

Young onset dementia: Negotiating future workplace roles and identities

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A diagnosis of young onset dementia (i.e. under the age of 65 years) often comes at a time when people are living with the demands of a family and/or elderly parents of their own to care for. Financial obligations such as mortgages, school or tuition fees, supporting young children or young adult children, may all contribute to an overwhelming sense of chaos and confusion for a family. At the centre of the family unit is the younger person with dementia themselves, who is learning to live with their diagnosis (Beaumont, 2009; Roach, Keady, Bee, & Hope, 2008).

Often the first signs and symptoms of young onset dementia are noticed prior to diagnosis by the person with dementia and their family, but not overtly identified as a form of dementia. Strategies to cope with memory difficulties become important in the life of the younger person with dementia. Maintaining employment can become problematic for the younger person with dementia during this stage and performance issues at work, coupled with potential personality changes, can frequently mean a difficult or traumatic transition out of employment (Ohman, Nygard, & Borell, 2001). This may increase stress for the family as a whole, as financial strain is often placed on the family, and in many cases the spouse feels added pressure to support the household on their own. Moreover, the younger person with dementia can feel out of place as these transitions come ‘out of time’ in a ‘usual’ life cycle. This can place additional emotional strain on the younger person with dementia as they struggle to find meaning and purpose with their new place and role in the family and in society, particularly if exiting the workforce has come before a diagnosis and is either unexplained or insufficiently explained (Roach & Drummond, 2014).

As more and more research is done about young onset dementia, these issues, among others, have come to light. The significance of meaningful activity, of maintaining a valued role in the family unit, becomes paramount to upholding a sense of personhood. But how do we, as a society, find, develop and construct these meaningful activities? What work provides purpose for a person with young onset dementia? We know this will be unique for every individual, so how do we begin to design an individually meaningful programme for each younger person with dementia? This may seem like a daunting task but it does not need to be.

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The piece to this puzzle that is often missing is the piece that encompasses community engagement, public health and information provision. Promoting the facts that it is possible to live well with dementia, that it is possible to work well with dementia, and also to remain a citizen with dementia engaged in the local community, is crucial not only to reducing stigma, but also to moving toward an actual model of inclusivity for (all) people with dementia and their families. Throughout the dementia literature, social isolation is evident, particularly so for younger people with dementia and their family members. The younger person with dementia is frequently seen as ‘other’, both within a family unit and also within wider society. As we focus more intensely on reducing the ‘otherness’ within family units via family centred care, the family unit then becomes at risk of being perceived as ‘other’ from society. To really include families and individuals with dementia as fully functioning members of society, it is time to address the ‘otherness’.

It is time to educate employers in ways of working with younger people with dementia, of supporting such individuals to maintain the person in employment such as by modifying activities and negotiating new horizons of work productivity (Chaplin & Davidson, 2016; Ohman et al., 2001; Robertson & Evans, 2015). These new horizons mean that the younger person with dementia can continue to contribute in a meaningful way that maintains their personhood and supports their historical work role and biographical identity. As the movement toward using life story work with younger people with dementia continues to gather pace, it is imperative that we use this life story work in ways that make sense to the lives of those living with dementia. Workplace education and promotion projects have the potential to make great strides towards this move of inclusivity. Health promotion has greatly increased the acceptability and compassionate understanding of caring for employees with a variety of diagnoses and making reasonable adjustments to adapt the workplace to such diagnoses (Chaplin & Davidson, 2016). Through education, understanding and consideration of mutual goals and needs – the needs of an employer being balanced with the needs of a person with dementia – it is also possible to maintain purposeful activity for younger people with dementia. This activity does not necessarily need to be within the workplace that previously employed the person with dementia, or employed them at the time of diagnosis, as there will be instances where this is not appropriate. However, there are many large and small organizations that have detailed community engagement and social responsibility portfolios that could take on this role. Coordinated care where links may be made to charities, agencies, employers, and private industries can facilitate the necessary connections that can make these crucial, community-based programs a reality.

Not only do we need to push toward the inclusion of people with dementia in the workplace but we need to acknowledge and recognize the need for meaning within those roles. A recent publication (Robertson & Evans, 2015) that describes a work place programme designed specifically for younger people with dementia worked collaboratively with the project participants and family members to determine what the participant determined ‘good outcomes’ would be. These outcomes not only included improved well-being and socialization, but also contribution to society and engaging in worthwhile activities. This research is encouraging in the way that the regular workplace employees were educated and trained to work together with the younger people with dementia, who were essentially ‘volunteering’ at a hardware store (Robertson & Evans, 2015). We now need younger people with dementia to not only work alongside an educated and willing workforce, but to become part of it. Educating employers to hire younger people with

dementia, to support younger people with dementia, and to support their current workforce to work alongside people with varying levels of cognitive abilities is the crucial next step.

Likewise, as dementia villages continue to garner international attention as a step forward for creating home-like environments and, more importantly, engaging persons with and without dementia as part of the same community (Jenkins & Smythe, 2013), we can take these same lessons forward for persons with dementia earlier in their journey. We do not need to wait until people with dementia transition to a communal living facility in order to engage younger people with dementia as part of the community, especially after already experiencing increasing isolation while living at home with dementia. We should strive to maintain active engagement in the community for younger persons with dementia and their families at all stages of the condition. Engaging in meaningful activity can improve well-being, socialization, and also support family members to continue to work and support the family unit financially. By taking the next step and making persons with dementia an actual part of the workforce and reemploying them, they can be enabled to contribute financially to their family. Not only may this lead to a person with dementia feeling useful, purposeful and needed, it also can help in maintaining a sense of their biographical self (Roach, Drummond, & Keady, 2016). By engaging with the community at large in such a way, not only do we move toward a sense of belonging for the person with dementia, but also the family, and we move them further from the 'other'.

As employers strive to accept and reduce the stigma, and to accommodate physical and mental health issues for their employees, we need to raise awareness of dementia in the workplace and work collaboratively with employers to develop strategies to support not only caregivers, but also persons living with dementia. It's time to change the way we react to a diagnosis of dementia in those we know, be that personally or professionally, and turn the tables on young onset dementia by keeping those diagnosed with it at the table and engaged in the conversation.

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References

- Beaumont, H. (2009). *Losing Clive to younger onset dementia*. London: Jessica Kingsley.
- Chaplin, R., & Davidson, I. (2016). What are the experiences of people with dementia in employment? *Dementia, 15*(2), 147–161.
- Jenkins, C., & Smythe, A. (2013). Reflections on a visit to a dementia care village. *Nursing Older People, 25*(6), 14–19.
- Ohman, A., Nygard, L., & Borell, L. (2001). The vocational situation in cases of memory deficits or younger-onset dementia. *Scandinavian Journal of Caring Science, 15*, 34–43.
- Roach, P., & Drummond, N. (2014). 'It's nice to have something to do': Early-onset dementia and maintaining purposeful activity. *Journal of Psychiatric and Mental Health Nursing, 21*, 889–895.

- Roach, P., Drummond, N., & Keady, J. (2016). 'Nobody would say that it is Alzheimer's or dementia at this age': Family adjustment following a diagnosis of early-onset dementia. *Journal of Aging Studies, 36*, 26–32.
- Roach, P., Keady, J., Bee, P., & Hope, K. (2008). Subjective experiences of younger people with dementia and their families: Implications for UK research, policy and practice. *Reviews in Clinical Gerontology, 18*, 165–174.
- Robertson, J., & Evans, D. (2015). Evaluation of a workplace engagement project for people with younger onset dementia. *Journal of Clinical Nursing, 24*, 2331–2339.

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