Written evidence from the Herpes Viruses Association

Who we are and what we do:

The Herpes Viruses Association (HVA) is a patient run health charity. Its main activity is providing advice and support to people who have been diagnosed with the skin condition known as genital herpes. Genital herpes is a disease caused by one of the herpes simplex viruses (HSV-1 or HSV-2). These viruses are also responsible for facial cold sores. It is estimated that at least 66% of all adults, worldwide carry at least one of these viruses by age 25, the more common one being HSV-1.

The HVA works closely with medical professionals and is represented on the Herpes Virus Advisory Panel of the British Association of Sexual Health and HIV. It is Information Standard certified.

The HVA advises patients through its website, telephone helpline, email communications, instant messaging and in person. Patients who require extra support can become members, attend events, receive targeted communications and join a secret Facebook group.

Provision of a confidential sexual health service for patients with genital herpes is essential because of stigma

The charity was founded in the 1980s following the stigmatisation of genital herpes by a marketing campaign that preceded and accompanied the launch of the first successful antiviral drug. It is mostly undiagnosed because most of the people who are infected notice little or nothing in the way of symptoms. This means that it is often caught from sexual partners who are carriers and are unaware of their status.

An unlucky minority suffer from frequent recurring symptoms and/or a reluctance to enter into relationships as well as social anxiety.

Genital herpes is now widely accepted as one of the most stigmatised of all medical conditions. A Harris Interactive poll in the US in 2007 found that 39 per cent of patients were troubled by social stigma and 38 per cent made up excuses to avoid sex during an outbreak, rather than tell a partner. Only HIV was ranked higher for stigma, a truly bizarre finding for an infection that is carried by at least three quarters of the population (mostly on the face, where stigma is much lower).

The interaction between medical professional and patient at the time of diagnosis can be critical and support or lack of support thereafter can be life changing. In 2018 author and data scientist Seth Stephens-Davidowitz carried out a study into Google search data to find insights into human behaviour. He discovered that one of the most common disease diagnoses that trigger a
Access to clinics has become more difficult in recent years, as reported by patients calling our helpline.

**Provision of antiviral treatment for patients with genital herpes at sexual health clinics is essential because of the stigma**

The development of safe and effective antiviral drugs in the last forty years has transformed the patient experience for many of those who are chronically affected by herpes. Daily use of antiviral medication can prevent recurrent symptoms and reassure those who are anxious about infecting partners.

Over the last decade sexual health service delivery has undergone a revolution. Clinics are now administered by local authorities and most have been tendered out to private companies. The freezing of council budgets has resulted in overstretched and under resourced services. These changes have made it increasingly difficult for the many patients who need ongoing treatment to get it.

The provisions of the 1917 VD Act stipulate that clinics should provide patients with the treatment they need, free of charge when they need it. In 1917 there were no long term treatments for any sexually transmitted diseases - the future needs of returning patients were not anticipated by legislators.

The resulting confusion means that some clinics are still providing cheap ongoing treatment, while others tell the patient to ask their GP. Because of the herpes stigma, many patients prefer their diagnosis to remain confidential and are reluctant to request medication from their GP. Some GPs are less well informed about the safety and efficacy of antiviral drugs and may refuse treatment. This unsatisfactory situation results in some patients going without medication while others are forced to buy the drugs they need online, thereby paying twice for healthcare, firstly through taxation and secondly out of their own taxed income.

The paradox of herpes is that because symptoms heal by themselves, treatment is not essential. This understates the psychological impact of herpes on many people who allow anxiety about this hidden condition to deny them the sexual relationships that most people take for granted.

Clinics should be required to provide ongoing treatment for patients diagnosed with genital herpes, if they request it for psychological reasons or because they suffer from frequent outbreaks. Nobody should be forced to explain this problem twice or persuade reluctant GPs to prescribe treatment, when many of them lack the understanding and expertise to counsel and advise patients properly about this delicate matter.

Herpes antiviral medication is generic, safe, cheap and effective. The impact of requiring clinics to supply patients with ongoing treatment would have a minimal impact on budgets. The benefit to patients in social and sexual wellbeing would be immense.
Patients report that they are no longer allowed to access medication at confidential clinics and they cannot risk their family GP knowing they have the condition.

Summary from the Herpes Viruses Association:

Funding for sexual health must be improved and ring-fenced so patients can access this important service.

September 2018