The power of resilience

Created *30 Aug 2012 - 3:20pm*

re·sil·ience [ri-zil-ee-uhns] noun
2. ability to recover readily from illness, depression, adversity, or the like; buoyancy.

Unlike dictionaries, psychologists vary in their definition of resilience with some saying it is less about actual recovery and more about 'the ability to establish and maintain a stable equilibrium across and over time'. [1] Nevertheless, DAVID MENADUE investigates a trait we could probably all do with a little more of.

One thing is for sure. Positive people know about resilience . . . particularly those of us who lived through the horror years of the eighties and early nineties. Just getting through that period — when many of our friends were dying and society was reacting with fear and hostility — took a lot of resilience.

Even with much better prognoses, an HIV diagnosis today is still a big deal.

There's the initial shock, followed by wondering how you will be treated and what it all means for your health. Some people find it easier to adjust, while others — battling feelings of stigma, fear of rejection and uncertainty about the future — find it extremely hard.

According to the recent NAPWA stigma audit, a significant percentage of positive people in Australia feel that living with HIV is something to feel guilty or ashamed about. Forty percent also agreed with the statements that 'most people think that a person with HIV is disgusting' and 'I have been hurt by how people have reacted to learning I have HIV'. [2]

Much of the stigma attached to being HIV positive occurs because we have either been treated badly in the past when the information became known or because we fear this will happen if we were to reveal it. One way to tackle this is to mount anti-stigma campaigns which expose the unfairness of it all. But it is also important to build the capacity of positive people to cope with negative comments by adopting a resilient attitude.

HELP WITH BUILDING RESILIENCE

For a number of years, the Bobby Goldsmith Foundation (BGF) in Sydney has held a range of workshops to help people with HIV build their skills in resilience.

One of these, a four-day retreat called PosQuest, has been run in partnership with Petrea King from Quest for Life. Petrea has had a lot of experience helping people with cancer and other chronic illnesses and her groups have often included people with HIV.

'Participants found some sections of the program to be quite confronting . . . because we ask people to share their stories,' reveals Peter Thoms from BGF.

'This can bring up feelings of anger and guilt related to getting HIV but also about things to do with people's upbringing, family, school and personal relationships.'

Peter believes that the way forward is to let go of the past and to change the view that 'if only this hadn't happened, my life might be OK'.

'While it may be useful to understand why you have got to where you are today, and to try to prevent repeat behaviour or negative thinking, it isn't useful to cling to the past,' he says.

The course suggests that participants live in the present as much as possible. But how people actually develop a positive frame of mind varies from person to person. Some find sharing their story or writing it down helps.

Others succeed through meditation, yoga and learning mindfulness techniques. For some, developing a more

Information on the NAPWA website is provided subject to conditions of use that can be view at napwa.org.au. Visit the website for updated versions of this information.

spiritual outlook on life is the key.

Unfortunately, funding for the PosQuest course has been withdrawn, but people with HIV are still able to attend general Quest for Life courses (www.questforlife.com.au [1]).

RISING FROM THE ASHES

BGF has run Phoenix courses for many years, helping positive people to identify their skills and explore how they might develop them to re-engage with the workforce or as a volunteer. They also support people to deal with depression by assisting them to attend workshops run by the Black Dog Institute.

‘People might just want practical advice on how to deal with “the system”,’ says Peter.

‘Some get very frustrated with housing agencies or Centrelink,' he says, ‘because they see the bureaucracy as being stacked against them. Simple, practical tips on understanding the best path to deal with these agencies can help people feel less overwhelmed and disempowered.’

Peter has noticed that some people who have lived with HIV for a long time share a particular set of challenges. Many have left the workforce because of illness or the prospect of illness and have lost a lot of their previous skills and confidence. Some are too young to be out of the workforce, while others are dealing with the effects of early ageing and other health problems.

‘Many are socially isolated,’ he says. ‘They live in one-bedroom public housing where sharing is not possible and feel unable to engage with former friends or go out socially because of the cost or because they don’t feel accepted in those circles anymore.’

Many talk about a change in attitude towards people with HIV in the gay community. Younger gay men particularly are less aware that people with HIV are among them and less accepting when it is revealed. Many also talk of an ageist attitude that is sadly very prevalent on the gay scene.

NEWBIE VIEWS ON HIV

Vic Perri from PLWHA Victoria runs regular Phoenix workshops (quite different to the Sydney courses) in Melbourne for people who are newly diagnosed or who have taken some time after diagnosis to be ready to deal with issues around living with HIV or to develop the confidence to join a group.

‘Many of the poz guys who come to my group have a strikingly common fear,’ reveals Vic.

‘They think they will die soon or have a dramatically shortened life.’

This is probably the number one concern expressed by members of Vic’s groups; followed by the worry that they may never have sex again, because they fear they may transmit the virus [2]A small infective organism which is incapable of reproducing outside a host cell..

He thinks it is probably understandable that HIV negative guys have not kept up with the latest on HIV treatments or know that many positive people are able to manage their sex lives, sometimes with negative partners.

Most of them probably don’t realise that around half the positive people in relationships are with an HIV negative person.

They are amazed when they find this out during the workshop.

HIV is not talked about in their circles and most of them don’t know anyone else who’s positive.

The group is conducted over a weekend and during its course a range of professionals come in to address people’s concerns.

Information on the NAPWA website is provided subject to conditions of use that can be view at napwa.org.au. Visit the website for updated versions of this information.

‘The real “light-bulb moment” for a lot of guys is when an HIV specialist doctor tells them how effective current HIV treatments are,’ says Vic, ‘and that it can be just one pill a day with minimal side-effects.’

Sex and relationships are always a topic for discussion.

Men in the groups worry that they will never find a partner or that only another positive person will have them.

‘Everyone hates the idea of rejection,’ says Vic, ‘and it just seems more likely when you have the virus.’

People have different views about the need for disclosing to a sex partner first up. Some believe it is a moral issue and the other person deserves to know. Others find that they can’t handle the rejection as well as they thought they could. The result is that they end up not telling anonymous, casual or one-off encounters and only consider it if they feel that some sort of relationship might develop.

‘I tell recently diagnosed people to be selective about whom they tell initially,’ says Vic. Whether it’s sex partners, friends, family or workmates, Vic suggests you think about who really needs to know and who doesn’t. And if you don’t think you can handle a negative response to not do it straight way.

He also has good advice for follow-up. ‘If you disclose to a potential partner who finds it difficult understanding the implications, bring them in to see an HIV peer support worker or even take them to your GP to help explain the relative risks of transmission.’

Vic thinks workshops like Phoenix successfully address the many misconceptions about what living with HIV will be like.

‘Unless people learn to deal ith their often unnecessary fears, they may end up living a life of emotional isolation,’ he ponders, ‘or worse . . . they may take a destructive path and resort to drugs and alcohol to cope.’

THE COUNSELLING OPTION

Goups are not everybody’s preferred way of dealing with things. Some people don’t want to tell their story in front of others and prefer to have one-on-one counselling to work through their issues.

Michelle Earle is an experienced HIV counsellor at the Alfred Hospital in Melbourne.

She thinks the objective of counselling should be to help people make a healthy adjustment to life.

‘Everyone needs ballast to keep afloat in a storm,’ she says. ‘We all need something to deal with the stresses that life throws up for you.’ When she starts to counsel someone, she looks to see if they possess certain key components to help them make that adjustment. Do they have a healthy self-esteem or an adequate way of coping with stressors? Are they in denial over any fundamental issues or at a loss to find ways to solve the problems they are confronting?

‘These are hallmarks of how resilient people are,’ she believes.

There are external factors she looks for as well, including how strong their relationships are with their partner, family and friends.

‘If someone is isolated without a support network, they may have a harder time getting on top of things,’ Michelle says.

She believes that people also need to be involved with some meaningful activity in their lives.

It might be a job or being a volunteer or following a passion or hobby. Michelle sees many people in her practice who have great potential but lack the vehicle to show it in their lives.

‘Counselling can help awaken some of these possibilities,’ she says, ‘providing people are able to sort out the things that are holding them back.’

Information on the NAPWA website is provided subject to conditions of use that can be view at napwa.org.au. Visit the website for updated versions of this information.

‘People discover their own comfort level around disclosure,’ she says, given that there are some forums where it might still be problematic — such as the workplace or in certain family situations.'

DOING IT YOUR WAY

We all have different ways of living with HIV.

Disclosing your status and discussing its implications with just a few trusted friends may be enough to give you the level of acceptance you need to be a confident individual.

Others don’t care who knows . . . and this has been my approach — albeit over a number of years gradually building up the courage to let family, workmates and sex partners know. For me, this technique has decreased any internalised stigma I have felt about having HIV and any thoughts that I was hiding a big secret. But such an approach will not work for everyone.

Michelle Earle claims that most people she sees show quite a high level of resilience in adjusting to an HIV diagnosis over time.

‘People discover their own comfort level around disclosure,’ she says, given that there are some forums where it might still be problematic — such as the workplace or in certain family situations.

‘People tend to find a level of self-acceptance about their diagnosis that lets them get on with life.’

If you would like some help to deal with the various stresses related to living with HIV (as well as other things), some of the approaches mentioned above might help you build your own capacity for resilience. You might also like to check out some of these resources:

- FOR THE NEWLY DIAGNOSED
  Many AIDS Councils and PLHIV [3]Person (or people) Living with HIV. This term is now preferred over the older PLWHA. groups have advice for the newly diagnosed on their websites. Also see the booklet Next Steps, which is available from these agencies or online [4]
- FOR PEOPLE IN POSITIVE NEGATIVE RELATIONSHIPS
  Positive Life NSW has just released its second resource for people in serodiscordant relationships. Check out
- FOR PEOPLE DEALING WITH HIV AND AGEING
  Ahead of Time is a comprehensive booklet available from HIV agencies or online [6]

1. 1. Cichetti D and Garmezy N (1993). Prospects and promises in the study of resilience, Development and Psychopathology 5 (04):497-502
2. 2. NAPWA Stigma Audit 2011. The sample was of 697 HIV positive people in Australia. Thirty-six percent agreed with “I feel guilty because I have HIV”; 35% disagreed with “I never feel ashamed of having HIV”. See www.napwa.org.au [7]

- living with HIV

Links:
[1] http://www.questforlife.com.au
[2] http://napwa.org.au/glossary/term/125
[3] http://napwa.org.au/glossary/term/689
[4] http://napwa.org.au/resource/next-steps

Information on the NAPWA website is provided subject to conditions of use that can be view at napwa.org.au. Visit the website for updated versions of this information.

[5] http://sd2.positivelife.org.au
[6] http://napwa.org.au/resource/ahead-of-time-a-practical-guide-to-growing-older-with-hiv
[7] http://www.napwa.org.au

Information on the NAPWA website is provided subject to conditions of use that can be view at napwa.org.au. Visit the website for updated versions of this information.