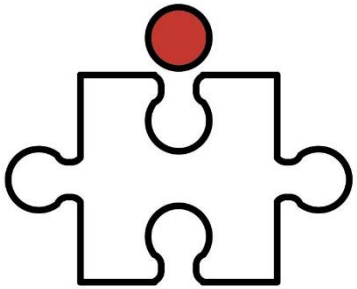
Genital ‘cold sores’: Helping you to Help your Patients with Herpes



Herpes Viruses Association
41 North Road
London N7 9DP

www.herpes.org.uk

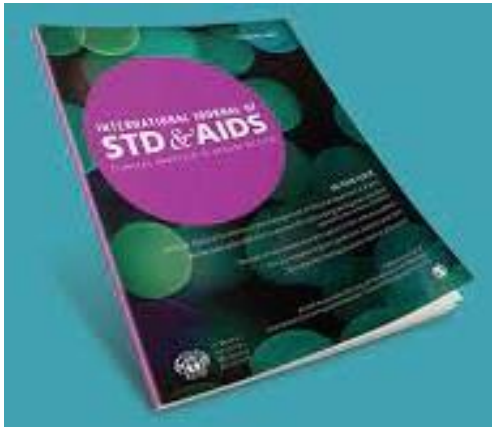
Your speaker…

Marian Nicholson:

- volunteer since 1985, when the charity was registered
- director of HVA from 1995
- member of the British Association of Sexual Heath and HIV (BASHH) “HSV special interest group” since 2004

Who we are, what we offer

- *Herpes simplex – the guide*: up to 10,000 copies distributed each year via GUM clinics
- Website: around 400,000 visits yearly
- 5 posters: accepted for BASHH, ASTDA and BASHH/ BHIVA conferences
- Zoom talk at IUSTI, Sep 2020 (Int. Union against STIs)
- Article in *Int. J. STI and AIDs*, November 2020



- Trials: 9 herbs trials/studies have found 3 useful herbal products

Who we are, what we do

The HVA's contact details are regularly given to patients by STI clinic staff – but we get no funding.

For the public, we have two office staff who:

- Answer questions sent through Facebook Messenger
- Answer email enquiries from patients and family members
- Answer questions sent to the HVA website
- Attend meetings organised by patients around the country (pre-COVID)
- Host one drop-in session a month in central London
- Host two Zoom sessions a month – details on website.

Helpline

- Daily helpline – weekdays, some weekends
- Helpline logs over the year show that:

  - average session: 9.2 calls
  - average duration of call: 13.3 minutes (range 2 to 102 minutes)
  - satisfaction score: 9.7 (out of 10)

- For members: quarterly journal *SPHERE* and leaflets for members; ‘workshops’ on talking to a new partner; seminars; ‘buddies’; events…

Today's programme

- Some 'medical' slides – with useful facts to support your patients… (Generally based on the BASHH guideline, 2014 – and the joint guidelines on childbirth by RCOG and BASHH)
- **What you can say to help the patient**
- The legal situation
- What we'd like you to do

Diagnosis – virus detection

- **Diagnosis has to be by swab test from active symptoms.**
- But treat empirically – early treatment works best.
- Patients could have ‘little cut’, ‘infected hair follicle’, ‘sore/itchy patch’, ‘little pimple’ – or the classic blister! Tends to be more sensitive than other skin conditions.
- Patients can buy blood tests (for HSV antibodies). All such serology tests are unreliable: up to 30% false negatives.* I.e. negative or equivocal result from a person with a viral culture that was positive.
- HSV-1 antibodies could be from genital or facial infection.
- **Serology may be helpful in the following situations (BASHH):**
  - recurrent genital disease of unknown cause
  - investigating asymptomatic partners of patients with genital herpes, especially pregnant women

* van Rooijen MS, Roest W, Hansen G, et al. Sex Transm Infect doi:10.1136/sextrans-2015-052213

Differential diagnoses: 29

- Herpes zoster (3% of genital sores)
- Candida albicans (thrush) (also oral)
- Lichen sclerosus
- Lichen planus (also oral)
- Lichen simplex
- Syphilis (also oral)
- Chancroid
- Moluscum contagiosum
- Lymphogranuloma venereum
- Bartholin's cyst
- Behçet’s syndrome
- Eczema
- Scabies
- Urticaria
- Erosive balanitis
- Proctitis (in MSM)
- Pemphigus vulgaris (also oral)
- Pityriasis rosacea
- Reiter's syndrome
- Boils
- Orf
- Trauma (including dermatitis artefacta)
- Drug reactions
- Malignancy
- Pyoderma
- Enteroviral infection
- **Primary facial symptoms may be confused with**
  - Impetigo
  - Tuberculosis
  - Aphthous ulcers
  - Tonsillitis or teething in infants.

Herps simplex is common

Only one in three knows they have it…

Statistics in UK – age 15

25 in 100 children have herpes simplex type 1

Statistics in UK - age 25

6 in 10 = type 1

1 in 10 = type 2

Statistics in Australia* – 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…

- 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

Poll 1: How soon will a patient notice symptoms?

4 or 5 days

2 days to 2 weeks

Indefinite

None of the above

All of the above

Transmission

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 sheet, cups or cutlery, baths or Jacuzzis.

It can appear years after infection, so you cannot use it to prove infidelity. (Unlike most STIs.) **Some people notice first symptoms years after original infection so:**

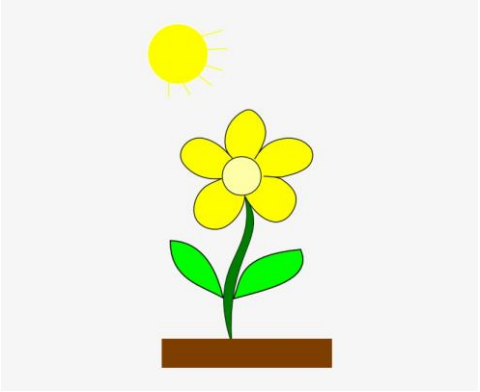
It isn't necessarily caught from the most recent partner. ('Cheaters charter'?)

Partners with same type are highly unlikely to reinfect each other.

Partners with the 'other' type have partial protection, i.e. reduced chance of symptoms.

c. Bright side (2)

Two virus types: either type can be caught anywhere, but -

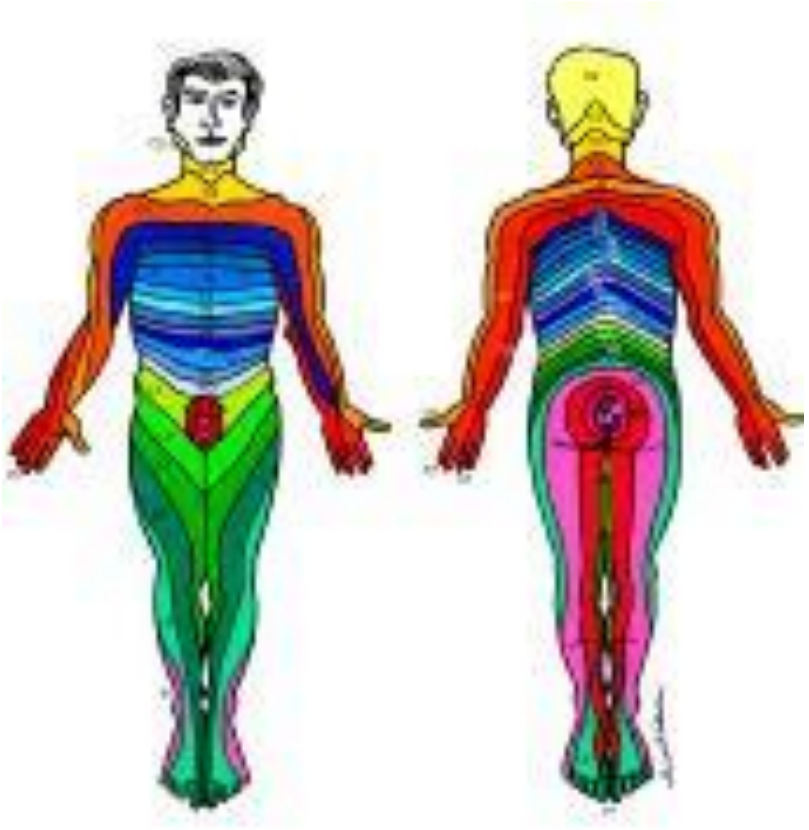


- Most people only catch one type.
- Each type gives partial protection against the other.
- Oral sex + cold sores = genital infection
- Type 2 is more likely to recur on the genitals: 4.6 outbreaks in first year.
- Type 1 is more likely to recur on the face - when genital, just 0.8 outbreaks.

It's not spread around the body once the primary infection is over – though it can appear nearby, within the dermatome.

Dermatomes – S1 to S5

- Slices are ‘like walking a dog through a bacon slicer’



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

Asymptomatic shedding

- Only from the affected area. (Yes, this needs to be said!)
- People taking part are not ‘normal’ – no controls and the need to do swabs will raise chance of viral activity.
- 19% don’t shed virus asymptomatically.
- NAATs pick up low levels of virus – even viral particles!
- It happens just before/after outbreak.
- It becomes less frequent –after a year the level of shedding is way down.
- 7 out of 10 people by age 25 are carriers, they shed too.
- PCR tests show 1.3% adults are shedding type 1* orally but we don’t kiss through cling-film

* Reichart PA. Oral mucosal lesions in a representative cross-sectional study of aging Germans. Community Dent Oral Epidemiol 2000; 28: 390–398.

Poll 2: Short course therapy for a recurrence (episodic treatment):

- 200 mg five times a day for 5 days
- 400 mg twice a day for 5 days
- 800 mg three times a day for 2 days
- I don’t know

Antiviral regimen - from BASHH guidelines

First symptoms (primary or initial)

- aciclovir 400 mg three times a day, 5 days
- valaciclovir (Valtrex) 500 mg bid, 5 days
- famciclovir (Famvir) 250 mg tid, 5 days (NB v. pricey!)

Recurrences:

1) Short course (episodic) therapy: **NB therapy must be self-initiated, preferably within 6 hours.**

- aciclovir 800 mg tid, 2 days
- valaciclovir (Valtrex) 500 mg bid, three days
- famciclovir (Famvir) 1 gram bid, one day (NB v. pricey!)

2) Suppression – 12 months supply:

- aciclovir	400 mg bid (or tid)	£70
- valaciclovir (Valtrex)	500 mg daily	£74
- If these don't work – double the dose. Or finally:		
- famciclovir	500 mg bid	£4,602

Treatment – suppression (cont)

Suppression should start 5 days before a person needs to be sure of not having an outbreak…

Safe: “Patient safety and resistance data for suppressive therapy with aciclovir now extends to over 20 years of continuous surveillance. This confirms that [it] is an extremely safe compound.” BASHH

No testing needed: “No need to monitor previously well patients and only a dose adjustment in those with severe renal disease.” BASHH

“The patient’s situation should be evaluated after a year.”

If the patient's situation is unchanged, there is no point in stopping suppressive therapy.

If the patient decides to stop suppression, allow two outbreaks to occur to assess their frequency [to allow for the “bounce back” outbreak] before considering further suppression.

Proctitis [inflammation of the rectum] is triggered by herpes simplex in 12% of MSM. So a man with proctitis should be given suppressive aciclovir.

BASHH statement on condoms

- Condoms are worth using especially if carrier is male – so don't say "condoms won't help".
- Using a condom as little as once in every three sexual acts has a measurable impact on reducing transmission.
- However, women are half as likely to infect men as the other way round.

BASHH with the RCOG: Childbirth (1)

BASHH and the Royal College of Obstetrics and Gynaecology: joint guideline on herpes simplex and childbirth, 2014

- Primary infection **does not** trigger a miscarriage.
- A foetal scalp monitor **can be** used if required.
- Women can have vaginal delivery even if **recurrent lesions** are present at term, this is safe. Babies acquire ‘maternal antibody’ from month 7 onwards.

Childbirth (2)

- Women can choose to take suppressive therapy from 36 weeks if they are worried about lesions at term.
- Women can choose to have a Caesarean section if they have a recurrence at term (in line with NICE guidelines that state that all women can opt for CS if they wish) though this is not considered necessary.
- Even if lesions were present during the birth, there is no need to keep a baby in hospital longer than any other baby ('normal post-natal care').

What you say to patients matters

a) Choose your words – graphic descriptions may help
b) Compare with other herpes viruses
c) Look on the bright side, offer ‘best outcomes’
d) Explain the hype
e) Explain responsible behaviour
f) Warn about the myths

Why you are here…

"**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."

Dr Colm O'Mahony MD FRCP BSc DIPVen.

"Each patient will be in a different state according to what they *already* think."

a. Choose your words

- **Call it 'herpes simplex' or 'cold sores'.** Helps to distance from the stigma of 'herpes'.
- **Don't use the initials: HSV.** This gets mixed up with HPV, HCV – or HIV.
- **Avoid these medical terms:**
  - ***'incurable*** – is a synonym for fatal. In fact, this is cured by the immune system.
  - **'*attack*'** - that's for heart attack or terrorist attack. Say recurrence, episode, symptoms, or flare-up.
  - ***'chronic'*** – that's a synonym for serious
  - ***'disease'*** – that's for "serious illness" only
  - ***'meningitis'*** – that's a (bacterial) infection that kills people
  - ***'sufferer'*** and *'**victim**' …*

b. Compare to other herpes viruses

- Compare to chickenpox (herpes varicella) and glandular fever (HHV5) or thrush.
- Don't use '*it's with you for life*' - tell them that chickenpox also remains in the body.
- Tell them *"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 pollution/dirtiness'.)

c. Look on the bright side

- **Not dangerous.** "You get better with or without treatment, like flu."
- **Some get symptoms only once.** Average is meaningless where range is 0-18! (Type 2 is 4.6, type 1 is 0.8 yearly.) Genetics play significant role.#
- **It's normal.** Professor George Kinghorn, GU consultant in Sheffield stated: *"… to be infected with a herpes simplex virus is a state of normality…"*
- **Only one person in three** has obvious symptoms that get diagnosed.

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.

From Dr Des Maitland's presentation

Herpes simplex – the 70s

- Frequent but non-serious medical condition
- Symptom relief only
- Little to no mention in medical textbooks[1]
- There was little to no shame or stigma associated with having 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. verer. Dis. (1975) **51:** 57

From Dr Des Maitland's presentation/2

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 US patent** (1985 capsules; 1991 tablets)
- **Don't believe the hype.** It was part of 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

Hype (early days)

Time magazine, 1980: ‘The new sexual leprosy’

Time magazine, Aug 02, 1982 >

SCIENCE

Environment: The OPEC of the Midwest (Environment)

Science: Singing the Blues at J.P.L

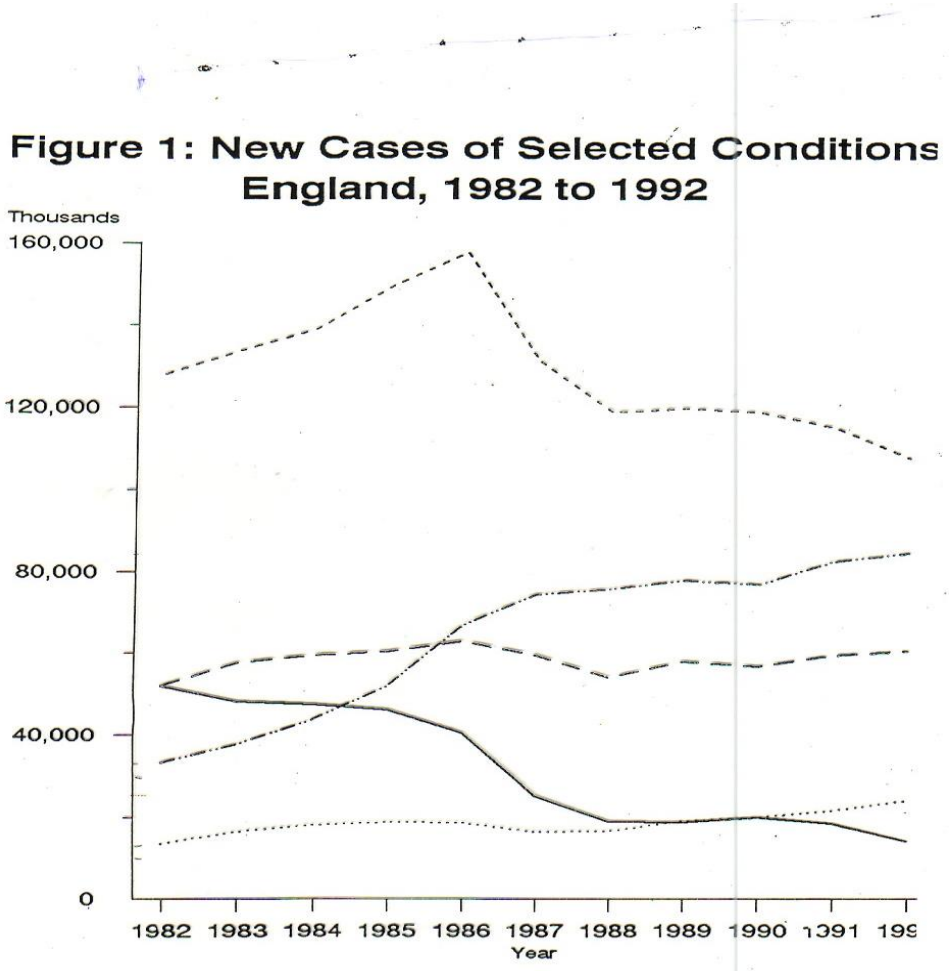
SOCIETY

In New York State: Culture's Front Porch (American Scene)

Behavior: Snake Venom and Earwax (Behavior)

The New Scarlet Letter (Behavior / Cover Story) **Herpes, an incurable virus, threatens to undo the sexual revolution**

Hype – the marketing strategy



KC60 statistics, now called UK Health Security Agency.

- - - - - - - NSGI

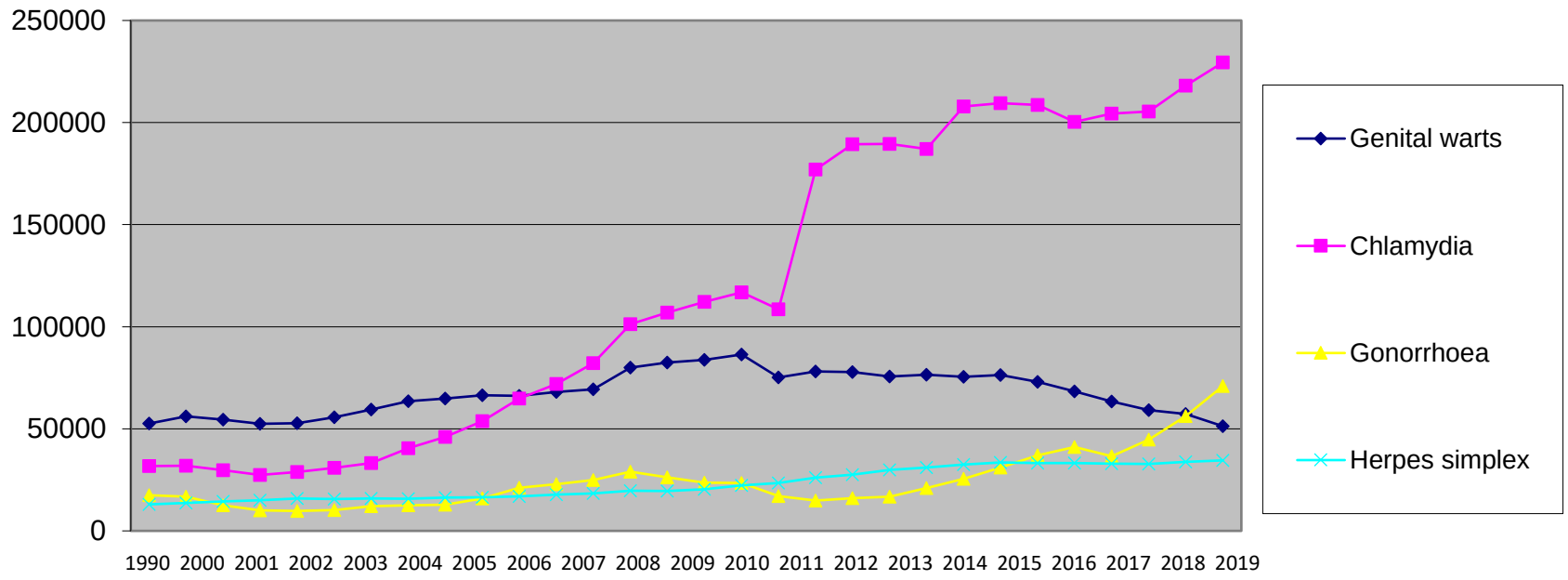
_____ all gonorrhoea

_..._..._... HPV

_ _ _ _ candidiasis

……..... HSV

The hype – more stats



2020: Total STI diagnoses were 32% down – herpes simplex was 40% down

Poll 3: What is the legal situation regarding 'disclosure'?

- No legal requirement for patients to disclose any STI or HIV
- Patients are obliged to disclose HIV but not other STIs
- Patients are obliged to disclose any viral STIs.
- Don't know

e. Legal situation

There is no legal requirement to disclose any STI or HIV.

BASHH guidelines were amended after the single UK case in order to protect healthcare professionals in future: "… disclosure is advised in all relationships – and you should document that you have done this."

If patients ask about the legal position, say that:

- Telling a partner before sex is protection from a criminal charge.
- Using a condom and/or taking daily antivirals is a defence against a charge of 'recklessly infecting a partner.'

See more about this on https://herpes.org.uk/news

f. Responsible behaviour…

- Is it necessary to reveal facial cold sore infection before kissing?
- There is no legal requirement to disclose any STI or HIV. But do not be reckless or malicious, and don't lie. BASHH guideline added "disclosure is advised in all relationships" to protect professionals.
- Disclosure reduces risk of transmission very effectively: "100,000 people having sex, 83 would acquire it."
- Use 'cold sore' so the partner doesn't overreact.
- It is common:
  - By age 25, 7 out of 10 past and future partners will have herpes in one place or the other – so they have total or partial protection.
  - Australian data, in 35-44 yr cohort: fewer than 15% women and 23% men are seronegative.
- Only one in three will notice when s/he is infected.
- HVA members' survey reported 83% success of disclosure.
- Persons who are undiagnosed are more apt to transmit infection than those with known infections. Corey, L. . Clinical Tools for Preventing Sexual Transmission of Genital Herpes. Medscape 03/29/2004)

g. Warn them about ‘myths’

- Not spread by hands or on towels, etc. [BASHH]
- Does not turn into HIV (common misconception)
- We are not impressed by ‘lysine supplements’
- Not a cause of cervical cancer – or other…
- **“Any story about it that is scary, or merely worrying, is likely to be wrong…”** Tell them to get the facts - from you or HVA helpline or website.

Nine humanherpes viruses

MEDICAL NAME:	CAUSES:	HOW COMMON?	HOW IS IT CAUGHT?	INCUBATION PERIOD:
These 'alpha' humanherpes viruses hide away in the nervous system between outbreaks				
herpes simplex types 1 and 2	blisters/sores anywhere on the body, especially face (we call them 'cold sores' or fever sores') and genitals (we call them 'herpes')	by age 14 about 25% by adulthood about 65% (or more) of which about 12.5% is type 2	contagious - direct contact with the affected area, "skin to skin with friction"	2 days or longer, but the most common period is 4 or 5 days
herpes varicella and herpes zoster	chickenpox shingles can be followed by PHN (post herpetic neuralgia)	by 12, almost 100% by 85, it is 50% by 60, it is 50% by 70 it is up to 70%	contagious and infectious it is not caught, it just develops when a person who has had chickenpox in the past is run down	2 weeks
These 'beta' humanherpes viruses hide away in the lymphatic system between outbreaks				
cytomegalovirus	glandular fever-like illness	about 50%	contagious	4 - 7 weeks
humanherpes viruses 6, 6a and 7	fever and rash in babies	virtually 100% by age 2	saliva	
These 'gamma' humanherpes viruses hide away in the lymphatic system between outbreaks and are implicated in causing cancer				
Epstein Barr virus	mononucleosis, called "kissing disease, or glandular fever	over 90% of adult population	contagious, usually saliva	
humanherpes virus 8	some implication in Kaposi's sarcoma			

Alternatives to antivirals (1)

- Antivirals do not work for everyone due to genetic variability, and some prefer alternatives.
- If sex is a trigger – use **a lube with silicone** (e.g. Durex Real Feel Silicone Based Lube, ID Millennium, Jo Silicone Premium)

The HVA has tested several alternative products and found three that are worth suggesting:

- Elagen (eleutherococcus senticosus): 100 people double-blind placebo-controlled trial 68% self-reported “stopped or greatly reduced my outbreaks” [1]

1 Panossian A1, Wikman G. *Evidence-based efficacy of adaptogens in fatigue, and molecular mechanisms related to their stress-protective activity.* **Curr Clin Pharmacol.** 2009 Sep;4(3):198-219. Epub 2009 Sep 1.

Alternatives to antivirals (2)

- Olive leaf extract: open label study against two other products (15 in each arm) found 11 out of 14 people self-reported “stopped or greatly reduced my outbreaks” [2]
- Lomaherpan (with melissa officinalis extract) has long history of topical use against cold sores [3]
  - as reported in *SPHERE.*

2. Panossian A1, Wikman G. *Oleuropein in Olive and its Pharmacological Effects* **Sci Pharm**. 2010 Jun 30; 78(2): 133–154. Published online 2010 Apr 23. doi: 10.3797/scipharm.0912-18 PMCID: PMC3002804

2. Schnitzler P1, Schuhmacher A, Astani A, Reichling J. *Melissa officinalis oil affects infectivity of enveloped herpesviruses* **Phytomedicine.** 2008 Sep;15(9):734-40. doi: 10.1016/j.phymed.2008.04.018.

To remind you of this info…

For you >

“Helping you to Help your Herpes Patients” – a crib card for you: bullet points of what to say with patients.

Download: https://herpes.org.uk/professional-enquiries/

or email info@herpes.org.uk

Helping you to Help your Herpes Patients

For staff: if you have any questions, or want cards, posters or leaflets: 020 7607 9661
Patients' helpline: 0845 123 2305

Do say to your patients:

- **'Cold sore - lower down'** – get away from the stigma of 'herpes' [1]
- **Not serious** – symptoms heal with or without treatment, just like a cold - for almost everyone it's just a minor skin condition [2]
- **It may come back, but many people get symptoms only once** – a recurrence is not inevitable. [2]
- **It's common:** by age 25 around 10% have HSV2, more than 6 million UK adults. [3]
  - And about 70% have at least one type – mostly without symptoms.
- **Some people get first symptoms years after infection** [4] so:
  - **You won't necessarily have got it from the one you are with.** This is the 'cheater's charter': "I've been told I could have caught it long before I met you."
- **Only 1 person in 3 notices symptoms and gets diagnosed.** [5]
- **It's not spread around the body once the primary is over.** [6]
- **Partners with same type rarely reinfect each other.** [6]
- **Two virus types** - either type can be caught anywhere, but -
  - Most people only catch one type [7]
  - Each type gives partial protection against the other [8]
- **If you hear or read anything scary,** it will be wrong or misleadingly stated - get in touch or ask the HVA helpline. [9]
- **Here's a patient card/leaflet/GUIDE booklet.**

Don't say to your patients:

- **Incurable** - often thought to mean the same as 'fatal.'
- **Attack (it's not a heart attack or terrorist attack!)** - say recurrence.

What we'd like you to do (1)

- Offer **pain advice**: lidocaine 5%, well-wrapped ice bag, cold wet tea bags, usual painkillers (with codeine?)
- Aciclovir for those who need it.
- Warn patients: when stopping prophylaxis an outbreak 4-5 days later is not an indication of future frequency.
- Maybe: mention the RVx vaccine trial: starting soon in west London. Phase 0/1 with a live attenuated virus vaccine. 100 patients; having lots of outbreaks; fares and a fee paid. Email info@herpes.org.uk for protocol.
- Give them our details, in case they have more questions…

What we'd like you to do (2)

Provide the HVA's website and helpline number: 0845 123 2305.

Give patients written information – they only remember a fraction of what they are told.

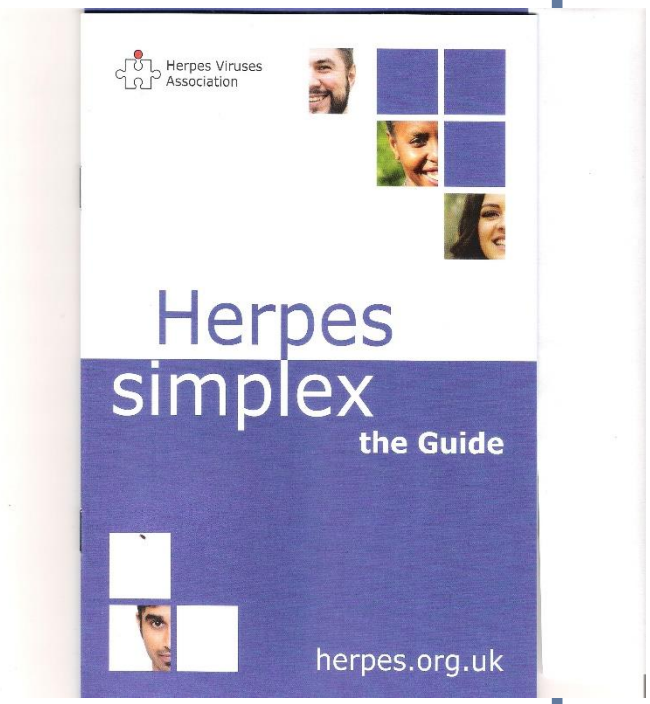
- True or False leaflets for the waiting room racks
- HVA patient cards

What we'd like you to do (3)

Or "Herpes Simplex - The Guide"
16 pages, 6000 words
(£90 for 100 > £310 for box of 400)

"The Herpes Viruses Association guide – to take away and read - gives the patient clear, unbiased information that can be discussed at the following consultation."

Dr Colm O'Mahony MD FRCP BSc DIPVen.



THANK YOU! Questions?

https://herpes.org.uk - info@herpes.org.uk