Treatments for HIV have increased the life expectancy of people living with HIV to almost the normal life span. Alongside the increase in life expectancy there is emerging evidence of a higher prevalence of mental health problems for those living long term with HIV.

The impact of living long term HIV on mental health is an emerging social issue. One of our motivations for writing this health information sheet is that the connections between the two are complex and not well understood. One thing that is known is that people living with HIV are more likely to be affected by mental health problems. We also know that it is not being HIV positive in and of itself that causes mental health outcomes. For people living with HIV the stress caused by marginalisation and discrimination in combination with other social determinants of health may in time lead to low self-esteem; disengagement with body, relationships and society; and isolation. The link between HIV and poor mental health is also strengthened by the fact that mentally unwell people are less likely to seek help and to adhere to HIV treatment regimes. A further contributing factor is that living long term with HIV can impact on the brain. One of the most common concerns among many HIV-positive people is dementia (Fight Dementia Org., ND). HIV associated dementia, was common before highly active HIV treatments were developed, but is now rare and generally associated with people who are diagnosed very late or do not take HIV treatments soon enough. However, milder forms of cognitive change may affect a wide range of people. Lastly, physical health related factors such as high levels of smoking, alcohol and illicit drug use have the potential to lead to poor health outcomes and other comorbidities.

It is not possible to address all these issues in one information sheet. With this in mind we have chosen to provide practical information on the social determinants of mental health and wellbeing, the common issues people may face, and things to keep in mind when supporting people with long term HIV.

Social Determinants
It is likely that most LGBTI people living long term with HIV have experienced stigma or discrimination in their lives. Stigma relates to negative attitudes and ideas about people while discrimination relates to the actions that lead to social disadvantage.

**Stigma** is negative judgment or disapproval based on a group of people’s difference from what it considered to be normal. The effects of stigma are well documented. Although it is a public phenomenon external to the individual, stigma becomes personal and is often deeply diminishing to the person who receives it (Goffman 1963, Brohan, Slade, Clement, & Thornicroft, 2010). Put simply stigmatisation makes people feel bad.

**Discrimination** is disadvantaged someone on the basis of the person belonging to a perceived group. This can lead to marginalisation of individuals. Evidence suggests that gay men who have HIV are at risk of a depression due to discrimination and marginalisation not just because they live long term with HIV (Newman et. al., 2009).

Stigma and internalised discrimination (also referred to as internalised homophobia) influence the mental and physical wellbeing of people living long term with HIV (Vanable et. al., 2008, ASHM, 2012) and can also impede the willingness of an individual to seek health care when needed (Fortenberry et. al., 2002). Stigma has been clearly linked to depression (Tanney et. al., 2011: 1, Young et. al., 2005).

Gay men and men who have sex with men (MSM) may feel the negative impact of stigma in relation to their HIV status (ASHM 2012). Within LGBTI communities there is evidence of stigma on the basis of HIV status—particularly in the area of sex and relationships. Although there is little social exclusion of HIV-positive men, many HIV-negative men report that they reject HIV-positive men as potential sexual partners. (de Wit, 2013).

While most of the research on stigma, discrimination and HIV status relates to gay men, other LGBTI people living with long term HIV are affected by a similar range of social determinants. Examples of the kinds of stigma these people may have experienced include being thrown out of shared housing, rejected by family or having employment terminated on another pretext.

**Use of Alcohol and Other Drugs**

Many studies show that people from LGBTI communities have higher than average usage rates of alcohol and other drugs. This is mostly a response to severe life stressors, violence perpetrated against them and being part of a non-accepted minority (Amico, 2011). Use of alcohol and other drugs are risk factors associated with higher rates of HIV and can have a negative impact in the ability of certain individuals to take appropriate medication if they have HIV.
Supportive Families and Healthy Relationships

Supportive families and healthy relationships can be particularly helpful and beneficial to people living long term with HIV (Carter and Hughson, 2012). Unfortunately LGBTI may experience rejection when they come out and often have less access to family support. Today many LGBTI people come out in their youth. A US study has shown that LGB young adults that experience high levels of family rejection, are more prone to poor mental health outcomes, and to more likely to engage in risky behaviors (Ryan et. al., 2009). Therefore LGBTI people living long term with HIV and without family support face multiple obstacles and emotional distress (Heckman, 2004).

Bereavement in the Community (pre 1996)

People living long term with HIV, especially if diagnosed in the 80’s and early 90’s, may have experienced the loss of a disproportionate number of peers and loved ones in the years when effective treatment was not available. Loss of loved ones due to HIV related bereavement has a great impact on those left behind, especially when the bereaved person also has HIV infection (Sikkema, ND). ‘Survivors guilt’, related to surviving those who had died of AIDS emerged as a social phenomenon in the 1990s (Odets, 1994). Later research undertaken with GPs suggest many positive gay men had experienced multiple losses which increased their risk of or the severity of their depression (Newman et. al., 2009).

---

1 The Alliance is an LGBTI inclusive organisation. However, in this document when data on all people in LGBTI communities is not available the appropriate initialism is used. Unfortunately, in this case data on intersex people’s HIV-related support needs and experiences were not available.
Story Box

Larry has been living with HIV for over 20 years. In the early years he lost many friends due to HIV and AIDS and sometimes feels guilty because he is still alive. His treatment regimen has improved over the years and his physical health is stable.

When Larry was first diagnosed his doctor told him that there was not much they could do. Two years later he lost the man with whom he had been partnered for 10 years to AIDS. His father told him that was what a sinner like him should expect from life.

This was the final straw in a long series of family rejections. The combination of lack of family support and all the other things going on in his life left Larry feeling that he could not cope anymore.

He did not feel like taking medication or doing anything much at all to look after himself. At the time Larry was unwilling and unable to seek help and his mental health deteriorated. In the end he only got better thanks to his own strength, the help of his friends and a devoted sister who had always been on his side.

It took Larry a long time to get back on his feet and start to feel better again. He now actively guards his health, lives a healthy lifestyle and consciously engages in positive thinking. He has become a public speaker telling people what is like to live with HIV and how rejection and ignorance played a big role in making him feel unworthy. He also loves to tell them that he fought back those negative experiences and won.
Summary

It is important for those working with, people and friends and family of people living long term with HIV to be aware of the social determinants linked to poor mental health. These include stigma and discrimination, loss of employment and accommodation, alienation from family, death of friends and loved ones and higher usage rates of alcohol and other drugs. Psychological interventions can make a difference in the health and well-being of someone living long term with HIV (NAT, 2010). Unfortunately LGBTI people engage with mental health and suicide prevention services at far lower rates than the general population and service provision can be ad hoc. Health promotion, prevention strategies and early intervention are all required for better mental health outcomes. Strategies to improve the inclusiveness of services by increasing staff and management understanding of the experiences of LGBTI communities are essential. For more information on some initiatives that are already in place, you can access the LGBTI Health Alliance website.

People from all LGBTI communities have been affected by HIV. Gay men and men who have sex with men have been the most affected and studied of the LGBTI groups however, as part of the LGBTI community lesbians, bisexual people, trans people and intersex people as part of the LGBTI community are also affected.

This health information sheet was drafted by Dr. Michelle Mars and Belinda Marchesiello and Andrew Little

The Alliance would like to thank everyone who made comments on this paper particularly Ben Wilcock and Michael Frommer from Australian Federation of AIDS Organisations (AFAO) for comments on drafts of this paper.
References


HIV Australia (2009) Primary Health Care Project on HIV and Depression. HIV Australia, vol. 7. (4). Australian Federation of AIDS Organisations (AFAO), Sydney


