

poslink

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RESILIENCE

‘You never know how strong you are until being strong is your only choice.’

Bob Marley

RESILIENCE



LIFE



RESILIENCE

The first decorations appear around Melbourne from late October. Before Cup weekend, local shopping centres have areas cordoned off where a gaudy red throne waits for a big jolly Santa to be wheeled in from somewhere. From the very shiny plastic decorations, the fake snow in shop windows on 35 degree days, the plastic reindeer suspended from ceilings and the terrible renditions of Silent Night from unseen speakers, our senses are assaulted from all directions. We are expected to believe in the illusion that at this time of year there can be only one experience – of jollity, parties, extravagant presents, happy families and holiday fun.

It can be an especially tough time for people living with HIV. It is as if the seasonal merriment serves to highlight the challenges posed by living with this virus. At family gatherings, many HIV positive people speak of having to pretend to be happy, especially if they have disclosed their HIV status to their families. Alternatively, there may be a need to self-censor if only certain family members are aware of their diagnosis. For many gay men, being with family may mean exposure to ignorance and homophobic attitudes. You may also be spending time with children, which may bring up feelings of how HIV has reduced or negated the possibility of ever becoming a parent.

For people who have been living with HIV for 20 years or more, this time of year may act as a reminder of mortality and the uncertainty surrounding the future. For many, it becomes a kind of milestone in the calendar. Some HIV positive people, diagnosed last century, would mark each time as though it was possibly their last. I believe this experience can still influence people's thinking today. This time of the year may allow HIV positive people to look back at happier and more carefree times, as well as those which were dominated by fear.

There are no simple solutions, and I don't know anyone with a straightforward answer. It may, however, be worth examining your anticipated sense of dismay, apprehension and frustration as 2015 draws to a close. Ask yourself what the festive season means to you in 2015, what it has meant in the past, and whether it makes sense to feel unhappy when past and current experiences aren't more aligned.

If loneliness is your greatest challenge, acknowledge that you are definitely not alone in this. Try to identify ways you may be able to connect with others. Take a break in your day – venture outside with a book, go to the beach, pack a lunch and go to your local botanical gardens. Most importantly, do something that you enjoy which brings you happiness.

If you are suffering financial hardship, again, acknowledge that you are not alone. It is certainly possible to reduce expenditure by thinking about more creative ways of giving.

Very few people would be happy to receive a gift that would increase a friend's monetary worries.

There is a possibility that we may be caught up in a pattern of behaviour that moves between threat and drive, controlling the way we respond or react. The hype of the season can make us feel that we have less than others, prompting us to act and spend beyond our means. We buy something and this gives us some transitory feeling of satisfaction, but then feel fearful that the gift isn't good enough, so the cycle begins again. We now cannot enjoy what we have bought and experience stress. The constant movement between drive and threat reminds us we are not good enough. This is fertiliser for feelings of anxiety and depression. Locating a spot within ourselves where we can feel warmth and compassion is desirable. Talking to a professional about ways to achieve this may be useful, but be aware that many of these professionals and agencies often take an extended break over this period; often the one time when people living with HIV are most in need of some extra support. As a counsellor I have noticed that January and February are frequently the busiest months.

Even though it is not easy to buck a trend and impossible to alter past experiences, it may be possible to increase your understanding of the issues and to engage in a conversation with someone about what might be changed or managed differently. We are all told to get ready for the season, but perhaps the best preparation of all is to tell one or two trusted people about your reality so that you know that someone truly understands what it is like for you.

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CAN YOU LEARN RESILIENCE?

David Menadue

No one can tell you how to live your life with HIV. Even if they try, you will still eventually work out that ultimately you are on your own journey. That might be rocky for some and relatively plain sailing for others.

How we learn to adapt to a diagnosis, whether recent or long-term, is a sign of our ability to be resilient – to bounce back, to go with the flow, to see the positive side of negative experiences, to learn about inner strengths that we never knew we had.

Not everybody has this in-built resilience. Who knows where it comes from? Living with adversity in your early life (and many gay men or people from culturally and linguistically backgrounds (CALD) probably know a thing or two about that)? Coming from a family that taught you great coping skills or strong self-belief? Just being a tough little bugger?

I'm a firm believer that resilience can be learned, even for those who find getting over a big setback in life (like an HIV diagnosis or an HIV-related condition) a great hurdle. Peer support groups and counselling can help draw out the roadblocks in your life, and make you realise you are not on your own and that your experience is likely to be shared by others.

Petrea King, a well-known facilitator of positive wellbeing courses in Sydney (and who used to run courses for people with HIV) said to me once:

“The way forward is to let go of the past, to change the view that ‘if only this hadn't happened, my life might be OK.’ It's useful to understand why you have got where you are today, to maybe use that to try to prevent repeat behaviour or negative thinking, but it isn't useful to cling to the past.”

King suggested people try to work their way through these issues by writing down their experiences, sharing their story with others or learning meditation or yoga.

Sharing your story with others certainly worked for me. While there weren't any great courses, like the programs currently offered through Living Positive Victoria (see below) in my early time with HIV, a group of some of the earliest people diagnosed with HIV in Victoria set up Melbourne Positive Friends, a peer support group we ran in our own homes without a facilitator or any funding. We didn't need that, but we needed each other.

In the time of the Grim Reaper campaign, when the stigma against HIV+ people was enormous, we needed a safe space where we could be open about our status. No judgement, no blame, just helping and supporting each other through a rough time.

When people started getting sick and dying in the group it was incredibly confronting.

“Will I go through that? Will I be next?” was what everyone thought at some stage. It was hard to get over the feeling that you were fated to die, that it would be easier to give up and hide away from the rest of the world. Melbourne Positive Friends lifted me out of those troughs even when I lost really close friends.

I developed the confidence to talk openly about living with HIV and to join the fledgling People Living with HIV/AIDS Victoria organisation (now Living Positive Victoria). I found the peer support I got from being around relatively confident positive people stimulating, even if some people were feeling anger and frustration around the progress and availability of treatments back then.

Now I see younger HIV+ people doing the same: attending peer support groups, getting involved with Living Positive Victoria, Positive Women Victoria or Straight Arrows, enrolling in the Positive Leadership Development Institute (PLDI) to help develop the skills to become leaders in the community.

Not that these initiatives are for everybody. More private people might find one-on-one counselling like the Victorian AIDS Council's Counselling Service a useful way to develop a more resilient approach to the issues that life as an HIV-positive person can throw at you.

Some of the most resilient role models you can see around you are those of us who have lived with HIV for a long time. They have often learnt techniques to deal with the knock-backs from HIV-negative potential partners (including managing to seduce them anyway). Having dealt with a much harsher reality about living with HIV in the past, they have learned to live without much internalised stigma, and to treat HIV as a relatively minor issue in their lives.

Maybe a conversation with an old bugger like me might help, although I guess some may not have moved on from the past, as Petrea King says – and so might say the odd scary thing to a newly diagnosed person, including wagging fingers at them for getting the virus in the first place.

Hopefully though, most of us aren't like that. I personally am so pleased when I see young people with HIV living confident lives, aware that they have a relatively normal lifespan ahead of them. Not everyone will feel able to come out in the media, to put their positive status on an online dating site, take on other leadership roles. You can also find your own level of involvement with other HIV+ people by attending a peer support course like Phoenix.

If you can learn to live holistically with HIV as a part of your life, you have not only learnt to be resilient to HIV – you will have become a more resilient human being.

Just starting off, on this path? Phoenix is a group for newly diagnosed for people living with HIV (PLHIV) run through Living Positive Victoria, Positive Women Victoria and Straight Arrows.

For immediate support please call Lifeline on 13 11 14 or contact VAC on 9865 6700 to access additional support. Or to access further information about Phoenix contact 03 9863 8733 or the new Phoenix for Women please call Positive Women Victoria on 03 9863 8747.

WHO ISSUES RECOMMENDATIONS ON LINKAGE TO CARE, RETENTION, TO HELP BRING HIV TREATMENT TO ALL

Keith Alcorn

Published: 01 December 2015

The World Health Organization (WHO) has issued new recommendations on how to organise services in order to promote linkage to care and retention in care as part of its new guidelines recommending antiretroviral treatment for all adults and adolescents.

The recommendations on antiretroviral treatment and for pre-exposure prophylaxis for people at substantial risk of HIV infection were announced in September 2015. This month the World Health Organization makes a series of new recommendations on service delivery. These are designed to maximise linkage to care and retention in care as part of efforts to expand access to antiretroviral treatment to ensure that 90% of people diagnosed with HIV infection are on treatment by 2020.

HIV programs should provide people-centred services that are organised around the health needs and preferences of people living with HIV, WHO says. This means following the evidence regarding how to optimise linkage and retention in care, through decentralisation of care, reduction in clinic visits and clinic waiting times, and “upholding individual dignity and respect, especially for vulnerable populations.”

The new recommendations include:

- Routine viral load testing should be carried out 6 months and 12 months after starting antiretroviral treatment, and if the patient is stable on ART, every 12 months thereafter.
- Less frequent clinic visits and medication pick-ups are recommended for people on stable ART: every 3-6 months is sufficient.
- ARVs can be distributed by trained and supervised lay providers; lay people and other trained and supervised non-laboratory staff can also undertake blood finger prick sampling for collection of blood for treatment monitoring.

- Testing sites should have in place support interventions to ensure linkage to care, such as linkage to case management or peer support and navigation. Data should be used to identify how the quality of linkage can be improved.
- Programs should provide community support intervention such as adherence clubs to encourage retention in care, and programmes should promote adherence through the use of interventions such as peer counsellors, mobile phone text messages, reminder devices, medication adherence training and the use of fixed-dose combinations and once-daily therapy.
- Adolescent-friendly services should be implemented within HIV services to improve engagement and outcomes.

In a response to the new guidelines the International Treatment Preparedness Coalition called for the international community “to ensure that adequate, community-led treatment education is an integral part of treatment scale up.” They also urged government to ensure the rapid adoption of the recommendation on viral load testing, and to ensure that any charges to patients for viral load testing should not be a barrier to care.

The new guidelines also recommend the use of the integrase inhibitor dolutegravir as an alternative first-line treatment adult option for the first time. Dolutegravir was licensed to the Medicines Patent Pool by ViiV Healthcare in 2014, allowing the drug to be used in fixed-dose combinations by generic manufacturers supplying lower-income countries. The International Treatment Preparedness Coalition has called on ViiV to extend the eligibility criteria for its license to the Medicines Patent Pool to allow middle-income countries to obtain the drug more cheaply.

Aurobindo, an Indian manufacturer, announced this week that it will make its generic version of dolutegravir available at \$44 a year, matching the price of efavirenz for lower-income countries.

The guidelines also recommend the use of a 400mg efavirenz dose as an alternative first-line option for adults and adolescents in order to improve the tolerability of efavirenz, following the finding that a 400mg dose was just as effective as a 600mg dose, but with fewer side effects. The Indian manufacturer Cipla announced this week that it is preparing to launch fixed-dose combinations containing efavirenz 400mg. Mylan Laboratories will also launch its own fixed-dose combinations in early 2016 at a price of \$99. UNITAID says that switching to a 400mg dose of efavirenz could result in savings of US\$80 to 100 million globally by 2020.

http://www.aidsmap.com/page/3018612/?utm_source=NAM-Email-Promotion&utm_medium=aidsmap-news&utm_campaign=aidsmap-news

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