

LGBTI fact sheet 8d - Young onset dementia

Additional considerations for LGBTI peoples with young onset dementia (YOD)

Dementia that starts before the age of 65 is known as young onset. In Aboriginal and Torres Strait Islander peoples young onset dementia is defined as dementia which occurs before the age of 50 (1).

- YOD is associated with higher levels of distress and burden in the person with dementia and family carers than those with late onset dementia (1, 2).
- The emotional and financial strain that results from reducing or prematurely stopping work and potentially balancing the care needs of the person with YOD with those of children and/or older parents contributes significantly (3, 4).

***Note:** As it is often not anticipated, younger people with dementia tend to experience extended delays in receiving a diagnosis (5).

- They will typically have experienced the distress of unexplained symptoms where they are aware that something is wrong but they are unable to obtain answers.
- The trauma and frustration associated with the delay is further exacerbated by their limited access to relevant information, support and services. The situation is exacerbated further still when

the younger person identifies as L, G, B, T or I.

Lack of services

- An estimated 26,443 Australians currently have young onset dementia and numbers are predicted to increase (6). Community and residential care services, however are primarily tailored to the needs of older people (1, 3, 7).

***Note:** Very few services cater specifically for the needs of those with YOD, significantly limiting their access to LGBTI inclusive services.

- Younger people tend to be affected by the less common forms of dementia such as frontotemporal and Lewy body dementia which often present with more challenging BPSD (1, 4, 8).
- Those diagnosed with HIV-associated dementia also tend to be younger.
- Assistance with managing BPSD is one of the primary reasons carers of those with YOD seek formal services (3, 8), in spite of the lack of specific services for this age group.

Additional issues

- Although the principles of managing BPSD are the same whatever the age of the person who is L, G, B, T or I, younger people with dementia are obviously at a different stage of their life and hence, experience additional issues. They may:
 - become further isolated by the dementia

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- have been forced to retire early and could still have significant financial commitments
- have a partner/carer who is still employed and/or dependent children living at home
- be relying on older parents who are becoming too old or unwell to continue in the caring role
- be more aware of their dementia and more distressed when they recognise that they are losing everyday skills
- be physically fit with higher levels of frustration which can lead to additional challenges when managing some BPSD
- feel even more out of place in aged care services than older LGBTI peoples. (1, 9-13)

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See *Fact sheet 1 – Overview* for details.