Working with your doctor
Finding the right one and making it work

PLUS Is HIV really that big a deal anymore?
In one study, 100 PLHIV with multiple drug resistance were each given a combination trio of the newest antiretrovirals: raltegravir, darunavir/r, and atazanavir/r. Most of those in the study had been on treatment for over 13 years and twenty of them had received an AIDS diagnosis in the past. At the start of the study their median CD4 counts were around 250, their lowest ever CD4 was 80 and their average viral load around 16,000. After 96 weeks, 90% of them maintained undetectable viral loads.

This is good news considering how much resistance they had shown at the start of the study. There were no major side effects (like changes in lipid levels) and they increased their CD4 count by an average of 180.

This study shows that people who are struggling to achieve an undetectable viral load may do better on this new regimen.

DOLUTEGRAVIR LOOKING GOOD AFTER INITIAL CONCERNS

The VIKING II study of the new-second-generation integrase inhibitor, dolutegravir, studied people who were very treatment experienced, who had viral loads greater than 1,000 copies and who had resistance to the integrase inhibitor, raltegravir.

Initial trials using dolutegravir once daily were unsuccessful, but when the dosing was increased to twice-daily it seemed to be more effective. Nearly all (96%) of the participants taking the drug achieved undetectable viral loads. These good results open the way for further trials to confirm whether it performs equally as well over a longer period.

GOOD NEWS FOR TREATING HCV AND HIV TOGETHER

Having hepatitis C (HCV) and HIV together can mean some complicated treatment choices.

However, the new HCV drug, telaprevir (TVR) appears to perform well in combination with pegylated-interferon (PR) and HIV meds.

The reported study had three separate arms: TVR+PR without HIV meds; TVR+PR+Atirpla; and TVR+PR+Truvada+atazanavir/r. All these drug combinations were compared to standard treatment (PR) without TVR.

The people in the study had HCV viral loads greater than 600,000 and 10% of them had advanced liver fibrosis.

TVR was taken every eight hours with food and dosed for the first 12 weeks of HCV treatment (which normally continues for another 36 weeks to achieve clearance of HCV). But by week 4, 70% of people taking TVR had undetectable HCV. This is known as a rapid virological response (RVR) and indicates that there’s a 90% probability of these people clearing their HCV.

More of those also taking Atripla (which contains enfuvirtab) than those taking atazanavir achieved undetectable HCV (75% compared to 64%). Only 14% of people who didn’t take any TVR (just the standard treatment PR) achieved undetectable HCV. What’s more, taking HCV treatment along with HIV antiretrovirals appeared not to affect how well their HIV was controlled.

These are excellent results and hold out lots of promise for better treatment for people with both HIV and HCV.

TESAMORELIN REDUCES GUT FAT, MAY IMPROVE BONE MASS

A drug approved late last year in the US to treat excess ‘gut’ fat or visceral adipose tissue (VAT) appears to also improve bone mass. Many PLHIV experience the former as a symptom of HIV-related lipodystrophy and many of us also have an increased risk of bone mass loss (sometimes called osteopenia).

Tesamorelin (Egrifta) stimulates the pituitary gland to release growth hormone which can reduce visceral fat. In a trial it was found to reduce VAT by 18% over 52 weeks.

The study followed 412 people receiving HIV treatment for 26 weeks and found that tesamorelin increased bone tissue production as measured by some key blood markers. This is an interesting finding, which may lead to further research on the drug’s action in stimulating bone mass increases.
Research conducted by the Kirby Institute at UNSW (formerly the National Centre in HIV Epidemiology and Clinical Research) has shown that the annual incidence of anal cancer in Australia has increased by almost 50% in the last 20 years. What’s more, the rate of increase has been twice as fast for men, about 20 times higher for gay men and even higher for those with HIV. In fact, overseas data suggests that up to one in a 1000 positive gay men per year may develop the disease.

More than 80% of anal cancer is caused by a type of human papillomavirus, HPV16, which is preventable by the currently available HPV vaccines (Gardasil or Cervarix) that are currently offered for free in Australia to girls and young women to prevent cervical cancer. The vaccines are most effective when given to children, before the start of sexual activity, but unfortunately they are not funded for male vaccination.

Last month, the Pharmaceutical Benefits Advisory Committee (PBAC) rejected an application by the vaccine’s manufacturer, CSL, to fund vaccination coverage for school-aged boys. According to minutes from the March meeting, the PBAC rejected the submission because of unacceptably high and uncertain cost-effectiveness. It is likely that a new application for funding of vaccination of boys will be submitted later this year.

HPV is easily transmitted through sexual contact. Studies conducted by the Kirby Institute have shown that almost all gay men in Sydney have anal infection with this virus, and about 30% carry the particular high-risk type, HPV16, in the anus.

Anal cancer is mostly asymptomatic in its early, easily treatable stages. In the later stages the chance of survival is poor because the disease has already spread. It is hoped that screening may detect precancerous lesions which can be treated and thus prevent anal cancer, or allow the detection of anal cancer at its very early stages when survival rate is very high.

At this time, there are no guidelines as to who should be screened and how often. There are many questioned to be answered before routine anal cancer screening can be recommended.

The SPANC study, currently underway at the Kirby Institute and St Vincent’s Hospital in Sydney aims to answer these questions. So far, close to 100 HIV positive and negative gay men have joined the three-year-long cohort study. But more are needed.

Information, including how to participate, can be found at the study website: www.spanc.org.au

Anal cancer screening needed

Young on DSP encouraged to work

Wayne Swan recently unveiled a budget with welfare-to-work forming the centrepiece of his agenda and, as suspected, disability welfare-to-work forming the final approval in Budget. The sponsor company of Sculptra in Australia, Sanofi-Aventis, has finally had confirmation from Medicare that the two item numbers for the injecting procedure have been approved.

The company will be sending advice to relevant doctors shortly, but the expectation is that the listing will be from 1 July. This means that there will now be a heavy subsidy towards the price charged by a number of doctors, with some agreeing to claim only the rebate amount. Good news for the many PLHIV who have been waiting on this outcome for some time.

Sculptra is a cosmetic filler used to treat facial lipoatrophy caused by HIV treatments. The product was made a Medicare item in 2009 but subsidising the cost of injecting the product has taken till now to receive final approval.

Sculpta, at last!

Capsaicin patch relieves neuropathy

The pooled results of two clinical trials suggest that a skin patch with the chilli pepper-derived chemical capsaicin can relieve HIV-related neuropathy pain by about 30 percent.

Chilli peppers and mustards have been used for centuries in topical balms to treat chronic pain. Only during the past few decades, however, have scientists figured out how capsaicin — the chemical that gives chillies their pungency — works as an analgesic: It depletes a neurochemical called substance P responsible for transmitting pain.

The three-month improvement in neuropathy pain doesn’t come without side effects, however.

Genotype tests get final approval in Budget

Good news from this year’s Budget is the decision to list the HIV genotype test as a funded Medicare item.

Approval of the test, which measures drug resistance, has been promoted long and hard by both community and clinical groups as a vital tool in Australia’s HIV treatment arsenal.

NAPWA, in partnership with ASHM and the Kirby Institute, needed to file a submission without any commercial sponsor, and the complex process for considerations and assessments has taken nearly a decade to reach this conclusion.

Several drug manufacturers provided funds to support the group’s submission costs, highlighting the fact that partnership and resilience are the hallmarks of Australian HIV advocacy.
Once-daily nevirapine approved in the US

The US Food and Drug Administration have approved a new once-daily extended release formulation of nevirapine, known as Viramune XR. The new 400mg tablet will be an alternative to the current twice-daily dosing schedule, and can be taken without or without food.

The 48-week result, presented last year at the 18th International AIDS Conference, showed no significant difference in rates of viral suppression or adverse events between the two formulations.

Nevirapine is not suitable as first-line therapy in men with CD4 counts above 400, or women with counts above 250, due to the increased risk of hepatotoxicity, unless the benefit of treatment with the drug is considered to outweigh this risk.

Prolonged process for approved drugs

The government caused turmoil by announcing in February that all new medicines will now require cabinet approval before they can be subsidised on the PBS.

At the time, cabinet deferred subsidising seven new medicines and in April the government’s expert advisory body, PBAC, recommended a further six receive a subsidy. Cabinet will now have to consider these for approval or also defer them indefinitely.

The pharmaceutical industry believes the new process breaches a memorandum of understanding between it and the Commonwealth, and companies say they will have to reconsider marketing new drugs here as a result.

NAPWA’s Jo Watson believes the decision should be reconsidered.

‘The PBS listing process has served us well,’ she said ‘and has ensured a transparent and cost-effective approach to delivering the best medicines to Australian patients.’

NAPWA and many other health consumer groups believe this government decision will have an adverse effect on the health of individuals.

Federal health minister Nicola Roxon is considering allowing patient groups a say on medicine subsidies but argues that ultimately it is the government’s responsibility to decide whether or not to list a drug, taking into account fiscal circumstances.

The Consumer Health Forum CEO, Carol Bennett, spoke for many when she noted: ‘It is hard to believe that these decisions about people’s health reside best in the hands of our politicians.’

Tenoforv may reduce inflammation

It appears that the antiretroviral NRTI tenofovir (found in Viread, Truvada and Atripla) may also have a calming effect on the immune system and provide protection against infections other than HIV.

Laboratory tests have found that tenofovir offered two types of protection. First, it suppressed the production of inflammatory messengers, such as Interleukin (IL-8). Tenofovir also appeared to keep the balance of IL-12 and IL-10 stable. The drug enhanced the IL-12 levels, thus increasing their ability to respond to other infectious pathogens, and it kept IL-10 levels low, thus keeping the body from putting the brakes on the immune response.

Further research will be needed to determine whether these findings actually translate into a clinical benefit in people’s bodies.

Concerns over hepatitis C outbreak

Monitoring by the Victorian Department of Health has revealed that between May 2010 and April 2011, 37 HIV positive gay men were diagnosed with hepatitis C (HCV) in the state, a significant increase on previous years. In at least 19 of these cases, sexual transmission of HCV was suspected by the diagnosing physician.

People Living with HIV/ AIDS Victoria has joined with other community organisations to alert positive gay men to the risk of HCV.

‘We want people with HIV to know that sexual transmission of hep C does occur and it is more common in positive people. The risk of sexual transmission is higher for those who engage in group sex, fisting, use of sex toys and non-injected drugs, as well as for those with some sexually transmissible infections (STIs),’ said PLWHA Victoria President Paul Kidd.

While the majority of cases of HCV infection have been linked to injecting drug use and other forms of blood-to-blood contact, reported cases of sexual transmission are increasing. Clusters of cases of apparently sexually transmitted hep C among HIV positive gay men have recently been reported in London, France and the Netherlands.

Hep C is a serious health challenge for anyone, especially if you also have HIV. The best way to reduce the risk of contracting or transmitting hep C is to use condoms and water-based lube, latex gloves when fisting, and to avoid sharing sex toys.

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PositiveLiving | 4 | WINTER 2011
We have known for some time that HAART reduces the likelihood of transmitting HIV, and the recent results from a large clinical trial seem to confirm the fact . . . in heterosexual couples, at least. The study showed that when the positive partner in a serodiscordant relationship is on treatment, the risk of transmission is reduced by 96%, compared to the risk when treatment has been deferred. The HPTN 052 trial, begun in April 2005, was conducted at 13 sites in nine countries and enrolled 1,763 serodiscordant couples, 97% of which were heterosexual. All the positive partners had CD4 counts between 350 and 550 at the beginning of the study and included 890 men and 873 women. Half of those received treatment immediately, and half had treatment deferred until their CD4 count fell below 350 or he or she developed an AIDS-defining complication. Everyone receiving counselling on safe sex, free condoms and treatment for any sexually transmitted diseases that occurred during the study. When the monitoring committee examined the interim results in April, it found 39 new HIV infections. Twenty-eight of the infections clearly came from the person’s partner (based on genetic analysis of the virus) and 27 of these were in the group where treatment with antiretroviral drugs had been deferred. While the results are positive, there is now even more urgency to test this approach in a gay male population. ‘Gay men still make up the vast majority of people living with HIV in Australia and we look forward to seeing further research focusing on this population,’ said Jo Watson, NAPWA’s Executive Director. HIV treatments are specifically for people living with HIV to best manage their own personal health, but NAPWA continues to support other ongoing research about the potential benefits of treatments across diverse populations.

Drugs linked to heart risks, minimal

A Canadian study has associated abacavir, efavirenz, lopinavir and ritonavir with an increased risk of heart attack. The research also showed that patients with HIV have twice the risk of heart attack compared to matched HIV negative controls.

However, the investigators were eager to place these findings into context. They emphasised that the level of increased risk associated with each of these drugs is minimal compared to traditional risk factors such as smoking, family history, hypertension, diabetes and high lipids.

The researchers were surprised by the association with efavirenz, and commented that ‘although efavirenz is known to have a small lipid effect, no other biological mechanism can be offered at this time to explain this finding.’ They suggest that the finding could be because patients who are perceived to have an increased risk of cardiovascular disease are often treated with efavirenz.

Moreover, a recent meta-analysis of randomised studies has showed that therapy with one of these drugs – abacavir (Ziagen, also in the combination pills Kivexa and Trizivir) – did not increase the risk of heart attack.

Numerous studies have found that HIV has a negative influence on heart health. Some studies have found an increased risk of heart attacks, while others have documented blood vessel dysfunction. Not all studies have consistently confirmed that HIV causes heart troubles, however, and since many people with HIV have other known risk factors – such as smoking, diabetes and histories of drug use – experts are still trying to pinpoint the role HIV plays in cardiovascular dysfunction.

Until we know more, our best defence is a combination of the following: a balanced diet and exercise; smoking cessation; and taking supplements including fish oil for inflammation and reduction of blood lipids, vitamin D, vitamin B complex or a multivitamin with lots of B (to promote healthy cholesterol) plus anulin-based fibre. Oh, yes . . . and keep taking your HIV meds.

New hope for vaccine

Melbourne University researchers have identified antibodies in a breakthrough that brings closer the hope of developing an effective vaccine.

A study of 100 people with HIV, recruited from The Alfred Hospital and the Melbourne Sexual Health Centre, has shown that antibodies were so successful in suppressing the virus that it had to mutate around them. The discovery has raised hope that the antibodies, if introduced to healthy people, could prevent the virus taking hold.

‘We’ve been working on this problem for over 10 years,’ says Stephen Kent, of Melbourne University’s Department of Microbiology and Immunology. ‘The vaccines we’ve tried in the past have induced some immune responses but have not been very effective.’

He thinks they now know why. They were inducing the wrong immune responses.

Professor Kent and his team studied blood samples of HIV positive people and analysed how the antibodies called antibody-dependent cellular cytotoxicity targeted the virus. They were surprised to see the virus mutating around these antibodies. ‘As a result,’ he says, ‘the antibody isn’t entirely successful in getting rid of the virus in people with HIV.’

‘But if you were to have these antibodies before you caught the virus and it started replicating – giving the immune system a head start – we think it would prevent the virus taking hold at all.’

UN sets ambitious goal on new infections

The United Nations has set an ambitious goal of no new HIV infections or AIDS-related deaths by 2030.

The UN Secretary General’s 2011 Report on AIDS highlights new strategies in the fight against the disease and urges universal access to treatment, care, and support, and an end to discrimination.

The report notes an overall global decline in HIV infections, but cautioned against complacency as every day about 7,000 people, including 1,000 children, become infected.

This number has declined by 19% in the decade before December 2009, with at least 33 countries experiencing a decline in HIV incidence of at least 25%. But despite the overall decline, the number of people infected is increasing in Eastern Europe, Central Asia, North Africa, and the Middle East and parts of Asia. Globally, infection rates are falling, said Charles Gilks, head of the UNAIDS program in India. Mother-to-child transmission is also declining while treatment coverage is increasing, he said.

In the pipeline are promising trials involving a vaginal microbicide and the use of PreExposure Prophylaxis (PrEP) as prevention against the virus. The appeal is the third major initiative on AIDS to be launched by the United Nations in the past decade. The two previous ones were the ‘Three by Five’ goal of providing three million people with AIDS drugs by the end of 2005, and the objective of universal access to these drugs by the end of 2010. Both initiatives fell wide of their mark although the UN says they generated momentum and building medical infrastructure in poor countries.

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Choosing your doctor

Who you see for your healthcare is often quite dependent on where you live. Some of us are spoiled for choice because we have many options available.

Some people see a GP for most things but get their HIV care from physicians who are specialists in infectious diseases or sexual health and are based in hospitals or sexual health clinics. Others are more comfortable having one doctor to look after all their health care and usually have a GP who is also an HIV specialist.

No matter what their specialty, you get the best HIV care from a practitioner who has experience treating other PLHIV. As a guide, if you’re seeing a doctor for the first time, ask them how many patients with HIV they have treated and how many they currently see.

Now that we are living longer with HIV, it’s important that all our health issues are being addressed and this is often best done through a GP. If your GP isn’t an HIV specialist, make sure they regularly get expert advice on HIV issues.

The Australasian Society for HIV Medicine (ASHM) provides both types of GP training — for those who specialise and prescribe HIV treatments as well as for those who are happy to share your care with an HIV specialist.

Finding things in common

Treating HIV is pretty complicated. There are choices to consider at every stage of the disease, so it’s best if you work together as a team. If you and your doctor have the same approach to your health care, it will be easier to choose and stick to a treatment plan and you are less likely to come away from appointments feeling confused or disappointed.

Some doctors are conservative. They prefer ‘tried and true’ methods. Others are more aggressive and are willing to try newer treatments. Some are optimistic by nature, and focus on the hopeful or positive side when they talk about test results or future prospects. Others are realistic. Some are pessimistic.

Some doctors are comfortable also suggesting complementary therapies such as massage, acupuncture or herbs. Others stick strictly to Western medicine. If you want a lot of emotional support, you probably won’t be comfortable with someone who only talks about test results. The more comfortable you are with your doctor’s approach to HIV treatments, the easier it will be for you to get the kind of health care you want.

Many people do better when they take an active role in planning their own health care. These people often do a lot of reading on their own, bring information with them and work together to make health care decisions.

Others are more comfortable with the doctor making important decisions.

Ask other people with HIV about the relationships they have with their doctors.

Decide how you want to work with your provider. See if that fits with the way the doctor likes to work with you.

Changing providers

Over time your health care needs might change. So might your ideas about treatment. Although it may be safer to stay with a doctor who has known you for a while, you always have the right to change to another. Or to seek a second opinion.

If you are shopping around, be honest with the doctor/s you are seeing about what you are doing. You don’t have to commit to anyone on your first visit.

Talk frankly with them about your health, experiences with HIV and treatments to date. You may find they have a refreshing approach to a health issue that you have been struggling with for some time.

Baseline information

It’s important to make sure your doctor has all the information they need to give you the best advice. This starts with your past medical records, which may have to be transferred from another office. This can usually be arranged from your new clinic. Sometimes all records are transferred, but most often just a summary is provided. When you start working with a new doctor, they will probably do a lot of tests to collect baseline information.

Tell them how you feel about taking medication, and about living with HIV. Some people don’t mind taking a lot of pills. Others prefer to take as few as possible. How willing are you to make lifestyle changes? Are you prepared to change your diet or the amount of exercise you do? Your doctor should also know about other treatments you are using or want to try, including non-medical ones.

Be honest about your lifestyle. Eating, sleeping and receptionist) how long it usually takes to get an appointment and their contingency plans if your need is urgent. Find out how well they usually stay on schedule during the day. Is time important to you or are you willing to wait?

Remember, you don’t need an HIV specialist to help you with most of your health care needs. If a good HIV provider is hard to find, or if it’s hard to get an appointment, use a GP for your general health care. Just be sure they know what treatments you are on; and when you are dealing with HIV issues that you see an experienced HIV provider, or one who consults with an expert.

Confidentiality

Many people are very concerned about keeping their HIV status private. This is often the case in smaller communities. You might when they arrived. There are ways to prepare for your appointments and techniques to get the most out of them.

Getting the most from every visit

Doctors’ appointments are usually only 10-15 minutes long and people can leave with more questions than
Preventing in advance

What’s been going on since your last appointment? Write a list to use during your appointment. Be sure to include:

- New health problems or symptoms, related to HIV or not. How long have they been going on? How serious are they? Don’t ignore feeling tired, not sleeping well, trouble concentrating, stomach problems or emotional issues like anxiety.
- Major changes in your living situation, including employment, relationships, non-HIV health issues, and so on.
- New or increasing side effects or reactions to your medications. Again, for how long? How serious are they?

Don’t be a hero

If you’re having a hard time, taking your treatments, tell them. Perhaps a side effect that didn’t bother you before is getting impossible to deal with. Maybe you’d do better with a different regimen altogether.

You may not have time to discuss all of these, so focus on the most important ones. You can leave a note with the doctor to let them know about the items you didn’t get to discuss.

Bring information with you to help your doctor. This might include pill bottles for all of the medications and supplements you’re taking, or test results from other health care providers.

If you have a lot to discuss, book a longer appointment.

Get your questions answered

When you walk into your appointment, you should know the most important questions that you want answered before you leave. It’s a good idea to write these down. This will help you organise your thoughts and make it easier to know if you’re missing something.

Take your list into your appointment. Tell the doctor about your questions. If the appointment is ending and you don’t have your answers, ask again. Doctors have to manage their time, but you also have to manage your appointment time. You might only have fifteen minutes every few months, so make the most of it.

MEDICATIONS: If a new drug gets prescribed, make sure you leave with information on exactly how to take it. What’s the dosage? How often? Does it matter if you take it with food, or on an empty stomach? Does it have to be kept in the refrigerator?

Know what side effects to expect. Are there things you can do at home to deal with them? When should you call the office if the side effects are too severe or go on for too long?

TESTS: If your doctor wants you to have some medical tests, be sure you understand what the test results are supposed to show and what your doctor will do with them. Is there a better time of day to take the test? Do you need to fast beforehand? When you discuss the test results, ask again if you’re not sure what the test is for and what the results mean.

Take the answers with you

There’s usually a lot of information going quickly back and forth during a health care appointment. Be sure to take the important information home with you.

Some of these tips might work for you:

- Take notes during the appointment.
- Ask for written material about medications, side effects, and illnesses.
- Talk to someone. See if there’s anyone in the office you can talk to, like a nurse, to go over what happened in your appointment. If you see a counsellor, it’s often a good idea to make an appointment to see them on the same day you have a doctor’s appointment.
- Bring a friend with you to the appointment. Let them know what you want to get out of the session. You could give them a copy of your questions, so they can make sure they all get answered. They can also pay attention to what the doctor says. That way you can sit down together after the appointment and be sure you didn’t miss anything.

Finding an HIV s100 prescriber in your area

Whether you are on treatment or not, it is important to be monitored regularly (usually every three months). Antiretroviral drugs can only be prescribed in Australia by doctors who work in large public hospitals or in public sexual health clinics; or by specially trained, community-based GPs known as HIV s100 prescribers.

Some clinics are free and some are not. Make sure you ask about any costs involved when you first ring up to make an appointment.

Portions of this article have been drawn, with thanks, from resources produced by The Body and AIDS InfoNet.
‘So, what’s the big deal about having HIV?’

This is what a friend asked David Menadue, recently.

OU LOOK OKAY. It’s a manageable condition, now,’ he said. ‘Sometimes I think you guys make too much fuss about it all.’

This is what my 35-year-old friend Troy said to me the other day. How do I respond to this sort of thing? How do we counter the growing perception among HIV negative guys that getting HIV is not something to worry about?

Most of us know people who have gone through hell and back when they were newly diagnosed. But apparently, their experience is not enough of a warning to persuade people like Troy to avoid HIV and to regularly use condoms.

Perhaps it’s understandable. People probably look at our outward appearances these days and think our lives are rosy and uncomplicated. They don’t see the gaunt faces, skinny arms and legs and other telltale signs so much anymore. And many of us have been doing well with very few health problems for many years.

I decided to ask four positive people, with a range of years’ experiences living with the virus what they feel about the statement that having HIV is no big deal, anymore.

• Phil.

Years living with HIV: 4

A recent partner who had contracted Chlamydia suggested Phil might want to get himself checked out. He was on holiday in Sydney at the time so he went to a local GP practice and they did an array of tests including HIV.

Phil wasn’t all that surprised when he received his HIV diagnosis. He had been having quite a lot of unprotected sex so it was a bit of a reality check to be finally given the news. But he believes that it was all handled quite badly. The GP informed him he was HIV positive with no pre- or post-test counselling and referred him on to a local hospital.

He was staying with his family at the time and got mixed support from his brothers when he told them. ‘I still can’t bring myself to tell my parents,’ he says.

He found it hard telling previous partners, some of whom he cared about very deeply. His most recent partner proved to be very supportive, while another said that it ruled out any possibility of them having a relationship in the future as he had no intention of having a boyfriend with HIV.

‘It has closed a lot of doors relationship-wise,’ says Phil, acknowledging that this aspect of being HIV positive has been the biggest reality check.

‘If you think about it,’ he says, ‘the odds of finding a partner out of the one in ten men who are supposedly gay are small anyway. And to then try and find one who is willing to accept your HIV status really limits your choices.’

Phil did what a lot of newly diagnosed guys do when they find they’re not coping with being positive. He started regularly using recreational drugs. At first they seemed to help him relax and made it easier to tell others about his status. He always tries to disclose to partners but often finds it difficult.

‘If you don’t do it on the first date, when do you do it?’ he asks me. In the first week, the first month or never?

Phil had this need to disclose drummed into him by a social worker in New South Wales, where it is law to reveal your status before you have sex. However, a close friend who lost a lot of friends to HIV advised him not to disclose because of the potential for discrimination.

He struggled with the dilemma but has decided that he must now disclose because it feels right, and he has always liked being straight with people. He’s changed his status to...
positive on internet dating sites and while he doesn’t get as many hits, he finds the ones he does get are more genuine and interesting anyway.

When Phil’s drug use started to affect his health and his work, he sought counselling and has found that changing his riskier lifestyle has reduced his stress levels. He has also started to speak to other gay men through various peer support programs.

‘I tell them that having HIV is a lot more than just taking a few pills each day. It affects your relationships, your physical health and your mental health.

‘I don’t live with regret but I do look longingly back at the time before I was positive and wish I had made a few different choices.’

Meg. Years living with HIV. 10

Meg is an exceptionally fit and healthy 44-year-old. She takes three pills in the morning and only needs to see an HIV specialist once every six months to get her sexual health checked.

HIV is not something she thinks about much at all. The impact of it on her life is minimal. But this wasn’t always the case. When she was diagnosed ten years ago, Meg had been in a year-long relationship with a man who had left his marriage just before they met.

‘I developed a lot of bone pain and became very unwell,’ she told me.

Her doctor diagnosed cytomegalovirus (CMV), but when she looked it up on the Net, she kept being referred to HIV sites.

‘I told my doctor it couldn’t be that but to check anyway,’ she said.

The day she found out coincided with her niece’s first birthday party. Everyone in her family was so jolly, she felt she couldn’t ruin the mood and tell them. Besides, her partner was an Anglican priest and she didn’t want either of her parents to know that she had been sexually active.

Meg felt an overwhelming sense of guilt that she had lost her innocence. She believes she took on the negative stigma that people often associate with HIV: sex, disease and death.

‘I didn’t know what to expect from other people if I told them,’ says Meg. ‘I felt so isolated for such a long time.’

She didn’t know what to think about her future health or life expectancy. Her GP proved to be pretty hopeless as he hadn’t diagnosed anyone with HIV before. Already dealing with chronic fatigue syndrome, the HIV only made her symptoms worse.

Slowly, Meg began to manage her chronic fatigue syndrome and got her HIV successfully treated at the Melbourne Sexual Health Centre. The doctors there were much more knowledgeable and she received counselling to help her adjust to her diagnosis.

She also discovered the PLWHA Victoria Speakers Bureau which helped her enormously.

‘Talking to others about HIV has helped me break down my own stigma about being HIV positive,’ she confesses.

‘For a long time, I could see no upside to having the virus. Then I found that I could improve other people’s knowledge and awareness.’

Meg is not having a sexual relationship at the moment but knows that when she does, it will mean having to tell her partner about her status.

She still wonders about her future but tries not to think about it too much and simply gets on with her life.

Sandy. Years living with HIV. 17

When Sandy was diagnosed with HIV in 1994, she couldn’t believe that her husband may have cheated on her.

‘He was so jealous of me around other men,’ she says.

When she told him about her diagnosis, he assured her it must be her fault and so she flashed back to years before when she’d helped some guy with a cut on his foot.

‘But I’d had two children since then,’ she reveals. Luckily, neither of them tested positive.

Sandy had no one to tell or get support from. She was fortunate enough to have been referred to a specialist who had worked previously at Fairfield Hospital and who knew a lot about HIV. He told her to take off her rose-coloured glasses and face the fact that she must have contracted HIV from her partner.

Sandy remembered a time she had found a condom pack from a Melbourne club. She rang them up and found out they were a gay sex-on-premises venue and confronted her husband about it.

‘He came up with a good excuse about meeting someone to collect a debt and I didn’t think any more about it,’ she recalls.

Sandy’s life filled with turmoil as she struggled to come to terms with her prognosis, what it might mean for the care of her children and dealing with an increasingly problematic relationship with her partner. The stress began to take a toll on her health and she suffered a form of mental breakdown.

She then went through a highly traumatic time in hospital where she nearly died from an opportunistic infection. She also developed resistance to the antiretrovirals she had been on since her diagnosis and was left with very few treatment options.

‘The doctors said they didn’t know if I could cope with the toxic side-effects but somehow she persevered and somehow survived a truly awful time,’ she relates.

Sandy believes that it doesn’t matter when you were diagnosed – 20 years ago or just yesterday – it will always have a devastating effect on your life.

Today she works as a peer support worker with Straight Arrows, an organisation for heterosexuals with HIV, and sees people with new diagnoses all the time. It’s the ripple effect of a diagnosis, she believes, that takes its toll. Even if it doesn’t affect you straight away, over time it adds an element of uncertainty in your life as you disclose to friends, family, sexual partners, health care workers, employers.

‘We all know it takes a toll on your body from day one and is much worse the older you get,’ she says.

‘If you care about yourself, you don’t want this virus.’

Max. Years living with HIV. 25

HIV has put Max through the mill over the years. He lost a partner and numerous friends to the virus, lived through several AIDS-defining illnesses in the late eighties and early nineties and survived years of inadequate and toxic treatment regimens to get where he is today.

‘One of the worst things I had to go through was anal cancer,’ he admits. ‘I could have died from it.’

He underwent radiotherapy, highly invasive surgery and years of meticulous self-care, but today he appears to be cancer free.

‘It still affects my everyday life in some ways,’ he says.

Max believes that there are few good things about being HIV positive. His experience living with it has made him more resilient and he is determined to understand as much as he can about the condition in order to minimise the chance of any future problems.

His period of personal growth began eleven years ago when he joined the HIV sector and he now coordinates the Positive Speakers Bureau for PLWHA Victoria, a job he finds very fulfilling. He believes that speaking about your own experiences can help you feel confident, overcome stigma and help others to make safer decisions in their sexual lives.

‘I am perplexed by some of the conversations I have had with younger negative gay men,’ he says.

Max finds that many of them think it is safe to have unprotected sex with positive guys. They use the Swiss Statement to argue that the risks are very small if your involved in medical care for the rest of your life,’ he warns them.

‘It’s not quite fifty percent don’t do well on the treatments and there are side-effects attached to many of them. Try to think about what your life might be like a few years down the track,’ continues Max.

‘Those of us who have lived with it for years know what damage it can do to your body and how quickly it accelerates the ageing process. And there will be no cure for a long time yet,’ concludes Max.

I hope my friend Troy (and others like him) read these stories and appreciate how much we don’t want others to become HIV positive.

Like it or not, getting HIV is still a big deal.
Positive male fertility

Wendy from NSW writes:
We are a discordant couple (my husband is positive and I am not) and we would like to have a baby. What are our options?

Dr Louise replies: This is a tricky area, Wendy, and I thank you for raising it. Firstly, we would recommend that your husband is on HAART and has a fully suppressed viral load.

We know that transmission of HIV can occur in unprotected vaginal intercourse at a rate of about 1 in 1000 sexual encounters. However, other factors which increase the risk of transmission include inflammatory conditions, such as untreated or undiagnosed STIs and ulcerative conditions in either partner. Also, viral load in seminal fluid doesn’t always correlate with blood viral load. So, even when HAART has fully suppressed viral load in the blood, HIV may still be found in the semen and the seminal fluids. This is why we recommend continuing to use condoms for sexual intercourse.

To date, we don’t have enough data available on the use of Pre Exposure Prophylaxis (PrEP) in this setting, so we need to wait for further information.

Some couples accept the small but real risk of HIV transmission to the female partner and choose to have unprotected intercourse at the time around ovulation. Your GP can give you information regarding signs of ovulation and cycle information.

For some couples, pregnancy occurs quite quickly. For others, however, even when both partners are fertile and ovulation does occur, pregnancy does not always follow.

Other couples utilise various assisted reproduction techniques (ART) to decrease the risk of HIV transmission.

ARTs use a technique called sperm washing, where the semen is placed in a centrifuge and spun, thus separating the sperm from the seminal fluid. At some centres, the washed sperm then goes through HIV RNA testing, but this is a very specialised and expensive technique.

In vitro fertilisation (IVF) is where conception takes place outside the woman’s body allowing incubation to occur in the test tube.

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Sometimes this doesn’t worry me but other times I wish I had a better sex drive. I don’t have a problem getting an erection but often find coming difficult. I have had very few problems associated with HIV and the only other medication I am taking at the moment is an antidepressant.

Dr Louise replies: I can almost see other readers nodding with you in agreement, Wei. This problem is very common. But before I can really answer you directly I would need to know a little bit more about you personally. Have you ever been on HIV treatments? How long have you been on antidepressants and which ones? Have you any other medical conditions or past history? How are you feeling at the moment? Are you in a relationship?

Libido is a complex thing relying on a combination of biological, personal and relationship factors all working together. At different times in our life, depending on all those things, our libidos may be high or low.

Many conditions can alter libido. Medical conditions (especially chronic ones), pain, fatigue and stressors, along with relationship problems can all lower libido.

Depression itself can affect sex drive and ability to have an erection or ejaculate. Sometimes this doesn’t worry me but other times I wish I had a better sex drive. I don’t have a problem getting an erection but often find coming difficult. I have had very few problems associated with HIV and the only other medication I am taking at the moment is an antidepressant.

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Vicky Fisher suggests adding spinal twists to your yoga practice.

**Gentle exercise**

**Cross-legged seated pose (Sukhasana twist)**

Sit on the floor in a comfortable cross-legged position. If you find you are slumping forward to try to stay upright or your knees are way up in the air, then place a rolled blanket or telephone directory under your bottom to raise your hips higher than your knees. This will take the effort from your spine and torso. Relax your thighs, knees and ankles towards the floor. Let them be heavy and passive. Take your right hand onto your left knee and your left hand on the floor just behind your buttocks. Close your eyes. As you breathe in, imagine your spine extending upwards. As you breathe out, begin to twist your torso gently towards the left. Let the twist start below your navel, in a corkscrew motion, slowly and gently. Use your breath, both to help your spine extend and then to move into the twist. Relax your jaw, tongue and eyes. Come out of the twist on an inhalation and release your hands. Take your left hand on to the right knee and the right hand behind you on the floor and repeat on the right side, turning effortlessly towards the right with your breath. Inhale to release the twist.

**Sage pose (Maricyasana)**

This pose can help relieve backache and fatigue, and improve circulation and breathing.

Still seated on the floor, extend both legs out in front of you. Bend up your right knee, place the sole of the right foot on the floor close to your right buttck. Draw the bent leg in towards your chest with both arms and let your spine lengthen upwards. Place the right hand on the floor behind your right buttock and draw the knee in again. Bend up your left leg, place the foot on the floor close to your left buttck and draw the knee in towards your chest. Take your left hand behind you on the floor and wrap your right arm round your left arm. Feel your chest opening, your spine lengthening and the slight twist from your waist upwards. Release the twist on an inhalation and straighten your legs out in front again. Bend up your left leg, place the hand on the crook of your left elbow. Close your eyes if you wish. Inhale as you lengthen your spine and exhale as you begin to turn your torso, shoulders, then your head towards the right. Feel your chest opening, your spine lengthening and the slight twist from your waist upwards. Release again.

Vicky Fisher has been practising yoga for more than 25 years. She is a qualified Hatha yoga teacher and has been teaching in Sydney for the past five years.

**With a background in counselling,**

Kate Bennett works with positive people throughout Tasmania.

James had been excited by the opportunity of a fresh start when he moved to the Apple Isle to be with his new partner. Unfortunately, after a short time the relationship began to deteriorate. Things got even worse when his contract ended and he was unable to find another job. He realised that he had been financially supporting his partner and when he could no longer do this the relationship crumbled. His partner became abusive and that’s when he turned to Kate for support.

Although James’ job and relationship problems were not directly HIV-related, the distress and anxiety they caused undermined his general health and well-being, reducing his ability to cope. In fact, by the time he talked to Kate, both his self-esteem and his CD4 count had plummeted and his mental health was quite fragile. James tried to end the relationship but due to his ex-partner’s intimidation was too afraid to leave. Kate worked with him to develop strategies for managing his fear and his ex-partner’s behaviour. Eventually, James moved back to the mainland where he had a network of friends and job contacts. He was also familiar with the medical services there and Kate provided him with counselling and psychology referrals to ensure he would have support in his recovery.

James is determined to create a more supportive environment for himself. He is happier now and determined to control the life events which might affect his HIV health.

**Mailbox**

Dear Positive Living,

I was diagnosed with HIV in 1992 and put on the Disability Support Pension which I’ve been living off ever since. Last June I had a pension review and according to Centrelink I rated BELOW the 20 point criteria you now have to meet to qualify for the DSP. I don’t know if it’s a blessing in disguise but fortunately I also care for a person with a severe mental illness so I was able to go on to a Carer Payment. It’s not ideal but I could have ended up on Newstart Allowance having to look for a job. Imagine a 59-year-old guy in rural Australia looking for someone to employ him?

My main grievance is how I was treated throughout the process. At one point my pension and my Health Care Card were both cancelled. This caused huge anxiety and I get enough of that just living with a person with mental illness. I certainly don’t need any more. Another time, when I was checking on the progress of things, a staff member of Centrelink asked me how long I expected to recover but it leaves a very bitter after taste.

I hope this message is of some use to others when dealing with Centrelink.

And it may prompt certain Centrelink staff to buck up their ideas. It seems that it’s all about money not people. But I suppose that’s society these days.

Regards, Ross

■ **We’re always interested in hearing about your experiences, good or bad. If you have news you’d like to share, send your letter to pl@napwa.org.au.**

**We Call Them the Treataware Outreach Network (TON)**

**THERE IS A NETWORK OF WORKERS LOCATED AT AIDS COUNCILS AND PLHIV ORGANISATIONS AROUND AUSTRALASIA WHO UNDERSTAND THE VARIETY OF TREATMENT ISSUES FACED BY POSITIVE PEOPLE. WE CALL THEM THE TREATWARE OUTREACH NETWORK (TON).**

**PositiveLiving | 11 | WINTER 2011**
I will not be silenced and I will not give up and I will not be ignored.

With these words, Elizabeth Taylor lent her voice to the voiceless, her iconic image to those who had previously been invisible, and her compassion and determination to a cause many others had shunned: the fight against HIV.

Her willingness to speak out against apathy and silence in the early, frightening days of the epidemic and her instinctive sympathy for those in need earned her a place as one of the most influential advocates for people living with HIV around the world.

Dame Elizabeth Taylor has reportedly left a large portion of her $US600 million fortune to HIV charities, including The Elizabeth Taylor AIDS Foundation and amfAR, the HIV charity she founded in 1985.

Farewell, Liz. And thank you.