Young onset dementia

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Study participants

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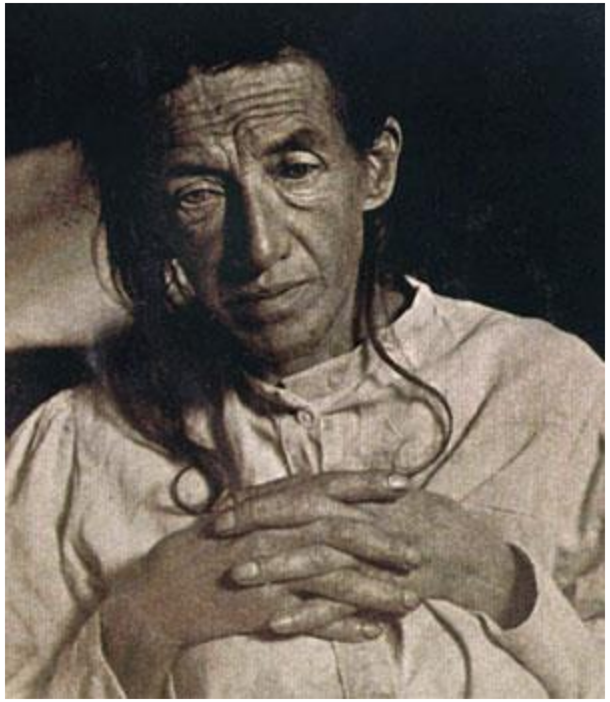
Young onset dementia in historical context



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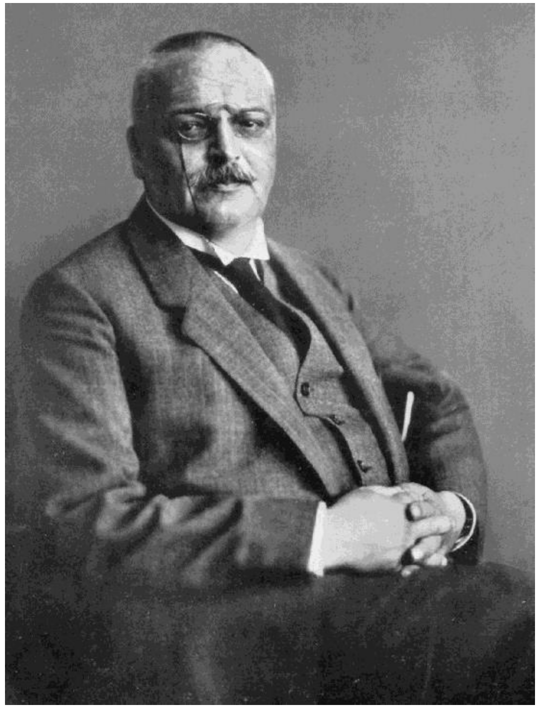

Dr. Alois Alzheimer

What is young onset dementia?

- **People with YOD are more likely to:**
- Be working
- Have children living at home
- Have a rare form of dementia
- Experience long diagnostic delays
- Live at home for longer

Young onset dementia (YOD), also called early-onset dementia, refers to dementia that develops in people under the age of 65.

The World Health Organization estimates that young onset dementia represents 6 to 9% of all dementia cases (WHO, 2012).

What we know

- Barriers to care: receiving a diagnosis, obtaining information, accessing health and support services.
- Canadians with YOD waited three times as long compared to older adults with dementia to obtain a diagnosis (Novek, Shooshtari and Menec, 2015).
- Family members report high levels of stress, mental health problems, financial impacts and social isolation (Bakker et al., 2014; Ducharme, 2015).
- Children have significant unmet needs for care including access to information and counselling, and access to age-appropriate support services (Millenaar et al., 2014).

Research Study: Perspectives on health and support services for people with young onset dementia

Aim of the study: to examine health and support services for people with YOD in Manitoba from the perspectives of people living with the condition, family members and care providers.

Interviewed:

6	• People living with young onset dementia
14	• Family members
16	• Care providers and policy stakeholders

Diagnosing Young Onset Dementia

Family Perspectives

- Long wait times to see multiple specialists
- Value clear and sensitive communication

Provider Perspectives

- Diagnostic complexity and uncertainty
- The absence of a multidisciplinary dementia clinic
- Age restrictions for health and support services

"Yeah 2010 is when we started down this road … and it was the end of 2014 when we actually got the diagnosis. So it was a long four years, it was harsh, …I don't even know how we made it through." (Spouse)

"[Ideally] you'd probably start off with a neurologist to make sure you don't have a treatable neurologic disease. Second is to be seen by a psychiatrist to make sure you don't have a treatable psychiatric illness… and then probably a neuropsychologist. So probably you'd need to make three stops, three referrals, three different waiting lists, so it's really quite cumbersome." (Physician)

Financial issues and resources

Dementia is a costly disease, with significant financial ramifications for patients and families

People with YOD are often forced to give up employment, and they may not be financially prepared for early retirement

Family caregivers may also have to reduce their hours or give up employment to provide care

"It took a couple of years before I actually realised, oh my goodness, there's this funding available through disability pension. And fortunately it's retro-active, but it didn't go back far enough to cover the whole time. (Caregiver)

Financial resources

- Community financial Counselling Services (CFCS): www.debthelpmanitoba.com
- Society for Manitobans with Disabilities
- The Alzheimer Society
- www.getyourbenefits.ca
- www.newfinancialreality.com

If you are not able to earn income because of health issues or a disability, there are some government programs that might help you:

- Canada Pension Plan – Disability Benefits
- Employment and income Assistance – Disability Benefits
- Disability tax credit
- Primary Caregiver Tax Credit (Manitoba)

Recreational programs and social inclusion

- Meaningful and age-appropriate social activities
- Support groups for people with YOD and carers

“It's tough because everybody gets up and everybody goes to work or everybody goes to university….And there's me and [the dog] and I love her to death but everybody's gone.” (Participant with dementia)

We did try a day program though and most of the people - it wasn't so much their age as their abilities - and you really didn't like that at all and you were among the youngest person there but you were the most fit person there, so you didn’t feel like you fit in there and you didn’t like it. I couldn’t convince him to go back” (Spouse).

Recommendations

- Increase awareness of young onset dementia.
- Better coordination of the diagnostic process and post-diagnostic care.
- Improve access to tailored information and support.
- Develop community based programs for people living with young onset dementia and their families.
- Review age restrictions.

Innovative services

- Specialized young onset dementia clinics (UK)
- Key support workers (Australia)
- Specialized, multidisciplinary day programs (e.g., Frontotemporal Dementia Day Program at Baycrest)
- Specialized recreational programs (e.g., Young Onset Dementia Association in Waterloo, Paul’s Club in Vancouver)

Thank you!

For more information, please visit: youngonsetdementiastudy.com

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