



HPV & Throat Cancer

**Talking to patients
and their families**

**A guide for clinicians and
other health professionals**

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Introduction

Most patients with HPV-related throat cancer think their doctors and other health staff could have done better when talking to them about HPV and its role in their throat cancer, according to a recent Throat Cancer Foundation survey.

At the time of their diagnosis, patients were generally unaware of any available information sources related to HPV and throat cancer and would have welcomed them. There were several specific issues they wanted to know more about, including what HPV is and how it causes throat cancer, why only a small number of people with HPV go on to develop cancer, and how successful treatment for HPV-related throat cancer is likely to be.

The survey revealed that most patients did not know that HPV was a sexually transmitted infection before they were diagnosed and only one patient in six was told about this by a doctor or other health professional. The majority said they felt surprised, shocked, embarrassed or ashamed when they found out that HPV is sexually transmitted. Many were worried that their partner would think they had had sex with someone else or that their partner had done this.

The Throat Cancer Foundation also surveyed clinicians and other professionals involved in the care of patients with HPV-related throat cancer. The results suggest most were unaware of any existing information or guidance for clinicians and other practitioners on how best to communicate with patients. Virtually all of them said they would welcome resources that they could show to patients.

We have therefore produced two new guides that we hope you will find useful. The guide for clinicians and other health professionals aims to help with potentially difficult conversations with patients about HPV and throat cancer. The second guide is specifically for patients and their families.

The content of both guides has been checked and approved by medical experts in the field of HPV and throat cancer. It draws on their expertise, that of the Throat Cancer Foundation and other research and best practice. It also takes account of the European Head and Neck Cancer Society's best practice guidelines on the psychosocial management of HPV-related head and neck cancer.¹

This guide is not intended to provide detailed scientific or clinical information about HPV and throat cancer. Its main aim is to help clinicians and other professionals engage with patients who want to know more about the issues.

About the Throat Cancer Foundation

We are a national charity which aims to raise awareness of cancers that affect the head, mouth and neck and to prevent future cases by funding research into prevention and cure and by campaigning for universal HPV vaccination.
www.throatcancerfoundation.org

The psychosocial impact of HPV-related throat cancer

Patients with a cancer diagnosis will almost inevitably experience a range of distressing emotions including fear and confusion. This can be compounded by the knowledge that their cancer has been caused by a sexually transmitted infection.

One study found that a third of male patients reported a sense of stigma and embarrassment and 50% reported that their HPV diagnosis had a negative impact on their sexual relationships.² Another study, this time mixed-sex, found 'significant psychosocial consequences including stigma, self-blame and relationship problems.'³ It is also common for patients to feel guilt, anger, sadness, shame and helplessness related to the sexually transmitted nature of HPV.¹ One in seven patients said they fully intended to keep their HPV status secret from others; the reasons included embarrassment and stigma.³

A study of UK print and online newspaper coverage of the link between HPV and throat cancer, in particular the disclosure in 2013 by the actor Michael Douglas that his cancer was caused by HPV transmitted by oral sex, suggested that inaccurate and sensationalized reporting could serve to increase the stigma associated with this condition.⁴

Patients often lack accurate knowledge about HPV. More have heard of it since the introduction of HPV vaccination for girls but public awareness of the signs and risk factors for throat cancer is known to be poor.⁵ 84% of patients with HPV-related throat cancer felt they did not understand the issues to their satisfaction.³

Clinicians and other health professionals are well placed to provide clear, accurate and helpful advice to patients and their families. This can help to inform and, hopefully, to reduce emotional distress.

How to approach the issue

Health professionals involved in throat cancer care may not have experience in talking to patients about sexually transmitted infections. Some may feel embarrassed or awkward, especially when talking to older patients. The Throat Cancer Foundation survey of health professionals found that 50% did not mention to patients that HPV-related throat cancer is caused by an infection transmitted through oral sex.

The following broad principles might be helpful:

- **Be accommodating.** Invite patients to ask questions about HPV and allow time for this. Tell patients how they can access more information in their own time. They can be referred to the Throat Cancer Foundation guide for patients.
- **Be honest.** Do not avoid the fact that HPV is sexually transmitted or the specific routes of infection. Be honest too about any gaps in medical knowledge.
- **Be non-judgemental.** Be careful not to imply that a patient, or their partner, is to blame for an HPV infection. Avoid pejorative words like 'promiscuity' and 'infidelity'. Provide reassurance that oral sex is a very common and normal sexual activity.
- **Be inclusive.** Do not assume that older patients do not want to talk about sex or that they are no longer interested in enjoying sexual intimacy. Use vocabulary appropriate for patients' literacy and culture. Do not assume that all patients are heterosexual.
- **Be normalizing.** Emphasise that HPV is a very common infection and is actually hard to avoid. It could be helpful to compare it to the common cold or flu.
- **Be positive.** Explain that throat cancer caused by HPV usually has better outcomes.

Health professionals vary in their knowledge of HPV and cancer. One study found that while, overall, health professionals were well-informed and were willing to discuss HPV with throat cancer patients, oncologists had significantly greater knowledge than specialist nurses, speech and language therapists and others.⁶

It would therefore be good practice for multi-disciplinary cancer care teams to share knowledge and to discuss how best to communicate with patients in order to ensure that they receive clear, consistent and appropriate evidence-based information in line with the broad principles described above.

What patients want to know

The Throat Cancer Foundation surveys of patients and health professionals, as well as other studies, have identified a number of questions that many patients have about HPV and throat cancer.

'What is HPV?'

- Human papillomavirus (HPV) is the name for a group of viruses that affect the skin and moist membranes lining the body.
- There are around 200 types of HPV.⁷ Many are harmless. Some cause minor problems such as verrucae. But some types can cause cancer or genital warts.
- The high-risk types of HPV, which can cause cancer, include types 16 and 18.
- Vulnerable areas for high-risk HPV infection include the cervix, vagina, vulva, penis, anus, mouth and throat.
- HPV and HIV are often confused but they are completely separate infections.

'How common is HPV?'

- HPV is very common and most sexually active people (around 80%) will acquire a genital HPV infection, including the types that cause cancer, at some point in their lives.⁸
- It is impossible for someone to know that they have caught HPV. When they are infected, there are no immediate symptoms like a fever. Most people also clear the infection from their bodies within a year and before it can cause any problems. Only a very small proportion of people go on to develop cancer.

'When did I catch HPV?'

- It is impossible to say. There is no test that can tell someone when they were infected by HPV. However, it is highly likely that someone with cancer was infected many years before their diagnosis. The average time span from HPV infection to the onset of throat cancer has been estimated as around 12 years¹⁴ but the latency period could be as long as 30 years.¹⁵
- It is also impossible to know who you caught HPV from. It could be a current or a previous partner.

'How did I catch HPV?'

- HPV is passed between people by skin-to-skin contact. This includes sexual activities that are very common and normal, including oral sex. It is possible, but not proven, that open-mouth kissing can also pass on HPV⁹ and some people who are virgins are known to have been affected.¹⁰ HPV can also be spread by sex toys.¹¹
- HPV can affect people who are heterosexual, gay, lesbian or bisexual.
- Because the infection is so common, many people are infected shortly after becoming sexually active for the first time. There is a 50-80% chance of HPV transmission following unprotected sexual intercourse with someone with a current HPV infection.¹²
- A person who has had only one sexual partner can get HPV although people who have many partners, or who have sex with someone who has had many partners, are more at risk. Acquiring HPV does not mean that someone has taken risks with sexual health since using a condom is not a completely effective way of preventing transmission although it does reduce the risk.
- Oral sex is the most likely cause of throat cancers that have been caused by HPV. However, not every case of HPV-related throat cancer is caused by oral sex.¹ One review found that over 50% of patients with this cancer had five or fewer sexual partners and up to 40% reported never having had oral sex.¹³
- High-risk HPV types cannot be caught from toilet seats, hugging, holding hands, swimming pools or hot tubs or sharing food or cutlery. It cannot be caught by kissing on the lips or cheek.

'What cancers does HPV cause?'

- HPV causes about 5% of all cancers worldwide. The best known is cervical cancer. HPV also causes cancers of the vagina, vulva, anus, penis, mouth and throat. Throat cancers caused by HPV include cancers of the oropharynx (which includes the back of the tongue and the tonsils), and the larynx.
- The proportion of throat cancer cases caused by HPV is uncertain but may be as high as 72% in Europe and North America.¹⁶
- The number of throat cancer cases caused by HPV has increased sharply over the past 40 years and this trend is very likely to continue.¹⁷

'Why have I developed throat cancer?'

- Doctors are not sure why some people with HPV develop throat cancer while most do not. It is not linked to smoking or alcohol since non-smokers and moderate or non-drinkers can develop this cancer if they have HPV. However, people who have HPV and who also drink alcohol above safe levels or smoke may be more at risk.¹ Having more sexual partners also increases the risk because someone may be infected by HPV more than once by different partners at different times.
- People with reduced levels of immunity may be more at risk of cancer caused by HPV. People who have HIV are at greater risk, for example.¹⁸
- Both men and women are at risk of throat cancer but men are much more likely to be affected. This might be because men generally have more lifetime sexual partners than women and have been more likely to drink alcohol above safe levels and to smoke. It might also be because men naturally have slightly weaker immune systems.¹⁹ There is some evidence that men may be more at risk from 'giving' oral sex to a woman than vice versa because the vulva sheds more HPV than the penis.²⁰ Men who have sex with other men have a higher risk than heterosexual men.¹
- A patient who has previously had genital warts can be reassured that this did not cause their cancer because warts are caused by different HPV types.
- Since HPV is almost impossible to avoid, nobody should feel responsible, blamed or guilty for catching it or for developing cancer.

‘Can I develop another cancer caused by HPV?’

- The level risk is unknown but generally believed to be very low.²

‘Is my partner at risk?’

- A partner is not at any greater risk of catching HPV or developing cancer than anyone else. One study found that the partners of patients with throat cancer caused by HPV were no more likely to have been infected with a high-risk HPV type than the general population.²¹ In any event, most partners will, like most other people, naturally clear any active infection.
- People with HPV-related throat cancer do not need to change their sexual behaviour with partners following a diagnosis.²²
- A partner could consider HPV vaccination. This would prevent any new infection, reinfection or reactivation of an existing infection, but vaccination for adults is not available on the NHS and is expensive. Also, vaccination is not a treatment or a cure for existing active HPV infection. A partner might find it helpful to discuss whether to get vaccinated with their own doctor.
- Testing for HPV is not considered to be useful as a way of preventing throat cancer. This is because there is no treatment which clears HPV from the body because most HPV infections do not cause any problems.
- A partner should be aware of the symptoms of the cancers caused by HPV and get advice if they appear. They can ask their dentist to check for any signs of throat cancer during a routine check-up. Women should take up invitations for cervical cancer screening.
- Successful treatment for throat cancer usually eliminates all risk of passing on the virus unless a patient is reinfected after treatment. It is conceivable that a patient could be reinfected by a long-term partner who may have previously passed on the virus that led to the development of cancer. Patients should discuss with their doctor whether they should be vaccinated against HPV either before or after cancer treatment.
- There is no need to inform any past partners about an HPV infection. This is because most people are infected at some point in their lives and clear HPV naturally without any ill-effects.²³

'Are other family members at risk?'

- No. HPV is not spread through sharing a toilet, plates, cups, cutlery or kissing on the cheek or lips.
- Mothers can, very rarely, pass on HPV to babies either in the womb or when they are born.²⁴ Doctors do not know whether this can cause cancers in children when they become adults but it is unlikely.
- Children can be protected against HPV infection in the future by vaccination. In the UK, girls are offered free vaccinations by the NHS at the age of 12 or 13. Vaccination normally happens at school. Boys are not currently offered free vaccination in the UK but they can be vaccinated privately, although this is expensive (typically £150 per dose with two doses required for adolescents).
- Many health practitioners, professionals and patient groups, including the Throat Cancer Foundation, believe that both boys and girls should be vaccinated by the NHS because would prevent many cases of throat and other cancers in the future. Currently, however, only girls aged 12/13 are vaccinated by the NHS, usually at school. The government's vaccination advisory committee (JCVI) is currently reviewing this whether the NHS vaccination programme should be extended to boys.

'How does having HPV affect my cancer?'

- Throat cancer caused by HPV is generally easier to treat and the outcomes are much better than for other cases of throat cancer. This type of cancer responds better to chemotherapy and radiotherapy and has a better survival rate. Patients with throat cancer caused by HPV have a lower incidence of second primary tumours and a decreased risk of relapse.¹⁷

'I feel embarrassed and ashamed about my HPV infection'

- This is a normal and common response to finding out that you have caught a sexually transmitted infection.
- A Throat Cancer Foundation survey of patients with throat cancer caused by HPV found that only one in six people felt having HPV did not matter to them. Two thirds of the people surveyed said they felt surprised, shocked, embarrassed or ashamed. A quarter of people said they were worried about what their partner might think (for example, that they had a relationship with someone else) and one in 10 people were worried that their partner had infected them as a result of a relationship with someone else.
- It is important to remember that HPV infection is very common and affects most people at some point in their lives. It is about as hard to avoid as colds and flu. It can be caught from just one sexual partner and possibly even from open-mouth kissing. It also takes many years before an infection causes cancer.
- The fact that a patient's cancer was caused by HPV does not automatically mean that they or their partner have had large numbers of sexual partners. It also does not mean that they or their partner have had sexual experiences that most people would find unacceptable.
- Surveys of sexual behaviour in the UK have found that most people have oral sex either occasionally or regularly and consider it to be entirely normal. In the UK, around 75% of men and 65% of women born between 1946 and 1955 reported ever giving or receiving oral sex, but this proportion was over 90% among men and women born 20 years later.¹⁷
- An HPV infection definitely does not mean that a patient or their partner has had sex with someone outside of the relationship.
- If a patient and/or their partner are very distressed by the fact that the throat cancer was caused by HPV, or if this is affecting their relationship, they could consider counselling. This could be for the patient alone or for both partners. The cancer care team can arrange a referral.

Where can patients get more information?

- Patients can ask a member of the cancer care team.
- The Throat Cancer Foundation website is a useful resource and patients can also ask an expert a question via the site.
www.throatcancerfoundation.org
- Macmillan Cancer Support hosts an online community group for people affected by head and neck cancers, including throat cancer. This is a place for people to support one another, ask questions and share experiences.
www.macmillan.org.uk
- Cancer Research UK's website provides more detailed information about how HPV can cause cancer.
www.cancerresearchuk.org
- NHS Choices has information specifically about oral sex and cancer.
www.nhs.uk

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Further reading for health professionals

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A 3D illustration of the HPV virus

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