From PLWHA to PLHIV

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An article published in the *Sydney Star Observer* on 28 May (' AIDS has had its day [1]') said that NAPWA is advocating for a change in the language used to describe people with HIV. This article generated a lot of interest and so we'd like to explain in a little more detail what's going on.

The article said that NAPWA had issued a statement calling for a move away from terms like 'HIV/AIDS' (in favour of just 'HIV') and 'PLWHA' (replaced by ' PLHIV [2]Person (or people) Living with HIV. This term is now preferred over the older PLWHA.'). It was based on a document published on the NAPWA website – our internal [3]. The style guide was adopted last October, but has only recently been published on the web.

The move away from the term 'AIDS' reflects a change in the terminology used by medical professionals and global bodies such as WHO and UNAIDS [4]Joint United Nations Programme on HIV/AIDS. UNAIDS is the main advocate for accelerated, comprehensive and coordinated global action on the epidemic. . In the early days of this epidemic, HIV and AIDS were considered distinct conditions, with people progressing through four distinct stages – asymptomatic HIV, symptomatic HIV, AIDS-related complex (ARC [5](AIDS-RELATED COMPLEX) (Early Symptomatic HIV Infection) 1. A group of common complications found in early stage HIV infection. They include progressive generalized lymphadenopathy (PGL), recurrent fever, unexplained weight loss, swollen lymph nodes, diarrhea, herpes, hairy leukoplakia, fungus infection of the mouth and throat and/or the presence of HIV antibodies. 2. Symptoms that appear to be related to infection by HIV. They include an unexplained, chronic deficiency of white blood cells (leukopenia) or a poorly functioning lymphatic system with swelling of the lymph nodes (lymphadenopathy) lasting for more than 3 months without the opportunistic infections required for a diagnosis of AIDS. (See Also AIDS WASTING SYNDROME).) and AIDS.

That terminology hasn't been used for a long time – HIV disease is now rightly seen as a spectrum, not as a series of inevitable stages. The treatment approaches for people at one end of the spectrum may be different from those at the other, but people with HIV are all treated as having the same condition – HIV infection.

The power of language to influence perceptions is well known – the GLBTI community is well aware of the stigma created by offensive epithets and the empowerment that comes from taking control of language. Just as gay men and lesbians have reclaimed words like 'queer' and 'dyke' over the years, people with HIV infection have also claimed the right to influence the words used to describe them.

In the early years, we were known as 'AIDS patients', 'AIDS cases' or, more pejoritively, 'AIDS victims', 'sufferers' or 'carriers'. All of these terms dehumanise, disempower and stigmatise people with HIV.

In response, the term 'people with AIDS' was adopted, and this evolved into 'people living with AIDS' and later 'people living with HIV/AIDS'. Today NAPWA and many other organisations have adopted 'people living with HIV' as the preferred term, with the initialism 'PLWHA' being replaced by 'PLHIV'. We're progressively incorporating this new style into printed resources and our website as well as internal communications.The same evolution has occurred in the name changes adopted by Positive Life NSW (formerly PLWHA NSW) and Treataware (formerly the AIDS Treatment Project Australia).

We're not trying to push this change onto anybody (four of our member organisations use the PLWHA form in their names) and nor are we planning to change the name of our organisation any time soon. But we are very clear that the way we talk about ourselves is a strong way to encourage others to adapt to changing times.

This article appears in the Sydney Star Observer of 11 June 2009.

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Links:
[1] http://www.starobserver.com.au/news/2009/05/26/%E2%80%98aids%E2%80%99-has-had-its-day/13319
[2] http://napwa.org.au/glossary/term/689
[3] http://napwa.org.au/papers/2009/napwa-language-and-style-guide
[4] http://napwa.org.au/glossary/term/396
[5] http://napwa.org.au/glossary/term/403

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