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Sphere

The Herpes Viruses Association | THE JOURNAL

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'Come Curious' YouTube channel talks about herpes – and does it right

Come Curious, the influential taboo busting YouTube sex channel for young people has boldly taken on the herpes stigma by revealing that both of its presenters, Reed Amber and Forbidden Florence, have herpes themselves.

In a 23-minute video, the presenters tell viewers how common it is, what to do about recurrences and how most people in the world have herpes and don’t know. They also relate their own stories about catching it, how they reacted to it and how little it affects them now.

They kick off by explaining that the information they share is from the HVA website and they thank us for providing clear and non-scary facts.

A number of Americans have posted videos about herpes, often without understanding that the most significant thing about it is the stigma, while failing to put it in its proper context as a common skin condition. We congratulate Reed and Florence for their bold and unapologetic approach.

Frank and refreshing

The two friends started the Come Curious YouTube channel in 2015 and it now features over 200 videos about all aspects of sex and relationships. The content has been viewed over 19 million times. They have written this on their site:

“We’re two friends who share a passion for SEX. We love to talk about it and we’d like to share our conversation with you. We believe that being open and talking about sex will spread valuable knowledge and relieve some anxieties that surround the subject. We are happy to share our experiences and opinions on sex, naked bodies and anything else that we see relevant. No one should ever have to feel uncomfortable about something that everyone in the world questions.” https://www.youtube.com/watch?v=gElc6SkYsPI

DENA MICHELLI – personal transformation

A psychological impact of a genital herpes diagnosis can be as devastating as a bereavement or a divorce. But there is an upside. Life changing events like this can make us stronger and more capable.

Dena Michelli, author and personal and professional transformation expert has helped many people to change their lives. She can help you.

Nigel Scott says: "Dena Michelli is an inspirational speaker and human being. She has spoken to HVA members on three previous occasions and each time she has made a difference to the outlook of many of the people in the room.

"Every big event in our lives changes us. If we understand how we can turn bad news to our advantage and emerge in better shape than we started, nothing can stop us.

"Read Dena's words and learn. I know I have."

Dena Michelli: My background is in trying to understand the effect that trauma or a challenge can have on people and how they subsequently make sense of this in their lives. I will show you what came out of this. Think about whether this means anything to you, whether it resonates with your experience. Ask questions and share your experiences. You might even inspire each other to embark on a journey such as the one that I am going to describe.

Challenge can be empowering

When people are affected by something that is deeply challenging they go through a process, and the process can be illuminating or damaging. This journey may apply to some of you.

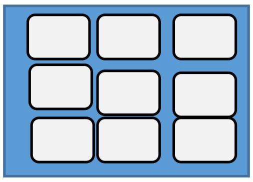
What is the route that enables us to progress through transformation and change and find a place of joy, happiness and fulfilment at the other side?

I am going to draw this shape - this is called the Change Curve, or the Transition Curve, or the Curve of Transformation.

It shows the emotional process that people go through and it describes "the transformative journey."

Follow the transformative journey

We start off with a Meaning Perspective (MP). This is a psychological structure, a filter, which allows you to make sense of your life, of your observations and of your experiences.



A starting Meaning Perspective (MP)

We go through life with this MP in front of our face, so that everything we do and experience is filtered through this MP. "I am this kind of a person." If what we are experiencing fits our MP, then we feel comfortable with it, but if it doesn't fit, then we get anxious or confused and we don't know how to make sense of it.

We want to get back to where we have come from. So then we have to go on the journey…

The trigger for change

There you are, living your life and all your experiences fit into your MP. Then something happens to challenge it, a trigger.

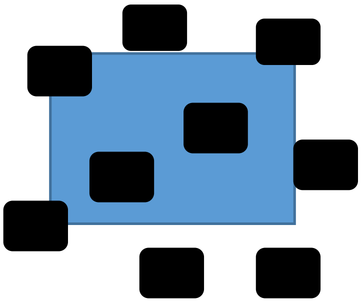
Can you think of a trigger that would change the way you look at yourselves, and change the way that you look at your lives?

Audience suggests:
A near death experience
A traumatic divorce
Redundancy
Having a child/death/accident
Coming into money
A herpes diagnosis!

DM: Exactly! This trigger comes along and our MP is blown apart. It changes our sense of identity. "I am not this kind of person!" Your structure goes and you lose a sense of meaning in your life. I remember when I had my baby boy thinking "I am not a mother - I want a record player, not a baby. Can I take him back?" [LAUGHTER]

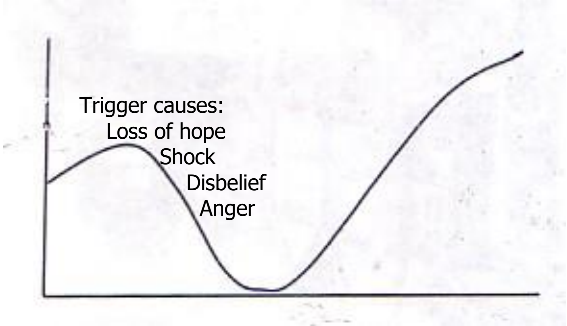
Dropping off the cliff

Now I am exaggerating here to make a point because there will be other aspects of your life which will still hold meaning, your job perhaps. But the trigger may affect things that are precious to you. It - the trigger factor - won't go away. You feel that your identity has exploded. People literally comment that "I was in bits", "I fell apart", "I am at a loss". You feel disassociated from your life, confused. When things fall apart, you ask yourself "Who am I now?"



An exploded MP "in pieces"

A lot of people call this the trough, the abyss, the pit, depression, the dark night of the soul... People use very graphic terms. "I fell off the edge of the cliff", "I descended into the trough." It was almost a physical sensation for them. Does this ring bells with anyone?



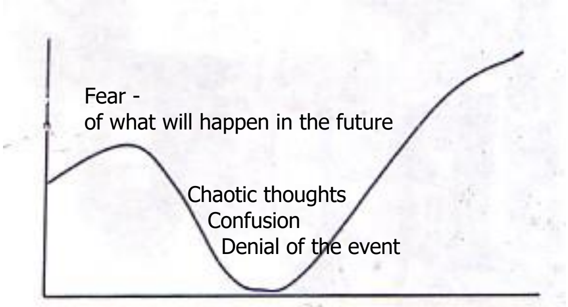
Denying that we have a problem

OK, so when we are in the process of 'the fall off the cliff' we often find ourselves in a state we can call 'chaotic' or 'confused'. From there we try to get back to where we started from, because that's what we know, that's what we trust. We call that denial or regression - getting back to how we were without facing up to the fact of what has changed. We blank out the change. Can you think of ways that we might try to do this?

Audience suggests:
We escape, through:
- Drinking
- Drugs (legal and illegal)
- Other risky behaviours
- Trying to carry on as normal
- Workaholism
- Other displacement activities
- Shopping [LAUGH]

Despair

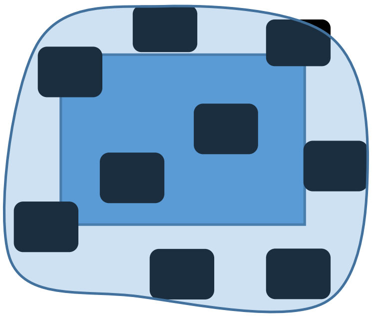
DM: Yes, we may become alcoholic, drug addicts, workaholics. We look for ways to



Trough/pit of despair/depression/dark night of the soul numb our sense of disruption and, because we are intelligent human beings, we can also use intellectualisation. We tell ourselves stories that make it OK. We use 'justification', 'rationalisation'… We create a story for ourselves that makes it make sense for us: "because I am a bad person…" "I must have deserved it…"

It can be a difficult place to get out of. Some people languish here for a long time.

Marian: I speak to people on the phone who are clearly stuck at the bottom of this curve. They are stuck in their "new shape". And sometimes they have been there a long time. I think the longer you've been convinced that it is all miserable, the longer it takes for you to actually start moving on.



A stuck MP

DM: Yes, some people don't ever leave the pit - here's a story. An elderly woman died. She'd been a recluse all her life. In her garage, they found an old Ford from 1947, with very few miles on the clock but a bunch of dried-up bluebells on the back seat. She'd been on a picnic with her husband when they were newly married, and he'd dropped dead from a heart attack. Her life had been blown apart and she'd got stuck in the trough of misery. She stayed in denial.

Understanding

What can we do to try to get out of it? We have been through the shock, the anger, the regret - and now we are moving towards acceptance. What can we do to start to move forwards away from our loss of MP?

Man 2: You can embrace it.

DM: Tell me more – how would you embrace it?

Man 2: By talking about it, by admitting it…

DM: Very good.

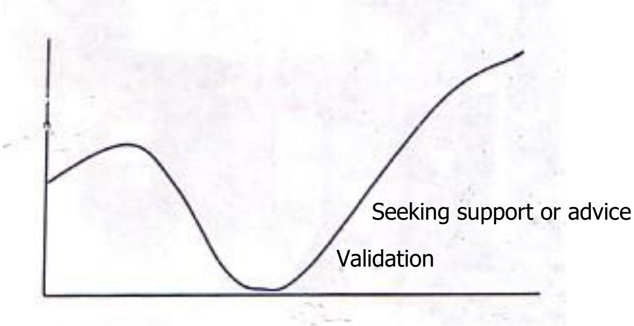
Woman 1: You have to figure out what you are going through, all those things are a form of grief. They are all forms of loss and if you get attached to the loss you won't want to move on. It's really grief…

DM: Yes, I absolutely agree with you. And what are we grieving over?

Man 2: Loss of identity

DM: Yes, loss of our sense of who we are, we are losing ourselves, our place in our world. Which is why it so profound. So talking about it is extremely important. Since you have lost the structure, who might you seek help from?

Audience suggests:
Counsellors
Therapists
Friends
Groups



DM: Yes, talking to others in the same situation is very good… for shared experience, for talking. **And in my research, if people are not seen, heard and validated they will not travel [on up the slope].** Now that is a big claim, especially if you think about men. [LAUGH] In all seriousness, recently a man told me "The problem with me is that I never talk and what happens is I spiral down and there is no end." Culturally men have a pressure on them not to talk, to share, but they still need to.

Talk about it to get over it

Man 3: The problem with that is that it all depends on what's wrong. Society might not be helpful or sorry for you, it all depends on what is wrong with you...

DM: That's right. Sometimes the whole of the angst of society is projected onto certain crimes and conditions. **'Prejudice' it is called.** And it is a hell of a block. This is why we see groups clustering together. Because they have to have that structure, that support, that validation. It is a human condition, a need.

How do we get out of it? We get together, we talk, we get information – more facts. What else? Create a new story. Change the way you look at the problem. Learn who you are. Get help from supportive organisations. Focus and get into the present.

Woman 1: Learning about your condition is a very important thing because you get empowerment back.

DM: Yes, indeed, learning… Accepting the situation, learning about it, taking suppressive medication, acquiring knowledge so that you can explain it. Creating a 'new story' for your future life.

Some people find that cognitive behavioural therapy (CBT) is helpful in getting them to adjust, to reassess. Talk about it with people in your life or a therapist or with professional organisations…

Learn that **"I cannot change the world, but I can change how I look at it."**

All these will help you to feel normal again, step by step.

Be in the moment

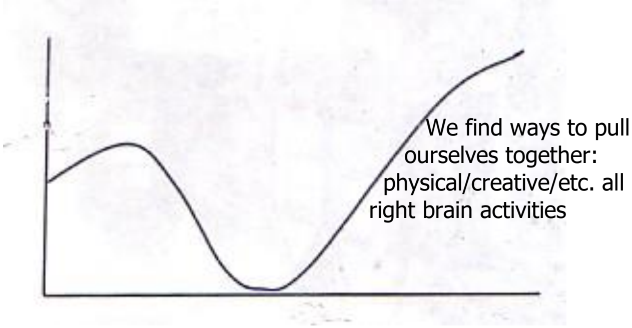
You may have fears regarding your future. Some people live their lives in fear. "I'm a worrier." But this does not help. You need to live in the here and now.

This is when other things will help you to start moving up the curve. You can use physical activity (running), creativity (photography/ watercolour/writing poems/dancing), yoga/meditation, and study…

Take yourself offline. Cycling, gardening, meditation, yoga, meaningful conversations, young children requiring attention. It can help to make meaningful connections with others, perhaps in singing, music or any sort of project. You will become more optimistic, connected, trusting of yourself and others. The Meaning Perspective that has blown apart will be repaired.

In following this course of action you will gain direction and put yourself back together, by gaining a purpose. Your experience will turn into wisdom. Nothing is wasted. Every experience serves a purpose. You can now help others with your new wisdom…

We find coping strategies and we become more integrated. We say things like "I found myself", "I began to know who I am", "I am putting myself back together".

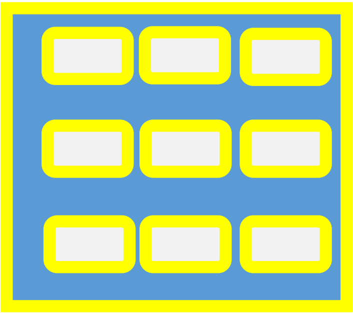


We find ways to pull ourselves together: physical/creative/etc. all right brain activities

Integration allows us to move on

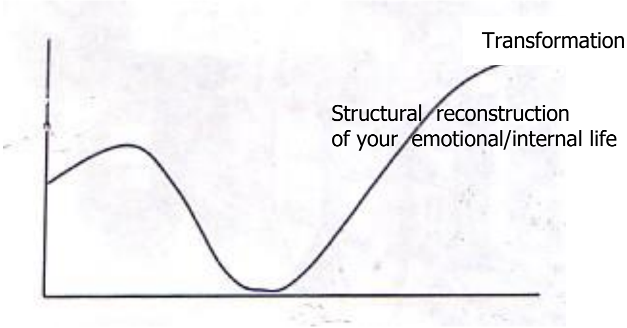
What has happened is our MP starts coming back together again but in a new configuration and you are beginning to pull bits of your experience together. It is a process of integration. We are collecting all sorts of bits of information together and beginning to say, 'Ah ha, now I understand.' So we are beginning to integrate – and we are beginning to build back - and learn from - the soup that we have been in.

And what happens is we come out on the other side with a Meaning Perspective (MP) which is a different MP because it has integrated all this learning and it is bigger, better and brighter than the one that we entered the process with. We can measure this by the line now being higher than it was before the trigger: that increase is called 'transformation'. And the definition of transformation is that your MP has fundamentally changed. The way you see the world, the way you make sense of the world, is now different.



A shiner, bigger, better MP

Experience has turned into wisdom. We now understand ourselves better than we did before. Then we share, we give back. We help others… We were on our knees. We've been to the bottom. We've learnt more, we've grown. We are now bigger and better. This is a personal development bonanza.



Life's journey: transform to grow

This process is a description of life's journey and we go through it a number of times as we grow. We begin to notice it when we go from 'infant' to 'adolescent' when we let go of mother's apron strings and enter the world as an individual in our own right. To do this we have to jettison some of our parents' injunctions. They don't like it: they feel invalidated when you say "I don't like your values; I am going to find my own". And they say "No son/daughter, this is our family code, you stay with us". But that will restrict you and you cannot express yourself fully. So then we have the teenage years of rebellion.

Then again in midlife, we have the midlife crisis. What happens when we hit midlife we have to find new meaning. People say that don't they? When they have been redundant or faced an illness… They say: "Actually that was the best thing that could have happened to me." Not at the time, but looking back… "I would never have experienced this kindness, these people I've met, this learning that I have found." And I imagine that there are a number of people in this room who feel that.

Throughout your life, you will meet people who are surprising. They can help you. As they say in Harry Potter, "Help will always be given at Hogwarts to those who ask for it."

Relate this to catching herpes simplex

Woman 3: Can we relate this to our journey, when we've caught herpes?

DM: Yes, absolutely. Because when you first get diagnosed I guess it is a real shock. And I guess your world tumbles in. 'Oh my God it is never going to be the same again. I am no longer this person.' And you have all the prejudices that society projects upon you. We know that they don't hold water but we know that they have deep impact. So then you go on your great search, in this group, with your colleagues, with these beautiful people that accompany you on this journey.

I do think that when you have embraced life, and have been burnt and scarred, you are a much richer person.

There's that great expression "Accept yourself warts and all." I do think it so important to love yourself, because you can't bring yourself wholly into a relationship, unless you are whole yourself.

Don't avoid the challenge

You can refuse to move on, and people do; they remain at the start, at the top on your side of the cliff. "No, no, no I am not going." If you refuse it, then you deny your capacity to grow to your full potential. So you are damned if you do and damned if you don't - so you may as well do it!

Marian: And that has terrific resonance for what we are here for. You can stay exactly where you are and say "I am never going to have sex again with anybody, ever", or you can say "I am going to move on."

DM: And it is in moving out of the abyss, that you find the creative force, it is where the ideas and opportunities, options – all those wonderful things - lie. You can be incredibly inventive.

Woman 1: So we choose to stay at the start, or we can choose to move on, or we are pushed off…

DM: Exactly… Enjoy the journey, fly…

We thanked her.

APPLAUSE!!

Dr Charlotte Hopkins on ‘What I tell my patients about herpes’

Charlotte is a Consultant and Deputy Chief Medical Officer, working in sexual health at Barts Health Trust, serving the City & East London

CH: I work in a new clinic in Stratford, the Olympic Park. It’s a lovely space. I have been a consultant for nine years. I trained at Mortimer Market Centre and subsequently moved to Whipp’s Cross. I have worked in sexual health for over fifteen years and now I work a lot with HIV patients.

On Monday mornings, I run a ‘complex clinic’ and quite a few of the people who come to that have problems with their genital herpes. I am quite generous with aciclovir for such people. After all, it is cheap as chips now.

I have some questions for you all now: which statement is true, which is false?

A. Genital herpes is mostly caused by type 1
B. Genital herpes is mostly caused by type 2

Audience: Most people chose B. type 2.

CH: In fact, most genital infection these days is caused by type 1 but type 2 is responsible for most of the recurrences. We think that the reason for the increase in type 1 is because oral sex has become so common and because far fewer people catch type 1 facially as children than, say, 100 years ago. We sometimes see people catching type 1 genitally when they already have (type 1) cold sores, but this is not that common.

If you have type 1 in one place and then catch type 2 the symptoms are likely to be less severe.

“Do condoms help to protect you from catching herpes?” Yes or No?

Audience: Most people chose A. Yes

CH: Condoms will reduce the risk but are most effective in preventing transmission of STIs like chlamydia, syphilis, gonorrhoea and HIV, because herpes outbreaks can, in some instances, be outside the area that is covered by the condom, so not as good – but still worth using.

C. The appearance of a new infection means that it has just been caught.
D. You cannot tell when you have caught herpes.

Audience: Most people chose B. You cannot tell.

CH: Herpes is not a sign of infidelity. Most infections are acquired subclinically. This means that people catch it, but they fail to notice symptoms. In fact, most people catch it off a person who has no idea that they have it. So herpes can suddenly appear during a relationship. I tell patients that they cannot blame the partner when herpes simplex pops up. “I’ve been twenty years with my partner, and now this.” Yes, that is what happens.

I can often diagnose just from hearing what the symptoms are. For instance, “I have pain weeing” - not necessarily genital herpes. But “I have pain weeing when it goes over the sores”. That’s what you expect from genital herpes.

People frequently ask me “What is the impact for my partner?” Well, the first thing to know is that it is common. A quarter of people have genital herpes. So everything you are worrying about needs to be put into that context - many people have it, and it is not something that doctors worry about people having.

If you are now in a long-term relationship don’t do anything different. Just abstain from sex when you have an outbreak. We don’t test partners - except when a man has it and is planning a family, then we may test the woman. [This is because it is important that he does not infect his partner in the last couple of months of pregnancy. If she already has it, there is no need to worry.]

You don’t have to tell

If you are starting a new relationship, it’s your business. You don’t have to disclose this but you should be responsible. If the relationship is going somewhere, and you do tell them, it is unusual for them to walk away. We find the same with HIV. It is not a deal-breaker with someone who is into you.

“Can you cure it?” I explain that like chickenpox, cytomegalovirus (CMV) and glandular fever (Epstein Barr virus) we have it in our bodies. It lies dormant in the nerve ganglion [junction box] and then it reactivates, or not. It is totally treatable like rheumatism... Aciclovir is well-tolerated; in my experience of 15 years no one has reacted badly to aciclovir. And no monitoring is required now, unless you already have damaged kidney function. I usually give people a 6 month course of aciclovir.

Treatment

There is also valaciclovir (or Valtrex). This is a pro-drug, a slow release drug as the compound gets converted into aciclovir in the body. This means that it stays in the body in higher concentrations for longer. Many people find that one a day is enough to suppress the virus. [But half a pill twice a day can be more effective for some people.]

If you get breakthroughs on aciclovir twice a day, then take it three times a day, every 8 hours.

“Is it dangerous to take suppression all the time?” I reply that it is fine, even in pregnancy. No monitoring is required.

“I don’t want to take antiviral pills; I want to see if I can get better.” I tell them that’s OK. They can always take it later if they want to.

“What about asymptomatic shedding?” This means that the person does not have any visible symptoms, but nonetheless, a very precise test can detect virus on the skin from time to time. Only 10-25% of the time in the first year. After ten years, it averages 2% of the time. Treatment halves the amount of shedding you will have. So that would be another reason why a person might want to take suppression for the first year, because this cuts shedding significantly. Taking suppression does not delay the time your body takes to build up your immunity to the virus.

Resistance to aciclovir is very rare. It is due to a genetic difference in some people whose bodies do not react in the usual way to the enzymes that the antiviral targets.

After a year - or even a few months - people will decide they don’t need it. They stop taking it and are warned that they may well have a rebound outbreak straightaway. They can use the ‘episodic treatment’ [800 mg three times a day for just a few days] and wait to see how long it is till they get the next outbreak, six weeks, six months… If it’s six weeks, they may choose to go back on suppression, if it’s six months, they may choose to use episodic treatment.

I give two boxes of aciclovir to people who are discontinuing suppression so that they can treat rebound outbreaks episodically.

It is good practice to stop suppression after a year to reassess the patient’s situation.

Blood tests – usually not a good idea

“Can I have a blood test?” **I wish the blood test had not been invented! It just ties people in knots.** We do use a blood test for the IgG or IgM response in a few cases, when there are atypical [unusual] symptoms.

So, for instance, in early pregnancy, to see if the partner of a man who knows that he has it is actually susceptible to catching it from him. If she does not show any antibodies, then we will counsel them to have protected sex or no sex in the last few months of her pregnancy to avoid her catching it near term. It takes 6-8 weeks for a person to build up antibodies. If there is that long before the birth, we allow normal delivery. But if a mum catches it and her baby is born sooner than 8 weeks afterwards, the baby will not have protective maternal antibodies and is at risk of catching herpes during the birth - so in such cases a C-section is done.

Aciclovir can be taken by mums from week 36 to ensure that they don’t have an outbreak at term. It does not have a licence for use in pregnancy, because drugs are not tested on pregnant women, but it has been used for over 30 years and there have been no reports of any problems.

Questions?

Carl: My doctor says that condoms don’t protect for asymptomatic shedding.

CH: Shedding happens in the region where you get it for about 30 days during the first year [in scattered periods of minutes or hours]. And suppressive treatment will halve that rate.

Carl: After 12 months, should you continue to take suppression?

CH: Recurrences vary from person to person so it is a personal choice.

Chris: Are antibody levels as shown by the blood test important?

CH: This is not a yes/no test. The test calls it a positive result if the level is over a certain cut-off point, but a person can have a healthy response to the virus and have antibody levels below this cut-off point. So, no, your antibody level is not important.

Chris: What about vaccines? Does the HPV [wart] vaccine help? What about the chickenpox vaccine?

CH: No the HPV vaccine is targeting a very different virus.

Marian: I’ve got some new news! I just learnt that the doctor at the sexual health clinic in Reading who I’ve been in touch with, has got funding to run a trial of the chickenpox vaccine to find out if it reduces herpes simplex recurrences. This follows a small French study of 17 people carried out by Dr LeGoaster that seemed to show that it did. We cannot see why this should work, but Dr Palmer is going to do the trial again with more people. You heard it here first!

Chris: What about the other things that people write about, such as apple cider vinegar?

CH: These reports are anecdotal. If a person is doing something or taking something when their outbreaks slow down or stop, they may think that this helped, but it is just a coincidence.

What can really make a difference is sleep! We need enough sleep to have effective bodies…

Simon: Do diabetics and others with chronic conditions get worse symptoms?

CH: If another illness is poorly controlled, then you are going to get worse symptoms. So, for instance, we see people with diabetes getting a lot of thrush.

Woman: I get it with my period. Would a different [contraceptive] pill or the mini-pill help?

CH: Yes, we see that, and women getting BV [bacterial vaginosis] regularly with their periods. Some women do find that when they change their contraception to alleviate hormonal swings [being on long active implant for instance] that stops the outbreaks.

WE THANKED DR HOPKINS - APPLAUSE

Ask Marian or Nigel if you have questions about how to get antiviral therapy - and the best way to use it: daily? or just when you feel the outbreak? info@hva.org.uk or phone 020 7607 9661 - 10am till 8pm

Also, more and more people tell us how brilliant Lomaherpan cream is: https://herpes.org.uk/shop

The HVA is invited to the annual conference of the British Association for Sexual Health and HIV (BASHH) – we are given a free entry. Nigel Scott went to the Belfast conference. This time Marian Nicholson went to Birmingham.

There were talks from early on Sunday 30th June through to mid-afternoon on Tuesday 2nd July and the staff on duty at the International Conference Centre (ICC) in Birmingham commented to Marian that *"Your group works really hard… You start really early... And most people coming to conferences have much longer breaks…"*

Marian attended many of the sessions, only missing the ones about HIV treatment. She also hosted a Sunday afternoon meeting for Birmingham members in the ICC Starbucks. Check the programme for the full list of talks.

Here are her comments from a few of the talks she attended:

Day 1

Measuring unmet demand for sexual and reproductive health services in inner South East London: a cross sectional survey - *Nora Cooke O'Dowd, London*

Dr O'Dowd had run a pilot survey in 9 London clinics on how many people are turned away from clinics now that the service is being provided by local councils and not directly by the NHS. 1,500 patients were included in the analysis, two thirds of them women. Result: 57% of them were asymptomatic, so just wanting a check-up. A significant number of people who cannot get into the clinic on the day, even though they are offered an appointment for later on, do not come back.

Unintended consequences: the potential impacts of the BASHH 2019 gonorrhoea guidelines - *Chandni Patel, Liverpool*

Gonorrhoea is becoming a major concern to sexual health doctors since there have been several drug resistant (DRG) cases in the UK. There are two strains of DRG - one from Japan and one from South East Asia. One of these DRG cases needed to spend three days in hospital on an antibiotic drip to clear his infection.

The guidelines expect clinics to 'contact trace' – see 1st talk on Day 2 for what that is – and to treat all contacts whether they have symptoms or not, to be on the safe side. So the study asked the question, "What happens when you treat asymptomatic people just because they are contacts?" Is this a good or bad thing? The results turned out to contradict the intention of the guidelines, i.e.

if the contact turns up within 14 days they should be treated - but if later, don't treat as it will be too late by then unless they have symptoms. [Don't ask Marian for more details on this as she is not a bacterial specialist!]

What's new in … NATSAL (The National Survey of Sexual Attitudes and Lifestyles) - *Cath Mercer, UCL Centre for Sexual Health & HIV Research*

Every decade a huge survey is conducted about lifestyle and sex. It asks ten thousand carefully chosen representative people some pretty acute/intrusive questions about their sex lives - not just how many partners they've had, but also exactly what they did!

She encouraged us all to go to the draft list of questions and say how important we felt each one is. Since they want to add more questions - some will have to go. If any of our readers are chosen for this survey - let us know.

The draft was open to 22nd July. We invited members of our Facebook page to respond.

The Times

30th Nov 2001

"I don't think we've had sex since the last survey"

More partners, page 10

Evaluating online and clinic-based STI screening services: a case study of umbrella sexual health services, UK - *Louise Jackson, Birmingham*

'Online services' means 'self-testing kits in the post.' In a year, they sent out 31 thousand kits and 18 thousand were returned (from 14 thousand people since some had more than one). Nearly all of these turned out to be negative and 15% of the people with a negative chlamydia result come to clinic anyway - for reassurance? But as a kit is 1/3 the cost of a clinic visit, this is cost-effective thing in a time of tight budgets.

Do sexual health practitioners experience vicarious trauma? - *Jodie Crossman, Sussex*

This was a fascinating talk, because the HVA's helpline volunteers might also be affected by 'vicarious trauma.' This is the emotional load one gets from listening and empathising with people who have had bad experiences. [We are aware of this and ensure that all of the helpline volunteers know they can phone the office for reassurance and 'off-loading'.]

The survey consisted of 10 questions to all BASHH and SSHA (Society of Sexual Health Advisors) people. There were 121 responses: 60 nurses, 24 health advisors, 24 doctors and several 'others'. Two thirds said it was somewhat or very true (that they had experienced vicarious trauma), 11 said not true.

Fortunately, half of them say they get good support. Jodie Crossman ended by encouraging all clinics to make it easy, and to support staff to seek help.

Trans men and smear test outcomes: results from ClinicQ – *Tara Suchak, London*

Although this is unlikely to affect most of our members, it was interesting to consider the fact that a trans man should have smear tests for cervical cancer for as long as 'he' still has a womb. How tricky is that to organise? A bloke asking for a cervical smear appointment, a bloke in the waiting area! Tara Suchak asked all providers to consider this and make it possible.

Even trickier is the situation where a trans man has changed to a new GP, so that he is only known as 'a man'. However, we were told
that many trans men will have a hysterectomy after 2 years because the testosterone they take might trigger cancer.

Day 2

Partner notification and partner types - *Claudia Estcourt, Glasgow Caledonian University*

Partner notification – contact tracing - is the system used to reach all the partners of people diagnosed with one of the 'important' STIs like gonorrhoea or chlamydia, to ensure that these partners get the treatment they need even though they may not have symptoms. So if the patient in the clinic is nervous about contacting his/her partners, the clinic staff will undertake to do so without revealing who has told the clinic to get in touch.

This NHS system for partner notification in the UK is so good that is has been taken as a model by WHO and CDC (World Health Organisation and the Centres for Disease Control and Prevention in the US) regard as '*the* way to do it.'

There was a poignant question from the audience at the end of this: 'Now that STI services are commissioned by local authorities, which means that in some locations there are no health advisors at all, has this had a negative effect on our partner notification system?' The implication was that the questioner thought it had!!!

WHAT DO SEXUAL HEALTH ADVISERS DO BEHIND CLOSED DOORS? The development of local and national codes for complex patient interventions by sexual health advisers - *Ceri Evans, London*

Ceri Evans is the chief health advisor at 10 Hammersmith Broadway and has been involved in the writing of the BASHH guidelines on genital herpes. She had the brilliant idea of getting health advisors to categorise the work they do all day by providing a list of the 10 tasks they are performing: not just talking to patients but also providing prescriptions, etc. This idea will show the commissioners more effectively what health advisors do and why the job should not be abolished. [See preceding paragraph]

Day 3

PSYCHOTHERAPY: How to make sex, sexy again - *Lucy Stuart, Sussex Partnership NHS Foundation Trust*

“I want it to be how it used to be” is a common request to this psychotherapist. She explained how she helps couples to reawaken their sexual enjoyment.

She gives them rules to follow: no sex or any skin contact at all, but you must talk about sexy things with your partner, every day for a week. Then, no sex but you are allowed to kiss, and make these sexy comments. Then, no penetrative sex, but you are allowed to have skin contact with ‘non-sexual areas’ i.e. no touching breasts or genitals. Then, no ‘actual sex’ but you are allowed to touch the sexy areas.

It really works! But of course, both partners need to be in on the rules…

DERMATOLOGY: Use lidocaine, not EMLA cream *- Fiona Lewis, Guys and St Thomas Hospital*

Fiona Lewis showed some slides of women with problems. The most important thing you will want to know is “EMLA is not suitable for vaginal sores.” She considers that the ingredient prilocaine in EMLA contributed to the inflammation the woman in her example was suffering from. She told us “Plain lidocaine is the answer.”

“Informed Consent and Sex: Is Disclosure of a Herpes Diagnosis a Moral or Legal Obligation?”

Pavandeep Sangha prepared and presented a paper with the above title to the BASHH Conference in Birmingham. It was the only herpes presentation at the conference. Nigel Scott summarises it.

Pavandeep after her talk, with Marian >

Prosecutions for STI transmission are rare in the UK and in recent years have mainly focused on HIV. This is because, until fairly recently, HIV acquisition was expected to lead to an unpleasant and untimely death, so there could be no doubt that intentionally passing on such a deadly virus could amount to grievous bodily harm. Fortunately, treatment has improved to the point where nowadays people with HIV can expect to live to a ripe old age and lead a normal life with no risk of infecting partners.

Herpes simplex is different. It is common, usually undiagnosed and has no impact on life expectancy. It is mainly caught from undiagnosed partners, or else those who are diagnosed but do not know that the early signs of an outbreak might make them infectious.

Two thirds of all humans have caught herpes somewhere on the body, so why is there a debate on the legal implications of non-disclosure and why has Pavandeep written about it at all? The answer is to be found in the reverberations resulting from one accidental prosecution that took place in 2011.

Only one accidental herpes case

There has been only one criminal case involving herpes simplex in a UK court: David Golding was advised to plead guilty to transmitting herpes to his girlfriend – despite the fact that it is virtually impossible to prove that he was the cause of her infection and that this fact was never established.

The purpose of Pavandeep's paper is to explore the concept of informed consent: whether disclosure of a sexually transmitted infection should be a moral or legal requirement, and whether changes to the law could be implemented, taking into account Beauchamp and Childress' widely accepted simplified model of the four principles of medical ethics.

She concludes that there are more reasons to argue that sharing a diagnosis is a moral rather than a legal obligation and that this alone leads to informed consent. Furthermore, disclosure cannot be a legal duty – given that at present, in most cases there is no way of proving that one individual definitely infected another.

In the UK individuals can be prosecuted for the crime of 'intentional or reckless sexual transmission of a serious infection'. It is recognised that transmission of some sexual infections can have serious or life-threatening consequences for the inflicted individual's health amounting to 'grievous bodily harm', but it is not always clear what this amounts to.

Is herpes 'serious' in a legal sense?

Herpes may be an 'incurable' virus that remains in the body causing recurrent infections but 'serious complications are incredibly rare' and it is a very common infection, so it is debatable whether it constitutes 'really serious bodily harm'.

Pavandeep raises the issue of whether knowledge of a partner's condition and the possibility of transmission implies acceptance that infection could happen even without any detailed knowledge of risk.

She then examines herpes transmission in particular and whether it can be looked at using Beauchamp and Childress' simplified model of the four principles of medical ethics: autonomy, beneficence, non-maleficence and justice.

Is it reasonable to make assumptions?

Autonomy consists of the individual being able to decide and have control over what happens to their own body and in court cases complainants allege that they would not have engaged in ***unprotected*** sex with the defendant if they 'had known that he had a sexual infection'. Risk assessment has become difficult in the case of herpes because of the discovery of asymptomatic shedding (however unlikely) or in cases when the partner shows no symptoms or few symptoms and has not been diagnosed.

In the Golding case, the Appeal Court judges accepted expert witness testimony that it was likely that the defendant would have been told about herpes transmission risk when he was diagnosed. This is what is supposed to happen but there is no evidence that it took place and Golding's own testimony disputes this.

The court then ran with an assumption that Golding chose to ignore prodromes or warning signs of infection and was therefore "reckless" in a legal sense.

With regard to the second point, given that 70% of the population have at least one type of herpes simplex and only one in three are diagnosed, it is almost impossible to pinpoint when infection took place and it is possible that the complainant's first symptoms happened when they did by coincidence.

Take responsibility for your own health

Beneficence is broadly defined as 'doing good' and **non-maleficence** is to 'avoid causing harm', which can be used to imply a moral obligation to not infect others. In other words, is a person who knows they have herpes under an obligation to tell, when most people don't know and won't tell and in any case, many people take no steps to protect themselves from the unknown?

Using or not using protection is a choice made by everyone who has sex, but according to the current Offences Against the Person Act 1861, the overall onus lies on the individual who knows and puts an 'unwitting' person at an increased risk. The law accepts that there is a stigma surrounding STIs and the people who have them and still believes that a person should not cause harm by transmitting an infection because they have an obligation to not make others ill.

Justice, 'the moral requirement to treat people fairly and impartially and with a proper regard for their entitlements and deserts' can be expanded out to consider the legality behind STI transmission. The complainants in cases in that have occurred assumed that everyone who has an STI would disclose this information before engaging in unprotected sexual activity, but they found that this is not always the case.

Therefore, it is important to consider what, if any, the repercussions may be of knowingly transmitting an STI which affects the health of another person and whether the law is actually equipped to deal with this.

How people are prosecuted

Currently transmission of an STI is prosecuted as part of the Offences Against the Person Act 1861 which carries a maximum penalty of five years' imprisonment.

Most people have herpes

Herpes viruses remain in the body but genital herpes is 'not a life threatening condition' to any greater extent than facial cold sores. Two in three people who have herpes simplex are undiagnosed so can be impossible to tell if a partner has herpes or not. There is no clear method in criminal cases to assess the extent of the defendant's knowledge about herpes and therefore whether transmission was actually 'reckless' if they did not know about the 'ease of transmissibility'.

There is also concern over how to decide if someone is guilty of genital herpes transmission when there is no way to directly prove that one individual passed it to another. Therefore, it is arguable that David Golding should never have been prosecuted.

Golding should not have been prosecuted

To summarise, 'The Golding Case' is the only case regarding herpes transmission to be prosecuted in UK courts and in Pavandeep's view it should remain that way. STI transmission, and legal cases related to them, are problematic for UK courts because of variations in ideas around informed consent from a legal, medical and societal viewpoint.

She believes that there is arguably a moral obligation to disclose a herpes diagnosis to enable informed consent – but that as long as there is no way to prove person-to-person transmission this should not be a legal requirement (especially as herpes can be asymptomatic or 'dormant' for years before appearing).

Pavandeep concludes with a plea for improved sex education and public health information to enable everyone to form a clear understanding of what information is required for consent to sexual activity.

To conclude, consent is required before any sexual activity and it is the duty of those involved to ensure that consent is informed based on any risks which may be known.

Whilst there is a moral obligation to not infect people with herpes, it cannot be a legal duty when there is at present no method to definitively prove that one person definitely infected another. Therefore, Pavandeep concludes that sharing a herpes diagnosis is a moral but not a legal responsibility, as long as the sexual activity is consented to with an informed understanding of what herpes is and how it might be caught.

After the presentation, MARIAN went to the microphone and said:

"Thank you for the presentation. I would like to invite you all here to help the HVA to fight stigma. When a patient raises these issues, tell them how unnecessary the stigma is. Tell them we should treat genital herpes infection the way we treat facial infection."

MY STORY

Why my partner is glad I went to an HVA meeting!

When I first met my boyfriend it didn't enter my head that it would be unsafe to make love – my only concern was not getting pregnant. We used condoms for the first few weeks until I went on the pill.

After six months together I started to feel sore 'down below' – still STIs never entered my mind – until I got even more sore and had a look at myself in a mirror. I couldn't believe what had happened to me - there were about six marks which I

thought looked like cigarette burns. I googled like mad and was sure I knew exactly what it was!

When I confronted my boyfriend, he said that he had first noticed a pin-prick sort of rash which was painless a few months ago. The doctor had told him that it was herpes-related, but nothing to worry about, and he showed no signs of concern. He has had a few more painless rashes since - and since he had been told not to worry about them, he hadn't!

I, on the other hand, was totally devastated: I was so angry with my boyfriend and the doctor who had treated him. We were in the final stages of buying our first home together and I felt like our whole sex life and future were ruined.

I felt very frightened because I was told 'there is no way of eradicating the virus', and I worried about having to spend the rest of my life in pain and feeling depressed. [Editor: why don't they say that any recurrences are less painful, shorter, etc.?] I was also worried that if our relationship didn't work out, no-one else would ever want me. After all, how do you say "Hello, my name is Jane, and I've got herpes"?

Another reason I became very angry and upset is because my recurrences were very frequent – at least every month, although not as severe as the first. My boyfriend's recurrences are very mild, and he doesn't understand the effect my recurrences have on me – he says I overreact! I suppose that the more upset I became, the more recurrences I had. Luckily, now I have a wonderful understanding doctor. When he understood how upset each outbreak made me, he has put me on a six month course of aciclovir tablets, and so now I feel a lot more relaxed.

Last night, I went to my first HVA meeting – three other women and one man. We were all in the same boat, and they were all so nice and understanding. Well, I suppose they would be, wouldn't they?

I can't believe I feel so different already! I've had the virus for twelve months now, and for the first time since then I don't feel alone and isolated. And most importantly, I've now got people I can talk to, who really do understand. My boyfriend - soon to be husband - is glad too as I can 'sound off' to them and not to him!

I wish that the Herpes Viruses Association was more widely known, because I've been going to my local sexual health clinic for twelve months, and it was only when I became very upset that they passed on the helpline number. Why wasn't there a notice on the wall? [**Editor's note -** we can send you posters to take to your clinic.] I would have gone to meeting much sooner if I had known. I now know that I can cope and I am not going to let HERPES affect my life – it is not the end of the world!

Jane

Editor's comment: check out the meetings on https://herpes.org.uk/events - and contact us on info@hva.org.uk if you are interested in having an event near you. We know there are people in Cardiff, Liverpool, Newcastle-upon-Tyne, Leeds who are thinking about holding meetings. Do so! They are great!

Sphere
The Herpes Viruses Association | THE JOURNAL

41 North Road, London N7 9DP

Registered Charity No 291657

Members meet in Bristol

There was an excellent turnout for the get together that Sarah-Jane organised in Bristol over the weekend of September 21st. There were people from England, Wales and the USA. The weather was fantastic. On the Saturday morning, people assembled at the Watershed Arts Centre (photo below), where there was plenty of room to spread out. Nigel from the office was there for an 11.00am chat and advice session and was able to pass on some useful tips to several members. After a couple of hours, the party adjourned and then reconvened later for a 3.00pm pirate-themed boat trip. Avast behind, me hearties! A rum-bunctious time was had by all.

Suitably inspired, an enthusiastic member from **Cardiff** wants to organise a meeting there soon. Nigel plans to attend there as well, so watch this space.


Outside the Watershed

Meetings around the country

BRIGHTON MEET-UP
Saturday, October 26th - 7pm till whenever we fancy.
The Craft Beer Company, 22-23 Upper North St, Brighton BN1 3FG.
If you have any problems finding us, feel free to call Samantha on 07758237478. Talking to others who totally understand is so great!

New host/ess??? Bury hosted meetings every 6 weeks for about 20 years. The most recent hostess now has too much in her life to hold these. Is there anyone in Bury who could take over from Val. Phone Marian or Nigel to discuss: 020 7607 9661 from 10am to 8pm (most weekdays).

GLASGOW/Edinburgh – John is happy to organise a meeting or just chat with locals - text him at 07851 789 220.

Up your way? Cardiff - soon! And there have been meetings in **Newcastle, Carlisle** - and a member (lady) in **Leeds** is thinking of having a meeting. **Would you like to meet up in your area?** Find a venue, and then coordinating with the office agree a date. (We will get a well-informed person to join you, a helpliner, a 'sorted' member or staff member.) We will invite the HVA's members - and if you would like, we can advertise the event to the website readers to get more people along.

Meetings in London: the 'day' and 'drop ins'

Come to your "day" Saturday, Nov. 30

* * * * *

Get your head around herpes and telling a partner

The First Day of the Rest of Your Life!

- Feel confident about talking to a partner about herpes. Increase your self-esteem
- Be happy

Join other members and achieve these aims.

The day includes:

- **the 'herpes hype' – how it started and how to counter it**
- **medical facts: transmission, recurrences and how to stop them**
- **where outbreaks can – and can't appear**
- **assertiveness - 'how to get your message across'**
- **understanding your fears and emotions**
- **talking to others – a dry run to get you started**

When?

Saturday 30th November *- from 10.30 am to 6.00 pm (doors open at 10.00 am)*
Cost? *£39 to members (includes buffet lunch, teas, coffees, etc.)*
Where? *At our office: 41 North Rd, London N7 9DP – easy tube, parking free.*

Meeting others – making new friends – will transform your outlook:

"All brilliantly explained and talked through"

"I really feel I'm getting there"

"Everyone should come to one of these!"

- Worth £129 – but we charge only £39 - pay £39 as a donation on https://herpes.org.uk/donations/ (put £1 donation x with 39 in the box below)
- Or phone 020 7607 9661 with your card

- **People often continue chatting in the nearby pub afterwards.**

Questions? Ask Marian or Nigel - 020 7607 9661 (weekdays 10 am to 8 pm)

Drop-in sessions in London - see below

What are the meetings like?

Chat with others about your experience, about partners and telling them, how to control symptoms and more. Everyone who comes is in the same boat as you are… Marian usually hosts and can answer any questions and pass on years of familiarity with this: info@hva.org.uk or phone Marian 020 7607 9661 or on the day 07719 280 683.

Time and place

Weekdays: 6.30 pm. If no one comes by 8 pm, Marian will leave - but as long as you arrive by 7.55 pm, we'll talk as long as you like…
Saturdays: 3-6 pm, we will be chatting - at 6 we may go and eat somewhere nearby – if we decide to.

Venue directions – Meet Marian in the Atrium Lounge, President Hotel, Guilford St, WC1B 5BB - see below. Turn left out of Russell Square tube, first left down Herbrand Street. The hotel is straight ahead. Inside, turn right through the big doors into the Atrium. Good if you don't like pubs! Look for SPHERE sign on table (size and shape of a Toblerone bar!)–

5th Oct. Sat. pm	3.00 - RUSSELL SQUARE
15th Oct., Tues. eve	6.30 - RUSSELL SQUARE
2nd November, Sat. pm	3.00 - RUSSELL SQUARE
13th Nov., Wed. eve	6.30 - RUSSELL SQUARE

Saturday - all day on 30th Nov., 10am-6pm: First DAY of the REST of your LIFE – at the office - see boxes above

7th December, Sat. pm	3.00 - RUSSELL SQUARE
12th Dec., Thurs. eve	6.30 - RUSSELL SQUARE
4th January, Sat pm	3.00 - RUSSELL SQUARE
14th Jan., Tues. eve	6.30 - RUSSELL SQUARE