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Media Release

### **Diagnosis of younger onset dementia has life changing impact on families**

Dementia is not something you associate with young people yet it is estimated that there are more than 24,400 Australians living with younger onset dementia.

A diagnosis of younger onset dementia is not only challenging for the person who receives the diagnosis but has an enormous impact on the entire family. Currently there are no official figures as to how many young people in families are impacted in Australia.

Isolation and guilt are the overwhelming feelings, according to children of a parent with younger onset dementia at the recent Supporting Young People having a parent with Younger Onset Dementia Workshop.

Karen Hutchinson, workshop organiser and author of the recent paper "The emotional well-being of young people having a parent with younger onset dementia," published in *Dementia* told workshop attendees, that children of a parent living with younger onset dementia are often the invisible carers and are not recognised by health care providers.

"Our study identified four common experiences of young people living with a parent with younger onset dementia," said Karen Hutchinson. "These included the emotional toll of caring, keeping the family together, grief and loss and psychological distress."

Presenters told the workshop of feelings of disengagement, anger and despair when a parent was diagnosed with YOD.

"There was a big change in the way people treated me when they found out my mother had dementia. Nobody was giving me guidance or monitoring my behaviour," explained one young person who had a parent diagnosed with younger onset dementia.

"Support from extended family disappears and friends disappear due to the stigma associated with dementia. People don't know how to deal with someone with dementia and distance themselves."

The workshop, hosted by the NHMRC Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People ([Cognitive Decline Partnership Centre](#)), a \$25 million program and part of the \$200 million Boosting Dementia Research Initiative, brought together individuals and organisations from across the dementia and youth sectors in Australia including support services, aged-care providers, clinicians, people living with younger onset dementia and their children.

The real life stories from young carers provided a vivid and emotional insight into what it means to belong to a family when a parent receives a diagnosis of dementia. Challenging behaviours, managing parent's cognitive and functional decline, difficulty with accessing, navigating and availability of services, struggles for assessment for respite care and placement of the parent as well as whole family issues associated with the complex situation were just some of the issues highlighted.

Reassurance that these issues are being recognised and addressed was provided by the support services, Headspace, Young Carers NSW, Alzheimer's NSW Younger Onset Dementia Key Worker Program and Alzheimer's Australia.

The recent national launch of Alzheimer's Australia Younger Onset Dementia Key Worker program is one such initiative that provides individualised support and services for people with younger onset dementia and their families.

"The Key Workers have a mix of clinical, counselling and case management backgrounds, and offer assistance across a range of client needs," said NSW Team Leader, Marie Gorman.

Key Workers are responding to clients across vastly different stages of the dementia journey, and the complexity is very variable."

Mark Gaukroger, Director Dementia policy at the Department of Health and Ageing said, "The most important thing is the sustainability of the carers and the access to all the support services. We have gained a much greater understanding that dementia is not solely a health issue but has huge social implications"

The overwhelming message of the workshop was the issue of information outreach.

"We need to look at how we better engage with young people of parents with younger onset dementia to inform them of the numerous channels of support out there. It was good to hear about the services available, and I hope that there will be growth of this support in the future," said Karen Hutchinson

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