## **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: 0345 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 <sup>(2)</sup>
- It may come back, but many people get symptoms only once a recurrence is not inevitable. <sup>(2)</sup>
- It's common: by age 25 around 10% have HSV2, more than 6 million UK adults. <sup>(3)</sup>
  - $\circ$  And about 70% have at least one type mostly without symptoms.
- Some people get first symptoms years after infection <sup>(4)</sup> 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. <sup>(5)</sup>
- It's not spread around the body once the primary is over. <sup>(6)</sup>
- Partners with same type rarely reinfect each other. <sup>(6)</sup>
- Two virus types either type can be caught anywhere, but -
  - $\circ$  Most people only catch one type <sup>(7)</sup>
  - Each type gives partial protection against the other <sup>(5)</sup>
- If you hear or read anything scary, it will be wrong or badly explained get in touch or ask the HVA helpline. <sup>(8)</sup>
- 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, episode, flare-up.
- You've got it for life not said about chickenpox or thrush! (1)
- We need to see your partner no testing without symptoms. (9)
- You can go to prison/be sued if you don't disclose. No! There is no legal requirement to mention any STI get good information. <sup>(10)</sup>
- **You'll need a C-section** BASHH/RCOG joint guidelines state it is unnecessary. (Optional: take antiviral tablets from week 36.) <sup>(11)</sup>

Herpes Viruses Association, 41 North Rd, London N7 9DP - office 020 7607 9661https://herpes.org.uk- info@herpes.org.uk- helpline 0345 123 2305

# Help us to end the stigma

Notes/references for "Helping you to Help your Herpes patients"

### Medical statements, mostly from the BASHH 2014 "Anogenital Herpes Management Guideline"

- There are 9 humanherpes viruses: including herpes varicella (chickenpox) and glandular fever, both of which are well-known to the public.
- (2) People with a particular genetic type (just their bad luck!), or who are immunocompromised may have severe and frequent episodes. Very rarely, facial cold sores (but never genital infection) can recur *in* the eye or brain and can cause blindness or death.

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.

(3) Up to 60% of new cases are type 1 (e.g. Cambridge)

Vyse AJ, Gay NJ, Slomka MJ, Gopal R, et al. The burden of infection with HSV-1 and HSV-2 in England and Wales: implications for the changing epidemiology of genital herpes. *Sex Transm Inf* 2000;**76**:183–187

- (4) The patient has been carrying the virus in a dormant state without having had primary symptoms – 15 years is the longest we know of.
- (5) BASHH 2024 Guideline: "Prior infection with HSV-1 modifies ... first infection by HSV-2, usually making symptoms less severe."
- (6) Catching the virus gives immunity against catching the same type on another area - from either self-inoculation or a partner. Even during a primary episode, it is extremely rare to spread the virus to new sites. [BASHH] If spreading in this way were common, there would be anecdotal stories of children with cold sores all over their skin.
- (7) Types 1 and 2: clinical difference is a preference for a specific area of

the body. This influences the frequency of recurrences. HSV-1 genitally: average recurrence = 0.8 times a year, HSV-2 average = 4.6 times a year. [BASHH]



As a helpliner says: "Type 1 is like a flower that blossoms more frequently when planted in a sunny spot. Type 2 flowers more often in a shady location. So genitally, type 1 is less likely to recur."

- (8) HVA was accredited to the Information Standard (NHS 'kitemark').
- (9) It may be advisable to trace contacts and test them for other conditions, but partners should not be told "You don't have herpes simplex," if no symptoms are visible at the time of examination. Serology is seldom appropriate.
- (10) Only one case in the UK (Golding, 2011) which followed multiple mistakes by legal professionals.
   Defendant was incorrectly advised to enter guilty plea.
- (11) During pregnancy, herpes simplex is a concern only: if the mother contracts the virus during the last trimester - this may trigger labour, and the baby may be exposed to infection. In the primary episode, the mother will not yet have established antibodies to pass to the baby (transplacental protection), so her baby could be infected during the birth. Only in these cases is a Caesarean section expected. However: The risk to mother and baby from a *recurrence* is much lower than the risk from C-section.

2024 guideline by BASHH and RCOG: https://www.bashh.org/\_userfiles/pages/fil es/clarkeetal2024jointbritishassociationfors exualhealthandhivandroyalcollegeofobstetri ciansand.pdf

#### Herpes Viruses Association: updated February 2025