

## Beyond Diagnosis: Recognising HIV as a Long-Term Condition

Thanks to the availability of effective treatment methods, people diagnosed with HIV today have a near normal life expectancy. This fact sheet summarises key information and research related to recognising HIV as a long-term condition. This is vital because currently joint strategic needs assessments and other health strategies do not always identify HIV as a long-term condition. As HIV disproportionately affects gay and bisexual men this carries the risk of leaving their specific needs unaddressed.

### HIV Prevalence

The Health Protection Agency (2012) estimates that approximately 96,000 people were living with HIV in the UK by the end of 2011. This represents an increase from 91,500 people in 2010 and equates to 1.5 per 1,000 in the overall population. The two groups most affected in the UK are gay or bisexual men and men who have sex with men (MSM) (47 per 1,000) and the black African community (37 per 1,000) with prevalence rates being even higher in the major cities. A study investigating the situation in London (12.3%), Brighton (13.7%) and Manchester (8.6%), for instance, found that roughly 1 in 10 MSM are living with HIV (Dodds, Johnson et al., 2007). In turn 2 in 3 men diagnosed with HIV are MSM (HPA, 2012) and older gay men becoming infected with HIV in their 50s and 60s, are just as likely to report unsafe sex as younger HIV positive men (Elford et al., 2008).

### HIV Treatment

While there is no cure for HIV, work continues to develop a vaccine and microbicide (barrier product) to prevent it. Alongside this treatment methods for HIV are constantly progressing offering people living with the condition much better outcomes, especially if the infection is detected early. A person diagnosed with HIV today at 20 can expect to live to nearly 70, and a person diagnosed at 35, the average age of diagnosis in the UK, has a life expectancy of over 72 (The Antiretroviral Therapy Cohort Collaboration, 2008). Therefore, many people live with HIV in the long-term, managing the condition and its treatment over years. Thankfully as a consequence of medical advances treatments have become much more tolerable and less invasive. Whereas those diagnosed in the past had to cope with complex regimes with many side-effects, today initial treatment for someone newly diagnosed consists of just one pill a day. Still, it is not uncommon for people with HIV to suffer treatment side effects such as nausea, diarrhoea and prolonged headaches. In addition, some experience changes in body shape, depression and other mental health issues.

### Living with HIV

The potential treatment side effects as well as actual symptoms of HIV can significantly affect people's ability to manage employment, social networks and tasks of daily living and might necessitate some form of care and support. As with other long-term conditions those living with HIV report higher than usual levels of mental health issues such as depression and anxiety (Chapman et al 2005; Sederer et al 2006), which in turn

has negative impacts on physical illness, too, due to the relationship between emotional and physical wellbeing (Delahanty et al 2007). As a consequence the prognosis for their long-term condition and the quality of life people with HIV experience can both deteriorate markedly. In addition, the costs of providing care may increase as a result of less effective self-care and other complicating factors related to poor mental health (Naylor et al., 2012).

In addition, research suggests that HIV infection interacts significantly with other conditions, especially for gay and bisexual men and MSM. For instance, HIV positive gay men are 80 times more likely to develop anal cancer than straight men, and twice as likely to develop anal cancer than HIV negative gay men (Silverberg et al., 2012). People with HIV are also more susceptible to conditions associated with ageing such as cardiovascular disease, cancers, dementia and osteoporosis (National Aids Trust, 2013). At the same time older gay and bisexual men who are disproportionately affected by HIV are more likely to be single, to live alone and to be socially isolated (Age Concern, 2002), and are less likely to have children. This makes them more reliant on formal care and support (Ward et al., 2010). However, it has to be appropriate care and support with 4 in 5 lesbian, gay and bisexual (LGB) people preferring an LGB specialist HIV worker (Williams, 2007).

## Recommendations for Action

- 1) INCLUDE references to HIV and the communities predominantly affected by it (e.g. gay and bisexual men/MSM) whenever planning, commissioning and delivering services for people with long-term conditions.
- 2) TARGET gay and bisexual men or MSM with specific health information and campaigns on long-term condition, especially in relation to HIV.

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