – There are currently therapeutic vaccines under study to treat genital herpes. Traditionally when one thinks about vaccines, they are being used to prevent some illness or condition from happening. But with these vaccines,

they are being investigated as a treatment rather than a preventative measure. These vaccines work by boosting ones' own immune system's functioning to deal with herpes more effectively to reduce viral shedding and outbreaks.

Other Treatments

There are also treatments for herpes that do not involve medicines. Reasonable attempts to reduce tension or stress may be beneficial for some people. Exercise is becoming an increasingly popular way to raise one's spirits. Counseling, relaxation techniques, massage and meditation all fall into this category. Before paying \$100 plus per hour for counseling, however, check the credentials of the therapist. A real professional will not be offended that you ask about his/her qualifications. Also, beware of the medical person who says that adding a psychological approach to treating a physical illness is pure rubbish. The mind-body connection can be powerful.

Treatments Shown To Be Ineffective In Treating Herpes

Ether

Chloroform

Neutral Red Dye With Light Activation

Lithium Succinate Cream

BHT

Glossypol

Proflavine

Small Pox Vaccine (May Also Be Harmful)

Bacillus Calmette-Guerin (Bcg) Vaccine

Influenza Vaccine

Polio Vaccine

Lysine

Symptom Relief

The physical symptoms of herpes can range from very painful to slightly bothersome to none. Suggestions for relieving some of the symptoms are included in this chapter. These are not cures, and the suggestions are not verified by scientific experiments.

Loose clothing, cotton underwear

Mechanism of action: allows air to circulate more freely around the genitals. This speeds drying of the lesions, and reduces chaffing. Synthetic fabrics don't "breathe" well. Women: use pantyhose with cotton crotches, when possible. Better yet, wear long skirts with no panties.

Use: self-explanatory

Precautions: none

Availability: most everywhere

Cost: depends upon how fashionable you are

Drying agents, such as Burrow's solution, and cornstarch

Mechanism of action: speeds the drying of lesions by absorbing excess moisture.

Use: dissolve drying agents in water, using directions on the package. A good method is to use a sitz bath (a small amount of water used to soak the genital area only vs. the whole body.) Sprinkle cornstarch lightly over the genitals.

Precautions: soaking too often or too long may make the outbreak worse. Two 15-minute soaks a day is probably enough.

Availability: can be purchased at your local drugstore. Special sitz bath tubs are also available - new mothers with sore stitches and people with hemorrhoids also buy these tubs so you need not feel conspicuous.

Cost: \$1.00 to 5.00

Note: a total warm bath may help lesions feel better, and be relaxing, in general. Bubble bath, however, may be irritating.

Sprays that contain anesthetic (pain killing) agents

Mechanism of action: spray is applied to the skin; the nerve endings it touches will be temporarily numbed. These same products are sold to relieve pain of sunburn, hemorrhoids, and other skin problems that produce pain.

Use: Using a spray makes it possible to avoid touching the lesions.

Precautions: Sprays can cause skin irritation on some people.

Availability: can be found in drugstores and grocery stores. These products generally contain an active ingredient ending in caine (e.g., xylocaine, procaine, etc.) Ask the pharmacist for guidance in choosing a product if you are having trouble.

Cost: 5.00

Here are some miscellaneous suggestions for symptom relief that sound a bit strange, but work for some people.

Tannic acid, found in black tea, has been found to be useful in reducing itching and pain. Loose tea can be put in the bath, or a moist tea bag can be placed against the lesion (it also helps a sunburn feel better.)

Ice applied directly to the area of the outbreak has been reported by some people to lessen the severity of an outbreak, and, if used during prodrome may stop the outbreak from coming on. You may have difficulty picturing the scenario of ice applied to the genitals. However, it is not difficult. Place some cracked ice in a plastic bag, tie it off tightly, and wrap it in a thin towel. You now have an ice pack. Put it inside underwear to hold it in place. Oral outbreaks may also be helped by ice application.

For women, particularly, urine passing over lesions can cause a stinging, burning sensation, due to acidic urine passing over openings in the skin. Pouring water over the genitals while urinating, or urinating into a tub of water (a sitz bath would work), will help dilute the acid and wash it away. Increasing fluid intake will also make the urine less concentrated, and less likely to burn.

Vaccines

There are currently no prophylactic vaccines available for herpes.

Pregnancy

Genital herpes is of particular concern to pregnant women. Certainly, women with herpes can have healthy, normal children. However, some special problems may arise with pregnancy and genital herpes.

Ideally, type specific antibody testing would be done during the pregnancy to determine who in the relationship has herpes and who does not. So how would that work? Blood would be drawn around 15-20 weeks of gestation. If the mother were positive for HSV 2, even if she has never had symptoms, then precautions would be taken at the end of pregnancy and at the time of delivery, to protect the baby. These precautions include suppressive therapy from 36 weeks until delivery, avoiding the use of scalp electrodes for fetal monitoring during labor, avoiding premature rupture of membranes, and performing a c-section if an outbreak is present in the boxer shorts area at the time of delivery. The likelihood of newborn contracting herpes in these circumstances is very small. For the woman with established genital herpes going into the pregnancy, the risk of neonatal herpes is about 1 in 5500 deliveries.

If the mother's blood test shows that she is antibody negative for HSV 2, then optimally, her partner would be tested for antibody. If her sexual partner is HSV 2 positive and the mother is HSV 2 negative, then precautions should be taken so the mother doesn't get infected with HSV 2 in the third trimester of the pregnancy. A primary outbreak in the last trimester of pregnancy puts mother and baby at a greater risk for a premature delivery, and at much greater risk of infecting the baby at birth. Women that contract herpes during late pregnancy that have NOT had an opportunity to make antibody prior to

delivery, have a 30-50% chance of infecting their baby. Couples in this situation should avoid intercourse in the third trimester. If this is not workable, then the infected male partner should be placed on daily suppression and condoms should be used with every intercourse.

If the mother's blood test shows that she is antibody negative for HSV 1 and 2, and her partner's blood test shows infection with HSV 1 only, and the partner has ever had a cold sore, then the partner should not give oral sex to the mother during the third trimester. New HSV 1 genital infection during the third trimester can result in transmission to the neonate and be very serious indeed. If the partner tests positive for HSV 1, the mother is negative for HSV 1 and 2, and the site of the partner's HSV 1 infection is unknown, abstaining from both oral sex and intercourse during the third trimester is the safest course of action.

The major concern about herpes and pregnancy is that the baby may become infected with herpes virus if it passes through the birth canal when herpes virus is there. Even if antibodies to the herpes virus are transferred from mother to baby during pregnancy, the antibodies are not adequate to completely protect all babies against infection. Newborns do not have an immune system that is capable of dealing with herpes, and they can become very sick or die from herpes infections.

A woman who falls into one of the following categories should be followed carefully during her pregnancy and delivery:

- 1) A woman who has a history of having genital herpes, or who recently acquired the disease, or
- 2) A woman whose sexual partner has herpes infection (this is genital **or** oral herpes, if oral sex is shared from partner to mother).

All of this information can be pretty scary for all pregnant women and especially for women who have known genital herpes. But sharing information openly with OB clinicians will most always result in safe deliveries and healthy babies.

Newborns should not be exposed directly to cold sores. If the mother has a cold sore at the time of delivery, she should avoid kissing her baby until the cold sore has healed. The same is true for all other people with cold sores who are around a newborn.

If the mother has no breast herpes lesions, she may certainly breast feed the baby.

Women's Concerns

It has been suggested in the past that women who have herpes have an increased risk of developing cervical cancer. Portions of the genetic material of the herpes virus have been identified in tissue samples from women with cervical cancer. However, the role of herpes as a *cause* of cervical cancer is completely unproven. Many factors are linked to cervical cancer: early sexual activity, multiple sex partners and smoking. But clearly the prime culprit in cervical cancer is certain strains of genital wart virus or HPV. Women who have herpes should not be concerned about a greater risk for cervical cancer if they do not have human papilloma virus (genital wart virus).

Sexuality

First, and most importantly, herpes does not bring an end to sexuality. Having herpes does mean that some changes will need to occur in the way a person expresses their sexuality. Generally, the greatest concerns lie in the area of transmitting the virus to another person.

When considering what kind of sexual practices can spread the virus, just remember that the virus should not come into contact with the uninfected partner. For instance, if a man has herpes on his penis, he may still be the giver of oral sex to his female partner (assuming he has no oral infection). This may all seem very obvious, but thinking about the various combinations of body parts and mucous membranes may open up new possibilities for sexual expression when symptoms are present. It can also clarify which sexual practices present the greatest risk for transmission to others.

Intercourse should be avoided completely during outbreaks for maximum safety when one partner is infected and the other is not.

Sleeping in the same bed with someone who has herpes will not, by itself, transmit the virus. Virus is not shed asymptotically from places where there is thick skin, like the buttocks. It may be better to wear underwear, pajamas, or a

nightgown to bed during an outbreak if there is likely to be contact with lesions during the night (old habits and sleepy erotic instincts tend to ignore herpes). Cuddling and snuggling with a partner during an outbreak is very important, to let them know that they are still desirable and loved. Outbreaks are a time for support and extra closeness in other ways besides intercourse.

Occasionally, someone with herpes will have difficulty performing sexually - inability to achieve an erection and/or premature ejaculation in men or difficulty achieving an orgasm in women. Sometimes these problems are directly related to the fear of giving herpes to their partner. If one ejaculates rapidly, the penis is in the partner a shorter time, and the virus is less likely to be spread (or so the fearful thoughts go). If someone is worrying a great deal about transmitting the disease, it is hard to focus enough on the feelings, both physical and emotional, surrounding lovemaking, to achieve an orgasm. The key to resolving these problems probably lies in talking openly and gently about them with the partner involved. Good communication skills are an invaluable aid. If you need a tune-up here, see *Tender Talk: A Practical Guide to Intimate Conversations*, also published by The Portland Press, at the address listed on the back of this book.

Some people say that having herpes has changed the way they begin a sexual relationship. This topic, along with how to tell a prospective partner, will be covered in the next chapter "Telling New Partners."

Telling New Partners

If you are not currently involved in a long-term relationship, the issue of telling new partners will come up. I think it is important to disclose your herpes status to new sexual partners prior to having sex. When making the decision to disclose this information, it is useful to put yourself in their shoes - would you have wanted to know your infecting partner had herpes before you had sex with him/her? Telling all future partners works best, for many reasons. First, they will be given the opportunity to make an informed decision about the future of their own health. Herpes means different things to different people. To some, it may be quite frightening; to others it isn't a big deal. For example, a woman who is trying to become pregnant would see herpes in one way, while a woman who has her family already, and has had her tubes tied

(permanent birth control) would see it in another. A person you have just met that evening may not wish to take the same risk that someone you have known for a long time would be willing to take. Second, if you do not tell a partner until after you have had sex, the question of trust comes up. What else have you not told them about yourself? Also, it takes a great deal of energy away from a relationship to hide something that is important. Third, you may be denying your partner an opportunity to be supportive of you in a sensitive area. Fourth, you may have the typical belief that you will have a hard time finding a partner who will accept you with your herpes. Telling a prospective partner will test the validity of that belief. Our experience indicates that far more people accept sexual partners with herpes than reject them. This is clearly linked to the kind of relationship they have established prior to "getting the news."

So how do you actually tell someone that you have herpes? Find a time when the two of you can be alone. It is preferable to bring up the subject long before you are heavily into foreplay. Rather, choose a time when it looks like things could get sexual, but haven't gotten there yet. You may wish to begin by saying something like "It looks more and more like our relationship is developing into something sexual. Before that happens, I need to let you know something that may present us with a challenge. I have genital herpes." Don't expect that the first time you do this you will be calm, cool and collected. You may even back out once or twice.

When you tell someone, choose your words carefully. Avoid words such as "terrible, incurable, and incredibly painful." Try to be as matter of fact as you can. If it helps, practice in front of a mirror, or try it out on a close friend first. Would you feel so awkward about telling someone you were diabetic, or had a heart condition? Probably not, but this seems different because it involves your sexuality. Statistics do show that the more sex partners your have, the more likely it is that you will get a sexually transmitted disease. But remember, in this case, it only takes one sexual encounter to contract an infection that stays with you for your lifetime.

So now you have told them. What next? Let's say they sit there, looking stunned. You might say, "Do you know what herpes is, have you heard much about it?" I think it is very useful to have some suggestions for books that they might read, this one for example. Or perhaps the longer version of this one, "The Good News about the Bad News" Or they may want to view the patient counseling DVD on our website. Let's say they look at you with great passion, and say quickly, "It doesn't matter. I'm ready to sleep with you no matter what you have." Sounds tempting – instant acceptance. But think about the reason you told them; a chance for them to make a well thought out choice. That's hard to do on the spur of the moment.

The last thing you need is for them to wake up in the morning and regret their impulsiveness. One option would be to say, "Actually, I'd like you to take some time to think about it. If you still want to be together, let's just sleep together, but hold off on sex until you've had time to digest this for a little while." Certainly, another possibility is that they will say, "Wow, I was worried about bringing that up, but I have herpes too." Well, SOMEBODY has to tell first, right? If you both have the same viral type of herpes, you need not worry anymore about passing virus back and forth. That does not occur.

Let's say they look at you with shock and say, "I couldn't possibly take the risk of getting herpes. You're a nice person, but I think I'll say good night now." So the worst scenario has come to pass, and you feel hurt and defeated. Try to take a little time and get some perspective. They were rejecting the *herpes* and not you as a total person. It is important to remember that the rejection does not make you worth less as a person. You may be deprived of a relationship that you really want. However, there are people out there who will accept you and take the risk. The next time, or the time after that, it will go better. Let's say they want some time to think about it. They don't call for a few days, and when they do, they seem less passionate, more like a friend. The important thing is to give them time. Remember that you told them so they could make a choice. Some people can do that faster than others. If the relationship pleases you, it is probably worth the wait to see what will happen next. Let's say you decide to sleep together and the relationship falls apart a month later. Some people quickly say, "Well, it was the herpes. He/she just couldn't handle it." Maybe it was, but herpes can become a dumping ground for the relationship not working out, when in fact it had nothing to do with things ending. It is a temptation to stop looking at the other aspects of how you function as a partner, and focus only on the impact of herpes.

The next section of this book is authored by Dr. Ricks Warren, a psychologist on the faculty of the University of Michigan. He has counseled many people with genital herpes over the years, and offers a unique insight into effective strategies for dealing with the psychosocial issues surrounding genital herpes. I know you will appreciate his down-to-earth guidance and practical suggestions.

Making Adjustments

L. Ricks Warren, Ph.D., Psychologist
Ann Arbor, Michigan

I am a psychologist in private practice that counsels people with a variety of problems. In recent years, I have become involved in counseling people who are attempting to cope more successfully with having genital herpes.

My approach to counseling is based on the notion that our sustained emotional reactions result not only from what happens to us but largely from what we **think** about what happens. It goes something like this:

Let's say two people go through a divorce. One person thinks, "I am a total failure, and I am doomed to be alone forever." The resulting emotions would likely be depression and despair. The other person thinks "I have suffered a great loss, but it is certainly possible to make a new life for myself." The resulting emotions for that person are likely to be sadness and grief, but hopefulness about the future.

In the above example, two different people have the same thing happen to them (divorce), but they feel quite differently because of their different ways of thinking about their divorce.

My approach to counseling, then, attempts to help people in distress identify the particular beliefs that are causing their continued emotional upset. After determining their unhelpful beliefs, we work together to develop more helpful and realistic ways of thinking. The result is emotions that actually help them obtain their goals in life. Since I have been practicing this kind of counseling for the past 20 years, I was not surprised that people with herpes varied greatly in their emotional reactions. Many people take the news in stride, make the necessary alterations in their sexuality, and proceed with their lives without much difficulty. However, some people have more trouble doing this. My goal with these people is to help them discover their specific beliefs about having herpes that are creating their emotional discomfort.

Let me hasten to add that I am not minimizing the difficulties that herpes presents to some people. As with any change in health status, one's lifestyle may have to be changed in certain ways, and a variety of emotions (like anger, frustration, sadness) are normal, especially in the beginning. However, by changing certain ways of thinking depression, anxiety, shame, and hostility can be reduced so that people with herpes can adjust successfully to this change in their life.

What are the main types of thinking that cause the most emotional distress? The specific categories of problem thinking are

listed below, with examples of destructive thoughts, along with a more constructive alternative.

Overgeneralizing

Destructive thought: I am a less worthwhile person since I have genital herpes.

This type of thinking causes problems because it involves identifying with one's herpes - "I **am** my herpes."

Constructive alternative: My worth as a person is not affected by having herpes. I am a person with hundreds of different characteristics, some positive and some negative. Herpes is only one characteristic, not all of me.

At times, particularly during outbreaks, you may like yourself less, feel like you are less desirable, less attractive. The herpes seems to dominate your thoughts, and you find it hard to remember what your attributes are. But they're there; just keep reminding yourself about them. No, you aren't perfect, but you weren't before you had herpes either. People are drawn to you or move away from you for a variety of reasons; herpes is only one of many. Having herpes will challenge you to build on your strengths, and encourage you to look honestly at your shortcomings.

Destructive thought: I will **never** find anyone who will want to be sexual with me, because I have herpes.

This belief (rather like fortune telling), generalizes from the present to the entire future, with no evidence to support the conclusion.

Constructive alternative: Where is the proof that I will never have sexual, long-term relationships? Some people may not want to take the risk of getting herpes, but there are most likely people who will, especially if the relationship is a good one.

When some people are first diagnosed as having herpes, they swear they will never have sex again, that the risk of being rejected by someone is simply too great to bear. This kind of thought implies that there is no way you could stand it if you were rejected. What about a life alone? Wouldn't that, in the long run, be very hard to stand (if you would have preferred to be with someone)? How would it feel to be 85, alone, and have to look back and say, "Well, at least I didn't give anyone

small blisters on their penis/labia?" The reality is that once you begin having sex in your life, it is very hard to simply stop being sexual. The frustrations and emotional conflict that arise as a result of trying to become celibate due to herpes may be worse than having herpes. It is important to remember that the fears about transmitting herpes will ease with time, and a realistic plan to prevent transmission will replace the fears.

Destructive thought: Let's say I am honest with a sexual partner, and they are willing to have sex with me, even with the herpes presenting a small risk. I would be a terrible person, totally responsible for ruining their life, if they got herpes from me.

This belief is an example of **over** responsibility for another person's right to make choices. It also assumes that herpes would be **devastating** to them.

Constructive alternative: A full life involves risk taking. While I would be deeply disappointed and sorry if an informed sexual partner contracted herpes from me, it would not be all my fault. Other people have the right to make their own choices and take risks. It doesn't have to devastate their lives.

Transmitting herpes is only one risk that you will take in a relationship. You also risk losing someone to an incompatibility in personalities, risk that you will grow apart over time, and risk that issues like money, children, and sex will present irresolvable problems. The list is long, and herpes is only one item on the list.

Catastrophizing

Destructive thought: Having herpes is a catastrophe!

This belief usually implies that having herpes is simply too much to bear, and that one cannot possibly be happy in spite of having herpes.

Constructive alternative: Having herpes is certainly inconvenient, and an unfortunate hassle. However, other people manage to ^[1]_[SEP]find happiness (they do, you know), in spite of their herpes, and so can I.

If you really think that having herpes is a catastrophe, get more information about the disease. The more you know, the better you can cope. Seeing a counselor may also be helpful (further detail ^[11]_{SEP} in the treatment section.) Having a close friend to talk to will be very useful keeping all your thoughts inside can make you feel pretty lonely.

Demanding

Destructive thought: I **should** not have contracted herpes, and my infecting partner **should** not have given it to me.

These thoughts involve jumping from the realistic desire to have avoided getting herpes to the unrealistic demand that such an undesirable thing **must** not have happened.

Constructive alternative: I wish so much that I had not contracted herpes, but at the time I got it, I was unaware that my partner was contagious. We did the best we could given the information we had at the time.

Destructive thought: I **should** not have to deal with the pain, discomfort, and practical problems associated with herpes.

This thought also implies that one's preference for not having to endure misfortune **must** be granted.

Constructive alternative: I certainly don't like dealing with the disadvantages of having herpes, but life often deals us unfair blows. It is truly part of the human process.

It is not essential to use the specific constructive alternatives suggested above to replace the self-defeating ones, but it is important that you come up with your own believable, more helpful ways of thinking.

In order to believe the helpful beliefs more than the unhelpful ones, three steps are recommended. First, try to see why the helpful thoughts are actually more reasonable than the unhelpful ones. Second, frequently, **remind** yourself that the unhelpful thoughts will lead to emotional distress while the helpful ones will lead to emotions that will help you achieve your goals. Third, **act** in accordance with the more helpful beliefs. This involves facing the discomfort of risking new relationships, if you are currently unattached. It involves **not** becoming reclusive and acting as if you do not deserve the

benefits of sex and intimacy.

In summary, herpes itself may involve physical discomfort and impose certain restrictions on one's spontaneity. Many people experience a variety of intense emotions when they first find out they have herpes. Anger, sadness, and confusion are normal. However, if you are significantly depressed or immobilized with fear of the future, there are effective ways of combating these difficult emotions and regaining your confidence. See if you can identify the beliefs that are hurting you and make a concerted effort to change them. For help with this process, I would suggest reading *Feeling Good* by David Burns and *A New Guide to Rational Living* by Albert Ellis and Robert Harper.

Personal Recollections

One Man's Story

I am a 30-year-old man, have a professional career, many friends, lots of outside interests, and genital herpes. In all of my life, I have had two sex partners (sort of).

About three years ago, I had intercourse for the first time. My upbringing, very Catholic, frowned heavily on premarital sex, so I waited a long time. The woman I slept with was a good friend, someone I had known for years. We made love once, and I wore a condom. However, before we had intercourse, she also gave me oral sex. About a week later, I noticed a rough, sore area on my penis. My family doctor said it was probably a friction burn, so I ignored it, and sure enough, it went away.

My next partner was someone I never did have intercourse with, but we engaged in a fair amount of oral sex. A year after the first rough spot appeared, a second one came up. This time I went to a private sexually transmitted disease clinic where they cultured the spot. It came up positive for HSV 1.

So in my life I had had intercourse once, wearing a condom, and here I am with genital herpes. In the three years I have apparently had it, I have had only the one recurrence. Both women deny any history of genital herpes, but the first one does have a history of cold sores. I cannot remember whether or not she had a cold sore on her mouth when we had sex together,

and neither can she. In either case, I certainly do not, in any way, blame her for this.

I have not had sex since then, mostly because of my difficulty in dealing with the sex-before-marriage issue, but also because of the herpes. Telling someone would be very hard for me, but the fear of giving it to someone else is even greater. I've been reassured that the rate of viral shedding for genital HSV 1 is low, but I'm afraid anyway.

Interestingly enough, herpes has had, in one way, a positive impact on my life. Before the herpes, I tended to be rather intolerant of other people's flaws, particularly things that I interpreted as an absence of moral character. But now, I too, have a "flaw." Truly, it can happen to anyone. The people at the clinic have helped me to see this as less catastrophic, and when I compare it to people who have other serious illnesses, I am able to see it in a more realistic light. The fear that someone I know might find out I have herpes is a major concern. I know other people who have herpes, but I cannot bring myself to share this with them. Perhaps I am worried that they would think I was not as "good" a person, though in my heart, I do not think that about them.

I still have a ways to go in adjusting to this disease. On the other hand, I think I have already come a long way. Thoughts of herpes do not constantly run through my mind anymore. I hope one day soon I will meet someone I care enough about, and trust enough, to tell that I have herpes. In fact, there's this very attractive woman who works in my office that I've been admiring lately. Perhaps I'll soon take that risk!

One Woman's Story

My story about herpes began two years ago. I had been dating the same man for about a month when it became clear that the relationship was going to expand to a sexual involvement. One evening, he gave me the painful piece of news that he had genital herpes. He was having recurrences about once every two months, lasting a week, sometimes more. This man had become very special to me - we were involved in the same career, we enjoyed many of the same activities like sailing, the symphony, and dinners with mutual friends. The decision to sleep with him in spite of the herpes was not a difficult one. I knew a little about the disease, and had read the Time magazine article, the one with the big red H on the cover. He assured me that he would always check himself for sores before sex, and if I wanted him to, he would wear a condom when we made love (I didn't want him to.) He took medicine to deal with his outbreaks, but his doctor didn't see the need for him to

take the medicine daily. So we began to sleep together at least 3-4 times a week. He was always careful to check himself first. A few times lovemaking was interrupted by him saying he felt some twinges, and wanted to stop just to be safe. This was quite disconcerting, and I found myself thinking about getting herpes when we were making love, instead of thinking about what was happening in bed. At times, this made it difficult to achieve orgasm. But as more time went by, I began to think less and less about herpes, and more and more about how happy I was with this man.

One night we made love in the middle of the night, and in the morning, he spotted a small sore on his penis. We both panicked, and I immediately went to my nurse practitioner for an exam, which revealed nothing irregular. However, about two weeks later, I noticed a very tender area on my right labia. Looking with a mirror, I saw only a small spot that looked like it had been rubbed raw. Being the cautious type, I went back to the nurse practitioner for another exam. She felt that it was probably not herpes, but took a culture anyway, just to ease my mind, I think. Five days later she phoned me to tell me it was positive for HSV 2. I went back a third time to see her for more information and a shoulder to cry on. My partner was incredibly supportive, and felt considerable guilt over infecting me. The sore area was gone in a couple of days. I felt fine for a month, and then, just before my period, another sore appeared. Even though I knew I had been taking a risk, I felt angry and powerless. But because my partner already felt so bad, I kept all that inside, and tried to be calm and reasonable at all times. Around that time, the relationship began to go downhill. We talked less, fought over little things, and made love infrequently. Now I was mourning the loss of intimacy we had had, *and* the problem of having herpes. I thought, "What if no one else wants me now that I am imperfect?" The relationship had looked so promising in the beginning, so much in common, so special. What had gone wrong? I think that his guilt about giving me herpes, and my unspoken resentment had clearly taken its toll.

We decided to seek counseling. We had both been divorced once, and had come to the realization that good couples are partly made, not born. If we wanted this to work, we would have to work. The psychologist helped us talk about our unspoken agendas, and encouraged me to look at my fears about herpes in a more realistic way.

Fortunately, this story has a happy ending. I started on daily suppressive therapy to reduce the frequency of my outbreaks, and just having them mostly gone makes me feel so much better. We have worked through many of our problems, and discovered that for us, herpes does not need to be a major factor in our relationship. We are still dealing with the day-to-day couple issues that everyone faces. Time had allowed us both to see that herpes is only one small part of who we are and

what our relationship is all about. I'm glad we hung in there together and got help for our issues. I feel really hopeful about our future.

Definitions

ANTIBODIES - proteins produced in the body to overcome the toxic effect of antigens (viruses or bacteria). These are detected in blood tests.

ANTI-VIRAL - any substance that attacks a virus and suppresses or stops the activity of the virus.

ASYMPTOMATIC - having the virus present at some place on the body without any apparent or recognized symptoms.

CAESAREAN SECTION - delivery of a baby through an incision made in the mother's abdomen.

CERVIX - the neck of the uterus (or womb) that is located at the end of the vagina.

HYSTERECTOMY - surgical removal of the uterus (can also include removal of the ovaries, fallopian tubes, and/or cervix).

IMMUNE SYSTEM - body system that fights infections.

ORAL-GENITAL SEX - any sexual activity that involves direct mouth to genital contact.

ORGANISMS - any form of plant or animal life. Here, we are referring to bacteria, viruses, protozoa and fungi.

URETHRA - the tube that leads from the bladder to the outside of the body that carries urine. In the male, this tube also carries semen out of the body. ^[1]_[SEP]

Recommended Resources

The following are physical and website addresses for people seeking more information about genital herpes. These change over time, so forgive us in advance for addresses that are out of date.

For excellent resources on genital herpes and other STDs:

The American Social Health Association
PO Box 13827
Research Triangle Park, NC 27709-3827

Websites:

www.westoverheights.com - (Q and A forum about herpes, video conference with Terri Warren, western blot order help)

http://depts.washington.edu/rspvirus/documents/hsv_western_blot.pdf - (herpes western blot information)

www.ashastd.org (nonprofit info on all STDs, expert Q and A forum))

www.IHMF.com (international perspective on HSV)

www.niaid.nih.gov (National Institutes of Health website)

www.cdc.gov/std/ (Centers for Disease Control website)

www.herpeshomepage.com (networking site)

www.MPwH.com (meet others with herpes)

www.healthcheckusa.com (order you own blood test)

www.herpeselect.com (info on blood test)

Hotline: Toll free herpes hotline: (888) 411-4377

Good Books:

The Good News about the Bad News, Terri Warren

Managing Herpes: How to Live and Love With a Chronic Std.

Charles Ebel and Anna Wald

Understanding Herpes. Lawrence Stanberry

To order The Updated Herpes Handbook by phone: 503-459-2700

To order by mail:

Westover Research Group

8477 SW 69th Place

Portland, Oregon 97223

Discounts are available for purchases in larger quantities.