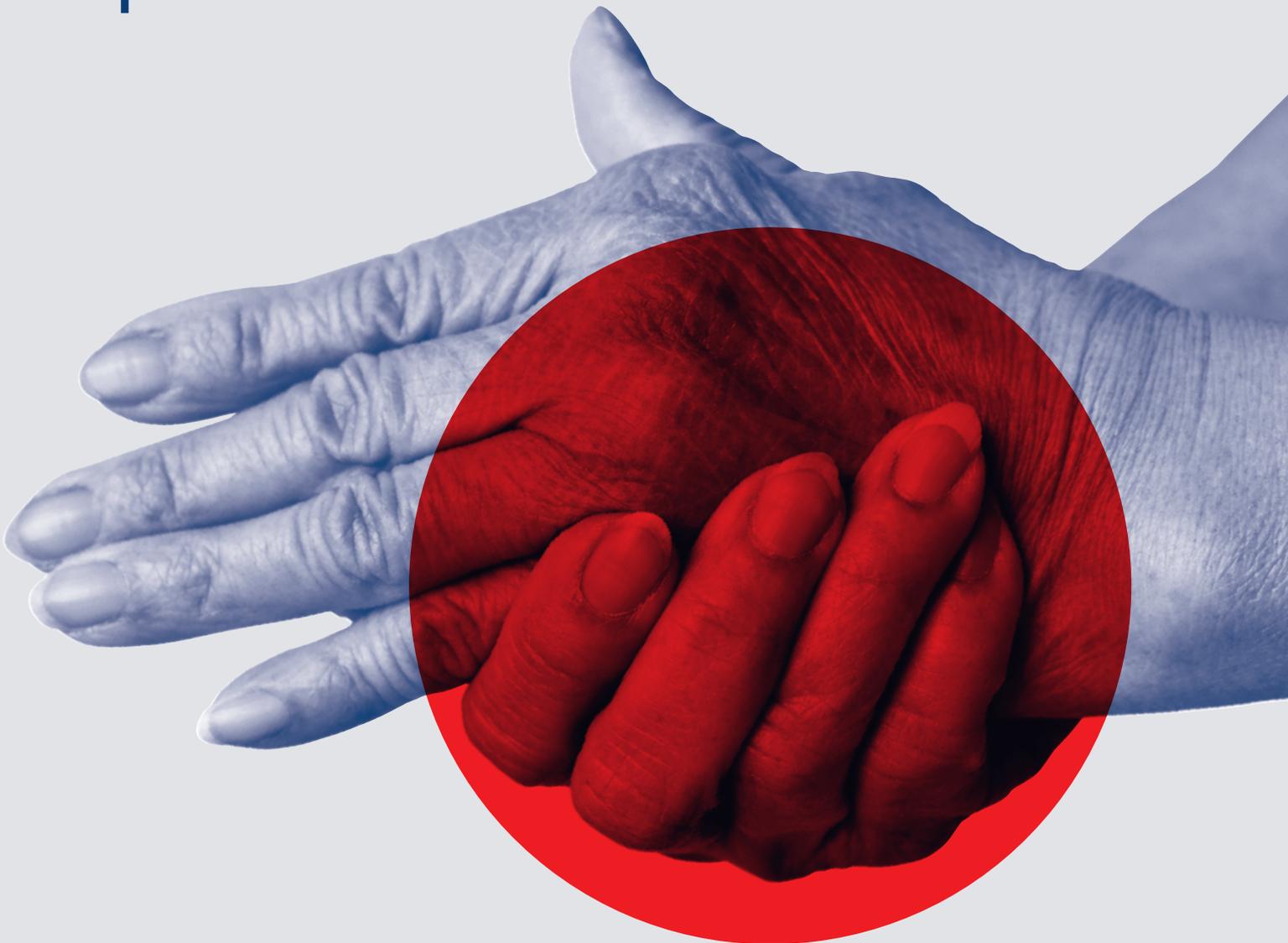


HIV treatment update

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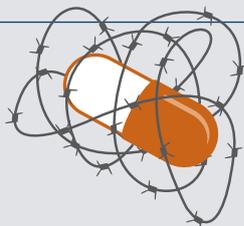


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HIV treatment update

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For more information about *HTU's* medical review panel, please visit www.aidsmap.com/page/1445504

Each feature in *HTU* is also reviewed in advance by a readers' panel of people living with HIV. We are grateful to our panel for their knowledge, attention and enthusiasm. If you would like to be a member of the *HTU* readers' panel, please email info@nam.org.uk.

About NAM

NAM is a charity that exists to support the fight against HIV and AIDS with independent, accurate, up-to-date and accessible information for affected communities, and those working to support them.

For more information, and details of our other publications and services, please contact us, or visit our website, www.aidsmap.com.

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In this issue

**Gus Cairns**

Editor

Welcome to the first edition of the new quarterly *HIV treatment update* (HTU). We've made a few changes, as you can see, including a bit of a makeover to HTU's design.

As well as adding an extra feature article, we've revamped *News in brief* (page 16), providing short summaries of some of the most significant or intriguing recent news stories with links to the full reports and references on our website, www.aidsmap.com. We've included a small selection of news from aidsmap's news 'aggregator', as well as the stories NAM editors have written ourselves.

This autumn edition reflects the diversity of the community with HIV in this country, a diversity emphasised by the conference I went to a few weeks ago (see *Upfront*, opposite). Speakers ranged from Jonathan Grimshaw MBE, now 57 and one of the first Brits to be diagnosed with HIV back in 1984, to Matilda, born with HIV after that year and one of a new generation of young people, mainly African and mainly born with the virus, who are raising an increasingly bold profile in the activist world.

Our articles cover everything from a web-based STI/HIV partner notification service for the largely young users of the UK's gay dating services (page 18) to the aches and pains of peripheral neuropathy and arthritis (page 4), an issue that can affect anyone but more often affects us as we age.

Our guest writer Daniel Lombard (page 8) investigates something that only a few of us have ever had to face but which should concern us all: the sometimes appalling barriers to medical care faced by detainees with HIV in immigration removal centres, a group of vulnerable people at the mercy of the state, but often failed by the system.

And on page 12 we cover an issue that affects everyone living with HIV, of whatever age, nationality or sexuality: the need for emotional and psychological support. One of the important things about the new standards for psychological support, produced by the British Psychological Society, British HIV Association and the Medical Foundation for AIDS and Sexual Health, is that they emphasise that anyone with HIV at any time may have emotional and relational issues caused by living with the virus and will need help at the appropriate level; you don't have to be climbing the walls to need it (though you should have access to the right help if you are). Essentially it's a plea to the commissioners and funders of the NHS that HIV can hurt mentally too, that mental pain has physical consequences and that starving people of emotional support will end up costing the community more, whether it's in antidepressant pills or Employment and Support Allowance.

Happy reading and enjoy yourselves for (gulp) the rest of the year.

Upfront

Taking charge of our future

by Gus Cairns



"No Decision About Me without Me" was the strapline for the first conference of people living with HIV in the UK since Positive Action in 2008.

One hundred and thirty people living with HIV came together in London on 24 September to talk about the issues facing us as a patient group and as members of society. Issues which stood out included: changes to the NHS and social care; HIV and ageing; HIV and young people; HIV prevention for positive people; advances in treatment; and the use of new media in activism.

It's interesting comparing discussions here with the ones back in 2008 and realising how much our world has changed.

The two most prominent issues at the 2011 conference weren't predicted in 2008: the wholesale reform of the NHS and of public health and the related cuts to HIV health care, social care and prevention.

The Chair of the All-Party Parliamentary Group on AIDS, Pamela Nash MP, opened the conference. She said that late diagnosis remained one of the greatest challenges to HIV health care and saw it as largely being caused by stigma: as a gesture against stigma, she was about to take an HIV test herself and would announce the result on World AIDS Day. She also emphasised that opportunities for diagnosis are still being missed. Budget-cutting not only means loss of services but loss of a generation's expertise.

Jonathan Grimshaw MBE, one of the first people diagnosed in the UK, gave a plenary speech. Asking what 'activism' was, he named six overlapping components: mutual peer support; advocating for treatment; self-empowerment; involvement in decisions; asserting human rights; and combating stigma.

The biggest challenge to the continuing empowerment of people with HIV was that the current model of HIV care was unsustainable, he said. "Because treatments are successful, there are now 100,000 of us, and we are seeing some social care and even

some treatments withdrawn or restricted. Stigma and poverty blight the lives of too many." The ageing of the HIV-positive population and how to resource their future medical and social care needs was also problematic.

Not all the HIV-positive population is older: a member of the Children's HIV Association's youth committee spoke about her own nervousness about being an activist. "I don't feel like a 'vigorous campaigner for a cause'; I just want to make a change," she said. "The challenge is to get young people involved without scaring them off."

Neil Beasley, a Terrence Higgins Trust (THT) board member, mapped out the health and social care landscape of the next few years. One challenge is money: THT had a 25% cut in statutory income this year and it expects next year to be worse.

Another challenge is that HIV services will be commissioned by two very different ends of the health spectrum. Under the *Health and Social Care Bill* (due to be discussed in the House of Lords in October), HIV health care and treatments in England will be commissioned by the NHS Commissioning Board, a new non-departmental public body (previously known as quangos); on the other hand HIV testing, STI services and HIV prevention services will no longer be run by the NHS but by local authorities, as part of an expanded public health remit.

The dangers of fragmentation are obvious, as is the striking lack of primary care and GP involvement – an opposite pattern to other

chronic health conditions such as diabetes.

A workshop on health and social care uncovered a number of opportunities for patient power within the new structures. From this month, local authority prevention and testing services in England are being overseen by health and wellbeing boards whose job is to co-ordinate services. They will include councillors, GPs and the local directors of public health and social work but must also have patient representatives.

Another opportunity to get involved in England is through HealthWatch, local authority 'consumer forums' that are part of the Care Quality Commission and will replace the current LiNks (Local Involvement Networks) from October 2012.

How to get involved at the 'top end' and influence the NHS Commissioning Board is more problematic, but one opportunity may be provided by NICE, the National Institute for Health and Clinical Excellence. NICE's Evidence Accreditation Criteria are now applied to the production of BHIVA guidelines – not only on HIV testing and prevention, but also the next set of treatment guidelines – to ensure patient involvement in their production as well as assuring the quality of evidence used.

On the local level, HIV Forum Link, up till now an *ad hoc* federation of clinic patient groups, is seeking voluntary organisation status and may provide a more co-ordinated patient voice in the future alongside the UK Community Advisory Board.

At the end of the day, Jonathan Grimshaw remarked on the constructive and engaged atmosphere at the conference and the lack of over-strident demands. Although people with HIV may face a straitened existence in the future in terms of benefits and treatments, the system is not automatically loaded against us and the opportunities to have your voice heard are, if anything, better than ever. nam

“Stigma and poverty blight the lives of too many.”

Jonathan Grimshaw

Slides from the day are available on the Positively UK website:

➔ www.positivelyuk.org/conference.php



Growing pain

As people with HIV live longer, they are facing pains old and new. *David McLay* reports on peripheral neuropathy and arthritis.

Oh, these pains! Are they HIV or are they age? It can be difficult to know when to mention an ache or a pain because it may be HIV-related, and when to chalk it up to the body's natural decline. Considerable attention is given to life-threatening conditions such as heart disease and diabetes among people with HIV, now that effective HIV treatments are leading to a longer life with the virus. But less attention is paid to painful conditions, such as peripheral neuropathy and arthritis, which can sometimes cast a heavy cloud over the seemingly sunny prospect of a longer life.

It can be a struggle to get pain and its underlying cause acknowledged, so it is refreshing when a doctor leads the way. In this case, it's Dr Sarah Cox, consultant in palliative medicine at London's Chelsea and Westminster Hospital, and the condition is peripheral neuropathy (PN) – a neurodegenerative condition often associated with changes in sensation in the extremities. "HIV PN is a common problem that is probably under-recognised in HIV," says Dr Cox, who treats many of the HIV-positive people with PN who seek care at the hospital.

Across the English Channel in Amsterdam, Dave R would probably agree. HIV-positive since 2004, Dave was diagnosed with peripheral neuropathy in 2009, though the 61-year-old recalls feeling early symptoms of the condition three years earlier. "I was feeling as though I was walking on bare bones, with no fat or muscle to cushion the impact. That wasn't happening all the time but it was the first time I became aware of problems with my feet." Dave also lives with painful arthritic back problems, but that's another story. (See *Joint and muscle pain* for more on rheumatic conditions and HIV.)

A lag between symptoms and diagnosis is not uncommon. Dave feels: "Diagnosis can take forever. There are so many side-effects of HIV medication that can confuse the picture and if you have other problems as well, it's difficult to pin down what causes what and why, especially in the first stages of neuropathy, which are generally fairly mild."

He continues, "The symptoms trundle along from month to month, sometimes hitting plateaux but gradually getting worse until you need to press your case somewhat harder." Fortunately for Dave, his doctor and other doctors, including Sarah Cox, are listening.

Increasing incidence

PN, officially known as HIV-associated sensory neuropathy, affects sensation in the limbs, generally the feet and much less frequently the hands. There can be a loss of sensation or an overly painful reaction

“HIV peripheral neuropathy is a common problem that is probably under-recognised in HIV.”

Dr Sarah Cox,
Consultant in palliative medicine,
Chelsea and Westminster Hospital

to touch. Severe burning pain or a 'pins and needles' feeling is also common.

PN can be caused by advancing HIV infection itself or by antiretroviral drugs.¹

While the virus does not infect neurons (nerve cells), there is evidence that HIV infection leads to damage to the axon – the long, conducting 'wire' – of the neuron and to the myelin sheath that surrounds and protects the axon.² Nerve destruction results in altered sensation signals being sent to the central nervous system. Not surprisingly, PN is more common in advanced HIV disease.

Some older antiretroviral drugs, particularly the so-called d-drugs, d4T (stavudine, *Zerit*), ddI (didanosine, *Videx*) and ddC (zalcitabine, *Hivid* – now withdrawn from the market), also cause mitochondrial toxicity, which can lead to neuronal dysfunction and death.³

Remarkably, while rates of most HIV-associated neurological conditions (conditions related to the nervous system) have decreased since the introduction of effective antiretroviral therapy, rates of PN have increased, with prevalence estimates ranging from 9 to 60% of HIV-positive people who have access to antiretroviral therapy.

"We had expected to find that HIV PN incidence would fall as HIV treatment is more effective and we use less of the nucleosides implicated," Dr Cox says. "We are still trying to understand what other factors might be maintaining the prevalence of HIV PN."

HIV-related neuropathy tends to emerge gradually, while antiretroviral-related neuropathy emerges more rapidly and can usually be stopped from worsening by stopping the drug.

The CHARTER study – a prospective, observational study of over 1500 people

with HIV in the US that looked at the impact of antiretroviral therapy on neurological function – reported that 57.2% of participants had at least one sign of PN. Of those, 60.8% reported a sensory symptom of PN and 38% reported some level of pain.⁴ Put in the context of the entire study population, one in five (21.8%) were living with PN pain. PN is also a serious issue in developing countries where the use of implicated drugs, particularly d4T, is still common.

The CHARTER study also assessed the impact of PN on quality of life, and showed that depressive symptoms were more common among those with PN pain. Moreover, pain was almost twice as likely among people with depression. Not surprisingly, the study reported that people with mild, moderate or severe pain scored more poorly on the quality-of-life subscale of the Medical Outcome Study HIV Health Survey (MOS-HIV), a validated scale of health and wellbeing among people with HIV. Moreover, people with PN pain were more likely to be unemployed and to need help with daily living.

Many of the factors normally associated with an increased risk of PN are those that would be expected. Having another condition which can also lead to PN increases the risk. Low CD4 cell counts, lowest-ever (nadir) CD4 cell count and high viral load – all signs of a weakened immune system and advanced disease – also increase the risk. Being older (and being taller) also increases the risk of PN... not such good news for people with HIV who are on successful therapy and now expecting near-normal lifespans. PN may be another one of those things – along with such issues as the long-term effects of antiretroviral therapy and what appears to be premature ageing – that more and more people with HIV can expect to face as they live with a chronic infection.

Living with PN

Diagnosis of PN is based on symptoms (what people feel and tell their doctors about) and signs (physical indications noticed by a doctor during an exam). Certain neurological tests are carried out in some centres in order to distinguish HIV PN from PN resulting from its many other possible causes including:

- Diabetes or insulin resistance
- Heavy alcohol consumption
- Thyroid disease
- Syphilis
- Kidney disease
- Vitamin B12 deficiency
- Other infections (shingles, CMV).

Neuropathy related to HIV or antiretrovirals usually affects both sides

of the body symmetrically, whereas other types may not. When investigating pain symptoms, doctors routinely check for these other conditions. If any are diagnosed, they can be treated.

"When a diagnosis of HIV PN is made," Dr Cox says, "we would start by explaining what HIV PN is, how it may have been caused and what to expect." Then the first goal is to prevent further damage by identifying any aggravating factors and trying to control or eliminate them. This includes proper management of the HIV infection. Neurotoxic drugs are identified and stopped or replaced with a safer alternative if possible. In addition to the d-drug antiretrovirals, other potentially neurotoxic drugs used in HIV include dapsone (for PCP prophylaxis), isoniazid and ethambutol (tuberculosis drugs), thalidomide (a treatment for aphthous ulcers, or canker sores, in the mouth) and certain cancer drugs.

At present we don't know how to cure or reverse neuropathy: attempts to develop therapies that promote the regeneration of destroyed nerves have so far failed. Dr Cox says: "We explain that we cannot reverse the condition and that treatments we offer will be to mask the symptoms."

Treatment options for neuropathic pain can be grouped into five broad classes: anticonvulsants; antidepressants; non-specific analgesics; topical treatments; and complementary therapies. However, Dr Cox adds, "In terms of treatment, many of the usual treatments for pain in neuropathy have been shown not to work in HIV PN." Moreover, there are no treatment options for other symptoms of PN, such as numbness or tingling.

In 2010, a systematic review and meta-analysis co-authored by Dr Cox reported on the results of 14 prospective, double-blinded, randomised, placebo-controlled trials of treatment options for HIV PN.⁵ The authors concluded that only two available

“The value of doing your own research is that you can walk into a doctor’s appointment strengthened by knowledge.”

Dave R

treatments – smoked medicinal marijuana and high-dose topical preparations of capsaicin – showed efficacy.⁶ Marijuana needs no introduction; capsaicin is the active ingredient in chilli peppers and is used in many topical painkilling preparations such as *Qutenza*, where its pain-stimulating effect paradoxically seems to overwhelm the signals that cause chronic pain.⁷ First-line treatments, including the anticonvulsants lamotrigine, pregabalin and gabapentin (see below), tricyclic antidepressants such as amitriptyline, the anti-arrhythmic drug mexiletine, the amino acid (and popular supplement) acetyl-L-carnitine and low-dose topical capsaicin (0.75%) were no better than placebo at decreasing PN pain in people with HIV.

While the systematic review and meta-analysis results showed no efficacy with many treatments, they may still have some merit. Some drugs may work for some individuals. Also, combining treatments,

which is common, may result in at least partial relief. Doctors will prescribe familiar painkillers first before moving on to stronger ones such as opiates and PN-specific medications such as amitriptyline.

Dr Cox also advises her patients on how to live with PN day to day. "We point out the particular problems associated with loss of ability to distinguish when something is hot and how it is important to test bath temperature with an elbow rather than feet. We advise individuals to inspect the bottom of their feet for damage and be very careful breaking in new shoes. I usually suggest they avoid walking barefoot."

Dave has tried six different drugs alone or in combination, and all have been "unsuccessful in taming the pain". He is weaning himself off oxycodone, preferring for now to live with the pain: "I try to mentally control the pain and relax as much as possible plus accept that the pain is there and not try to fight it by tensing up or becoming too depressed."

In addition to managing the pain, learning about the condition has also helped Dave. "Very early on, I was more than a little frustrated at the lack of information available to HIV patients with neuropathy," he recalls. So he set up a website, originally in Dutch and now also in English, along with a blog to provide information about neuropathy, from which people can make their own decisions and ask their own questions while sharing the experiences of others. The blog is available at www.neuropathyandhiv.blogspot.com.

According to Dave, "The value of doing your own research is that you can walk into a doctor's appointment strengthened by knowledge and maybe not be so confused when you walk out. Neuropathy is not an easy thing to explain; if you have some idea beforehand it will help enormously."

Finally, Dave points out the importance of a support network. "Having chosen wisely, make friends of your two main healthcare providers: your home doctor [GP] and your HIV specialist. It's a long journey with neuropathy; you need to have someone on your side who knows what you and they are talking about."

As for family and friends, he adds, "They won't understand what's happening to you and possibly after several weeks of moaning, will be distinctly unsympathetic too. If possible, take a family member or a friend with you to a consultation with your doctor. It's vital that you're taken seriously because, otherwise, you can feel very lonely while you're suffering. You're going to need a listening ear or a shoulder to cry on at some stage in the future."

Sound advice, indeed. 

Treatment options for PN

Note that many of these have not been proven to be effective in treating HIV PN.

Anticonvulsants – gabapentin, pregabalin, lamotrigine

Antidepressants – TCAs (tricyclic antidepressants) such as amitriptyline and nortriptyline; SNRIs (serotonin-norepinephrine reuptake inhibitors) such as duloxetine and venlafaxine

Nonspecific analgesics – NSAIDs (non-steroidal anti-inflammatory drugs) such as ibuprofen, naproxen and paracetamol (acetaminophen); opioid analgesics such as oxycodone, fentanyl and morphine

Topical treatments – lidocaine and capsaicin

Complementary therapies – acetyl-L-carnitine, co-enzyme Q10, cannabis, hypnosis, acupuncture and acupressure

Joint and muscle pain

Burning and stinging feet are not the only pain that people with HIV are facing as they look towards a long life with the virus. As Dave R can attest: along with PN, he lives with arthritic back problems, which he suspects are in part due to playing rugby during his school years. While Dave's arthritic condition preceded HIV infection, many other people with HIV are finding that rheumatic diseases – diseases of the muscles and joints – can be true pains in the proverbial.

Rheumatic conditions include a broad spectrum of conditions that affect the joints and musculoskeletal system. Familiar conditions include different forms of arthritis, systemic lupus erythematosus (SLE or lupus), fibromyalgia (muscle pain) and gout. They can be mildly painful at best and debilitating at worst.

Many rheumatic conditions are autoimmune conditions and have long been a part of HIV disease. There are several potential mechanisms to explain how HIV can lead to rheumatic disease. Among them is that HIV particles are similar to other antigens in the body. Infection with HIV can cause the body to initiate an autoimmune response that can underlie conditions such as arthritis or lupus.

Before the introduction of ART, estimates of the prevalence of rheumatic disease in people with HIV ranged from 11 to 72%, with joint pain affecting 5 to 45% of people. Different forms of arthritis were common, as well as muscle weakening. In the ART era, the prevalence has been reported as approximately 9%.⁸

Along with the decrease in prevalence, the types of diseases have also changed. Less common are exotic beasts such as diffuse infiltrative lymphocytosis syndrome (DILS, a painless condition that causes swelling of the salivary and tear glands and often lymph nodes) and spondyloarthritis (inflammation of the joints in the spine), while musculoskeletal problems, such as osteopenia (low bone mineral density), and infections still occur.⁹ Starting antiretroviral therapy can cause IRIS (immune reconstitution inflammatory syndrome), which can lead to new cases or reactivation of pre-existing cases of rheumatic conditions such as rheumatoid arthritis or lupus.

In untreated HIV infection, rheumatoid arthritis and lupus are dampened because a weakened immune system is not able to produce the cytokines, cellular messaging chemicals like tumour necrosis

factor (TNF), that are involved in the ongoing inflammation underlying these diseases. Restoring the immune system reactivates these pathways leading to flare-ups. The symptoms of IRIS usually get better spontaneously, but can be very severe while they are happening.

Gout and its precursor hyperuricaemia (high levels of uric acid in the blood) also have a high prevalence among people with HIV. Hyperuricaemia has been reported in up to 42% of people with HIV, and gout is about tenfold more common than in HIV-negative people. Hyperuricaemia has been linked to certain antiretroviral drugs, specifically ddI and d4T. The mitochondrial toxicity associated with these drugs is thought to cause changes in the body's metabolism that lead to increased levels of uric acid in the blood.

Finally, fibromyalgia was the second most common rheumatic condition in a cross-sectional US study of HIV-positive people taking ART. Seventeen percent of people reported the syndrome, which includes long-term, body-wide pain and tenderness in soft tissues including the joints, muscles and tendons.

Living with arthritis and muscle pain

There are no guidelines for the treatment of rheumatic conditions in people with HIV. However, most therapies used in the general population appear safe and effective among people with HIV when used prudently.¹⁰ The UK Royal College of Physicians' guidelines for the treatment of rheumatoid arthritis recommend a combination of agents: short-term glucocorticoids to reduce inflammation, agents from a class called the DMARDs (disease-modifying anti-rheumatic drugs) and agents called biologics. People also use NSAIDs (see *Treatment options for PN*) or COX-2 inhibitors (another sort of anti-inflammatory drug) to manage the pain associated with the condition.

DMARDs include drugs such as methotrexate, hydroxychloroquine and sulfasalazine. Methotrexate was originally avoided in people with HIV because it suppresses the immune system. However, it is now used with careful monitoring of CD4 count and viral load.¹¹

Hydroxychloroquine is used to treat both rheumatoid arthritis and lupus, and is used in people with HIV. It has antiretroviral properties: in early studies, high doses of the drug were comparable to AZT

(zidovudine, *Retrovir*) monotherapy in controlling viral replication.

Biologics are another option for treating certain joint conditions. They are artificially synthesised analogues of naturally occurring proteins that block the action of inflammatory cytokines such as TNF, and include etanercept and the monoclonal antibodies adalimumab and infliximab. Since TNF-alpha enhances HIV replication in test-tube studies, researchers speculate that these TNF-alpha blockers may have antiretroviral activity. Clinical studies of these drugs in HIV-positive people are in their early stages, but look promising. The drugs do not seem to exacerbate HIV disease and appear to be relatively safe if used prudently and with regard for the potential for other infections.

People living with arthritis often try to manage the condition through changes in their diet and supplementation, and many claim some success. Supplements with anecdotally reported success include glucosamine and chondroitin, fish oils or omega-3 fatty acid supplements, gamma-linolenic acid (found in evening primrose, blackcurrant seed or borage seed oils) or other herbal therapies such as feverfew or willow bark extract. Other people adjust their diet, excluding gluten or other common food allergens, or following a vegetarian or Mediterranean diet. Quality placebo-controlled studies report some benefit linked to some of these dietary changes and supplements: people often feel fewer symptoms and some measures of disease improve. However, there is not one option that is clearly better and so, just as with HIV, people often try different approaches and see what works for them.

Remember, it is important to tell your HIV healthcare team about anything you are taking, including supplements and herbal remedies, in case there are interactions with your HIV treatment.





Barriers

Immigration removal

Evidence has shown that a series of failings in immigration removal centres (IRCs) has compromised the continuity of care for people with HIV. Guest writer *Daniel Lombard* investigates.

Immigrants who find themselves detained by the Home Office prior to being removed or deported from the UK are sometimes described as the most vulnerable people in society. Detainees with HIV are even more vulnerable, in part because they rely on UK Border Agency staff and private contractors to provide proper access to health care.

With a complex system overseen by Home Office officials, who commission services from a network of private-sector security and healthcare contractors who are expected to work seamlessly alongside NHS clinical staff, campaigners say it's not surprising that mistakes are often made.

Louise Whitfield is an associate solicitor at Pierce Glynn, a firm involved in challenging the poor standard of HIV health care in Immigration Removal Centres (IRCs) on behalf of detainees.

She explains: "The Home Office detains the person, private contractors arrange transport, private healthcare providers are at the removal centre and specialist HIV doctors are at the hospital, and in some cases there are community nurses involved.

You've got all those people trying to do different things. It's a very complicated set-up."

What the professional guidance says

Detainees are held within the UK's 13 IRCs. Under Home Office Detention Centre Rules,¹ each IRC must provide health care to detainees; it is generally accepted in law that this should be of the same standard of care as that provided to people living in the community. (Refused asylum seekers in England who are not in detention are only entitled to free health care at the discretion of the local primary care trust.)

Guidelines produced by the National AIDS Trust (NAT) and the British HIV Association (BHIVA)² explain that asylum seekers whose applications are rejected and are not awarded humanitarian protection or discretionary leave to remain are expected to return to their country of origin. The UK Border Agency can detain anyone who does not leave voluntarily until it is possible for them to be removed. According to the guidance, more than a third of all asylum

seekers come from Africa, the region with the highest HIV prevalence, and a significant number are detained in IRCs at some point during the asylum process. NAT and BHIVA state, therefore, that "there is an urgent need to consider the HIV-related health and social care needs of asylum seekers and others in detention".

Their guidance contains the following recommendations covering the three stages of the detention process: reception, detention, and removal.³

1) Reception

"Every detainee should be seen for a reception health screening within 24 hours of arrival in an IRC."

An arrangement must be in place between the IRC and the local HIV clinic to obtain antiretroviral medication within 24 hours for an HIV-positive detainee who does not arrive with his or her anti-HIV drugs.

Detainees who inform the IRC nurse that they are HIV-positive during the initial health screening should be given an appointment with the on-site GP within one week, and



Access to care

Specialist centres and HIV

an appointment with a local HIV specialist should be arranged at the same time.

2) Detention

"Those who are newly diagnosed with HIV in IRCs should be referred to an HIV specialist to access appropriate baseline investigations and any necessary treatment."

Detainees with HIV should be allowed to keep their medication with them and be supported to maintain confidentiality. Where this is not possible, IRC healthcare staff must ensure the detainee has the opportunity to take the medication as required.

3) Removal

Detainees must not be removed unless they are deemed to be "medically stable and fit to travel". Final judgement must be determined "on a case-by-case basis and should always rest with the IRC GP in consultation with HIV specialists".

Prior to removal, "IRC healthcare staff should ensure the detainee has been provided with:

- A letter for their future treating clinicians.
- Three months' supply of medication.
- Contact details of trusted HIV support organisations in their destination country."

Sarah Radcliffe, senior policy and campaigns officer at NAT, says the most contentious issue is often the provision of three months' supply of medication. "Some

detainees only leave with enough for one month," she says.

Substandard care - in handcuffs

A report produced by Medical Justice, an organisation concerned with the denial of health care to detainees, and published in March this year, laid bare the severe consequences of poor treatment for HIV-positive detainees.

It concluded: "The process of detaining people who are HIV positive inherently puts them at risk." It added that "the British government is willing to deport people who they know will die within a few years" due to limited treatment options available in some developing countries.

Failings included disruptions to ARV regimens, exposure to the risk of contracting opportunistic infections, and denying people access to HIV specialists in hospitals, according to the report, *Detained and denied: the clinical care of immigration detainees living with HIV*.⁴

Some people were forced to undergo consultations with healthcare professionals while handcuffed to escorts, while treatment was so detrimental that, in some cases, it "may have left [detainees] requiring complex clinical care for their HIV infection".

NAT has been aware of inconsistencies in delivering health care for HIV-positive detainees for "five or six years", according to Sarah Radcliffe.⁵

People often end up in detention after being taken by officers in the middle of the night, without having their drugs on them. In the worst cases, disruption to people's supply of HIV treatment can cause drug resistance to begin to develop.

To combat this, the NAT and BHIVA published their guidelines in a 24-page advice booklet, in 2009, for healthcare and voluntary sector professionals. *Detention, Removal and People Living with HIV* aims to share the principles of best practice in this field.⁶

The Medical Justice report found that, among 35 cases reviewed, there were 79 breaches of the NAT/BHIVA guidelines.

A spokeswoman for the UK Border Agency told *HTU* that the practice of handcuffing detainees for hospital appointments was not routine, and only used in certain circumstances, for example where there is a risk of absconding.

But Ben Holden, HIV consultant at Hillingdon Hospital in London, disagrees. "It's more common to see someone in handcuffs than not, though we have never had anyone try to escape. People have the cuffs kept on in the waiting area and then they are removed in the consultation room."

He adds that the use of handcuffs "simply adds to the upset and worry" for the detainee and other patients.

Following one incident in which doctors at Hillingdon Hospital refused to treat a

detainee, because a guard refused to uncuff him, UKBA officers installed extra security locks on the windows at the sexual health clinic to prevent anyone from escaping.

One of the organisations working alongside healthcare professionals at Hillingdon Hospital is Hillingdon AIDS Response Trust (HART), a local charity supporting people with HIV, including asylum seekers arriving at Heathrow airport.

Simon Bellham, manager of HART, says: "The quality of health care for people in this situation is extremely patchy. It depends which detention centre and which part of the country you are in.

"The system is geared towards security and the needs of the service, not the individual. I would like to see an overhaul of the entire system."

A complex system

Primary health care within IRCs is provided by private contractors, which should allow detainees access to HIV treatment and other secondary care, provided by local hospitals.

Where medication is concerned, the responsibility for prescribing drugs to detainees lies with primary care trusts (PCTs), but this will change with the ongoing NHS reforms. "It could be possible that will be done centrally in future by the [proposed] national NHS Commissioning Board," NAT's Sarah Radcliffe says.

Professor Jane Anderson, chair of the British HIV Association and HIV consultant at Homerton University Hospital in London, stresses that healthcare professionals in IRCs do their best under difficult circumstances.

"The GPs work very hard – I've met some of them and know how committed they are – but the healthcare system in removal centres is not set up to provide high-quality specialist care," she says.

The complexity of the system is compounded by a lack of co-ordination between the UKBA and private contractors, as Pierce Glynn's Louise Whitfield observes: "There have been a number of incidents where transport has been cancelled, because the detaining authorities take the view that a hospital appointment is less important than attending court, for example. That might be the correct decision for a dental appointment, but for an urgent medical appointment, where you could become fatally ill if you miss it, then it is clearly not correct."

In a case brought by Pierce Glynn on behalf of three detainees with HIV,⁷ even the evidence the Home Office relied on said: "The split of responsibility between community nurses, general practice [in the IRC] and the hospital in Sussex seems

“In detention you are likely to have clusters of stressors. People can stop coping and face depression; if they have chronic exposure to stress their resilience goes down.”

Lorraine Sherr,
Professor of clinical and health
psychology, University College London

extremely bureaucratic and complicated and almost inevitably led to a breakdown in communications."

Home Office detention guidelines⁸ originally stated that any person with a serious medical condition should only be detained in "very exceptional circumstances", such as where there are public safety concerns.

Following the trial involving the three detainees, however, the Home Office amended this guidance so that the very exceptional circumstances only applied to "those with serious medical conditions that could not be satisfactorily managed in detention" – leaving HIV-positive detainees with weaker legal protection.

Psychological impact

The psychological impact of living in detention with HIV should not be underestimated. As the NAT/BHIVA guidance states, not only do people have to cope with anxiety associated with HIV, they may also previously have suffered trauma through conflict, rape, torture and imprisonment.

Lorraine Sherr, professor of clinical and health psychology at University College London (UCL), says the constant stress could cause people with HIV to suffer mental breakdown and further damage to their immune system.

"In detention you are likely to have clusters of stressors. People can stop coping and face depression; if they have chronic exposure to stress their resilience goes down. You get multiple mental health issues, not just depression and anxiety but other conditions such as post-traumatic stress disorder.

"There's also a direct link between immune systems and mental health, and your ability to fight off infections will be affected by mental health problems."

The case for reform

Some experts, such as Louise Whitfield, agree with the recommendation from Medical Justice that no one with HIV should be held in detention for immigration purposes. While such a radical change is unlikely to happen, others put forward the following suggestions for improving health care for HIV-positive detainees.

- **Outreach services.** Instead of transporting detainees to hospitals, HIV specialists should travel to IRCs. Hillingdon Hospital's Dr Ben Holden says nurse prescribers could provide initial services, adding: "It would be better value for money than the current system that requires three guards per patient."

● **Advocacy services.** HART's Simon Bellham would like to see a dedicated worker in each IRC acting as an advocate for the physical and psychological wellbeing of detainees.

● **Mental health services.** UCL's Professor Sherr says: "Counsellors need to be aware of their limitations and know who they can refer patients to if certain problems are beyond their abilities to address, such as someone with post-traumatic stress disorder."

● **Information** for people at risk of entering detention. BHIVA's Professor Anderson says: "If we are caring for people with HIV at risk of being detained, it's important that they know how to ask for appropriate help and have contact information that they can pass on to IRC healthcare teams."

● **Better co-ordination** between services. NAT's Sarah Radcliffe says: "It's about joining the dots between the IRC management and healthcare teams and making health care for people with HIV a priority in amongst all the other pressures involved in detention settings."

The UK Border Agency has met with NAT and BHIVA to discuss a possible audit of the treatment of HIV by healthcare teams in removal centres, hoped to begin in early 2012.

Lisa Power is policy director at the Terrence Higgins Trust. She says this will be an important piece of work, but believes "there will still be problems with the immorality of sending someone away from the country to die".

The UK Border Agency says that it takes its duty of care to detainees "extremely seriously". A spokesperson adds: "We provide round-the-clock access to healthcare services in all immigration removal centres which are equivalent to those available in the community.

"HIV treatment is delivered through specialist PCT clinics. Every effort is made to ensure arrangements are in place in advance of detention and all detainees are interviewed by a healthcare professional within two hours of arrival where their care needs are identified and suitable arrangements put in place."

Despite these pledges, Power says THT will keep a close watch on the performance of UKBA and its contractors.

"It's so important that breaches are reported and investigated, and for charities like ours to hold the providers to account." 

Case study

George [not his real name], from central Africa, spent nine months in detention from August 2009 to May 2010. He had overstayed his visa and faced removal from the country, having been diagnosed with HIV shortly before entering detention. George was one of three people who challenged their detention on the grounds that "management failures" – he missed several healthcare appointments and ran out of medication for two weeks – had made their detention unlawful. This was rejected by the High Court in 2010 but an appeal is being considered.

George is now living in rented accommodation in Essex, awaiting judgements on various appeals. Here he recalls his traumatic experiences in Brook House immigration removal centre, near Gatwick.

"It's hard to describe the feeling of being in detention with a serious health condition. All the emotions you go through, it's something you only understand if you have been there. If someone said 'I give you £1 million for one year's detention or I give you no money to be free', I would be free every time.

"I came to London in 1993 to escape civil war in my country. I was refused asylum but appealed, and legal cases went on for a number of years.

"I reported to the Home Office as usual on 5 August 2009. I expected it to take five minutes but they told me to stay and detained me. Later I discovered it was because my appeals were exhausted.

"Before I was detained the doctor told me I had HIV but said I didn't need medication, which surprised me. After a month in detention I saw a nurse and HIV consultant who prescribed ARV medication. But I wasn't able to get this because he needed the file from my previous doctor and it took three or four weeks to arrive.

"I went to East Sussex Hospital every couple of weeks, but I missed three or four appointments because there was some blunder involving the contractor. A couple of times the cab didn't show up. Another time the person in the detention centre forgot to book transport.

"I was worried – if the first line of medication failed, I was in trouble. I was afraid my life was in danger because I could

get deported at any time, I was thinking how am I going to deal with this?

"I was very frustrated and anxious. I just kept it to myself; the only person I could talk to was my doctor. I could use the telephone but who could I talk to? I lost contact with my family a long time ago.

"I missed two weeks of medication and had to be moved to another regimen because I developed resistance. As long as you take the pills you feel you are safe. But when you miss it you think what's going to happen, am I going to be OK? I was afraid I would get AIDS.

"I was told three or four times I was being deported. Emotionally it is very difficult.

It's worse than someone beating you up, because then you know someone will stop and you can relax, but in detention it's like someone is beating you up and it will never stop. The Home Office is totally in control.

"I'm very grateful to my lawyer for supporting me

and providing a very good defence.

"I know my life is going to be difficult if I go back to Africa. I would have to live like a drug addict where you just get enough money to survive and you don't care about eating or sleeping. I don't think I would tell my family about my status because in Africa it is a shameful thing to be HIV-positive.

I'm worried I would not have access to the medicine I need. If it is available, it would be very expensive. As far as I know there are no pharmaceutical companies in my country. Even aspirin is imported so they probably wouldn't have access to complex medication like ARV."

“I missed two weeks of medication and had to be moved to another regimen because I developed resistance.”



Help when you're troubled

Getting
the right
psychological
support



Gus Cairns looks at the new *Standards for psychological support for adults living with HIV*.

People with HIV have higher rates of depression, anxiety and most other psychological problems than the general population. A large meta-analysis in 2001 showed that people with HIV are about twice as likely to be diagnosed with depression as the general population;¹ a study of UK patients in 2007 found that over two-thirds reported symptoms of depression and over 70% symptoms of anxiety;² and a community survey of people with HIV conducted in 2007-08 found that around 70% of people had issues with depression, anxiety and self-confidence and/or reported difficulties with sleeping or sex.³

In addition, people who already have psychological problems are more likely to have HIV or be at risk of contracting it. A World Health Organization (WHO) report found that HIV prevalence rates in patients with diagnosed psychiatric conditions in the US were between 5 and 23%, compared with a range of 0.3 to 0.4% in the general population over comparable time periods.⁴

It's good in itself to provide people with HIV with high standards of psychological support: as a report on mental health by the National AIDS Trust (NAT) in 2010 put it, "People living with HIV should not be required to struggle with depression, anxiety, or any other mental or emotional problem alone."⁵

Emotional problems can also have a direct impact on the physical health of people with HIV. Studies have consistently found that depression is the strongest single predictor of poor adherence to antiretroviral drugs⁶ and that the onset of depression is often accompanied by a drop in adherence.⁷ Some studies have found a direct link between depression and mortality in HIV-positive people not on HIV therapy,⁸ and long-term stress and anxiety have consistently been shown to depress the immune system.⁹

Finally, as numerous studies from places ranging from the US¹⁰ to France,¹¹ Australia¹² and South Africa¹³ attest, anxious and depressed people, with or without HIV, are more likely to have unsafe sex.

With treatments largely maintaining people's physical health, the emotional burden of living with HIV has become the dominant challenge to many of us. So support, counselling and skilled psychological help should be a standard part of the services available to people with HIV, like tests, pills and referral to experts.

Yet exactly what support services should be provided has never been codified in the UK. This is about to be remedied with a document called *Standards for psychological support for adults living with HIV*, issued jointly by the British Psychological Society (BPS), the British HIV Association (BHIVA) and the Medical Foundation for AIDS and Sexual Health (MedFASH).

A Cinderella service

Psychological services are often the targets of cuts when NHS money is short and tend to be chronically underfunded. They are also sometimes undervalued and may struggle to prove their necessity: there's a myth that their efficacy is hard to prove.

In fact, taken as a whole, 'talking therapies' are extremely effective. On average, psychotherapy has a 60% efficacy in improving symptoms of mental distress¹⁴ and improvements last for two or more years after therapy is ceased.¹⁵

It is also cost-effective. Depression, according to WHO, is the single largest cause of disability worldwide¹⁶ and contributes significantly to some of the top causes of mortality, including alcohol and drug use and suicide.

With HIV, there is evidence that psychotherapy improves mental health

“HIV is special because it's to do with sex, and mainstream psychologists and psychiatrists still don't have enough training or experience in dealing with sexuality.”

Stuart Gibson,
Clinical psychologist, CASCAID

and health behaviours like adherence, but also that it directly influences health. Stress reduction techniques have been found to enhance immune function in people with HIV¹⁷ and a meta-review found evidence that psychotherapy can directly improve immune status.¹⁸

Yet standard clinical guidelines still pay little attention to mental health and virtually none has been paid to psychological therapies in HIV treatment guidelines and clinical standards.

The current (2008) BHIVA treatment guidelines say that newly diagnosed patients should have "a psychosocial history taken to identify psychiatric problems, alcohol use and recreational drug use", but only thereafter mention psychology in connection with reasons to avoid efavirenz (*Sustiva*), though the next guidelines, planned for 2012, will say more. The BHIVA Standards for Clinical Care from 2007 say that HIV outpatient units (secondary care) should have "access to [a] health advisor/counsellor as required" and that HIV centres with inpatients should be able to provide "mental health [services] for patients with significant mental health needs".

The National AIDS Trust report

Awareness of this gap in the guidelines and of the danger of further fragmentation of inadequate services for people with HIV motivated NAT to convene three focus groups of psychology service users with HIV and an expert meeting.

The resulting 2010 report, *Psychological support for people living with HIV*,¹⁹ highlighted several issues.

One was the existing fragmentation of mental health services, which cuts were exacerbating. Mental health services in the UK are usually run by health trusts separate from those running primary care and hospitals. Local liaison arrangements and multidisciplinary teams have ensured that patients in need get some kind of joined-up service. But service reconfigurations can mean that, when HIV clinical services 'migrate' to another trust, mental health services don't go with them, necessitating the development – often in a situation of reduced services – of a whole new set of referral arrangements.

Another was that HIV was lagging behind other chronic disease areas in integrating psychological services. The National Institute for Health and Clinical Excellence

(NICE) has issued guidance on supportive and palliative care for adults with cancer,²⁰ for example, and on addressing chronic health problems in people who experience depression.²¹

A final point was historical. Psychological problems in people with HIV have not decreased in line with physical problems, not just because the stigma against HIV remains fierce, but because the very nature of living with HIV has changed. Dr Barbara Hedge, a consultant clinical psychologist from St Helen's and Knowsley Teaching Hospitals in Merseyside, points out that, when HIV was an incurable condition, people would tend to make 'downward' comparisons: "I'm glad I'm still alive" or "I'm glad I survived that infection". Life might be grim but people were glad for every extra day. Now HIV is a condition people live with rather than die from, people tend to make 'upward' comparisons with how they think life should be: "I can't get a relationship" or "I have to take pills that make me tired all the time".

The NAT report made a number of recommendations. The most significant one in terms of this article is that "relevant professional bodies, such as BPS and BHIVA, should collaborate to... publish standards on psychological support services for people living with HIV" and that "services should be commissioned on the basis of these standards".

The Standards for psychological support

Liz Shaw is a consultant clinical psychologist in sexual health and HIV at St Ann's Hospital in London, and chaired the group that wrote the *Standards for psychological support for adults living with HIV*. She says: "It was unanimously agreed at the NAT meeting that we had to take forward a set of standards. There is still a lot of specialist psychological provision in HIV but it's never been thought through strategically."

MedFASH undertook the writing and editing of the standards in collaboration with BHIVA and the Faculty for Sexual Health and HIV of the Division of Clinical Psychology at the British Psychological Society (BPS) with input from many other bodies including GPs, NAT, voluntary organisations and service users.

One of the reasons for the standards is to state exactly why HIV should be a specialist area in psychology. "It's the stigma," says Liz. "[It] isolates people, and isolation is behind a lot of psychological problems. People with HIV also have to deal with a lot of moral and ethical dilemmas: whether to disclose, for instance."

Stuart Gibson is a clinical psychologist at CASCAID, a multidisciplinary mental health

service for people with HIV in south London, and is also chair of the Faculty for Sexual Health and HIV.

He says: "HIV is special because it's to do with sex, and mainstream psychologists and psychiatrists still don't have enough training or experience in dealing with sexuality. As a result I still hear mental health professionals saying things like 'Well, they just have to tell every sexual partner that they have HIV', without any understanding of why that might be a hard thing to do."

I ask whether the mainstream of the BPS had questioned whether HIV presented the need for specialist guidance. Stuart says he is concerned lest the formal adoption of the standards is delayed by bureaucratic processes of approval but adds that "On the whole, the fact that we deal with sex can be used to our advantage. 'Oh, the HIV people care about that, we can leave it to them' tends to be the attitude."

Liz Shaw, however, notes that people with HIV can experience high levels of moderate distress, but they are not more likely than average to have the really severe mental illnesses like schizophrenia and bipolar disorder that can "push them up waiting lists".

She explains that the Standards are *not* a set of guidelines that tell practitioners what to do: "They are about what is required to put into place a good level of provision.

"In other words, they are about what needs to be there in order to ensure that wherever a person with HIV enters the system, there will be psychological support."

Four levels of care

One of the most important aspects of the document is its introduction of a 'stepped care' model of provision; it sets out four different levels of need that require four different levels of provision:

1. Information and support
2. Enhanced support
3. HIV-specialist counselling and psychotherapies
4. Specialist psychological and mental health intervention.

Rather than explain in medical terms what these levels mean, it's probably better to illustrate the different levels of need with these examples.

Level 1 – Information and support

Bob is diagnosed with HIV by his GP. He is a balanced and well-resourced person and the diagnosis was not entirely unexpected. He doesn't want to be counselled but is a bit nonplussed by his GP's ignorance of some basic questions he has, like the chances of

transmitting HIV to others. The GP refers him to the practice nurse who seems a lot more knowledgeable, points him towards information resources (like aidsmap.com) and knows a local support organisation he can attend to meet other people with HIV.

Level 1 is a basic grounding in the psychological impact of HIV. In some ways it's the most radical part of the document as it says that every healthcare practitioner who's likely to come across a person with HIV – GPs, practice nurses, peer support and other community workers, social workers, midwives and so on – should understand and have training in the basic psychological aspects of living with HIV, including stigma and confidentiality. At this level, the standard requires enough knowledge and sensitivity to avoid causing harm to people with and affected by HIV, rather than specific psychological skills.

Level 2 – Enhanced support

Stella finds her diagnosis, during pregnancy, harder to come to terms with. She doesn't blame herself, but has a lot of practical dilemmas and questions, like how to disclose to her present partner, whether she could infect her baby, and whether it will prejudice her residency application. Her low CD4 count also means she should start HIV treatment as soon as she can, but she doubts if she'll remember to take the pills. She airs her concerns at a peer support group at her local HIV organisation, and accepts an offer of three sessions with a counsellor there to help her explore her options and make decisions about disclosure, condom use and treatment.

Level 2 psychological support is provided by practitioners who have some specific experience of, or expertise in, providing general psychological help to people with HIV. They should be able to conduct a post-test discussion or an exploration of safer sex in a structured way, and be able to assess patients for possible psychological issues that need onward referral. They should be aware that key points in the lives of people with HIV may be especially stressful and should provide psychological screening at these points (which include diagnosis, starting or changing treatment, pregnancy, or experiencing other stressors such as housing or relationship problems). They should also be alert to changes in behaviour such as sudden non-adherence.

Level 3 – HIV-specialist counselling and psychotherapies

Riaz has had HIV for ten years and is on ARV therapy. He has been able to treat HIV as 'no big deal' and holds down a good job. Recently, however, after a bout of illness, he found that he had developed drug resistance

and his CD4 count had sharply declined. He is put on an effective new combination but, to his own surprise, finds himself suddenly very anxious and depressed, unable to get fears of death out of his head, blaming himself for the drug resistance, and dreading going into work. He mentions this to his HIV doctor, who refers him to a specialist HIV counselling service. After twelve sessions with the counsellor, he feels more settled, and realises that the drug failure had challenged a lifelong belief that he could, and must, deal with everything unaided.

The standards are explicit that level 3 support must be offered "by qualified and registered practitioners in counselling and psychological therapies". This level is for patients who present with more complex problems, adjustment difficulties, and moderate levels of diagnosable psychological conditions. Practitioners at this level should not only be able to deal with issues such as sexual risk reduction, or substance misuse, but should be able to assess patients for severe problems requiring onward referral. Resources may include specialist support groups as well as individual counselling. Liz Shaw says that the insistence that practitioners at this level must be qualified counsellors is one of the most important aspects of the document: it implies that, somewhere in every HIV centre or local service network, there must be someone whose job title is "HIV specialist counsellor" or equivalent.

Level 4 – Specialist psychological and mental health intervention

For Wendy, a recovering injecting drug user, HIV diagnosis feels like a final blow to an already shattered life. The news thrusts her into a profound depression; she can't eat or sleep yet can hardly get out of bed. She starts having thoughts that the neighbours know her HIV status and has used heroin to calm her fears. She broods on how she might kill herself. A nurse specialist with mental health training spots her major depression the next time Wendy is able to make herself go to the clinic. She refers her to the liaison psychiatrist, who prescribes an antidepressant and sets up some sessions with a specialist trauma therapist. There Wendy is able to start talking about the abuse she suffered as a child, and starts pulling her life back together.

Level 4 covers specialist mental health support provided by psychiatrists, clinical psychologists and specialist psychotherapists. It may or may not be HIV-specific: it depends on local provision but also on how directly the mental health condition and the HIV are bound up with each other.

“ [The Standards] are about what needs to be there in order to ensure that wherever a person with HIV enters the system, there will be psychological support.”

Liz Shaw,
Consultant clinical psychologist,
St Ann's Hospital, London

Stuart Gibson, however, says that providing a specialist team containing experts in both HIV and mental health means that they can sometimes work with people who aren't being helped by standard mental health provision: "We deal with a lot of people who are difficult characters and who have been diagnosed with personality disorders – meaning that, by definition, psychological support is difficult to provide. But we'll hold them because we know that, if they don't engage with the HIV clinic, their health will be at risk."

A specialist team can help in situations where mental health and substance-misuse problems are bound up with each other, "whereas, in other settings, people tend to get sent to addiction services and told to stop using first before the mental health issues that may have led them to take drugs get sorted out."

The stigma of mental illness, Stuart adds, means that psychologists have a useful role in explaining patients to other healthcare practitioners. "Doctors can sometimes have this naive expectation that if they tell a patient they *must* do something to get well, such as take their pills, they'll go and do it. Psychologists can help to explain why some patients don't seem to act in their own interest."

There are tricky areas that practitioners at all four levels need to take into account. One is the ability to listen for indications that the person is at risk of suicide, harming themselves or others.

The other is how to take into account organic and neurological illness, including HIV-related cognitive impairment. Originally the standards were going to exclude neurological problems but given that dementia and depression, for instance, may imitate each other or coincide, a requirement for cognitive screening is now included. Members of the writing group are pondering if there is still a need for guidelines covering diagnosis and treatment of HIV cognitive impairment detection and treatment.

The standards – currently a 61-page document, though efforts are being made to slim it down – may look daunting to a healthcare practitioner who isn't a mental health or HIV specialist. One aspect of the recommendations is to identify existing simple, validated, screening tools – standard questions, for instance – that can be used with relatively little advance training and which will at least provide some indication as to who might need onward referral.

The standards are, of course, being implemented at a time when mental health services are being cut back. The service provided by one interviewee for this piece was under threat of a complete funding cut, while the other had experienced 75% cuts to local provision in the last year.

It's probably not before time that we had, set down in black and white, the range of services that can make living with HIV not just possible – but bearable. **nam**

The draft *Standards for psychological support for adults living with HIV* can currently be read at www.bhiva.org/documents/Guidelines/PsychologicalCare/Standards-for-psychological-support-for-adults-with-HIV-consultation-draft-April-2011.pdf Once published, the final document will be available on the BHIVA website www.bhiva.org.

Resource

HIV, mental health & emotional wellbeing



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News in brief

As well as our news reporting, the news pages on our website now also include selected stories from other sources. Here we highlight stories from the last quarter – visit www.aidsmap.com/news for the full news reports and references to the original sources.

THE SEARCH FOR A CURE

Cure “getting nearer”

Gene researcher Sangamo Biosciences has said it is making “significant progress” toward a functional cure for HIV with its SB-728-T process. This involves taking CD4 cells out of patients’ bodies, using gene splicing to turn them into cells HIV can’t infect, and then injecting them back in. Fifteen patients given the therapy experienced increased CD4 counts and six who took a break from their HIV treatment had significantly reduced viral loads. One patient remained undetectable, despite coming off therapy; after a course of SB-728-T. If this state could be maintained without the need for more treatment, researchers would describe it as a functional cure, even though HIV hasn’t been eradicated from the body. The company is now looking for longer-lasting and more potent versions of the treatment, and trying to understand whether genetic make-up influences the likelihood of a strong response to the treatment.

➔ www.aidsmap.com/page/2081571

HEPATITIS AND HIV

Beware hepatitis D and E

Two studies recently focused on hepatitis D and E, viruses which may kill and cause liver inflammation; much less is known about them than hepatitis A, B or C, and they are less easily treated. A European survey of hepatitis D virus (often called hepatitis delta), a virus which ‘piggybacks’ alongside hepatitis B infection, found an increased risk of death in people with hepatitis B if they also had D. Hepatitis D was largely being transmitted through shared needles but could also be sexually transmitted, it was found. Meanwhile, a Swiss study found that one in 40 people with HIV had evidence of infection with hepatitis E, a virus spread through contaminated meat and water (like hepatitis A) including one in 30 with unexplained but persistently elevated liver

enzyme levels. Hepatitis E may be difficult to detect in patients with low CD4 counts.

➔ www.aidsmap.com/page/2063338 and

➔ www.aidsmap.com/page/2066086

PREVENTION

Prevention trials disappoint

Two programmes in southern Africa that aimed to reduce people’s HIV risk behaviour by training peer educators have published disappointing results. A study in South African schools found that a programme training schoolchildren to talk to friends about safer sex produced no increases in condom use and no reduction in the age at which people started having sex. And a programme training men who went to beer halls in Zimbabwe to educate their buddies also produced no differences in extramarital sex, condom use or HIV testing. In more bad news for behavioural interventions, a meta-analysis of trials of a widely-used counselling technique called motivational interviewing, which has been used successfully to help people stop drinking, using drugs and eating junk food, found that it made no difference to sexual risk behaviour.

➔ www.aidsmap.com/page/2077261 and

➔ www.aidsmap.com/page/2075726

EPIDEMIOLOGY AND BEHAVIOUR

No one way to stay safe

Using condoms 100% of the time, although still the single most popular HIV prevention method adopted by gay men, is now a minority strategy, an Australian study found. The national survey found that only a third of HIV-negative and a quarter of HIV-positive men attempted to use condoms for anal sex every time. In contrast, 38% of HIV-negative and 47% of HIV-positive men used a variety of strategies involving not using condoms when they knew, or thought they knew, that their partner had the same HIV status as themselves (serosorting). HIV-negative men,

in the main, only serosorted with committed partners but HIV-positive men were more likely to do it with casual partners too. Only 5% of gay men, whether HIV positive or negative, had no strategy for trying to avoid sexual risk while at the other extreme 5% had no sex at all and about 10% had no anal sex.

➔ www.aidsmap.com/page/2079364

HEPATITIS AND HIV

Coffee helps hep C treatment side-effects

Drinking coffee reduces the amount of liver scarring (fibrosis) in people with hepatitis C and also considerably reduces the side-effects of treatment, two studies have found. A study published in June found that people who drank three or more cups of coffee a day had an 80% reduced chance of liver fibrosis than people who drank none. Now a French study has found that people drinking three or more cups of coffee are also 81% less likely to report adverse side-effects of hepatitis C therapy such as depression and aches and pains.

➔ www.aidsmap.com/page/2074096

PREP

PrEP works for women too

Two trials of *Truvada* (tenofovir/FTC) pills used as pre-exposure prophylaxis (PrEP) to prevent HIV infections in HIV-negative people have produced the best results so far seen for the technique. In the Partners PrEP study, which gave PrEP to the HIV-negative partner in so-called ‘magnet’ or serodiscordant couples (where one partner is HIV positive and the other HIV negative), the efficacy of *Truvada* in reducing HIV infection was 83% in men and 63% in women – and in women, tenofovir alone was just as effective (68%). In the TDF2 study, PrEP was 80% effective in men but only 50% in women; but this still means half of

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News picks from other sources

the women who would probably have been infected with HIV were not, and efficacy was 73% in women with good adherence. The reason these figures are important is because a study called FEMPrEP closed in April because PrEP had not been effective in the women participating in it.

➔ www.aidsmap.com/page/1879841

However, another study, VOICE, which is comparing a microbicide or PrEP in women, recently dropped tenofovir PrEP because it is unlikely to work, but is continuing to study tenofovir microbicide gel and *Truvada* PrEP. Results are expected in early 2013.

➔ www.aidsmap.com/page/2090698

HIV AND CRIMINAL LAW

Canada's climate of fear

A vague law – and over-stringent interpretations of it – have made people with HIV in Canada “angry, confused and frightened” and have led counsellors to adopt a ‘don’t ask, don’t tell’ approach towards the sex lives of patients, a report says. Canadian law requires people with HIV to disclose before having sex that poses ‘significant risk’ of HIV infection. The report calls for better guidance for prosecutors. Meanwhile, a Canadian internet campaign that asked “If you were rejected every time you disclosed [HIV], would you?” seems to have changed attitudes. Men who saw the campaign were 82% more likely to acknowledge that gay men with HIV face stigma and 48% more likely to agree that this made them reluctant to disclose. It produced a 36% reduction in the use of terms like ‘clean’ or ‘disease-free’ in ads on the sex contact website on which it featured.

➔ www.aidsmap.com/page/2052837 and

➔ www.aidsmap.com/page/2080609

TRANSMISSION

‘Viral sorting’ gains ground

Two studies in the Netherlands and the US have found that gay men are increasingly taking their or their partner’s HIV viral load into account when deciding whether or not to have unprotected sex. The Dutch study found that 57% of gay men with HIV had taken their viral load into account when

deciding whether to have unprotected sex with a casual partner and 64% with a steady partner. The US study found that almost all HIV-positive gay men had disclosed to steady partners and regular ‘sex buddies’ and that viral load had been discussed with most of them. Viral load discussions led, if anything, to a slight *increase* in condom use. The study also found, however, that very few HIV-negative men were aware of or asked about their partners’ HIV status or viral load.

➔ www.aidsmap.com/page/2076682

MEN WHO HAVE SEX WITH MEN (MSM)

Middle East faces HIV rise

The predominantly Islamic states stretching from Pakistan to Morocco are currently amongst the world’s lowest-prevalence regions for HIV. However, an international team of investigators has found that what little evidence there is suggests that HIV is rapidly on the rise amongst men who have sex with men (MSM) there. More than one in four MSM in some parts of Pakistan has HIV and more than half of all new HIV diagnoses in Lebanon are in MSM, even though only 13% of the positive population is currently in this group, suggesting a large new increase.

➔ www.aidsmap.com/page/2023180

MEN WHO HAVE SEX WITH MEN (MSM)

Love and condoms don’t gel

Young gay men aged 16 to 20 are very much less likely to use condoms with a ‘serious’ partner than in casual sex situations, a US study has found. The 122 gay teens almost universally used condoms in casual sex situations, but were eight times less likely to do so when having sex with someone described as ‘someone you feel committed to above all others’, and ten times less likely when that someone was a man (at least a quarter of the group were bisexual). Being in a ‘serious’ relationship was more significantly associated with unprotected sex than any other risk factor. The problem was that ‘serious’, in this group, didn’t mean ‘long-lasting’; only 8% of ‘serious’ relationships lasted longer than six months.

➔ www.aidsmap.com/page/2056755

LSHTM

Prevention combo for Africa

LSHTM | 23 September 2011

A team of UK and US researchers led by the London School of Hygiene and Tropical Medicine have been awarded \$37 million to conduct the largest HIV prevention trial ever mounted. The PopART or HPTN071 trial will recruit 60,000 adults living in 16 villages in Zambia and South Africa, divided into two groups of eight villages each. Half of the villages will be offered an enhanced package of HIV prevention care, including at-home HIV testing, the offer of circumcision to all uncircumcised men, and immediate antiretroviral treatment for everyone found to have HIV while the other eight will receive the current standard of care. PopART will start in 2012 and if all goes well should finish two years later.

➔ <http://bit.ly/n32FzK>



Edurant® (rilpivirine) receives positive opinion from the Committee for Medicinal Products for Human Use (CHMP) for use in treatment-naïve adults with HIV-1

PR Newswire | 23 September 2011

Rilpivirine is closer to being licensed in Europe

➔ <http://tinyurl.com/6ggn8oa>



Online gamers crack AIDS enzyme puzzle

AFP | 18 September 2011

Online gamers have achieved a feat beyond the realm of *Second Life* or *Dungeons and Dragons*: they have deciphered the structure of an enzyme of an AIDS-like virus that had thwarted scientists for a decade.

➔ <http://f24.my/nmxmzm>



UK: Gay blood donations ban likely to be lifted

BBC | 08 September 2011

The lifetime ban on blood donations by men who have sex with men is expected to be lifted in the UK.

➔ <http://bbc.in/oujRqz>

Saving face

GMFA's sexual health messaging service

Gay men's health charity, GMFA, is launching a new service to make telling sexual partners about STIs less daunting. *Gus Cairns* investigates.

You're at the GUM clinic for a check-up and have just been told you have a sexually transmitted infection (STI). You're ushered in to see the health adviser. Maybe you're embarrassed, maybe you're in shock from the news of an HIV diagnosis; either way, you only half-hear them saying "...it's a good idea to contact people you've had sex with recently and let them know. One of them infected you and may not know it, and others may have caught it; they'd want to get a check-up too."

You know this is the right thing to do, but it's scary.

So you reassure the adviser you'll contact the two people you've mentioned (she doesn't need to know about the other five), but know you won't. Clutching your prescription, you exit guiltily...

Which would be a pity. Contact tracing is one of the most efficient ways of detecting STIs. An audit at London's 56 Dean Street clinic in July 2010 found that the rate of HIV diagnosis in men who have sex with men (MSM) referred by a sexual contact was 23%, significantly higher than the estimated prevalence of HIV amongst MSM in London (about 10%).¹ Contact tracing may also be a good way of detecting recent infections.

Now there's an alternative. The gay men's health charity GMFA is piloting an STI notification scheme – the Sexual Health Messaging Service (SHMS).

SHMSs are a new idea in the UK, but launched in the US in 1999, after a sudden upsurge in syphilis cases in gay men in San Francisco. Public health workers found that the only means many men had of contacting partners was through their online profile name. A collaboration with a dating website enabled the scheme to

“The subject of partner notification will still have to be handled with skill and sensitivity, but this provides one more option.”

Donal Heath,
GMFA

contact 40% of the named partners of men diagnosed with syphilis.²

An SHMS does the partner notification for you. In GMFA's scheme, if you know your partner's email address, mobile number or profile name on one of four gay men's dating sites (Manhunt, Fitlads, Gaydar or Recon) and the dating app Bender, it can send an automated message that you've been diagnosed with an STI and they should get a check-up. You can be anonymous, or identify yourself but let the system decide what to say.

GMFA's Donal Heath found that: "A lot of people I talked to at first said 'You can't do that.'" But after he explained how it would work, many clinics and potential users came round.

GMFA's system "is a hybrid of two approaches". US services have varied from open-access systems not even requiring proof of diagnosis to ones where messaging is done by health advisers.

inSPOT (www.inspot.org) is an open-access messaging system developed in San Francisco in 2004, now covering the US and Canada. You could in theory use it anywhere, though there is only referral information for these countries.

It emails illustrated e-cards to your contacts, bearing the heading "From a concerned friend". A typical one reads: "*It's not what you brought to the party, it's what you left with. I left with an STI, you might have too. Get checked out soon*" and directs them to inSPOT. You can be on-record or anonymous.

A 2006 report³ showed that 16,000 e-cards were sent (over 75% anonymously) to 26,000 recipients in 2005; 38% of recipients sought more information.

The snag with inSPOT is that anyone can access it, so it lends itself to stag-night



pranks. Donal says: "Though inSPOT seems well used, a lot of bogus messages have been sent."

Another approach is a collaboration between clinics and the gay dating site Manhunt. Here there's no direct contact, even anonymous and net-filtered, between patient and recipient. Health advisers from clinics and voluntary organisations put up their own profile on the site and do the messaging when someone is diagnosed.

"It seems to have been quite successful; what's great about this approach is that recipients of messages can reply and ask questions of the health advisers," says Donal. But so far there's not a lot of evaluation data.

However, it's resource-heavy in these austere times. One problem is that this approach still relies on the patient telling the truth about who they've had sex with. There's also the matter of people's contact names. "It might feel OK to tell the adviser about Niceguy42, but Rawfukka42 less so."

GMFA has compromised between the two systems. You can only get on the system if you have a diagnosis and are given a unique ID and PIN; then you can contact people yourself by logging in to a secure website address – delivering messages as an email, an SMS text or a dating-website message. The four-stage process feels familiar to anyone who's shopped online.

You don't have to specify your STI diagnosis (people may be scared of disclosing the more serious STIs like HIV) but GMFA's own research found that recipients

were much more likely to seek help if they were told, and more likely to respond to named rather than anonymous informants.

Then you add the contact details of your sexual partners and specify the messaging method. Messages are tailored to the specific medium. Typing in a profile name will pull up the profile so you can check you're messaging the right person. You then preview your message, tick boxes to say you understand the terms and conditions – just like internet shopping – and send. You can also ask your clinic to do it for you.

Donal sends a test SMS to my phone. A couple of minutes later my phone pings and the following message arrives, from 'gmfaNoReply': "Someone you had sex with has been diagnosed with an STI. We advise you to get checked at a GU clinic."

The notification contains a reference number and a web address to contact a clinic for a fast-track service. This reference is anonymous but detects that someone has responded, enabling clinics to measure the effectiveness of contact tracing. You or your clinic can also use it to tell the system about a check-up and any treatment. If people don't respond, they get one reminder message.

The project is a pilot, provided by seven GUM clinics in London, Brighton, Sheffield and Manchester, and relatively few people have used it so far.

"There's only a proportion of people for whom the SHMS is the ideal thing," says Donal. "In some cases it's *not* the right thing; for instance, if you are diagnosed with HIV

and need to contact someone so they can get post-exposure prophylaxis (PEP)."

The websites have been cautious about their users' possible reaction to getting unsolicited STI warnings. On Gaydar and Recon you have to specifically allow messages from GMFA. Gaydar is about to launch a publicity drive about the messaging service and will have a button on your profile to allow messages. If the pilot is a success, there are plans to expand it.

The SHMS system can't make partner notification completely painless. One study of gay men, two-thirds of them with HIV, commented that several with HIV "felt too consumed by their own thoughts and fears to consider engaging in partner notification".⁴ Equally, as Donal says, "People say they want to be informed, but finding out that you might have been in contact with an STI can blind you... Partner notification is a no-brainer, but where STIs are concerned emotions still have the power to overthrow logic."

"The subject of partner notification will still have to be handled with skill and sensitivity," concludes Donal, "but this provides one more option."¹⁰

More information

You can find out more about the scheme at www.gmfa.org.uk/shms. (Note: this is NOT the weblink you'll be given if you are diagnosed.) Alternatively you can contact GMFA on 020 7738 6872 or email aboutgmfa@gmfa.org.uk.

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