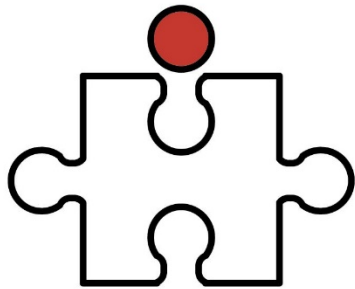


End the Stigma: Helping you to Help your Patients with Herpes



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When we began

Since 1985, when the Herpes Viruses Association was registered, the charity has been helping people diagnosed with genital herpes.

Our first director thought that providing the media with accurate information for two years, would end the stigma and he would be able to close the charity.

We are still here! People still feel the stigma once they are diagnosed with genital herpes. They learn about the stigma mainly by reading stories on the internet.

When the hype or stigma began

Until the 1970s

Genital herpes is a frequent but non-serious medical condition.

There is only symptom relief.

Little or no mention in medical textbooks – **example:** a 1975 textbook on childbirth with no ‘herpes’ in the index.^[1]

There was little or no shame, or stigma, associated with having genital herpes – **example:** a 1975 survey of “psychological morbidity” from people having a new diagnosis of an STI did not include genital herpes.^[2]

1. Obstetric and Gynaecological Nursing, Rosemary Bailey 1975

2. Mayou, R Psychological morbidity in a clinic for sexually transmitted disease. Brit. J. vener. Dis. (1975) **51**: 57

Disease-mongering began...

Acyclovir discovered: hype is created

- 1974 Acyclovir first created from Caribbean sea sponges.
- 1977 First report of its activity against herpes family of viruses.
- There is no market for this drug!
- 1979 first US patent (1985 capsules; 1991 tablets)
- **The hype** emerges in the USA in line with a marketing strategy to get the new antivirals to the public.
- Disease-mongering is a recognised ploy. [3]



3. Moynihan R, Heath I, Henry D (2002) Selling sickness: The pharmaceutical industry and disease mongering. *BMJ* **324**: 886–891

You can help with what you say:

What you tell patients will make a big difference:

"How the very first consultation is handled is crucial to the patient's future well-being.

"A bit of time, a lot of empathy and a clear explanation *minimising* the future consequences is necessary."

Professor Colm O'Mahony, MD FRCP BSc DIPVen.

Note that in this presentation, our sources for medical facts are BASHH and IUSTI.

(British Association for STIs and HIV and International Union against STIs)

Choose your words

Use the words that you would use with chickenpox (varicella) or facial cold sores – or thrush/candida.

Would you use these medical terms for the conditions mentioned above? In US/UK media they are used to ‘separate’ genital herpes from cold sores:

- **‘incurable’** – is a synonym for fatal. In fact, this viral infection is cured by the immune system. (But it can recur.)
- **‘chronic’** – in normal English that’s a synonym for ‘serious’
- **‘disease’** – that’s for ‘serious illness’ only
- **‘disclose’** – we don’t use that word for facial infection ...

You need to 'de-Google' them

- Patients will have read scare stories or misery stories on Google.
- Ask them what, in particular, is worrying them so you can address those exact fears.
- Patients don't realise it is normal to have viral, bacterial and fungal cells inside their bodies.
Explain: *"We have more virus, bacteria and fungal cells in our bodies than we have cells with our own DNA."* (This combats the patient's sense of 'now being polluted, or dirty'.)

Give patients the good news

- **Not dangerous.** “You get better with or without treatment, like flu.” Patients will be relieved and pleased that medicine is an option, not a necessity.
- **Some get symptoms only once.** Studies show 4.6 recurrences for type 2 in first year, and 0.8 for type 1. Genetics play a significant role.[#] **But** ‘average’ is meaningless for any one individual.
- **It’s normal.** Professor George Kinghorn, GU consultant in Sheffield stated: “... *to be infected with a herpes simplex virus is a state of normality...*”

Kriesel JD, Jones BB, Mastunami N, Patel MK, StPierre CA, Kurt-Jones EA, Finberg RW, Leppert M, Hobbs MR. C21orf91 Genotypes Correlate With Herpes Simplex Labialis (Cold Sore) Frequency: Description of a Cold Sore Susceptibility Gene. J Infect Dis. (2011) 204 (11): 1654-1662.

Facts that will help patients:

Herpes simplex is caught by skin contact, with the affected area (usually face, fingers, genitals), when the virus is active, with friction. It is not airborne.

It is not caught off towels or sheets, cups or cutlery, baths or Jacuzzis. (The Internet will tell them that this happens.)

People can notice first symptoms many years after original infection. so:

It is not necessarily caught from the most recent partner. This means a new infection with genital herpes cannot be used to 'prove' infidelity. (Unlike most STIs.)

Tell them that herpes simplex is common

Epidemiological facts can help normalise herpes:

WHO – below 40 years herpes simplex type 1 is 67%

WHO – 15-49 yrs herpes simplex type 2 is 11%

Statistics in Australia* – in 35-44 year age group:

Women: 85% have type 1 (Men 77%)

Women: 22% have type 2 (Men 19%)

London research found that if a person has had 7 partners, they are more likely than not to have genital herpes...

Only one in three who has herpes simplex type 2 is diagnosed – for the others it is too mild to notice.

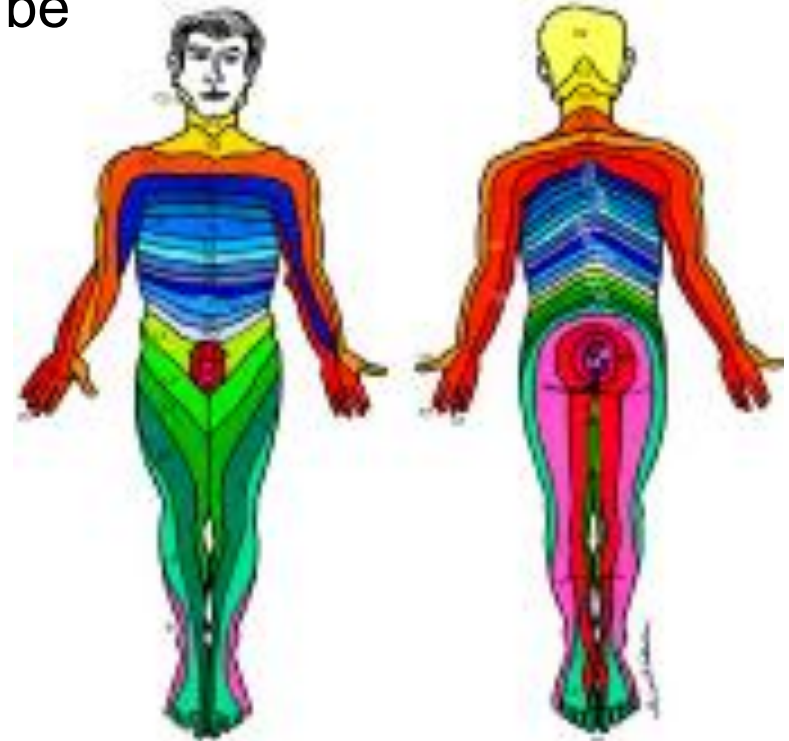
Cunningham AL, Taylor R, Taylor J, Marks C, Shaw J, Mindel A. Prevalence of infection with herpes simplex virus types 1 and 2 in Australia: a nationwide population based survey. *Sex Transm Infect* 2006;**82**:164-168 doi:10.1136/sti.2005.016899

Patients are confused re the two types... It is not spread around the body:

Two virus types: either type can be caught anywhere, by direct skin contact with active virus, but -

- Most people only catch one type.
- Each type gives partial protection against the other.
- Oral sex + cold sores = genital infection

Autoinoculation is unlikely once the primary infection is over – though it can appear nearby,
within the affected dermatome:



46% of women and 19% of men report anal recurrences

* Survey of 536 HVA members.

A final word:

As the patient leaves, you can add:

“Anything you read or are told about herpes that is scary, or merely worrying, is likely to be wrong... Ask me, or check with the Herpes Viruses Association.”

<https://herpes.org.uk> – includes resources in French, Italian, Spanish, Polish

THANK YOU!

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