

Extra support needed for younger dementia sufferers, report finds

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(Medical Xpress)—The unique needs of people with younger onset dementia have been addressed for the first time in new research by the [Social Policy Research Centre](#) (SPRC).

The report, "[Service and Support Requirements of People with Younger Onset Dementia and their Families](#)," commissioned by the NSW government, looks at the needs of [dementia sufferers](#) under 65 and Aboriginals with [dementia](#) under 50 years.

There is an estimated 8,000 people under 65 in NSW with the

condition. The younger onset means sufferers are often still in paid employment, raising a family and physically strong and healthy.

UNSW Associate Professor Karen Fisher said the report aims to help service providers develop targeted and relevant services for these people.

"Imagine if tomorrow you found out you had this degenerative condition, and couldn't work, or provide care for your family as previously planned. Few of us would know where to turn for advice about how to make that adjustment," she said.

Report participants said misdiagnosis was a major barrier to accessing appropriate support services. Most people experienced a lengthy [diagnosis](#) process that often involved convincing their GP that something was wrong. The most common source of diagnosis was from a [neurologist](#) (49 per cent), followed by a geriatrician (29 per cent).

Many participants expressed the need for an individual case manager to coordinate their care and offer support to their [family members](#).

More than 81 per cent of family members and carers felt they would benefit from respite care or domestic help, often so they could continue working when their partner couldn't.

Centre-based programs, excursions and exercise were cited by participants as helpful to managing their condition.

Provided by University of New South Wales

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