

Nearly 30 years after opening a specialty clinic designed specifically to make patients as comfortable as possible with concerns around sexually transmitted infections (STIs), Portland's pioneering HSV researcher and clinician has seen it all. The Helper looks at herpes and sexual health through the eyes of clinical expert Terri Warren, RN, ANP.



Your clinic offers a comprehensive slate of medical services, but how did Westover Heights develop into a resource known especially for its expertise in STIs and herpes?

We opened in 1982 specifically as a private STI clinic. I had done a rotation in nursing school at the county clinic and felt that many of the people there were really not comfortable in a public clinic setting, yet they didn't want to go to their family practice provider because that's also where their family went for medical care. A county clinic setting can sometimes not an inviting place to go, so we tried to make our clinic casually elegant, a place where they would feel comfortable right away.

I felt an alternative would serve a purpose and work as a business, and I opened the clinic straight out of nursing school. I worked with a physician who provided me with very specific prescriptive authority over the CDC treatment guidelines. I went to Seattle and did the STI training at the University of Washington and several other workshops with their STI teaching group. Through those connections with Larry Corey and his research team, my clinic became an informal satellite site for UW, as they were recruiting patients for research studies, particularly for herpes.

When a patient is newly diagnosed with genital herpes, what do they primarily need from their healthcare provider?

I think they need some very basic information at their office visit, maybe five key points like: having herpes doesn't change who you are, you can still have sex and children, it will not shorten your life, we can manage this with medicine, and you need to give yourself time to feel better. A provider should give these messages in a very concise way, because I don't think people are listening very well right at diagnosis. They also need resources to take home, some guidelines for searching good websites online. Basic reassurance and resources to read on their own are essential...we offer a follow-up appointment to everybody, but I'd say only 10%-15% of people make either a follow-up phone call or visit.

Is the need for patient resources what motivated you to write the Herpes Handbook?

Yes. I think people have a lot of questions and need a simple way to get those answers, and that's why we have it on our website for free. People need something they can read right away but also resources they can refer back to.

Talk about the psychosocial impact of a herpes diagnosis. Just how profound is it?

I think that initially people are completely taken aback. At our clinic the diagnosis happens in a couple of different ways: either somebody comes in with symptoms and we do a swab from the lesion, or we detect it through an HSV antibody test we do as part of an STI testing panel. So, patients find out either from a swab test or a blood test.

With the swab test, if somebody has symptoms we think look like herpes, we always tell them there's a good chance it could be herpes, but we never make a final diagnosis until we have some kind of lab test to confirm our impressions because even though it's our specialty, we can be wrong!

My feeling is that the diagnosing provider has a huge impact on how people deal with herpes in the future. If you can modulate that huge emotional reaction, right off the bat, people do better. I don't think doing so takes a long time, there are things you can say that take 5 or 10 minutes without having an all day discussion. Often when I talk to clinicians about doing testing they say "Oh, I just can't take the time to deal with the emotional reaction that people have," but my experience is that while some people do require a long time to talk, others are fine with basic information, then something to read or look at when they leave, and they need to know they can come back and set up an appointment if they want to. We do phone and in-person appointments, to talk about things once they've had a chance to read and digest it all. I think it's really kind of pointless to go into too many details when people are first diagnosed because they just can't absorb it.

We have a number of people who are only phone patients - they call in from all over the world, actually, to talk about their herpes concerns or to clarify test results. Some days I'm doing phone consults for the whole day now. It's nice – I can do it from home in my jammies or from on the road if I'm traveling with my husband in our Airstream. Even in the middle of the woods I can answer herpes questions.

In addition to time constraints, do you think the reluctance of clinicians to engage in herpes counseling is due to a lack of comfort with the subject?

Definitely. It requires talking in detail about sexuality and people have lots of questions about herpes and oral sex, about intercourse, about anal sex, about same sex partners, so many topics I don't think clinicians are comfortable talking about. I'm also not sure clinicians always feel comfortable with their knowledge base about herpes and sexual health, and feel intimidated by the subjects.

The other important thing is that primary care providers see really bad stuff: strokes, heart disease, diabetes out of control, and hypertension out of control... They just don't see why people are so upset about herpes, because their perspective is not the patient's perspective. They don't get what the patient is feeling, thinking. Clinicians might think "I'm dealing with people and the whole right side of their body doesn't work, why are you so freaked out about a sore on the genitals for a week every few months?" Both perspectives, the patient and the clinician, are honest; it's just that the gap can be very big.

Talk about HSV serology. Do we need to cast the net wider and do more HSV blood tests?

I definitely think so, I wouldn't dream of doing an STI screen without including tests for the things people are most likely to have. I feel like it would be bad medical practice to not to include a herpes test in an STI screening. There are some populations for whom HSV testing is really a no brainer: if they have a partner that's HSV positive, if they're leaving a relationship with someone who was HSV positive, if they're HIV positive, or if they have genital symptoms that can't be explained by some other diagnosis. I don't think we should be testing everybody, though; I don't think you should go in for your annual physical and be automatically tested for herpes, for example.

The problem with serology is this: we do about a hundred serologic herpes tests a month in our clinic, we have a highly complex CLIA certified lab and we run the tests in the office, but the issue is what do you do with the "low" positives? It's not a problem for us because we tell people right from the start of testing that if their index value on the HerpeSelect falls between 1.1 and 3.5, we will request your permission to run a second test. We deal with that aspect pre-emptively.

I think the other way clinicians can deal with the low positive HSV serology results is to make confirmatory testing reflexive; if you order an ELISA and the result is a 1.1 to 3.5 you reflex it to a Western Blot. I think it should be reflexed to a Western Blot, but having said that I will add the answer isn't always clear. We might get a 2.8 on an ELISA and then get an indeterminate Western Blot, for example, which isn't really rare. There isn't a perfect solution but reflexive testing is a reasonable approach. Sometimes we don't get a clear answer for people. They can

have an indeterminate Western Blot for years and a low positive ELISA with no symptoms, so we really don't always know if people have herpes or not and that drives them nuts...and I don't blame them.

When should a clinician do serologic testing for HSV-1?

We do it for both HSV-1 and HSV-2, because HSV-1 can technically be an STI.

The reason we often do it is to determine discordancy. If a couple comes in to my practice and are requesting an STI screen and one is positive for HSV-1 and the other is negative, that can be helpful to know. By knowing they are discordant for HSV-1 it's useful because the person who is HSV-1 positive may want to consider doing some protective mechanism, be it suppressive therapy, more condom use if they notice genital lesions, or if they know as a child they had a cold sore they may want to think about being more aware of that for oral sex. 40% of our new cases of genital herpes are due to HSV-1, so I think knowing a person's HSV 1 status can be a valuable piece of information. Genital HSV 1 is definitely on the increase. Thankfully, it recurs less and sheds less.

When we talk with someone whose partner is diagnosed with genital herpes and – as far as we know- they are discordant, they always try to nail us down with “What are the odds I'll get herpes?” What do you tell people who want you to assess their risk of HSV acquisition?

I say the studies are all over the place about that. A ballpark, average estimate is that male to female transmission without suppression, without regular condom use, with awareness that one is infected and the other is not, is around 10%. Female to male with the same circumstances is around 4%. If you add suppressive therapy it cuts transmission by about half, condoms maybe reduce transmission by about 1/3. Whether the impact of these risk reduction approaches is cumulative we don't really know. I'd say the key is simply in knowing that herpes is present, so you're aware of it and can do something about it. But remember, that in a sense, in studies, we are dealing with survivors in discordant relationships. You don't meet someone in a bar and say “Hi, I'm Terri, I have herpes, and would you like to do a study with me about herpes transmission?” They've already been together for quite a while before they make that leap, so they aren't truly a herpes-naïve couple, right?

I think one of the most useful things to tell people is they are probably most infectious in the first six to 12 months of having herpes, and that's a time you really need to pay attention. You could be shedding a lot more in that early period until your immune system gets a handle on the virus, compared to how much you'll shed in later years.

How has the way you relate to your patients changed over the last 10 years?

I remember when I first started doing this 30 years ago we believed people were only infectious during outbreaks. The biggest thing we've had to deal with is the information about asymptomatic viral shedding. It's become so apparent to me that herpes is much more of a psychological – rather than a medical- problem. When I opened the clinic in 1982, acyclovir had just been approved. Now we have three really great treatments and we know we can impact transmission. I offer the perspective to patients that they have a great deal of say over how this disease affects them, and it isn't like they have no control over their emotions. So it's not the disease but really how you view it that determines your emotional reaction. People can gain control over the thoughts they have. For some, it takes hard work.

What are you involved with in terms of research and clinical trials?

The trial we have coming up next involves a therapeutic vaccine, that is, seeing if we can give a vaccine to somebody who has herpes already and reduce their viral shedding and their risk of transmitting to others. We're also looking at whether or not people change their behaviors after being diagnosed with herpes, so we're doing some psychosocial studies. We will also be looking at a vaginal gel to see if it can reduce the risk of herpes transmission, this summer.

Will there ever be a prophylactic vaccine?

Who knows? We may actually have a therapeutic vaccine before we have one that's prophylactic (prevents acquisition of herpes). What intrigues me about a therapeutic vaccine is the potential for combining it oral antiviral therapy. What if we gave people a combination oral antiviral/therapeutic vaccine, how would that impact shedding? Could we get these numbers really low? Now that's a trial I'd love to do.

Terri Warren, RN, ANP, is owner of the Westover Heights Clinic, where she is also a nurse practitioner. Ms. Warren has served lead or co-author on dozens of clinical trials and research studies looking into various aspects of sexually transmitted infections and sexual health. She is the author of numerous books and journal articles, including the Updated Herpes Handbook (available for purchase [HERE](#)). Visit Westover Heights online [HERE](#) .