

Updating services for people with younger onset dementia and their caregivers

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Researchers from the Jockey Club Centre for Positive Ageing analyse the services available for people with younger onset dementia, looking to improve the lives of those affected and their carers

People who exhibit dementia-related symptoms when they are under age 65 are categorised as people with younger onset dementia (YOD). Currently, there are 4.9 million people with YOD,^(1, 2) accounting for 9% of the dementia population.

Compared to people with late-onset dementia, such as dementia onset at or after 65 years old, people with YOD face different challenges and therefore require different support in their daily lives. However, the existing dementia services mainly focus on the elderly with late-onset dementia, suggesting that people with YOD and their caregivers are not adequately supported.^(3, 4)

People with YOD are prone to be admitted to hospital due to mental and behavioral disorders, other nervous disorders, and epilepsy.⁽⁵⁾ They also have a higher chance of getting injured than peers of the same age; a cohort study examining the police traffic records and national health database system of 78,688 people aged 40 to 64 years showed that people with YOD had a higher risk of hospitalisation due to motor vehicle crash injury, especially those being diagnosed within one year.⁽⁶⁾

People with younger onset dementia need more hospital services

It takes two to three weeks for people with younger onset dementia to discharge from hospital, while their peers without dementia stay in hospital for four to seven days.^(5, 7) In addition, people with YOD are more likely to be readmitted to hospital; over half of the people with YOD would be readmitted to a hospital within three months after discharge, which is two times more than that of people without dementia in the same age group.⁽⁵⁾

After hospital discharge, people with YOD have high caregiving needs as around two-thirds of them cannot stay at home alone or only stay independent for half a day.⁽⁸⁾ While their family members bear a heavy responsibility in caregiving, studies show that less than half of the main caregivers receive support from other family members and friends,⁽⁸⁾ and most caregivers of people with YOD identified themselves as having poor or very poor emotional well-being.⁽⁹⁾

Compared with late-onset dementia, caregivers of people with YOD also face unique stress including lack of preparation for caregiving at a relatively young age, high stigmatisation due to lack of public awareness of YOD, and adverse effects on the family relationship.^(10, 11) The long-hour caregiving means that family members have to reduce their working hours or give up their work; in addition, the people with YOD may still be the financial contributor in the family at the time of onset, so when they lose the capacity to earn for living due to the onset, their caregivers face a double financial burden. A high proportion of families of people with YOD reported having a household income below or within the minimum acceptable standard for living.⁽⁸⁾

Age-appropriate, timely, and ongoing support for people with younger-onset dementia

Regarding the unique physical, psychological, emotional, social, and financial needs of people with YOD, it is important that they could get age-appropriate, timely, and ongoing support, especially upon diagnosis. A study showed that multidisciplinary, specialist YOD services can provide more quality and continuous care to people with YOD and their caregivers.^(8, 12) However, the existing support services are primarily designed for older people with late-onset dementia and, therefore not age-appropriate for people of younger age and their caregivers.^(13, 14)

Similar to people with YOD, service usage of family members of YOD is low.⁽⁸⁾ Only a few caregivers use the respite service regularly, indicating many of them could not relieve their stress from the long care-taking hours. Caregivers of YOD usually felt excluded and socially isolated as younger-onset dementia is less common than late-onset dementia.⁽¹⁵⁾

Understanding the mental health needs of dementia carers and their patients

Attending caregiver support groups can reduce isolation by sharing experiences with peers, but it is rarely used by caregivers of people with YOD.⁽⁸⁾ Family members who seek help from external organisations tend to use services provided by charity groups but not those offered by the government as the latter is not age-appropriate, more expensive or inconvenient opening hours.⁽¹⁶⁾ The high level of stress of caregivers YOD remains with the low usage of social services.

The needs of people with YOD and their caregivers differ from older adults living with dementia. As there is growing awareness of YOD, and therefore need for diagnosis and post-diagnostic support, there is a need for the government as well as non-governmental organisations to provide tailored services to this cohort so that they could continue living in the community with dignity and quality of life.

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More About Stakeholder

Jockey Club Centre for Positive Ageing

Person centered care model for people with dementia, supporting public education, research, and professional training in dementia care

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