



BASHH conference facilitator introduces “Marian Nicholson from the Herpes Viruses Association in conversation with a helpline” – there is a strict limit of 10 minutes with a timer embedded on the podium. Marian ended the ‘chat’ with 5 seconds left on the clock!

Marian: The HVA has been answering helpline calls since 1985.

Obviously - these are from the people who have not had all the answers at the clinic. Perhaps from lack of time. Or else because they’ve thought of more questions since leaving the clinic.

I am joined today by Ruth Mayo, one of our volunteer helpline. These helpline can - by the magic of tech - log into our helpline number from their homes to do their shifts.

Ruth, from the calls you take, what would you think the first thing the diagnosing health professional should say to the patient?

Ruth: Tell the patient to “forget everything you thought you knew about it.” I spend a lot of the call DEGOOGLING people! **You could ask the patient what in particular they are worrying about, and address that particular fear.**

Then, I would ask the health professional to use the word cold sore - that brings it into the normal vocabulary. After all no one tells a mum her child has herpes varicella! They say chickenpox.

Marian: Yes, the medical language can be frightening for patients. For instance, being told it is incurable is a real no-no - as to many, because we say an incurable cancer, that means it is fatal. What do you tell patients when they worry about it being in their body now, for life?

Ruth: I say, that like chickenpox, thrush, and glandular fever, it can reappear without it having to be caught again.

Yes, it is totally normal to have these in the body. People are totally unaware of

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 fears.
- They don’t realise it is normal to have viral, bacterial and fungal cells inside us. Explain it...

Words you choose matter

- Use words you would use with cold sores and chickenpox.
- Using ‘cold sore’ for genital infection can lessen stigma.
- No judgmental questions or comments – and beware of excess sympathy!

this and feel polluted. So telling them we have more virus and bacteria cells in our bodies than cells with our own DNA is helpful in overcoming their sense of being polluted.

And this will also help with their sense of shame! The word 'herpes' has been stigmatized to the point that people say: "I don't mind having it, if only it wasn't called herpes." So, it is not the condition itself that's bothering them, but the way society will perceive them.

Yes, the healthcare professionals can help by not making any comments about their sex lives - we do hear sometimes things like 'Well you must have been busy!' - comments that imply promiscuity.

People call, telling me they are afraid they will never be accepted by any future partner. So they can never have a relationship or have babies.

It is shocking that a condition that does not cause bodily harm - apart from uncomfortable sores - has been stigmatised in this way.

What else do you help people with, on helpline calls?

They need to be told, right away, is how incredibly common it is. We have UK data indicating about 70% infection rate by age 25. And this of course includes facial infection, because oral sex and cold sores are a very common way of catching the virus genitally.

And by age 35, we have data from Australia showing that over 85% of women and 77% of men carry at least one type of herpes simplex. So I always tell older callers about that. They've never met others with it because no one talks about it.

And I get questions about childbirth all the time. Vaginal delivery is suggested even when a woman is having a recurrence.

We do have to mention that women must not catch it at the end of pregnancy. That's when it can cause harm to the baby.

I think it would help normalise it if the healthcare professional would mention that "Pills can be helpful, but they are not essential. All outbreaks get better with or without treatment." Again, this will lessen the idea that this is a serious condition.

Do patients ask you about treatment?

Use data to show how common

- WHO – seven in ten have HSV:
 - 67% in the age group 0 -49 yrs carry HSV-1
 - 11% carry HSV-2 in 15-49 yr olds (increasing with age)
- By age 35 it is over 85% for women and 77% for men (Australia)
- Only one in three notices when they catch it.

Childbirth - Treatment

- Vaginal delivery even if recurrent lesions are present at term. Babies acquire 'maternal antibody' from month 7 onwards.
- Antiviral therapy is optional.
- Mention pain relief including lidocaine BP 5 %.

Yes, often they are asking about pain relief. I tell them about lidocaine, a well wrapped ice bag and of course normal pain killers.

Doctors should mention that antiviral treatment is not essential. This can help normalise it too.

Oh, and the other big topic is transmission... They worry about the possibility passing on to some one

Yes, for that, I find it helpful to tell them that women are half as likely to infect a man and that if the place where the outbreak happens on a man is covered by a condom, that is almost guaranteed protection.

And the infection data is handy because it becomes hard and harder to find a partner who could catch it from you the old you get.

I like to quote Prof. Lawrence Corey who states: "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)

And they are likely to ask about asymptomatic shedding - as that is a major fear factor.

Oh yes, I absolutely agree, but we don't have time to talk about that now. Thank you, Ruth.

Condoms and transmission

- Condoms, when the male has the virus, are often very helpful.
- But women are half as likely to infect men.
- You are very unlikely to re-infect anyone. (And most new partners have it already.)