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Gus Cairns

in this issue

A 'Happy New Spring' to you all and, if the winter seems never-ending and you didn't get a Valentine, first turn to the last article (page 18), which has some suggestions from Living Well about getting a little sunshine back into your life.

There's good news of an historic nature in this issue too. As you may have heard, for the first time doctors appear to have permanently cured someone of HIV infection (see page 14). This particular cure won't be possible for most people with HIV, but it shows it can be done. This is, potentially, such an important event that we've split the piece in two: this month you can hear about how they cured Timothy Ray Brown and what the challenges are to doing the same for others; next month, we look at promising leads being followed up in what is a new wave of optimism about curing HIV.

We allow ourselves to celebrate a bit of home-grown good news too, on page 10. Grants from the Big Lottery Fund and the Henry Smith Charity have enabled NAM to employ Jackie Ayugi as a Communities Engagement Officer. Her job is to help us develop closer ties with, and information better suited to, the African communities in the UK. This work has allowed us to produce a new resource, *HIV and African Communities in the UK*, which is out soon. Jackie writes about the similarities and differences between here and Kenya from her perspective as someone who knows a lot about the impact of HIV in both countries.

The main feature in this issue of *HTU* is about current and future changes to disability benefits (page 4). Losing benefit is not good news for anyone who may be relying on Incapacity Benefit and/or Disability Living Allowance to make ends meet. There's no getting round the fact that the toughening-up of the benefits system will result in some people with HIV needing to seek work with a nasty long gap in their CV and in a bad climate for jobhunting.

Yes, research shows repeatedly that working is good for you. Unemployed people generally die younger and are less happy than people with a job, and *HTU* intends to return to the subject of finding work later in the year.

Yet coming off benefits and entering the workplace after perhaps two decades or more of uncertain health and poor morale may feel like jumping from a plane without knowing if you have a parachute. The concern is that people with HIV will be thrust off benefit without any of the re-entry training that's supposed to be part of the new Employment and Support Allowance, and so far statistics seem to confirm this.

Criticism of the new Work Capability Assessment by HIV organisations has already led to changes that take more account of the impact of illnesses like HIV. That's why it's important to tell us about your experience of being assessed – see the article for more on how to let us know.



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

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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**NHS Pan-London HIV
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HIV prevention: does scaring people work?

A new 30-second HIV prevention advert,¹ from the New York City Health Department (NYC Health) and aimed at gay men, has caused a lot of controversy and divided HIV prevention advocates.

"It's never just HIV," it warns. "Having HIV puts you at higher risk of dozens of other diseases, even if you take medication." It then goes on to list three: osteoporosis, dementia and anal cancer. "Stay HIV-free: always use a condom," it ends.

Every fact in it is true and is something its target audience should probably be more aware of. But the controversy isn't about what the ad says, but the way it says it.

It starts with spooky music and the kind of voiceover heard in horror movie trailers. Pretty, yet troubled, young men eye each other suspiciously as the actor intones the text. This gives way to a set of frightening images. Someone's thigh bone snaps on the dance floor. A scan shows a brain shrinking to nothing (accompanied by a kind of frying sound). Then, introduced by the accelerating heartbeat that always precedes something really awful in a horror movie, there's a blink-and-you'll-hopefully-miss-it shot of what anal cancer really looks like (grim). Cue the young guys languishing in hospital beds.

Veteran US gay and HIV organisations GMHC and GLAAD quickly condemned the ad, calling it "sensationalistic and stigmatising". In a letter to the mayor, requesting the withdrawal of the ad, the city's HIV Health and Human Services Planning Council said that the ad implied young men were getting the conditions shown.² In fact, osteoporosis and dementia, though more common in people with HIV, are primarily conditions of age; anal cancer, while potentially lethal and a lot more common with HIV, is preventable with regular check-ups. In a press release, GMHC boss Marjorie Hill said that

"studies have shown that using scare tactics is not effective" in HIV prevention.³

Some prevention campaigners, however, thought the ad was great. Writer Larry Kramer, instigator behind the pioneering activist group ACT UP, applauded the ad. "Thank you," he said in an online response.⁴ "It's about time. This ad is honest and true and scary, all of which it should be. HIV is scary and all attempts to curtail it via lily-livered nicey-nicey 'prevention' tactics have failed." He went on to accuse Hill of lying when she said fear-based prevention campaigns did not work.

Clearly, if scary public health ads don't work, then an awful lot of money has been wasted on pictures of diseased lungs on cigarette packets. Trying to make people afraid of the negative health consequences of behaviour goes back to World War II VD ads and further.

And yet there's actually no terrifically strong evidence either way as to whether scaring people or, instead, giving them positive and empowering messages actually works better in HIV prevention. The most thorough review, conducted by two Yale University psychologists, dates from 2002.⁵ Its conclusion? Fear works...sometimes.

The authors pointed out that if you show someone a scary health-awareness ad, they can either react by avoiding the behaviour (good) or avoiding the fear (bad). Which way they will go tends to depend on whether they think they *can* avoid the negative consequences. So there are scary ads about cigarettes (because people can give up smoking) but not scary ads about Alzheimer's (because there's not a lot you can do about it).

The study showed that scary ads could increase HIV testing rates. But when it came to sexual risk behaviour, scare tactics only tended to have an effect on the people who were already 'low risk'. It might, for

instance, cause gay men who were already careful about HIV to avoid sex altogether.

But scare tactics don't work, they found, on people who are already 'high risk'; they only scare them further into being fatalistic. While citing ads with positive effects, it found some had negative ones, such as an Australian ad featuring HIV as the Grim Reaper. After that was aired, risk behaviour actually increased in gay men who'd seen it.

What people reporting high-risk sexual behaviour need instead are positive messages: you *can* adopt healthy behaviours, there *will* be positive consequences. Such 'gain-framed' messages have been found to work better – at reducing unprotected sex – for high-risk HIV-negative gay men than for HIV-positive ones.⁶

Scary ads like the New York one come from a frustration that HIV infection rates seem constant in gay men and so does risk-taking: in the last ten years, the regular UK Gay Men's Sex Surveys reveal, the proportion of gay men who sometimes don't use condoms has stayed stuck at around 50%.⁷ Gay men adopted condoms *en masse* in the late 1980s because there was something *really* scary around: a disease that was killing their friends young, and hideously. Gay men are unlikely to be that scared ever again.

We should continue to promote condoms, because they protect against HIV and other STIs. But we may be at saturation point when it comes to achieving increased use, and fear campaigns may have unintended, negative consequences. The answer is probably not 'condoms or else', but, as we learn more about the effects of PrEP, treatment as prevention and other measures, 'condoms plus'. ■

🔗 View the ad online at www.youtube.com/watch?v=dOANiu3YdJg

What's

disability living allowance

work-related activity group

tests Crackdown

healthcare professional

training

department of work and pensions

ot benefits

personal independence payment

challenge

allowance cuts in

employment and support allowance

down

an HTU guide



At least 40% of people with HIV are jobless,^{1,2} especially those who are long-term diagnosed. Most of them will be on Incapacity Benefit or other state-provided financial assistance such as Disability Living Allowance. The government says it wants to cut the number of people on health-related benefits by a quarter, but in practice is cutting more. *HTU* looks at what is happening to disability benefits and what is planned.

The crackdown on Incapacity Benefit

It had already started way before the last election; the current huge changes and cuts in disability and illness benefits are not entirely the Cameron/Clegg government's idea. In 2008, a report³ commissioned by the Department of Work and Pensions (DWP) said that 55% of the 4.7 million people of working age claiming a government benefit were doing so because they were sick or disabled, compared with 16% because they were unemployed.⁴ Lord Freud, now Minister for Welfare Reform, said that fewer than a third of people claiming Incapacity Benefit (IB) were literally incapable of work: the rest were either already fit for work or capable of being trained up for it.⁵

In October 2008 a new replacement for IB was introduced – Employment and Support Allowance (ESA). GP certification was replaced by a tough new medical assessment – the Work Capability Assessment (WCA) – conducted by independent healthcare professionals (HCPs) employed by a private company, Atos Origin, which is currently contracted to provide this service to the DWP until 2015 at a cost of £500 million, over seven years. DWP staff make the decision whether to award ESA but the opinion of the HCP is usually followed.

The emphasis of these assessments – 53,000 of them conducted per month – is on claimants' capabilities, scored according to a rigid 15-point scale for each type of activity. Can they feed themselves? Walk? Control their bowels? Lift things? Initiate activities without prompting?

The results were dramatic. A year after its start,⁶ *two-thirds* of new claimants applying for ESA were being initially turned down, despite the government

predicting beforehand that the refusal rate would be 20 to 25%.⁷ A review conducted by occupational health expert Malcolm Harrington⁸ found that the WCA was hard to understand, inflexible and clumsy. The initial application form, ESA1, ran to 52 pages and many people found it "difficult or impossible to complete". Forty per cent of claimants who appealed against a decision to refuse benefit were granted it. (The DWP has accepted Professor Harrington's recommendations and will be conducting five further, in-depth reviews on the WCA.)

Nonetheless, and allowing for the fact that 36% who applied for ESA dropped their claim, even after appeal nearly 40% of those applying for ESA were deemed 'fit for work', and therefore weren't eligible for any disability-related support in returning to work. Another 15% were placed in what is called the Work-Related Activity Group (WRAG) of recipients: this means that it was judged that with training and help they would be fit to work within a year. A mere 6% of applicants were placed in what is called the Support Group, meaning they were receiving ESA under similar conditions to the old IB. This compares with an 83% acceptance rate for IB.

The National AIDS Trust (NAT) published their own review of the experiences of ESA claimants with HIV.⁹ It found that the WCA had no allowance for key clinical indicators like CD4 count. It assumed that claimants' level of health was constant; there was, and still is, no capacity within the system for assessing fluctuating conditions such as fatigue, pain, continence or depression.

NAT also found some criteria hard to understand. For instance, a primary mental health criterion specifies that

claimants must have varying degrees of inability to "initiate or sustain any personal action...without requiring daily verbal prompting given by another person in the claimant's presence". This simply doesn't cover many psychological conditions.

NAT found that the Department for Work and Pensions (DWP) gave more weight to the Atos HCPs than to expert opinion, despite many HCPs appearing to be ignorant of HIV issues: NAT provides one example of a claimant who, saying she had chronic diarrhoea due to HIV drug side-effects, was challenged both by the assessing HCP and by the tribunal judge as to why, with a CD4 count over 350, she couldn't simply stop taking the pills.

It found that people were simply being deemed 'fit for work' instead of placed in the Work-Related Activity Group.

Sarah Radcliffe of NAT comments: "ESA could really benefit people living with HIV who want to...work, by providing individual support from a disability-specialist adviser. However, the assessment process sets the bar so high that many who would benefit the most are being found 'fit for work' and left to claim Jobseeker's Allowance instead."

Around the time ESA was implemented, the global and UK economies crashed, and the Conservative/Liberal Democrat coalition government is determined to use and extend the benefit changes now, to save money.

Spring 2011: migration time

If you're already on Incapacity Benefit (IB), none of this may have affected you yet. Well, it's about to: starting this April, and continuing till April 2014, people currently on IB will be assessed, using the same tests, to see if they are going to be

incapacity benefit

employment

The benefits, and how the government wants to trim them¹⁰

The government says that putting people on less generous benefits that are dependent on their showing willingness to work could save £3.4 billion. Add in proposed cuts of £1.8 billion to Housing Benefit, and we're talking nearly half of the £11 billion the government wants to trim from the total benefit budget. Much of the other half will be saved by pinning pension and benefit increases to the consumer price index, which excludes mortgage and rental costs.

Incapacity Benefit is intended to replace job income for people whose medical condition makes them unfit to work. It is paid at a rate of £91.40 a week for long-term claimants. Currently 2.6 million people of working age, or one in 15 of the total working-age population, claim IB: the largest group of economically inactive people, bar pensioners, in the population. This, along with ESA, costs £8.5 billion a year. The government wants to cut this budget by £2 billion, or 23.5%.

Employment and Support Allowance is payable at the same rate as IB for people in the Work-Related Activity Group, who are deemed to be able to resume or start work with support, and at slightly more (£96.85) for people in the Support Group, who are deemed unable to work. However, as explained above, it is intended to be considerably more difficult to claim and is paid at rates similar to Income Support (which is £64.30 a week for over-25s) while people are undergoing the assessment process. Contributions-based ESA will only be payable, under new proposals,

for one year for people who are in the WRAG and who are getting paid non-means-tested benefit from their National Insurance contributions. After this, it will only be paid on a means-tested basis; the government predicts that 40% of people on ESA will lose any entitlement to it at this point.

Disability Living Allowance is intended to pay for the additional costs of living with a disability; anyone who fulfils certain criteria can claim it, including people in work. At present, three million people claim it (60% of them of working age) at a cost of £12 billion a year. The majority of DLA claimants of working age are also on IB and/or Income Support, though a large minority are employed. NAT estimates that 7500 people with HIV, one in nine of those diagnosed, access DLA.

DLA is split into a 'care component' payable at three rates and a 'mobility component' payable at two rates. The maximum payable for people on the highest rates is £121.25 a week, with the lowest rates taken together coming to £37.90. At present, medical certification is provided by claimants' GPs, with medical inspection by the DWP only in some cases.

The government wants to cut a minimum of £1.4 billion, and up to £2.4 billion (20%), from the DLA budget and to this end is going to replace it with a benefit called the Personal Independence Payment (PIP), due to start in 2013 (see more in main piece).

DLA is a 'gateway' benefit to a lot of other disability allowances including travel passes and the disabled parking Blue Badge scheme. People who receive the higher mobility rate are also entitled to join the Motability scheme, which provides a car in lieu of that part of the allowance.

Housing Benefit (HB) is the single most expensive benefit apart from pensions, at a cost to the taxpayer of £21 billion a year. The government wants to save £1.8 billion from this budget. They will do this by placing a cap on benefit payable to people in private accommodation so that the maximum payable will cover just the lowest 30% of rents in the local area: previously this cap was 50%. This has been criticised as forcing people to move out of expensive areas like London and Brighton. This will disproportionately affect people with HIV, who are concentrated in such cities and attend clinics there.

One other important change, amongst others, is that people who have been on Jobseeker's Allowance for more than a year will lose 10% of their Housing Benefit.

The government eventually plans to unite all employment- and income-based allowances into a single allowance called **Universal Credit**. This will include ESA, Income Support, Jobseeker's Allowance, Housing Benefit and tax credits, but will exclude PIP, Carer's Allowance and some local benefits such as Council Tax Benefit.

ESA and support allowance

'migrated' to ESA. A lot of them are likely to lose this health-related benefit.

The most recent information, at time of going to press, is that the reassessment for ESA will start on 1 April 2011 and the government predicts that completing the process for all claimants will take at least five years.

If you are on IB and don't want to be thrust unceremoniously into the labour market, at least without some help, how do you make the most of your looming medical assessment?

There is some good news. Lobbying by HIV organisations, including NAT, has persuaded the DWP to include fatigue amongst the symptoms it assesses, for instance. But they report less success in persuading the DWP to develop ways of assessing intermittent conditions.

John O'Callaghan-Williamson is the founder of Tncell (www.tncell.org.uk), a grassroots HIV benefits and support website and blog, set up in January 2009 in the wake of a DLA review – due, he says, "to the fact there was no information readily accessible online".

He says: "There needs to be a standard client information toolkit for people with HIV. This would include simple advice like 'Complete your ESA50 forms [the questionnaire that forms part of the WCA] in pencil first, put them down for a few days, then review before completion'.

"Fluctuating conditions are going to be difficult to summarise on the form. I'd encourage people to complete either the 'additional information section' or submit additional pages (making sure you have your National Insurance number on all pages submitted), or ask if you can submit the relevant information in a different format [such as a comprehensive letter from your HIV consultant or, if you know them well, your GP] covering all the points the DWP needs."

disability living allowance

housing benefit

universal credit

He recommends avoiding online form submission and advises claimants to photocopy or scan all documents, to keep a diary of when forms need to be and were submitted, and to make notes of who they spoke to on the phone and when. In future, you will also be able to request that your Work Capability Assessment be recorded; this is being piloted at present.

Chris Morley is George House Trust's HIV Policy, Information and Publications Co-ordinator. He says: "There are also reviews of decisions, a pre-appeal stage, and sometimes asking for a review by the DWP rather than immediately appealing the decision is tactically better.

"In terms of your medical assessment, a good half of people report little medical HIV awareness, competence or much interest from the Atos Origin HCPs, though others report they were well considered. Take a friend for moral support and to remind you of what you need to say; bring written proof of your CD4 and viral load and ask that this be considered. Always appeal with the help of a benefits adviser and start the appeal within the time limit."

Above all, get help in at an early date, both from a benefits adviser and from your doctor. The requirements for medical evidence are both complex and specific and the best strategy is if you can get both professionals to collaborate, as your doctor will know how to describe symptoms accurately and a benefits adviser will know what the health assessors regard as relevant and irrelevant.

What's happening to DLA?

As we explain (opposite), a new benefit is also going to replace DLA, starting in 2013. We know that the new Personal Independence Payment (PIP) will be assessed in a similar way to ESA, which will in most cases involve a face-to-face meeting with a healthcare professional

contracted by the DWP, as with the ESA Work Capability Assessments.

At present, what will happen to DLA is in the form of proposals: the government has recently finished a public consultation but there are, as yet, few details of how PIP will work.¹¹ The consultation paper says that the cost of DLA has become unsustainable and that three times as many people as originally intended are claiming it. Claimants' entitlement to DLA is already subject to periodic review, but it is clear that the government intends to make it a great deal stricter. Reviews under the new PIP criteria are intended to start in 2013. Chancellor George Osborne said in the Budget¹² that the government wishes to save at least £1.4 billion from the DLA budget, mostly from people of working age.

The assessments will not only be stricter, but will be based on what a person can do rather than what help they need to do it. "The new assessment will focus on an individual's ability to carry out a range of key activities necessary to everyday life," the consultation paper says. This implies it will become much more like the ESA assessment, though focused on daily living rather than workplace tasks.

This could set up a confusing situation whereby claimants will be assessed for two different benefits, possibly by two different bodies, using similar but not identical criteria, and receive very different decisions.

"The government is exploring using the WCAs made for ESA to help decide PIP claims," says Chris Morley, "but the purposes of ESA and DLA/PIP are different. You couldn't call the PIP assessment a 'Work Capability Assessment' because it is intended to help with the extra costs of living with a disability, whether or not you are working: Stephen Hawking could get DLA."

John of T_HCell is concerned that any contradictions in the medical evidence submitted to ESA and DLA claims may trigger DLA reviews. In Scotland, WCAs and the old IB assessments have already been used to determine entitlement for DLA. Alison Lord, THT's Welfare Rights Officer for Scotland, says: "This is

Abbreviation guide

IB: Incapacity Benefit

ESA: Employment and Support Allowance, the replacement for Incapacity Benefit

DWP: Department for Work and Pensions

WCA: Work Capability Assessment, a procedure to determine eligibility for ESA

HCP: healthcare professional (employed to assess eligibility for ESA)

WRAG: Work-Related Activity Group: A majority of claimants awarded ESA are placed in this group, which offers back-to-work training and help and places limits on long-term ESA eligibility

DLA: Disability Living Allowance

PIP: Personal Independence Payment, proposed replacement for DLA, due to start in 2013

Help, advice and campaigning

For help and advice on benefits and signposting to local services: THT Direct: 0845 1221 200, 10am to 10pm weekdays, 12pm to 6pm at weekends. www.tht.org.uk

For blogs, peer advice, and news: T_HCell: <http://benefits.tcell.org.uk>

For help in north-west England: George House Trust: 0161 274 4499 or at www.gh.t.org.uk

For help and advice in East London: Positive East: 020 7791 2855 or at www.positiveeast.org.uk

For policy, news and campaigns: National AIDS Trust: www.nat.org.uk/Our-thinking/Every-day-issues/Benefits.aspx

For regular news updates and details of local HIV services: www.aidsmap.com

something we constantly have to challenge in DLA appeals, and there is already much case law about it."

Changes proposed for the new benefit include having a new 'daily living component' instead of the care component, with two rates rather than three. Only people with a long-term disability will be included: claimants will have to show that they have had their disability for at least six months and are likely to have it for at least another six, which will tend to, for instance, exclude people newly diagnosed with HIV, unless they have a previously diagnosed medical condition as well. DLA includes a list of conditions which automatically qualify people for the benefit such as kidney dialysis; the PIP consultation paper implies that this list will shrink and may vanish altogether, even for people with terminal diagnoses.

The consultation says everyone receiving PIP will be regularly reassessed for entitlement; this is not automatically the case at present for DLA, though there have been three review projects in the last four years to ensure correct payments, as well as random checks.

It also lays strong emphasis on the responsibility of the individual to report changes in their circumstances, including improvements in health, between reviews. "If an individual is found to have knowingly withheld information about a change in circumstance which would have resulted in a reduction in benefit, they will have to repay the amount claimed," the DLA consultation paper says. This is nothing new – DLA claimants have always had the responsibility to report changes in circumstances – and it is unknown whether the language of the paper implies a more rigorous process of fraud detection.

What you can do about it

Firstly, you might want to think about the advantages of going back to work. In the previous issue of *HTU*, we looked at the changes sweeping the HIV sector and ended the piece with Dr Mike Youle commenting that: "All my patients who take the jump into work have benefited hugely from it." Losing benefit may not be a disaster if it acts as a spur to re-skill.

Paul Clift, patient representative at King's College Hospital in south London comments: "For some people losing benefit may be a negative, but for others it can – and sometimes does – come as an encouragement to achieving a greater degree of self-realisation." *HTU* will be looking at the issues of going back to work in a later edition this year.

The first thing to do is get expert advice from the organisations quoted in this piece (contact details opposite).

If, after consultation, you are quite sure you are no longer going to be entitled to benefits and wish to avoid a Work Capability Assessment, you can give up a benefit voluntarily just by writing to the DWP and saying you wish to stop receiving it. However, you may be cutting yourself off from assistance (such as help getting back in to work), which you are in fact entitled to, and it may be better to notify a change of circumstances and proactively request a reassessment.

If you still need benefit, however, you don't have to sit there helpless while the benefit-reform juggernaut rolls over you.

If you receive notice of reassessment, don't panic! Follow the advice above, get expert advice on your situation, see a benefits adviser and your HIV specialist or GP, and document and make copies of everything you can. If possible, get your doctor and your benefits adviser to work together to describe and present your personal situation in a way that is clear and relevant for the health assessors.

Your experience may have useful lessons for other HIV-positive people and for the organisations supporting them as well. "Always share your experience with the HIV sector," says John. "Policy requires strong evidence to bring about a more equitable result for HIV-positive people. Work Capability Assessments are being annually reviewed and the more evidence we collect, the better the impact next year."

Lisa Power, head of policy at THT says: "People can do a whole range of things, depending on how confident they feel and which parts of the legislation affect them in particular.

"Firstly, if you get an unfair decision, you *must* challenge it, because challenges often work. Read stuff from the T_Hcell, THT, NAT and GHT websites; check your facts as well as talking from experience.

"You can write personally to your MP, or make an appointment to see them at their surgery, making sure it's one they do personally rather than a volunteer helper. Getting to talk directly to your MP has a lot of impact.

"You can join THT and be part of our campaigners' network. We will be running a number of campaigns related to the changes in benefits and legal aid." (See www.tht.org.uk/membership.)

NAT's new HIV Activists Network (see www.nat.org.uk/living-with-HIV/HIV-activists.aspx) will also be running campaigns relating to the changes in benefits.

The Disability Benefits Consortium (see www.disabilityalliance.org/dbc.htm) is a policy alliance of different disability groups which co-ordinates campaigns: groups like MIND and Parkinson's UK have also been instrumental in getting aspects of ESA changed, for instance.

NAM's editors will continue to cover these issues and the news pages of our website regularly contain relevant news items from other sources as well. Keep an eye on www.aidsmap.com/news for developments. If you have a story to share, do get in touch with us at info@nam.org.uk, using the subject line 'Information for HTU'. ■

Where I'm coming from...

I used to live and work in Kenya. Some of the key factors that contribute to the spread of HIV there include high unemployment and poverty, cultural and religious practice, failing health systems and a shortage of skilled healthcare workers. Political leaders have, at times, lacked the political will to ensure that everyone infected with HIV gets treatment.

Poverty, to a person living with HIV in Kenya, means lack of proper medical care and lack of proper diet, essential to withstand HIV. Most people there live on less than one US dollar a day, making it hard to prioritise health and medicine. Poverty makes living with HIV in Kenya difficult and challenging, and sometimes people are forced to sell their limited resources to seek medical care, which is not free at the point of delivery. Although antiretrovirals (ARVs) are free from government facilities, they are not always readily available so people are sometimes forced to resort to the private market.

Stress and depression are common amongst vulnerable groups, particularly young girls and women; some are driven to prostitution or take other sexual risks in order to sustain themselves.

Stigma and discrimination play a critical negative role in access to care.

Some people feel dirty, ashamed or guilty because of their HIV status. Many lead secretive lives, which may perpetuate the further spread of HIV, while some end up with alcohol and drug abuse problems.

In rural areas with poor infrastructure, people sometimes have to carry their ill relatives on bicycles, on their back or on wheelbarrows. Only a very few and scattered local health facilities have the specialist equipment needed for CD4 counts, viral loads or drug resistance tests.

My experience in my country gave me a passion to be involved in HIV prevention, care and support work. I came to England in 2008 and joined NAM in August 2010, taking on a new role with the organisation. At the heart of NAM's mission is a commitment to supporting all communities affected by HIV. Historically NAM's efforts to provide information for the African community were not always consistent or effective. Funding from the Big Lottery and the Henry Smith Charity enabled NAM to create a Communities Engagement Officer post, in order that NAM can better understand the information needs of these diverse groups and develop resources that are useful and relevant to them. This post represents a sustained commitment to this area of work. In

taking on this new role, I'm tasked with identifying and developing relationships with African communities and related organisations in London, working with them to make our information resources more known and available, and gathering feedback on their relevance, usefulness and acceptability within the African communities in the UK. Since coming to NAM I have found great motivation in working within an organisation that raises awareness, and supports those infected or affected by HIV.

The same but different

Africans in the UK are a diverse group. In the course of my work, I have met service users originally from 15 different sub-Saharan African countries ranging from South Africa to Somalia and Nigeria. My work has highlighted some similarities in issues in both Kenya and the UK.

Living with HIV is a challenge in both places, not only in terms of living with a long-term condition, but also overcoming socioeconomic barriers. These Africans are faced with a myriad of issues and challenges. The similarities that stand out include late diagnosis of HIV (often when HIV is already causing illness) and late treatment uptake. Africans in both countries are faced with high unemployment, housing problems and

from **Kenya** to



poverty, and experience fear of disclosure, stigma, discrimination and isolation.

Although, to a certain extent, there is still a strong support system from families and communities, both still hold the same cultural and religious beliefs, values, myths and misconceptions about HIV. During a discussion I attended with an HIV specialist and people living with HIV, one lady said: "I still believe that I was cursed by God, because since my husband died I had never had sex with another man." Some Africans pass blame to others when it comes to HIV and do not want to be associated directly with it. Over there and over here, people still find speaking openly about sexuality with children and peers shameful and taboo.

There are similar attitudes towards people in authority too. People in authority are regarded as godlike, and their decisions and actions never questioned. During one forum a lady commented: "Whenever I visit my HIV specialist I never ask questions or interrupt him. I know that everything that he says is true, so I don't need to read up on his decisions. After all, he is very educated and knows what he is doing. I just listen and comply."

The differences between Kenya and the UK were eye-opening though. I was

amazed at the services offered in London by African community organisations: drop-ins, lunches, complementary therapies, transport reimbursement, social and outdoor activities, volunteering, IT training, dancing, yoga... all geared towards getting the HIV-positive person moving forward with their lives and becoming more self-reliant. Community organisations here take people with HIV on as volunteers, in some cases enabling them to become permanent members of staff. One service user told me: "Because of the training I have received, such as power speaking and advocating for positive people, I am now a fully-fledged positive speaker attending parliament sessions; I've addressed MPs on policy issues affecting HIV-positive Africans living in London". I believe this is the way to move the HIV-positive African from isolation and help people give back to their own community. That's how a community develops and is able to tackle, as a community, its own issues.

I must applaud the treatment services here in the UK. Clearly the monitoring and regular care are superior to that in Kenya, but one thing I was especially impressed by is that patients can also be referred to mental health specialists and psychiatrists. This is something very rare in Kenya because psychiatrists are far too expensive to be consulted. UK clinics even

have home-delivery of patients' drugs. One support group participant told me it had given her peace of mind because she was afraid she would meet a friend or relative whilst carrying her drugs.

Yes, in both countries HIV services are under increasing pressure, and one issue facing both Kenyan and London clinics is trying to serve a large number of HIV-positive patients within a limited period of time. One lady commented: "I used to get a lot of support from my HIV specialist and sometimes could just call her when I was very sick and ask for advice. But now you only get to see your HIV specialist every three months."

Despite all the HIV-related services available in London, a significant number of Africans here are not able to fully benefit from them. Faced with language difficulties, housing problems, joblessness and poverty, uncertain immigration status and fear of stigma, many do not prioritise learning more about HIV and their health options.

Some people end up with jobs that they do not like or they are over-qualified for because qualifications obtained from their countries of origin are not always recognised by the British system. During one community support group I attended, a gentleman aired his frustrations. "I have a Masters degree in

Kennington

Jackie Ayugi, NAM's Communities Engagement Officer, reflects on her six months in post, and on the differences – and not-so-differences – between HIV in Kenya and London.

administration back home in Nigeria," he said, "but for the last ten years I have had no job that tallies with my qualification. I have been working in an old people's home for the last seven years to be able to pay my bills and send money home. I am just glad that my relatives back home do not know the kind of work I am doing; it's too shameful for a man of my status to be washing people's bodies."

He also had constant fear about his HIV status being revealed: "I have to make false excuses to be away from the office. I never say I am seeing the doctor, for fear my employer might think I am not well enough to work. He might ask me to do a medical examination, as he had done before with other African employees who kept missing work. All these lies make me sick."

Just under two-thirds of the half-a-million Africans living in the UK are first-generation migrants from Africa.¹ They tend to have strong attachment to values such as family dignity, honour, and respect for the authority of men and of elders. Open discussion of sexuality in public, or in mixed social settings is a taboo for most of them. For this reason, many African parents tend not to offer information about sex to their children. This responsibility passes (formally or informally) to others, including teachers. As a result, second-generation Africans in the UK may be left feeling confused by the silence at home regarding sex education, yet being taught in school about sex and relationships. The confusion is worsened by the sexual freedom displayed in the media – to which they have easy access – as well as in British culture.

Issues facing the African HIV sector here

My job has involved meeting many people, including HIV-positive Africans, HIV clinicians, social workers and community mobilisers, and attending conferences, meetings and peer-support group sessions for Africans with HIV in the UK. The more meetings I go to, the more certain issues stand out. These include:

Late diagnosis. Some Africans are reluctant to seek care or treatment due to fears of further stigmatisation; twice



Winnie Ssanyu-Sseruma, Meg Hillier MP, Elisabeth Crafer and Washington Kapapiro. Guest speakers at the African Health Policy Network conference in July 2010 – The Big African Society in the UK: Opportunities and Challenges. (Image courtesy of AHPN: www.ahpn.org)

as many non-pregnant women and more than twice as many heterosexual men are diagnosed with a CD4 count of under 200 compared to gay men, and most of these are sub-Saharan Africans.²

Some Africans who do seek treatment do so outside the borough where they live to reduce the chances of meeting friends, neighbours or relatives and, blaming themselves for their illness, try as much as possible to live very secretive lives. Some told me of gossip, distancing and harassment from friends, family and even previous partners after disclosing their HIV status.

Testing. For the same reasons, I found a lot of fear regarding HIV testing. People feared that if they went for an HIV test and were found positive they would be deported back to their countries of origin. Some service users lacked awareness about where to go for testing; some had little knowledge about HIV and how to prevent it; and some did not know who was eligible to receive HIV treatment in the UK without paying for it.

Safer sex. I found a lack of awareness of the implications of being in a serodiscordant relationship (where one partner has HIV and the other does not), and some people lacked the skills

they need to communicate openly with their sexual partners about HIV and to negotiate safer sex without threat of force. Some feared being criminalised if they infected another person.

Employment discrimination. Some Africans also highlighted problems with immigration and not being able to secure a job. Others thought that being HIV-positive meant they were not entitled to work. Some feared employment discrimination, hearing of cases where people might be required to have a medical check to secure a job. Some also feared that, once in employment, they might lose their jobs if their HIV status became known.

Other key issues. I've visited community organisations offering an impressive range of services. In terms of what organisations can do to support their service users better, certain other key issues also stood out from the discussions I have had with service users and service providers as things African community organisations can do to support their service users:

- Holding more awareness and prevention campaigns (for example, UK Africans, especially men, strikingly lack education on

the importance of consistent condom use).

- Providing more information on and education about available services.
- Creating better referral systems within and between organisations.
- Involving HIV-positive people in designing interventions to reduce stigma and discrimination and to help halt transmission.
- Working with faith leaders to reach wider audiences: training has been offered to some religious leaders (see *Faith in the Community*, in HTU 190).
- Developing more awareness of same-sex relationships, and tailoring their services to be more sensitive towards gay members of the African community.

Funding and the future

In my time so far as NAM's Communities Engagement Officer, I have found that African community organisations are hampered by a lack of infrastructure – both within the organisations and in allied services that might support and shore up their work – and a lack of funding. Some have been forced to merge while others, chasing grants, are broadening their area of services to general health, domestic violence, early pregnancy, female genital mutilation and other issues. Reductions in the number of paid skilled workers, due to budget cuts, sometimes lead to poor delivery of services.

When funding is provided, it is often only for certain boroughs and so organisations are often forced to turn away patients from other boroughs. The lead co-ordinator of one organisation told me: "Our charity used to serve clients from any borough but we now have no option but to send people back to their own boroughs. This I find difficult to deal with because some patients mention that they are afraid of been seen by their neighbours or friends at support groups."

I worry that the African HIV sector in the UK is under real threat of collapsing

or being overwhelmed. For the future benefit of the sector there needs to be better collaboration and more partnerships between organisations to reduce duplication of work. Although there are some efforts to unify them through initiatives such as the African Health Forum (AHF), the National African HIV Prevention Programme (NAHIP) and the African Health Policy Network (AHPN) a united voice is still needed to represent the African community. We need to share together our strength, expertise and experience.

One area in which African community organisations could make a big difference would be in helping to develop better communication and understanding between health professionals and community members, to be able to provide services that are more appropriate and relevant to the African communities needs.

The diverse African communities in London and throughout the UK need more information about HIV. For this to happen there needs to be better communication and trust between them and within them. I see my task as listening, learning and fostering this so-much needed trust in order to reduce the impact of HIV on people living with HIV. I believe it is time for Africans in the UK to take control of their own lives and health in order to make informed choices for their own future.

Those who access information resources such as those produced by NAM attest that they have benefited greatly in their overall quality of life and improved healthcare management. Their knowledge around adherence and health monitoring improves and they tend to cope better with their condition and their daily lives.

NAM is working in partnership with organisations and networks such as AHPN and NAHIP, and with other key African stakeholders, to guide UK Africans with HIV by utilising their strength, expertise and experience. We believe our support will contribute to building stronger African communities with more active citizens working together to tackle HIV and health problems.

New publication coming soon

I would also like to take this opportunity to introduce a forthcoming new resource, produced jointly by NAM and AHPN. In developing *HIV and African Communities in the UK*, we aim to provide a thorough mapping of existing HIV and related services for Africans in the UK, as well as to explore some of the key issues affecting people from these communities. We hope this resource will assist those working in the HIV sector, or with people of African origin, to find existing services, to identify gaps in provision, and to make better links between general health, HIV-specialist and non-medical organisations, to develop and improve services, referrals and support for African people living with HIV in the UK. ■

Contacts

To find out more about our publications, to send us feedback or to find out about services local to you, visit our website: www.aidsmap.com, email us at info@nam.org.uk or call us on 020 7840 0050.

For more information on the organisations mentioned in this article, visit their websites:

African Health Forum:
www.africanhealthforum.org.uk

African Health Policy Network:
www.ahpn.org

National African HIV Prevention Programme: www.nahip.org.uk

towards a cure for all

For the first time, someone has been cured of HIV infection. It was a brutal and expensive procedure but, as *Gus Cairns* reports, in the first of a two-part feature on curing HIV infection, it may signal the way to a cure for everyone.

The Berlin patient

On 13 December, NAM's website aidsmap.com published a news story¹ which, thanks largely to circulation on social media like Facebook and Twitter, received 50 times the usual hits.

It concerned the 'Berlin patient', who we now know as Timothy Ray Brown, an American living in Berlin. He will go down in history as the first person ever to be cured of HIV. His doctors had already published two papers on his case^{2,3} (see *HTU* issues 182 and 192) but it was only in a third paper, summarising late results, that they allowed themselves to say: "It is reasonable to conclude that cure of HIV infection has been achieved in this patient."⁴

The extraordinary explosion in interest hints that, however well we are doing on our antiretrovirals (ARVs), however normal a life we manage to live with HIV, most people still long to be rid of it.

Kill or cure

The cure Brown underwent was not one you'd wish on anyone, though. It only happened because he developed something else: leukaemia. This is cancer of the immune system, a wild overproliferation of the blood cells originating in the bone marrow. When Brown's chemotherapy failed and his leukaemia returned, his doctors decided on the last resort – a bone marrow transplant.

To do this, doctors destroy a large part of the immune system to kill off the cancerous cells. They then introduce a graft of bone marrow from a healthy donor who's as closely matched genetically as possible, so the host's body doesn't attack the new cells. These should then become the patient's new immune system.

What this also means, in a person with HIV, is that if the original immune system

is wiped out thoroughly enough, so are the CD4 cells that harbour the virus.

Brown's doctor, Gero Hütter, had an idea. He knew that about 1% of Caucasians have a genetic mutation called the delta-32 double-delete mutation. 'Double-delete' means they inherited a copy of the same defective gene from both parents. In these people, certain classes of immune cell lack a cell-membrane protein called CCR5.

The majority of human immunodeficiency viruses, and 99% of those transmitted, need to grab on to a CCR5 molecule in order to infect a cell: indeed one of the newer HIV drugs, maraviroc (*Celsentri*), works by blocking the CCR5 molecule.

People with this mutation are almost completely resistant to HIV infection and, more importantly in this case, to HIV proliferation: no CCR5 means no new cells to infect. So what would happen if Brown's immune system was replaced by one from a donor with no CCR5? Would his HIV disappear?

To cut to the chase, the answer was yes, and fast (for the full report see www.aidsmap.com/page/1577949). Despite being taken off ARVs the day before his bone marrow transplant, Brown only had one more detectable viral load before it disappeared entirely. Two months after his first transplant, all his bone marrow cells had become CCR5-negative. Five months after, his CD4 cells were acting as if there was no HIV in his body. At this point, however, the researchers could still find CCR5-expressing cells in his gut, so they hesitated to announce a cure. Two years later, they could find none anywhere, and the antibody responses which define whether someone is 'HIV-positive' or not were dwindling away to near-zero.

They also found no HIV in Brown's brain. They were certain of this because

17 months after his first transplant (he had to have a second at 13 months), Brown developed a brain impairment and had a brain biopsy. Hütter's team can't absolutely rule out this having been caused by a flare-up of HIV lurking in the brain, but the biopsy and analysis of Brown's cerebrospinal fluid revealed no evidence of HIV. They suggest it was probably due to immune deficiency caused by the transplant procedures and the chemotherapy. He suffered temporary blindness, memory problems and loss of muscular co-ordination.

Why it's hard to do

So we can't do for everyone as we did for Brown. Rowena Johnston is vice president and director of research for amfAR, the American Foundation for AIDS Research, which last year launched ARCHE – the amfAR Research Consortium on HIV Eradication,⁵ a network of researchers investigating a cure.

"With Brown they used a more intense and toxic regimen to prepare him for the transplant than is ever used in the United States," says Johnston. "But even if all the procedural details were worked out, you'd never find enough donors with the delta-32 mutation."

Something along the lines of Brown's cure has been discussed since the dawn of the epidemic. One research paper⁶ documented 32 attempts between 1982 and 1996 to eradicate HIV using bone marrow transplantation. In one in 1989,⁷ doctors succeeded in wiping out HIV from the T-cells of a man dying of non-Hodgkin's lymphoma within a month of a bone marrow transplant from a negative donor. He died two weeks later of the cancer, but autopsy specimens from brain, bone marrow, gut and other organs could find no HIV.

The reason HIV is so hard to eradicate is twofold. Firstly, a tiny proportion of

cells infected with HIV become 'resting memory' cells. These are cells whose job it is to stay secreted away in tissues like the brain, lymph nodes and gut, like sleeper cells in a resistance organisation, until a new infection comes along that resembles the one in which they were originally created.

Secondly, ARVs seem to block most, but not all, virus replication so there are still very low levels of virus replication in patients on treatment – its significance is an area of hot debate.

The problem with HIV is that one in every thousand to every million resting memory cells is a double agent. Instead of being equipped to fight HIV, it actually contains within its DNA, HIV's genetic code. As soon as you relax the police state enforced by ARVs, these cells set off a whole new wave of infection.

Cells that produce virus soon die, but putting people on ARVs means that the memory cells may never be activated. They can lurk in the body life-long, as a 'reservoir' of HIV.

If you take someone off ARVs for a short while, some reservoir cells die but other memory cells are infected, so you just replenish the reservoir. This is why structured treatment interruptions ('drug holidays') didn't work.

Steven Deeks is professor of medicine at the University of California and a veteran researcher into possible cures. He puts it this way: "The fundamental problem is that you're trying to stimulate the output of part of the immune system while dampening down another part."

What we need is some fiendishly clever way to get the HIV-infected lurking cells to come out of hiding and blow themselves up, while at the same time protecting uninfected cells from infection. They managed this with Brown – but only by replacing his immune system with someone else's.

Several other attempts to cure HIV didn't work either – although they may in the end contribute to a cure.

Very early treatment. If you know someone has acute HIV, within the first three weeks of infection, and give them ARVs right away, the number of infected

resting memory cells (the 'reservoir'), is 10 to 100 times less than in patients treated during chronic infection. In a few patients treated like this, after stopping ARVs the viral load stayed low.⁸ In another study, however, HIV returned 50 days after therapy in a patient treated early who only had one in every 1.7 billion resting memory cells infected.⁹ In any case, this strategy would only work for the small minority of people who test for HIV when they have acute infection.

Treatment intensification. If you added more drugs to someone's ARV regimen, would it drive their viral load down to a point below which there was too little HIV left for it to come back? A tall order if it requires fewer than one in two billion cells to be infected, but there were high hopes when the integrase inhibitor drug raltegravir (*Isentress*) came along, as it lowers viral load faster than other drugs. A trial found, however, that it had no significant effect on the residual replicating virus in the body.¹⁰ Similarly, maraviroc, the first drug of the CCR5 inhibitor class, failed to drive viral load down to any useful extent when added to a regimen¹¹ even though, as we have seen, CCR5 may hold the key to a cure.

Immune stimulation. You can use cytokines (naturally occurring immune modulators like IL-2 or IL-7) to activate resting cells to produce HIV and destroy themselves. But IL-2 had no effect on the number of resting infected cells,¹² and the type of cells it stimulated do not replace HIV-infected cells as a bone marrow transplant does. Also, IL-2 and IL-7 may cause resting infected cells to divide and replenish the reservoir.¹³ Immune stimulant drugs can be very toxic: many patients found IL-2 hard to tolerate and a previous study using IL-2 and another immune modifier called OKT-3 left some in intensive care.¹⁴

Therapeutic vaccine. Studies show that most of the minority of people who control HIV without drugs have CD8 cells (the ones that kill HIV-infected cells) with unusually high activity against HIV. You could try to enhance CD8 cell responses

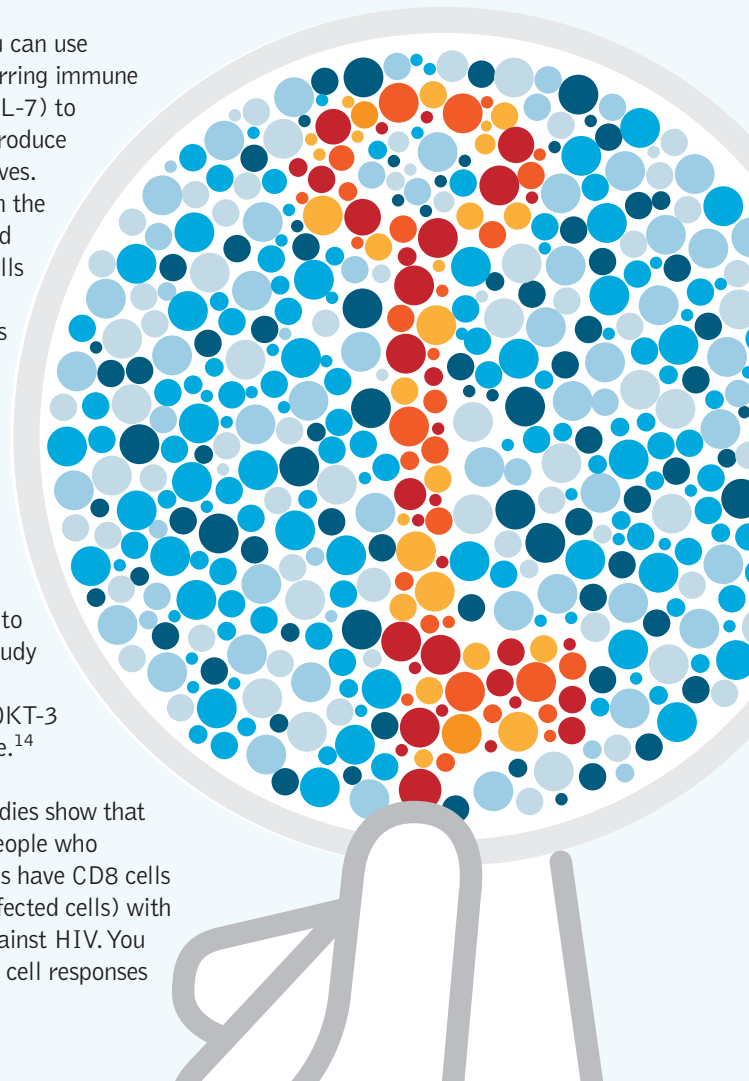
with a therapeutic vaccine, made from immune-stimulating bits of HIV. But therapeutic vaccines by themselves have no great record of success. They do seem to stimulate the anti-HIV activity of CD8 cells, but are ineffective at controlling HIV replication, probably because the virus can mutate to evade the surveillance of the CD8 cells.¹⁵ If it does, it can come back stronger than ever.¹⁶

And yet... the point about Timothy Ray Brown's cure is that, as Steven Deeks says, "For the first time ever, something worked."

Rowena Johnston adds: "What's important is that it focused attention that an HIV cure is possible and realistic and that this is a worthy research area to fund."

So how might we cure HIV infection in ways that are safer and less toxic than what happened to Brown? Clearly, if we knew, we'd be doing it. But researchers are engaged in the early stages of a number of promising strategies.

To find out what they are, you'll have to read part two next month... ■



news in brief



Treatment breaks

Treatment breaks permanently harm immune recovery

Patients who took breaks from treatment ('drug holidays') had substantially poorer CD4 count increases and substantially higher rates of death and AIDS, a study of 2700 patients from the Swiss HIV Cohort shows.¹

The poorer outcomes persisted over a seven-year period, even though the average cumulative time off HIV treatment was only nine months.

Patients started combination therapy between January 1996 and July 2008. They fell into three groups. Just over half of all patients had treatment interruptions ('interruptors'); 20% stayed on medication but had at least one viral load over 1000 copies/ml ('non-suppressors'); and 30% maintained a viral load under 1000 copies/ml ('suppressors').

Death rates differed dramatically. The annual death rate in interruptors was one death in every 51 patients, over five times higher than the annual rate in suppressors (one death in every 270 patients) and twice as high as non-suppressors (one death per 103 patients).

Over twice as many interruptors developed an AIDS-defining illness after starting treatment (10.5%) than suppressors (4.5%), and 75% more than non-suppressors (6%).

The longer the treatment break, the poorer the response: CD4 counts in people who had had cumulative time off therapy of more than 2.5 years actually declined over the seven-year period.

Cardiovascular disease

Increase in strokes in US HIV patients

A study from the US has found a 43% increase in the annual incidence of hospital admissions due to strokes in people with HIV between 1997 and 2006, compared to a 7% decline in the general population during that period. Hospital admissions for stroke rose from one in every 1250 HIV-positive patients per year to one in 555.¹ The study found that the absolute number of strokes in people with HIV went up 60% and the proportion of stroke patients who were HIV-positive went up 67%.

The likelihood of suffering a stroke, their severity, and the mortality rate due to them have all been declining since the 1950s in the general population; in contrast, these data do not suggest that strokes are declining in people with HIV.

HIV treatment

US treatment guidelines change

The latest US HIV treatment guidelines were published on 10 January.¹ These contain fewer and less contentious changes than the last set, which had a lack of consensus on whether to start treatment at CD4 counts over 500.

The updated guidelines extend treatment regardless of CD4 count to patients with tuberculosis, recommending that HIV treatment should be started within four to eight weeks of starting TB treatment, depending on CD4 count. The most radical change is a redefinition of 'virological failure' to mean a viral load of over 200 copies/ml. This is to rule out viral load 'blips' or variations in assays.

The only licensed antiretroviral drug in the CCR5 inhibitor class, maraviroc (*Selzentry* in the US, *Celsentri* in

Europe), is added to the list of drugs recommended for first-line use, though enough data on potential combinations only exist on use with *Combivir* (AZT/3TC) so far.

A resistance test for integrase inhibitors is recommended when failure of a regimen containing these drugs occurs. Finally the protease inhibitor saquinavir (*Invirase*) is downgraded to 'use with caution' after reports of heart irregularities in HIV-negative people.

HIV in the UK

HIV services to be commissioned nationally

It was announced on 21st December that the UK government proposed to commission HIV services nationally, instead of devolving commissioning to GPs, as is the case for most other conditions. A rearguard action by HIV organisations appears to have ensured that HIV remains a specialist area, allowing efficiencies to be made in the procurement of drugs and services.

It also proposes that genitourinary medicine (GUM) services are taken out of NHS management and commissioned by local authorities as part of their public health remit.

These proposals are out for consultation until 31st March.¹

Local authorities are likely to be legally required to provide open-access sexual health services, but with some flexibility about how they do so.

Lisa Power, head of policy at the Terrence Higgins Trust, said it was estimated open-access sexual health services would swallow around 20% of the whole public health budget.

For daily news reports and breaking stories from the major HIV conferences visit aidsmap.com

There are concerns that no money will be left for HIV and STI prevention and information activities, especially in competition with other public health priorities. Some national campaigns may be commissioned, but there is no specific mention of the national HIV-prevention programmes CHAPS and NAHIP.

Anti-HIV drugs

New 'non-suppressive' drug: first results

Seattle-based company Koronis has announced first human trial results for a drug, KP1461, that has, for HIV therapy, a radically different mode of action.¹ It does not stop HIV from replicating, but accelerates the rate at which HIV mutates. The idea is that runaway mutations will so degrade HIV's reproductive fitness that viral load will eventually start to fall anyway.

Tests on 80 volunteers have so far shown that KP1461 appears safe and produces the expected mutation rate. The next

trials will focus on whether this produces an eventual decrease in viral load, and to see how this drug could be combined with conventional suppressive approaches.

Gay men

Gay men's HIV risk remains high, but testing rates increase

The most recent UK Gay Men's Sex Survey (GMSS) report¹ reveals that over half of respondents had unprotected anal sex at least once in the previous year. It also finds a continued increase in the proportion of gay men who have tested for HIV.

Of 7461 men answering the 2008 GMSS, 54% had had unprotected anal sex at least once during the previous year. This is nothing new: over 50% of respondents who have anal sex have reported unprotected sex in every GMSS since 2000, from a low of 32% in 1994² and a study from Amsterdam has reported

almost exactly the same changes over time in unprotected anal sex in gay men.³

One in five HIV-negative men reported the riskiest sex for HIV acquisition (unprotected receptive anal sex with a partner of positive or unknown status). This was most common in men under 20. Over a quarter of HIV-positive men reported the riskiest sex for HIV transmission (taking the insertive role in unprotected anal sex with someone of negative or unknown status). Men in their 30s were most likely to take this risk.

HIV testing rates continue to rise, with 72% reporting having taken an HIV test at least once. However, only 46% of non-HIV-positive men reported having taken a test in the past year.

HIV prevalence varied significantly round the country, with 15% of men in London and north-west England reporting having HIV, but only 3.5% in the East Midlands and 1% in Northern Ireland.

references to all articles [continues on page nineteen]

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a winter of discontent?

New year can be difficult, with pressure to keep resolutions, the cold return to work and, this year, warnings about austerity ahead. But midwinter can be the perfect time to turn our lives around, says *Jane Common* from Living Well.

Big Ben, fireworks, and then, bang, bleak January. For many, the first two months of the year are hard. It's almost official now, with a dubious mathematical formula designed to calculate the most depressing day of the year: a toxic stew of cold, gloom, failure and debt, 'Blue Monday' (some say it was January 17th this year, some say January 24th) has been seized on by the media and by mental health charities, recognising a good opportunity to encourage people to make positive life decisions.

Who's singing the blues?

There's agreement that people living with HIV can be particularly susceptible to feelings of depression in January and February.

Dr Dimitri Spiliotis, a specialist psychologist in HIV and sexual health at Barts and the London NHS Trust, says: "Christmas has often been a challenging time, and many people living with HIV enter the new year feeling depressed and anxious. Newly diagnosed men and women could have just gone through the stress of disclosing their condition, or maybe they're finding the courage to do so.

"They might be feeling lonely and isolated – invitations can decrease as social networks adjust to the news. Another challenge is the weather. Feeling unwell and being blighted with colds and flu can cause stress and anxiety."

David Stuart, 43, diagnosed 24 years ago, agrees: "A lot of people don't have families they're bonded with, and live alone so, over the festive period, they can feel isolated.

"This sense of estrangement can stay with them and deepen; it's so easy to hibernate indoors, instead of going out and seeking social support. There are

often financial woes too, especially if people are on benefits and feel concerned about having gone into the red. I'm from Australia and the end of winter is a big blues time for me – I miss my family and the sun."

Beating the blues together

"People at this time of year should be compassionate with themselves rather than self-critical," says Dr Spiliotis. "Take it a bit easy and, instead of setting long-term goals, set up a short-term, realistic one. It's important too that people living with HIV do things that connect them with others, to ease feelings of isolation."

Anna Newent*, 30, was diagnosed with HIV in January 2010. Although she was devastated, she immediately told her friends what had happened.

"Everybody started crying," she remembers. "In a way, that made me stronger as I had to comfort them."

But, supportive though Anna's friends and family were, she found that she needed peer support. "I was frightened and confused. I thought HIV was an automatic death sentence," she says.

"And there was no one I could talk to as no one understood."

So Anna turned to a local HIV support service for advice – and, through them, found the strength that she needed. A year on, she's an outreach worker with them.

"This time of year is hard," Anna says. "My old group of friends are complaining about diets and going to the gym; I'm dealing with much bigger questions and challenges. But, because I've found a support group of people living with HIV, it improves my relationship with my old friends. I have

an outlet to talk about HIV, so I don't grow impatient with my old friends for not understanding."

Turning the blues into something positive: the Positive Self-Management Programme

For those living with HIV, social support from peers can be key. The Positive Self-Management Programme (PSMP), offered by Living Well, Body Positive North West and Terrence Higgins Trust, helps people cope with the day-to-day challenges of living with HIV in a supportive group setting, examining a whole host of issues.

Some are especially relevant at this time of year, such as techniques to deal with isolation. PSMP offers exercises for improving strength, nutritional advice and information on evaluating treatments. All these are often the subject of New Year's resolutions when, post-Christmas, people decide to take their health more seriously.

Even though David Stuart was diagnosed over 20 years ago, he still found becoming a PSMP facilitator last year an immensely fulfilling experience.

"I feel that I'm coping fine, [but] learning to be a facilitator reminded me that I can benefit from peer support – as everyone can," David says.

"For anyone considering PSMP, the new year is a great time to get involved. Yes, it can be a frightening period but it's also a time to address issues that might have held people back during the previous year. People might have decided that this year is going to be the one they start looking for a serious relationship. PSMP will help you prepare for that and the inevitable disclosure conversation.

Life coaching

So now is the perfect time to learn from your past and create a new future. Life coach Carole Gaskell, in her book *Transform Your Life*,¹ says: "Being low in late winter is common. But, rather than pushing your feelings to one side, allow yourself to acknowledge them so you can resolve them."

If you want to stick to those New Year's resolutions, life coaching could be the answer. It helps you identify your goals, work out a plan to stick to them and plot your progress. Clients at Living Well have used life coaching to establish relationships, build support networks – even relocate abroad.

So whatever you hope to achieve in 2011, life coaches and group facilitators can help.

Blue Monday...is a myth

Bad-science debunker Ben Goldacre investigated the Blue Monday equation and found it didn't stack up.² If you look at indicators of unhappiness, there's no consistent seasonal variation.

So winter may not be so bad after all. Even if we break our New Year's resolutions, the sobriety and determination forced on us by these dark days may end up making us happier and more confident. Happy 2011! ■

Living Well

Living Well empowers people to improve their quality of life through services such as PSMP, one-to-one and group life coaching and Stressless (workshops that help people focus and relax): www.livingwellcic.com; 020 3137 3373.

Terrence Higgins Trust's 'Learning Plus' PSMP:

www.tht.org.uk/howwecanhelpyou/livingwithhiv/learningplus

Body Positive North West's PSMP:

www.bpnw.org.uk/services/positive-self-management

Five quick mood-boosters

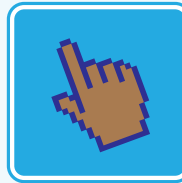
1. Get active.

Studies have shown that exercise can reduce anxiety, stress and depression³ – as well as all the other health benefits it has. Something that can make you healthier, make you feel better and help you sleep – what's not to like?



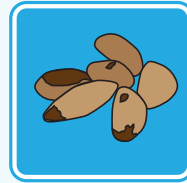
2. Log on to www.beatbluemonday.org.uk.

It has a list of the top ten ways to beat the winter blues and a blog where people have shared their own tips.



3. Nuts!

A handful of walnuts, brazils or seeds such as sunflower or pumpkin will give you a boost of the feel-good hormone serotonin as they're rich in selenium, which boosts its production.⁴



4. Get involved.

Phone a friend, arrange to go out, join a group or a club, take up a hobby, volunteer ... there are lots of ways you can help yourself to feel less isolated or bored.



5. Help someone else.

"The best way to cheer yourself up is to try to cheer somebody else up." So said Mark Twain, and the Church of England agrees, with tips for Lent including leaving money in someone else's shopping trolley or giving up your place in a queue for a stranger.



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