Positive Life NSW

the voice of people with HIV since 1988

9 May 2011

Ms Valerie Spencer Director, Residential Care Quality Section Quality and Monitoring Branch Office of Aged Care Quality and Compliance

DRAFT REVISED STANDARDS FOR RESIDENTIAL AGED CARE

About Positive Life NSW

Positive Life NSW is a community based non-government organisation that has represented the interests of people living with HIV in New South Wales since 1988. Positive Life NSW provides advocacy and representation to government and non-government agencies on HIV- related issues. It works to eliminate prejudice, isolation and discrimination. Positive Life provides peer support programs, HIV prevention and health education campaigns that focus on improving the health and wellbeing of all people with HIV in NSW.

General Comments

Positive Life NSW strongly advocates for a performance standard based reference that meets the health and social needs of people with HIV in aged care facilities. Performance standards are specifically relevant to the following areas:

- 1.3 Promoting privacy, dignity and choice
- 2.1 Assessment and care planning
- 2.3 Provision of specialist care

Key issues for people with HIV

In 2010, there were approximately 21 000 people living with HIV in Australia. 10 000 people live with HIV in New South Wales. The population of people with HIV has aged substantially. In 2010, one in four people with HIV were over the age of 55. By 2020, it is likely that 50% (5000 people) will be over 65. Some of these people will experience significant cognitive impairment and physical frailty and disability.

Infection with HIV is now managed as a chronic health condition due to the success of highly effective anti-retroviral therapy. Despite improved treatment, people with

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HIV are at an increased risk of hypertension and cardiovascular disease, diabetes, osteoporosis and other degenerative bone disorders. They are also at increased risk from a range of cancers, kidney and liver disease. A high proportion of people with HIV have multiple diagnosed co-morbidities that require specialised monitoring, treatment and care. The onset of these health conditions may be experienced at an earlier age. In addition, rates of depression and anxiety are significantly higher amongst people with HIV than the in the non-HIV population.

Approximately (15%) of people with HIV are heterosexual. The majority of people with HIV infection however are gay men (80%). Stigma and discrimination can be experienced by all people with HIV in health care settings, including residential settings. For heterosexual people with HIV, stigma and discrimination can arise based on assumption or prejudice about how HIV was acquired. Mainstream service providers are not always equipped to meet the needs of people with HIV, gay men, bisexual men, lesbians and transgender people due to lack of knowledge, understanding and acceptance of difference. In addition, lack of HIV awareness and fears of transmission can lead to stigma by staff. Access to specialist advice for assessors will improve the quality of assessment, care planning and the provision of specialised and multi-disciplinary care for people with HIV. It will also have an impact on choices related to their living arrangements and participation in activities that are appropriate and of cultural interest.

Recommendation:

That in assessing compliance against Performance Standard 1.3, policy or measures are specified to ensure compliance by providers in safe-guarding privacy, dignity and choice for people with HIV who are residents in aged care facilities.

That in assessing compliance against Performance Standard 2.1, policy or measures are specified to ensure compliance by assessors to appropriately assess the clinical, nursing and lifestyle needs and as a consequence develop and implement appropriate care plans.

That in assessing compliance against Performance Standard 2.3, policy or measures are in place to ensure that compliance in the provision of specialised nursing care meets the needs of people with HIV.

Conclusion

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With the increasing likelihood that some people with HIV will seek assessment and access to residential aged care facilities, Positive Life NSW considers it essential that services are available to meet their needs and that service providers are willing and skilled to meet the health, cultural and social support needs of all their residents, including those with HIV. We also commend to you the submission by ACON Health Ltd which provides further detail regarding the needs of older gay, lesbian, bisexual and transgender people, including gay men with HIV.

Positive Life NSW would like to thank the Department of Health and Ageing for the opportunity to provide comment on this review of the Aged Care Accreditation Standards Draft Revised Standards for Residential Aged Care. We look forward to the revised draft and to the acknowledgement of the care needs of our community within them.

For further information regarding this submission, please contact Rob Lake, CEO, Positive Life NSW on 02 9361 6011 or via email at robl@positivelife.org.au

Yours sincerely

Rob Lake CEO