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# aids treatment update

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# in this issue

During the course of researching this special issue of *ATU* on oral health and the dental profession, it became clear that the ongoing crisis within the NHS dental system does appear to have hit HIV-positive people especially hard.

The gradual erosion of free NHS dental care comes, perhaps, as a warning of what could happen when NHS healthcare in general changes to the payment by results system. The business-like, profit-focused attitude of some dentists – which appears to override any ethical responsibility to provide universal care – has led to some blatant cases of discrimination.

The short-term solution is for all HIV clinics to help their patients find good quality, timely, affordable, discrimination-free dental care.

In the mid-term, some guidelines from the British HIV Association would help standardise the quality of dental care available to HIV-positive people.

In the long-term, the government needs to fight HIV-related stigma and discrimination and work harder for equal access to healthcare for all, and in particular those of us who are unable to access private healthcare.

Doesn't it also make sense for NHS dentistry to be made available to all HIV-positive people free of charge, like the rest of our healthcare?

**page 3** This month's *Upfront* discusses the implications of an important new study which challenges conventional thinking regarding the importance of viral load measurements as a predictor of CD4 cell loss.

**page 4** In *Watch Your Mouth*, new *ATU* contributor, Derek Thaczuk, provides us with an overview of why oral and dental health matters to HIV-positive people.

**page 8** In *(Trans)mission impossible?* we investigate the complex reasons why dentists appear to discriminate against HIV-positive people more than any other healthcare professional.

**page 12** In *News in Brief* we find that CD4 counts don't significantly affect the risk of liver toxicity after switching to nevirapine; what happens to the one-in-six people new to anti-HIV therapy who interrupt their treatment within two years of starting; how to avoid HIV drug errors that can happen in hospital; and find that there's increased risk of HIV disease progression if CD4 counts don't rise despite having an 'undetectable' viral load.

**page 14** In *Dentists: the good, the bad and the ugly* two *ATU* readers share their experiences with the dental profession.



## aids treatment update

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# How much does viral load matter?

new study challenges conventional thinking, by Edwin J Bernard

Since the results of the groundbreaking 1996 MACS study - which found that viral load levels in the blood broadly predicted the rate of CD4 cell count decline - the consensus has been that in untreated HIV-positive individuals the CD4 count represents the current state of the immune system, whereas HIV viral load reflects the rate at which the immune system will further decline. However, it has since been observed that the rate of CD4 decline varies enormously between untreated individuals with similar viral load measurements.

Now a large, retrospective study published in *Journal of the American Medical Association (JAMA)* has found that viral load measurements predict no more than 9% of an untreated individual's rate of CD4 cell loss.

"These findings represent a major departure from the notion that plasma HIV RNA level is a reliable predictor of rate of CD4 cell loss in HIV infection and challenge the concept that the magnitude of viral replication (at least as reflected by plasma levels) is the main determinant of the speed of CD4 cell loss at the individual level," the investigators write. Using an individual's viral load as a prognostic tool to assess when to start therapy is "therefore of limited clinical value," they conclude.

## What does this mean?

An accompanying editorial in the same issue of *JAMA* argues that these findings "have several important clinical implications." The most obvious is that viral load levels should

perhaps play less a significant role when it comes to deciding when to start treatment: the decision should now focus primarily on CD4 cell levels, current health, and readiness to adhere to lifelong treatment.

The study's results do not call into question the value of viral load measurements for assessing how well anti-HIV therapy is working, however. This is still a very important way of making sure that HIV is not reproducing itself, so that it is unable to become resistant to treatment. Besides, we know that, in most cases, very low levels of HIV in the blood allow the immune system to slowly repair itself.

## New kinds of anti-HIV treatments

The hypothesis that followed on from the 1996 MACS study was that HIV must be directly responsible for killing CD4 cells. However, many studies have since suggested other indirect methods of CD4 cell destruction. Consequently, the *JAMA* editorial also argues that since we now understand that an individual's genetic make-up and other immunological factors affect more than 90% of CD4 cell depletion on an individual level, "future improvements in the treatment of HIV infection and AIDS," are bound to follow.

Just as significantly, then, by calculating that HIV levels in the blood are only directly responsible for less than 10% of CD4 cell destruction, this study suggests that scientists

should now be intensively investigating other ways of preventing HIV from killing CD4 cells.

We do know that HIV adversely affects the immune system by causing unusually high levels of immune system activation, and it could be that this may be more important than previously thought. It is possible that treatments that dampen down, rather than boost, certain parts of the immune system, may make anti-HIV drugs work even better.

It may also be that measuring and changing an individual's genetic response to HIV infection will play a much larger role in treating HIV in the future.

Many such treatments - including therapeutic vaccines, cytokines, immunomodulators and gene therapies - are in the early stages of development. *ATU* will be taking an in-depth look at these potentially exciting developments in our January/February 2007 double issue. ■



# watch your mouth

what everyone with  
hiv should know  
about oral health,  
by Derek Thaczuk



Most common oral and dental health problems are not really specific to HIV: the same infections and conditions seen in HIV-positive people are present, to some extent, in the HIV-negative population as well. However, as with other medical conditions, oral/dental infections and complications can occur more frequently or may be harder to treat when you are HIV-positive. Painful or otherwise awkward mouth problems can also make eating difficult - an unwanted extra challenge if you already have trouble maintaining your weight. And since dental problems are so visible, self-image and self-esteem can suffer if problems go untreated.

A variety of factors contribute to the risk and severity of oral health conditions. Many HIV-related oral health problems - such as *candidiasis* ('thrush'), oral hairy leukoplakia, Kaposi's sarcoma, and certain gum diseases - are probably due to immune suppression and are, therefore, more likely to occur in people whose CD4 counts are below 200 cells/mm<sup>3</sup>. People with higher CD4 counts - either due to effective anti-HIV treatment, or because HIV hasn't yet caused severe immune suppression - should have fewer of the conditions traditionally associated with a seriously damaged immune system. Studies have, in fact, shown 10-50% decreases in HIV-related oral problems in Europe and North America<sup>1</sup> as a consequence of the availability of anti-HIV therapies.

However, not all oral problems are less likely to occur today: some, in fact, have become more commonplace, such as oral warts<sup>2,3</sup>, and salivary gland disease<sup>1</sup>.

Dry mouth - a side-effect of many antiretrovirals, antidepressants, and other medications - is also fairly commonplace among people with HIV. Dry mouth can also result from inflammation of the salivary glands

due to HIV infection itself, and some people with HIV experience this very soon after infection. Chronic dry mouth should not be ignored, since it is a risk factor for tooth decay, cavities (known medically as *caries*), and other conditions including candidiasis (see below). 'Artificial' saliva substitutes are available, but it may be simpler to stimulate saliva flow by sucking on sugar-free sweets or chewing sugar-free gum.

Despite the wide range of oral problems that can develop in HIV-positive people, simple "common sense" preventative measures can be very effective, according to Professor Stephen Porter, Professor of Oral Medicine at the UCL Eastman Dental Institute in London.

Professor Porter offers the following advice:

- Maintain good oral hygiene by cleaning your teeth and gums frequently and effectively. This will reduce the risk of gingivitis, bleeding, and dental decay that could require treatment.
- Use a fluoride-containing toothpaste to protect the teeth from cavities. Cavities are less likely if you avoid eating or drinking too much sugary food or drink in the first place.
- See a good dentist regularly. An HIV-aware dentist can monitor for any changes suggestive of worsening of HIV disease, can help you with oral hygiene, and can advise you on HIV- or treatment-related oral problems.
- Know your mouth. By regularly examining your own mouth in the mirror, you can become familiar with its normal appearance. If you notice any changes, you should promptly follow up with your dentist and also tell your HIV healthcare provider.

## Specific conditions

### Gum disease

Periodontal, or gum, disease is caused by ongoing bacterial infection of the gums. Gingivitis, the mildest form, is marked by reddened, bleeding gums, and should be reversible with professional treatment and good oral hygiene. The more serious *periodontitis* involves extensive inflammation of the bones and tissues supporting the teeth, which can cause tooth loss.

Although gum disease can affect anyone, regardless of HIV status, two particular forms seem to be specific to HIV. *Linear gingival erythema* (LGE), formerly known as HIV gingivitis, is named for its distinct red band along the gum line. Unlike conventional gingivitis, LGE is not significantly associated with plaque and can be painful. If diagnosed with LGE, you should see a specialist in gum disease (known as a periodontist).

*Necrotising ulcerative periodontitis* (NUP), originally called HIV periodontitis, is a rapid and severe form of gum disease seen only in people with severe immune suppression. NUP can cause tissue, bone, and teeth to be lost very quickly, and can be very painful - all the more reason to keep a regular dental check-up schedule, particularly if you have low CD4 cell counts.

### Candidiasis

Candidiasis is probably the best-known HIV-related oral infection. Also known as candidosis or thrush, candidiasis is a fungal infection caused by the micro-organism *Candida albicans* (although other, non-*albicans* species of *Candida* are sometimes to blame). The infection can take hold in other places in the body, such as deeper in the gastrointestinal tract, or vaginally in women. When found in the mouth and throat, the infection is known as *oropharyngeal candidiasis*. Candidiasis may range from a minor annoyance to a serious, hard-to-treat infection, and can appear in several different forms. It is more than twice as likely to occur in smokers, and is usually seen when CD4 counts are below 200 cells/mm<sup>3</sup>.

The three forms of thrush that are most usually experienced by HIV-positive people are medically known as *pseudomembranous candidiasis*, *erythematous candidiasis*, and *angular cheilitis*.

Pseudomembranous candidiasis (the one you probably think of when you hear the term 'thrush') causes whitish patches in the mouth, tongue and/or throat, which can leave a reddened or bleeding spot if wiped away. The other forms of candidiasis may be less easy to spot or to identify: angular cheilitis

presents as a reddening or cracking at the corners of the mouth; erythematous candidiasis forms flat, red lesions on the tongue or palate.

Treatment for HIV-related candidiasis has essentially remained the same since the Eighties: the antifungal drug fluconazole (*Diflucan*) is usually used as a first-line treatment. Depending on the severity of the infection, fluconazole can be used topically (as a mouthwash) for mild to moderate cases, or systemically (in pill form). Due to the risk of drug resistance, fluconazole is usually only used systemically for more severe cases. Related 'azole' drugs (including ketoconazole, itraconazole and voriconazole) can also be used, but these are generally reserved for fluconazole-resistant cases. Nystatin ointment can be used to treat angular cheilitis.

### Oral warts

Oral warts are caused by human papilloma virus (HPV) - the same (sexually transmitted) virus that causes anal and genital warts. Oral warts appear as raised, dull-white bumps that may be cauliflower-like in shape. They have actually become more prevalent in people with HIV in the era of potent antiretroviral treatment<sup>2,3</sup> - an increase that may,

## smokes, pipes and pills

From a health viewpoint, not a single good thing can be said about smoking, and dental health is no exception. Unightly stains aside, **smoking cigarettes** increases the risk of gum disease and oral cancer. If you do continue to smoke, it's important to be even more proactive about oral hygiene and care than other HIV-positive people.

**Crystal methamphetamine** is in a class of its own: the nasty effects of habitually smoking crystal have earned the nickname "meth mouth". Methamphetamine manufacturing uses extremely caustic acids, lithium and lye, all of which have very corrosive effects when smoked and inhaled. Methamphetamine use also causes dry mouth, severe teeth grinding, and can lead to periods of very poor nutrition, all of which can contribute to severe gum disease and tooth decay.

**MDMA** (commonly known as 'ecstasy'), while nowhere near as damaging as methamphetamine, can also take its toll on dental health, due to its well-known effects of teeth-clenching and teeth-grinding[6]. If you are going to take this illegal drug, the usual precautions are in order - drink plenty of water for hydration, and chew gum if you need to work your jaw, although too much chewing could result in jaw pain.

paradoxically, be due to immune reconstitution. HPV infection may remain relatively 'dormant' - present, but not causing symptoms - while the immune system is suppressed. However, when successful HIV treatment leads to increased immune activity, this may actually stimulate the latent viral infection to actively produce warts. Oral warts may resolve on their own, or they may be removed by surgical or other methods, such as cauterisation. (For more on HPV, see ATU 151; November 2005)

### Aphthous ulcers

Aphthous ulcers (also known as 'canker sores') do not have a well-understood cause. In people with healthy immune systems, they often heal on their own within one or two weeks. However, in people with HIV, they can be larger, more painful, take longer to heal, and create vulnerable spots where secondary infections can occur. If ulcers are troublesome enough, they can be treated with steroid-based ointments and/or rinses.

In the most severe cases, systemic steroids such as prednisone may be used. In addition, thalidomide, which was removed from the general market decades ago because it caused serious congenital defects, has proved to be effective against mouth ulcers, and may be prescribed under certain circumstances. Some form of pain-relieving treatment, such as topical anaesthetics or systemic analgesics ('painkillers'), may also be necessary until the ulcers are resolved. Oral gels such as *Gelclair* can also be applied over the ulcers to reduce pain and promote healing.

### Kaposi's sarcoma

This form of cancer has become much less common in the era of potent anti-HIV therapy, but it is still sometimes seen, mostly in people with CD4 counts below 200 cells/mm<sup>3</sup>. Kaposi's sarcoma (KS) lesions - raised, reddish or purple blotches - can occur anywhere on the skin or sometimes internally, but are frequently found in the mouth.

Although human herpes virus 8 (HHV-8) has been identified as the cause of KS, there is no specific antiviral treatment against it. Various localised treatments can be used to reduce or remove lesions; chemotherapy may be needed if the lesions are widespread.

### Herpes

Herpes simplex virus (HSV) causes painful, recurrent blisters. HSV-1 most often infects the lips and mouth, causing 'cold sores'; the related HSV-2 causes similar blisters genitally or anally. (However, see the sidebar on oral HIV transmission.) All types of herpes are highly transmissible, especially - but not necessarily only - during the time that the blisters are visible. Once you have been infected with HSV, the infection is permanent, and although the frequency of blister recurrences can be improved by various antiviral treatments, it cannot be cured.

## oral/dental conditions, contributing factors and treatments

Condition	Contributing factors*	Treatments
Cavities ( <i>caries</i> )	Bacterial infection Dry mouth ( <i>xerostomia</i> )	Dental treatment: filling, restoration. Sugar-free mints or sugar-free gum; artificial saliva products.
Abscesses / tooth pulp infections	Bacterial infection	Antibiotics.
Periodontal disease: Linear gingival erythema (LGE)	Bacterial infection	Antimicrobial rinse; systemic antibiotics in severe cases.
Periodontal disease: Necrotising ulcerative periodontitis (NUP)	Bacterial infection	Antimicrobial rinse, antibiotics, professional cleaning ( <i>debridement</i> ), surgery, pain relief.
Candidiasis ('thrush')	<i>Candida albicans</i> ; other <i>Candida</i> species	Topical and systemic antifungals.
Oral warts	Human papilloma virus (HPV), possibly immune reconstitution	Surgery, electrocautery.
Aphthous ulcers	Unknown	Steroids - topical/rinse, systemic in severe cases; pain relief; thalidomide.
Oral hairy leukoplakia	Epstein-Barr virus (EBV)	No specific treatment.
Oral herpes	Herpes simplex virus (HSV-1)	Antivirals: aciclovir, famciclovir, valaciclovir.
Kaposi's sarcoma	Human herpes virus 8 (HHV-8)	Radiation, surgery, chemotherapy.
Syphilis	<i>Treponema pallidum</i>	Penicillin, other antibiotics.

\* Low CD4 counts, smoking, and poor oral hygiene are contributing factors to many forms of oral disease, so taking effective anti-HIV treatments, stopping smoking, and good oral hygiene may improve the condition without the need for any other treatment.

If the immune system is working well, herpes blisters generally clear up within two weeks. However, blisters may occur more frequently, last longer, and be more severe when you are HIV-positive. The antiviral drugs aciclovir (*Zovirax*), famciclovir (*Famvir*) and valaciclovir (*Valtrex*) can be used to reduce symptoms; chronic suppressive treatment may be used to control persistently recurring herpes. (For more on HSV and its treatments, see *ATU* 159; August/September 2006)

### Syphilis

Although the actual number of diagnosed cases remain lower than for other sexually transmitted infections (STIs), syphilis (caused by infection with the micro-organism *Treponema pallidum*) is on the rise in the UK, particularly among gay men. Syphilis causes a single, short-lived ulcer at the point of infection - mouth, genitals or anus - beginning one to three weeks after infection. This may be the only visible sign that you have become

infected. Since this lesion usually only lasts a week or so syphilis infection may be missed or misdiagnosed. If not treated during this 'primary' phase, infection persists, causing a variety of symptoms during its later phases. These symptoms quite often include oral ulcers and other oral complications[5]. Syphilis - which can be detected by a blood test - can be serious if not diagnosed early and treated effectively. (For more on syphilis and its treatments, see *ATU* 157; June 2006.)

### Oral hairy leukoplakia

This infection, caused by Epstein-Barr virus (EBV), appears as thready or 'hairy'-looking growths, usually on the sides of the tongue, which cannot be wiped or scraped away. Despite the ominous-sounding name, oral hairy leukoplakia is not especially serious. It generally causes no symptoms or problems other than the appearance of the growths themselves, and is usually not treated other than by addressing the underlying immune suppression. ■

## oral hiv transmission

It has always been challenging for experts to estimate the relative risk of HIV transmission via oral sex, mostly because it is difficult to isolate oral sex from other sexual practices. Several studies have estimated the risk of unprotected oral sex as something like one-tenth the risk of the highest sexual risk, that of unprotected anal sex. However, the experts do not all agree, and any estimates should not be seen as absolute.

Oral health problems almost certainly increase the risk of HIV infection for the receptive partner - the one giving a 'blow job' using his or her mouth. This seems intuitively obvious: if you are giving a 'blow job' while your mouth or gums are bleeding, damaged or infected, those vulnerable spots are prone to HIV and other infections. The flip side of the question - does this scenario also increase the risk to the insertive partner - the one receiving a 'blow job' - is much harder to answer, as Professor Porter explains. "There is a small, but unknown risk of HIV being transmitted from an HIV-positive receptive partner to an HIV-negative insertive partner," he says, "but the exact risk is unclear. This risk could potentially be increased if the receptive partner has gingivitis, as this may increase the amount of blood (and hence HIV) in the mouth. If the HIV-positive person is lacking saliva, any anti-HIV effect of the saliva will be reduced, again potentially increasing the HIV load in the mouth. Any genital ulceration on the insertive partner's penis would further increase the risk of HIV transmission."

Also, as Professor Porter points out, HIV is not the only sexually transmitted infection. "Oral-genital contact can spread viral infections: this is well demonstrated by the increasing number of genital cases of herpes simplex type 1 (HSV-1) which typically causes oral infection. Bacterial infections, such as syphilis, can also spread from the mouth to the genitals or anus. The use of a physical barrier (e.g. a condom or a 'dental dam') will reduce any risk of transmission from the mouth to the genitals or anus - as long as the barrier remains in place."



In *Watch your mouth*, we highlighted the importance of good oral health for HIV-positive people. And yet, whilst there are many things that we can do for ourselves to reduce the chances of problems with our teeth or gums, there is one area over which we have a lot less control: accessing good quality, timely, affordable, discrimination-free dental care.

This year, the media has been full of reports describing the extreme difficulties faced by the general public in accessing NHS dental care. But HIV-positive people have been experiencing these difficulties for years, and the problem isn't just limited to NHS dental care. NHS or private, HIV-positive people face a disproportionate amount of discrimination from dentists.

A 2006 survey of patients attending a large HIV clinic in north-east London found that one out of four people who had experienced any kind of discrimination due to their HIV status had been discriminated against by a dentist<sup>1</sup>.

Dentists admit that they discriminate, too. A recent survey of dentists in south Cheshire found that only 45% would treat a diagnosed HIV-positive person without hesitation; and 20% said that they would refer an HIV-positive person elsewhere<sup>2</sup>.

Why is it, that when we make it our mission to find a good dentist, it can feel like an almost impossible task? What factors make dentists think

twice about treating us - or refusing to treat us at all? And why do dentists discriminate against us - more than any other group of healthcare workers - despite the fact that this kind of discrimination is unethical and outlawed under the Disability Discrimination Act?

### It's not just us

NHS dentistry is facing a crisis of massive proportions. The rot set in when changes mandated by the Conservative government in 1990 meant that dental care was no longer universally free for people entitled to NHS services, unlike health care. Far from reversing this policy, the Labour government inadvertently made matters worse, culminating in the contract disaster this April which saw dentists leaving the NHS in droves. More than 1,600 of England's 21,000 dentists left the NHS at the start of April after rejecting a new contract that offered "a highly committed NHS dentist, on average, around £80,000 per year, with additional money for practice expenses, guaranteed for three years, along with a 5% reduction in work load."<sup>3</sup>

The result is that many people cannot find a local NHS dentist and those that do may have to pay private charges (which are up to three times higher than NHS fees<sup>4</sup>) and/or travel many miles from home, even in an emergency<sup>5</sup>.

Another consequence of the reforms that began in 1990 is that specialised dental services for HIV-positive people lost their funding. Today, there are

often long waiting lists for the two types of NHS services that tend not to discriminate against HIV-positive patients - the Community Dental Service or hospital-based Dental Access Centres - and some are only available to people with an AIDS diagnosis, which means that the majority of HIV-positive people are unable to access them.

Although there are no reliable data regarding how many HIV-positive people in the UK currently lack a dentist, it is estimated that only about half of the general population in the UK currently have a dentist<sup>6</sup>. Anecdotal evidence suggests that far fewer HIV-positive people seek regular, preventative dental care. Recently, I invited members of the *ATU* readers' panel to share their experiences with dentists. Many noted how hard it has been to find a dentist in the past, and some don't have one still. One panellist wrote that "[I] currently don't have a dentist (although I am looking for one), and haven't had one for a number of years."

# (trans)mission

are dentists' irrational fears making it harder to access dental care



### “We don’t treat people like you”

According to the National AIDS Trust (NAT), the most common examples of HIV discrimination in a dental setting are:

- refusal to treat;
- inadequate and/or inappropriate counselling;
- inadequate and/or inappropriate treatment;
- breach of confidentiality and privacy; and
- unjustified changes in practice and safety procedure.

Real-life examples provided by NAT include one dentist telling an HIV-positive individual that it was “illegal” for him to treat HIV-positive patients, and another saying, “We don’t treat people like you. We would have to

close the surgery for an hour afterwards to disinfect it.”<sup>7</sup>

A 2002 Terrence Higgins Trust (THT) report<sup>8</sup> chronicling the kind of discrimination HIV-positive people were experiencing at the dentist found:

- outright refusal of service;
- insistence on treating at the end of the day for “extra sterilisation procedures”;
- persistently putting people with HIV to the end of operating lists (and thus effectively never operating on them);
- writing “HIV” in large letters on the front of patient records.

And a 2003 investigation by BBC Online<sup>9</sup> found that seven out of 30 dentists contacted by the BBC refused to commit to treating someone who told them they were HIV-positive.

### What are the rules?

Discriminating against someone who is HIV-positive, purely because they are HIV-positive, is now against the law, thanks to the Disability Discrimination Act (DDA), which was amended in December 2005 to include HIV-positive people from the moment of diagnosis. Under the DDA, it is unlawful for a dentist not to provide services to an HIV-positive person that they would otherwise provide to members of the general public. To avoid breaking the law, a dentist would need to prove that any discrimination was justified.

In addition, there are two professional bodies that provide ethical and practical guidance to dentists. Specific guidance on discriminating against anyone with a blood-borne infection is provided by the British Dental Association (BDA). However, the BDA guidance is purely voluntary.

Highlights of the BDA’s guidance<sup>10</sup> include the following:

“Dental clinicians have a general obligation to provide care to those in need and this should extend to infected patients who should be offered the same high standard of care available to other patients.

It is unethical to refuse dental care to those patients with a potentially infectious disease on the grounds that it could expose the dental clinician to personal risk. It is also illogical as many undiagnosed carriers of infectious diseases pass undetected through practices and clinics every day.

“If patients are refused treatment because they are known carriers of an infectious disease, they may not report their conditions honestly or abandon seeking treatment; both results are unacceptable. Those who reveal that they are infected are providing privileged information.”

# n impossible?

? asks Edwin J Bernard

The General Dental Council (GDC) is the organisation that regulates dental professionals in the UK. All dentists, dental hygienists, dental therapists, clinical dental technicians and orthodontic therapists must be registered with the GDC in order to work in the NHS or in private practice. The GDC's regulations do not specifically mention blood-borne infections in their anti-discrimination guidance.

However, a spokesperson for the GDC told *ATU*, "We would take any allegation that a dental professional had discriminated against patients with HIV very seriously. Our guidance<sup>11</sup> makes it clear that dental professionals should not discriminate against patients on any grounds. It states that all dental professionals should: 'Treat patients fairly and in line with the law. Promote equal opportunities for all patients. Do not discriminate against patients or groups of patients because of their sex, age, race, ethnic origin, nationality, special needs or disability, sexuality, health, lifestyle, beliefs or any other irrelevant consideration.'

When the GDC was asked how many cases have come before them for refusal to treat because someone was HIV-positive, they were unable to provide any data. "We do not categorise cases to the level of granularity that would enable us to report on the number of cases involving refusal to treat on the grounds of HIV," said the spokesperson.

But from this December, the DDA requires all public bodies like the GDC to actively promote equality for all disabled people, including everyone with diagnosed HIV infection. What proactive measures is the GDC taking?

"The GDC is committed to promoting and developing equality and diversity in all its work," a spokesperson told *ATU*. "We ensure that our policies and ways of working are fair to all individuals and groups, regardless of their ethnic origin, race, colour, gender, religion, disability, sexual orientation or age. We proactively promote equality by making it clear to dental professionals that this is a key aspect of the professional standards

which they are required to uphold in their work."

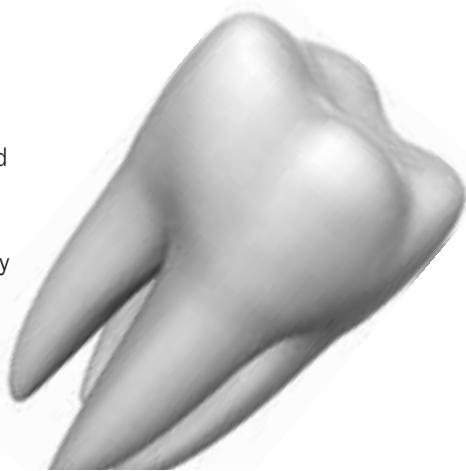
However, many dentists may still not be aware that HIV is a legally-protected disability.

### Dentists' transmission fears

In 2004, Professor Michele Crossley, of John Moore's University in Liverpool, undertook a detailed investigation<sup>2</sup> into dentists' knowledge of, and attitudes to, HIV. She identified all 330 dentists who were practising in the South Cheshire region (Chester and the surrounding towns between Liverpool and Manchester) and sent them all a questionnaire. Although only 152 (46%) responded, and these respondents might not represent all dentists, the study's findings provide some fascinating - and surprising - insights.

One of the most worrying findings was that although 99% correctly identified blood as a mode of HIV transmission, only 46% knew that saliva does not transmit HIV. Consequently, the study found that around one-in-three were worried about occupational exposure to HIV infection, although only 3% believed that HIV transmission was "very likely".

According to the Health Protection Agency<sup>12</sup> there have been no reports of a dentist becoming infected with HIV during the course of their work in the UK. Worldwide, no documented case of occupationally-acquired HIV infection has ever occurred in dentistry, and only 3% of all possible global cases of healthcare workers being infected with HIV at work involved dental workers.



### Dentists' exposure fears

In a more detailed follow-up study<sup>13</sup>, Professor Crossley asked fifteen dentists to talk more about their attitudes to HIV. It transpired that some of the dentists were more concerned about taking post-exposure prophylaxis (PEP; a month-long course of anti-HIV therapy to reduce the risk of becoming HIV-positive after being exposed to HIV) than the risk of acquiring HIV. One dentist had been on an HIV awareness course, which had changed his attitudes significantly, although he still had "mixed feelings" and remained fearful: "What continues to worry me," he said, "[is] the [drug] regime you had to go through [which] was horrendous."

Occupational HIV exposure usually occurs if a healthcare worker accidentally injures themselves with a needle or sharp object that had previously been in contact with HIV-infected blood. There are no data for the UK, but a 2006 review of HIV transmission in dentistry reports that in the United States (with a population five times that of the UK, and an HIV prevalence that is fourteen times greater than the UK) there were only 24 cases reported to the US Centres for Disease control between 1995 and 2001 where a dental worker was accidentally exposed to HIV-infected blood from a diagnosed HIV-positive individual. None of these exposures resulted in HIV infection.<sup>14</sup>

Consequently, not only are the odds of becoming HIV-infected after a needle or sharp instrument injury incredibly low (officially estimated to be 1-in-333 without PEP<sup>15</sup>), but the chances of this kind of accidental exposure happening in the first place are even more remote.

Perhaps the most surprising finding in Professor Crossley's study was that the greatest worry for dentists was dealing with staff fears about HIV: 59% cited this as a concern. Even though there are firm and stringent guidelines from the BDA regarding the importance of good

communication, staff training, and the use of universal infection control procedures, one dentist told Professor Crossley: "Fear isn't rational. It doesn't relate to risk. If people are afraid, as an employer it is my responsibility to make people feel safe."

### Public perception

Addressing dentist and staff fears could probably be improved by more training, and by the GDC making HIV-specific training mandatory. But Professor Crossley also identified areas that are harder to tackle, including public perception. One-in-three dentists were worried about losing other patients if it became known that they were treating HIV-positive people. Aside from the extremely important issue of breaching patient confidentiality, this also suggests that HIV remains a highly stigmatised condition, and that a widespread government campaign to inform the public of the real risks of HIV transmission is necessary. Certainly, the results of a recent European Commission survey<sup>16</sup> - which found that many people throughout Europe believe that HIV can be transmitted through kissing, giving blood, sharing a glass or using a toilet seat - suggest that widespread ignorance around HIV transmission risks may be fuelling HIV-related stigma and discrimination.

### Financial burden

To help deal with this, the BDA recommends that dentists display "an infection control statement. [which

may] help allay patient anxiety and gain their confidence." However, one-in-three dentists cited the financial burden of "extra" infection control that they thought was necessary when treating HIV-positive patients.

Universal infection control precautions, as recommended by the BDA, minimise the risk of blood-borne infection transmission between patients, and between dental workers and patients. They include the use of protective barriers (e.g. gloves, gowns or aprons, masks, and protective eye wear); careful handling and disposal of needles or other sharp objects; hand-washing and/or use of alcohol hand rub before and after a procedure; safe disposal of waste contaminated with bodily fluids and blood; proper disinfection of instruments and other potentially contaminated equipment; and the use of disposable, one-use instruments where possible.

One dentist told Professor Crossley, "Sure, there's the argument that routine [infection control procedures] should be sufficient but I would want to do more - it's probably fear on my part, but there's that additional anxiety. It's a fatal disease - probably patient to patient cross-infection would be less of a worry than patient-dentist."

Many dentists said that HIV-positive patients require disproportionate amounts of time to provide appropriate care, and some argued along the lines that "resistance from intelligent people to treating these patients is due to

financial reasons - at the end of the day, we're running businesses."

### Double standards?

The same law that protects HIV-positive people from being discriminated against by dentists also provides protection for HIV-positive people in the workplace. Current Department of Health (DH) regulations<sup>17</sup> mean that HIV-positive dentists are not allowed to practice any invasive procedure. This basically means that the only job they can do in a dentist's practice is to work on reception. Yet, the DH Risk Assessment Expert Group estimates that the risk of an HIV-positive healthcare worker infecting a patient is between 1-in-5 million and 1-in-10 million - practically impossible!<sup>18</sup>

Is it possible that this double standard - mandated by the DH and regulated by the GDC - is also inadvertently contributing to the ongoing discrimination that some members of the dental profession display towards HIV-positive people? ■

If you experience discrimination from your dentist, you can complain to the GDC through the following channels.

#### NHS dentists

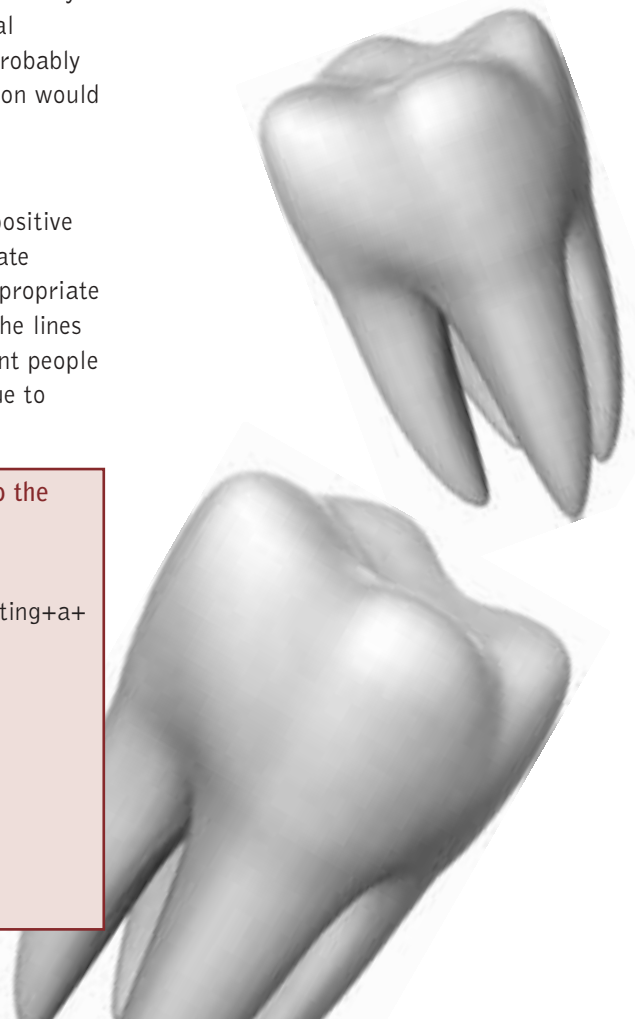
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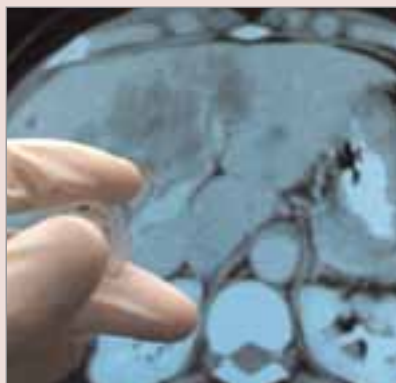
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fax 08457 778 878 web [www.drc-gb.org/about\\_us/helpline.aspx](http://www.drc-gb.org/about_us/helpline.aspx)



## side-effects

## CD4 counts don't significantly affect liver risks after nevirapine switch



Liver toxicity can be a problem in some people who take the NNRTI nevirapine (*Viramune*) as part of their first anti-HIV treatment. The degree of risk is different for men and women: men with CD4 cell counts above 400 cells/mm<sup>3</sup> and women with CD4 cell counts above 250 cells/mm<sup>3</sup> are most at risk for liver toxicity. However, the risk has been less clear-cut for those who have already achieved an 'undetectable' viral load on a non-nevirapine-containing anti-HIV regimen, who switch to one that contains nevirapine, and who have CD4 cell counts above these levels.

A study from Spain presented at the Forty-Sixth Interscience Conference on Antimicrobial Agents and Chemotherapy (ICAAC) held in San Francisco in September has found that people with 'undetectable' viral loads who switch from their current treatment to nevirapine when they have a CD4 count higher than the recommended range for starting the drug are no more likely to develop liver toxicity than those with CD4 counts within the recommended range.

The study - which pooled the results of four existing studies in what is known as a 'meta-analysis' - also found that the only clear risk factor for liver toxicity was having elevated liver enzymes at the beginning of the study. There were no deaths, and only a very few patients (1%) developed liver inflammation (hepatitis).

Whether or not you think you have a higher or lower likelihood of experiencing liver toxicity, it is important to look out for signs of liver toxicity if you are taking nevirapine. Symptoms include nausea, loss of appetite, fatigue, liver tenderness or swelling, malaise, yellowing of the whites of the eyes, dark greenish / brown urine, yellowing of the skin (jaundice), and greyish or white stools.

## treatment news

## One-in-six interrupt treatment within two years of starting

CD4 count-guided treatment interruptions as a long-term HIV treatment strategy have been extensively discussed in recent months, after the early discontinuation of the SMART study in January. The SMART investigators found that people who were randomised to interrupt anti-HIV treatment once CD4 counts rose above 350 cells/mm<sup>3</sup> and restart once CD4 counts fell below 250 cells/mm<sup>3</sup> had an increased risk of disease progression and death compared to those randomised to remain on treatment. Consequently, planned treatment interruptions are not currently recommended by treatment guidelines.

Nevertheless, many HIV-positive people continue to interrupt their treatment in the real world for a variety of reasons. These unplanned interruptions can occur due to intolerable side-effects, treatment fatigue, and situations where the treatment of another infection - such as TB - might jeopardise the effectiveness of either treatment. In addition, a variety of social and mental health factors may also lead to unplanned interruptions.

Researchers from CASCADE - a large observational study from Europe, Australia and Canada - have found that one-in-six people on their first anti-HIV combination were likely to interrupt treatment for at least six months within two years of starting. The study also found that temporarily discontinuing treatment appeared to be safe over the short-term for most people, although the risk was higher for people aged over 40, those with a pre-treatment CD4 count below 200 cells/mm<sup>3</sup> or with a CD4 count below 350 cells/mm<sup>3</sup> prior to interrupting therapy.

The investigators recommend that for these people in particular "caution and close monitoring are essential to ensure that risks are minimal."



## treatment news

## HIV drug errors can happen in hospital

The complexities of anti-HIV combinations, especially drug interactions and side-effects, can lead to errors in the way these medications are prescribed and/or taken in hospital, according to a study from Johns Hopkins Bayview Medical Center in the United States.

Even though medication orders at Johns Hopkins are managed using a computerised system that issues warnings if it detects interaction conflicts or questionable dosages, the study found that errors occurred for a quarter of HIV-positive inpatients admitted over a one year period. The study also found that these errors were often, but not always, corrected when the patient was discharged.

The study highlights how important it is for a patient to speak up when they think that something might be wrong. Most importantly, if you are already on anti-HIV treatment, make sure you know exactly what you're taking, how much you take (the amount of drug that it is in each dose and the number of pills), and how often and when you take them.

It may also be useful to keep a list of important medical information with you at all times, including the drugs you take and your allergies. You could also think about bringing a supply of your pills (in their original containers) to show the nurse or doctor on the ward.

## treatment news

## Increased progression risk if CD4 counts don't rise despite 'undetectable' viral load

HIV-positive individuals whose anti-HIV therapy succeeds in suppressing viral load to 'undetectable' levels, but who nevertheless fail to experience an increase in their CD4 cell count above 200 cells/mm<sup>3</sup>, remain at a high risk of experiencing progression to AIDS and death in the first year of HIV treatment, according a Canadian study presented at ICAAC in San Francisco.

The main goal of anti-HIV therapy is to suppress the replication of HIV in the blood to 'undetectable' levels (usually below 50 copies per millilitre of blood). This allows the immune system, measured by CD4 cell count, to strengthen, preventing the emergence of the collection of infections and tumours that is known as AIDS. A CD4 cell count above 200 cells/mm<sup>3</sup> is considered to be the minimum level needed to protect against potentially life-threatening AIDS-defining illnesses.

However some patients who commence anti-HIV therapy experience what is called an "immunologically discordant" response to their HIV therapy. This means that although their viral load is suppressed to 'undetectable' levels, their CD4 cell count fails to increase to above 200 cells/mm<sup>3</sup>.

The investigators studied 299 individuals who started treatment with potent anti-HIV therapy between 1996 and 2003 and found that 97 (32%) failed to experience an increase in their CD4 cell count during the first year of antiretroviral therapy, despite having effective control of HIV. When the investigators looked at the factors associated with an increased risk of HIV disease progression, they found that patients with 'undetectable' viral loads a year after starting therapy but whose CD4 cell count did not increase to at least 200 cells/mm<sup>3</sup> were four-times more likely to progression to AIDS or to die compared with those whose CD4 cell counts increased to above 200 cells/mm<sup>3</sup>.

However, studies from the UK presented at last year's BHIVA conference in Dublin, contradict these findings and suggest that CD4 counts do eventually rise if viral load remains 'undetectable'. At the moment, there are no approved additional treatments to improve CD4 cell counts under these circumstances.

Interleukin-2 has been studied for almost a decade, but has many side-effects. However, there is a renewed interest in developing therapeutic vaccines, and some have been shown to stimulate HIV-specific immune responses. Several therapeutic vaccine studies are ongoing in North America and West Africa.

# dentists:

two *atu* readers share their experiences with the dental profession

Although some HIV-positive people have experienced discrimination from dentists, and others continue to find it difficult to access a good, reliable dental practice, there are many dentists in the UK who are providing us with professional, discrimination-free care. Here, two members of *ATU's* new readers' panel share their experiences -- sometimes positive, sometimes not - and provide some hope for those of us who are still struggling to find that elusive dentist.

simon

“

I am now am fortunate enough to have good access to dental care, although this has not always been the case.

Soon after I had been diagnosed, I needed some dental treatment. I was feeling quite vulnerable, and so the community specialist nurse at my HIV clinic found a local dentist for me. At my first appointment, I filled in a form that asked for details about hepatitis and HIV as well as what medications I was prescribed. To my disbelief, the dentist informed me that I could not be treated there because "it would be unfair to other patients" and that they "did not have the facilities for patients with HIV". I don't mind admitting that felt humiliated, upset and angry, although I didn't show it at the time.

Since I needed to see a dentist urgently, the community specialist nurse made me another appointment at my nearest NHS Dental Access Centre. At the same time she made an appointment at my original dentist to offer some education around this subject.

At the Dental Access Centre I was treated as if I were a 'normal' patient. The dentist had absolutely no problems with my HIV or hepatitis B infections and explained to me that, as with any patient, they bag up and sterilise equipment after use. However, the Dental Access Centre is only a one-off service for people who need to be seen in an emergency.

# the good the bad and the ugly

My community specialist nurse then found me a Community Dental Service dentist at a health centre in a town fourteen miles away. This dentist is for dental-phobics and various conditions including HIV. My new dentist was wonderful. She told me that she would always take care of my dental needs, and that the only time I wouldn't be seen is if I were too ill and it wasn't wise for my health. She was horrified to hear of my first experience and how this had led me to having to use Dental Access.

I wish that others were as fortunate as I am now, since I know how important it is to be seen regularly, and I become saddened and angry when I hear of others who have experienced discrimination.

”

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michael

I live in Somerset, and when I was diagnosed HIV-positive 13 years ago, I was referred to an NHS dentist who was happy to have HIV-positive patients. I was a little unhappy about saying good-bye to my previous dentist, since I thought the treatment I received from his latex-gloved hands could never be bettered.

Gary - the dentist who runs the practice - has eliminated all prejudice, and there has been no 'last appointment of the day' syndrome. Although all the staff know of my status I feel entirely relaxed to talk about any aspect of the virus. The service is great, and I have found that if I call my dentist first thing in the morning because of a lost filling, in all probability I would be seen that day.

Although Somerset is not quite at the forefront of medical progress, the practice attracts bright young dentists straight from qualification, probably because Somerset is such a delight after inner-city training. Until I knew better I could have been alarmed, fearing I was to be a guinea pig for rookies to practice upon. Far from it! These young ladies - who have had recent practical experiences in places like Zambia and Siberia - arrived bursting with enthusiasm and cutting-edge knowledge, only too keen to get their hands on the challenge of a real life AIDS-ridden patient!

As I have clocked on in age (I am now 57) and the virus took its toll on my oral health, I have experienced a variety of issues, including gingivitis, extractions and cracked plates. Before starting on triple combination therapy, my monthly oral problems were constantly monitored and efficiently sorted, and for that I am most appreciative.

For the past two years I have suffered from aphthous mouth ulcers. These 50p piece-sized abrasions on the inside of each cheek have meant that from time-to-time I have had to go on a diet of liquidised meals only. Unfortunately, their origins or cause has not been isolated, and a "multifactoral origin" were the words

bandied about. My HIV consultant admitted to having no knowledge of such things or the time to research it, and suggested it was up to me to try and find some cause or treatment.

Thanks to my current dentist, and her ability to put things in motion, I have now seen three mouth specialists this week alone in various south-west towns. I now have some interesting steroid creams to try, and thalidomide - the increasingly talked-about last option - still seems a distance away. There may be no cure, they are HIV-related, but I do know if I want immediate relief, understanding and support I have it in a dental practice in small town a few miles from home.



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#### news in brief [page twelve]

##### CD4 counts don't significantly affect liver risks after nevirapine switch

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##### Increased progression risk if CD4 counts don't rise despite 'undetectable' viral load

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