

FORUM ARTICLE

Living with young onset dementia: reflections on recent developments, current discourse, and implications for policy and practice

Andrea M. Mayrhofer^{1*} , Shaheen Shora², Margaret-Anne Tibbs³, Sarah Russell³, Brian Littlechild⁴ and Claire Goodman¹

¹Centre for Research in Public Health and Community Care, University of Hertfordshire, Hatfield, UK, ²Hertfordshire Partnership University NHS Foundation Trust, Watford, UK, ³TIBBS Dementia Foundation, Bedford, UK and ⁴School of Health and Social Work, University of Hertfordshire, Hatfield, UK

*Corresponding author. Email: a.mayrhofer@herts.ac.uk

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Abstract

Recent research on young onset dementia (formal diagnosis at age <65) evidences emerging work around pre-diagnosis, diagnosis and the need to improve post-diagnostic support for this group. An increased awareness of young onset dementia has led to the establishment of peer-support groups, support networks and the involvement of people affected by dementia in research. However, the need to join up services at the systems level persists. Third-sector organisations that offer post-diagnostic support at the community level rely heavily on volunteers. Implications for policy and practice are that community-based commissioning of integrated services between health care, social care and the third sector would go a long way to providing the continuity and stability required in dementia support and care along the illness trajectory. This discussion document was written in collaboration with diagnostic services, the charity sector and conversations with people living with, and affected by, dementia.

Keywords: young onset dementia; rare dementias; dementia care; support; services; volunteering; community

Introduction and background

Of the estimated 850,000 people diagnosed with dementia in the United Kingdom (UK), approximately 5 per cent have been diagnosed with young onset dementia and rare dementias (Alzheimer's Society, 2014). Young onset means that people are under the age of 65 when a formal diagnosis is made. Literature published over the last 25 years (Mayrhofer *et al.*, 2017) has highlighted consistently that

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the support needs of younger people with dementia differ considerably from those of people diagnosed with dementia in later years. Younger people tend to find themselves still in employment, often need to seek financial and/or legal advice as employment is discontinued, and must negotiate changing family dynamics with a particular focus on children (Hall and Sikes, 2018) and often older parents. Their experience of ageing is largely determined by the support that is available to them and their families.

Clinicians provide a range of psycho-social interventions, third-sector organisations offer community-based support, and support networks have developed across the UK both for younger people with dementia (Dementia Engagement and Empowerment Project (DEEP), 2019) and for carers (Together In Dementia Everyday (TIDE), 2019). The national dementia strategy and the Implementation Plan (Department of Health, 2016) gave rise to developments such as Dementia Action Alliances and Dementia-Friendly Communities (DFCs). Yet, service provision is distributed very unevenly across geographical areas, and made possible only through increasing numbers of volunteers.

Illness progression, and therefore support needs, vary considerably in young onset and rare dementias such as fronto-temporal dementia and posterior cortical atrophy (*e.g.* Harding *et al.*, 2018; McIntyre *et al.*, 2019). Eligibility, type and level of post-diagnostic support for younger people with dementia are determined by Adult Social Care assessments (Age UK, 2019). Functional decline is often not visible in the early stages of young onset dementia. Combined with assessors' limited experience of working with people with young onset dementia, assessments are not always accurate, which complicates requests for meaningful support. Consequently, both in the early and more advanced stages of dementia, most of the support and care for this group is provided by family members and by third-sector organisations who rely on volunteers.

This reflective commentary was authored by clinicians, researchers, people living with young onset dementia and representatives of a dementia-focused charity. It draws on current research and considers how to take work on community-based dementia support forward.

Evidence from current research

Current research in dementia support and care addresses what good support could and should look like. The recently published MODEM Dementia Evidence Toolkit provides scientific evidence of studies pertaining to the care, support and treatment of people affected by dementia (Comas-Herrera *et al.*, 2017). Significant contributions to raising awareness about the condition and to providing support have also been made via Dementia Friends (Alzheimer's Society, 2017), Dementia Action Alliances (National Dementia Action Alliance, 2017) and DFCs (British Standards Institution, 2015). Recent work on DFCs (Woodward *et al.*, 2018; Buckner *et al.*, 2019; Goodman *et al.*, 2020) showed that, whilst young onset dementia was not addressed specifically, most of the people informing local projects are in fact those diagnosed at a younger age. The ANGELA project was designed to focus on people diagnosed with young onset dementia (UCL University College London, 2016), and the IDEAL study includes people with

young onset dementia in Phase 2 of the project (Silarova *et al.*, 2018). Findings across these studies are consistent with a range of smaller-scale studies on support for people diagnosed with young onset dementia (Mayrhofer *et al.*, 2017).

Evidence from Experts by Experience

Experts by Experience (EbE) are people affected by young onset dementia, whether the person diagnosed or their families. They are not research participants in the traditional sense, but people with lived experience of dementia who are willing to offer insights and advice. A frequent problem expressed in numerous support groups is the lack of service co-ordination. One couple shared that they ‘had 39 appointments before diagnosis’ (EbE02a). Another person stated that ‘referral mechanisms are not standardised; there was confusion over who could prescribe, whether it was the GP [general practitioner] or the consultant’ (EbE02b).

Clinicians are very aware of the specific issues that younger people with dementia encounter prior to receiving a formal diagnosis and are working to resolve this issue (Young Dementia UK, 2017; O’Malley *et al.*, 2019). There is also a recognition at diagnosis that these patients are different and need something different. As stated by a consultant psychiatrist (old age):

Young onset dementia presents its unique challenges from diagnosis to management and end of life care arrangements. The progression of the clinical presentation and functional decline associated with young onset dementia is far more rapid and severe compared to late onset dementia. Patients with young onset dementia present with more behavioural and personality changes earlier than with late onset dementia. It is far more challenging to manage these changes as this group of patients are physically younger, fit and very mobile. Younger patients with dementia, in my clinical experience, are far more sensitive to psychotropic drugs, more susceptible to side effects and therefore have less tolerance to be treated with this group of medication which currently is the only treatment available to control symptoms. (Consultant psychiatrist, old age)

Support in the community post-diagnosis

Once a formal diagnosis of dementia has been made, some memory clinics arrange for patients to receive a visit from an Alzheimer’s Society support worker who can signpost to various support options that might be available in the area. If appropriate, a carers assessment will be carried out by Adult Social Services and, if required, an appointment to see an occupational therapist will be arranged. However, many EbE perceive post-diagnostic services to be very disjointed. One person stated that ‘organisations don’t work together; each time we have to repeat our story ... that’s to the social worker, occupational therapist, or to the charity’ (EBE01). Social work staff are not necessarily trained to assess people with young onset dementia. As a husband observed: ‘they asked my wife whether she could cook; she said “yes”, but of course she can’t anymore’ (EbE03, spousal carer). Another person stated that despite a formal diagnosis and further assessments, ‘I am still sent to the job-centre although they know that I cannot work any longer’ (EbE09, person

diagnosed with young onset dementia). However, once a box on an assessment form has been ticked it may be difficult to undo, which means it is unlikely for appropriate support to be assigned.

We know that social workers are necessary as they allocate money and deal with paperwork, but all sorts of people come to the house, I forget who they are and who has been ... it all just gets too much. (EbE 06, carer of person with mid- stage dementia)

When speaking to various support groups it became clear that people were keen to just get on with their lives and continue to lead a 'normal' life as far as possible. They wanted normal experiences such as going out with others in similar situations to 'share a meal, watch a movie ... can we [can charities] match people together...?' (EbE 05). Young people with dementia felt that there was a lot of merit in connecting people to each other. As expressed by one person: 'support groups should not be split according to ages (diagnosed under the age of 65), but according to stages (of illness), interest and ability (EbE 03). However, younger people with dementia also needed to know that they could access help if or when required. As expressed in one group: 'we need an anchor, just in case ... someone familiar on the other end of a phone and someone who knows us' (EbE08).

Targeted service provision and specialist support are limited as there may be very few younger people with dementia in any one geographical area. For example, support groups for people diagnosed with rare dementias such as posterior cortical atrophy and fronto-temporal dementia are offered in London (UCL Rare Dementia Support, 2019), but are not widely available throughout the country. Community-based support therefore is a critical mechanism for families affected by young onset dementia.

This raises the question of how to plan, implement and sustain community-based support and build on approaches that have been shown to work. The Social Care Institute for Excellence (SCIE, 2018) advocates strength-based approaches (Blood and Guthrie, 2018; Baron *et al.*, 2019) that are not only person-centred, but also family-centred and include spousal carers, as well as young carers, or adult children who take on care responsibilities. Whilst person-centred theoretical frameworks are well articulated (Kitwood, 1997; Blood and Guthrie, 2018), it has been difficult to translate them into practice for younger people with dementia in ways that recognise and support their carers and dependants. The flexibility required to adjust generic dementia support as required has been lacking.

One model described as 'working well' employed trained case workers (key workers) who facilitate care co-ordination and support for younger people with dementia over a period of time (Clive Project (now Young Dementia UK), 1998; Sansoni *et al.*, 2014; Westera *et al.*, 2014). Trained case workers can maintain continuity of support by responding to changing care needs along the illness trajectory and its impact on the family. As expressed by a service provider:

...agency staff often come and go, but we train our case workers and employ them on a permanent basis. In some cases, we have been with a family for 10 to 12 years, even post bereavement. (Service provider 10). (Mayrhofer *et al.*, 2018: 9)

Social networks and social movements?

The recent rise of social networks is notable. Charities are working closely with people affected by dementia to ensure their voices are heard and their priorities known (DEEP, 2019; Dementia UK, 2019; Innovations in Dementia, 2019; YoungDementia UK Network, 2019). As pointed out by DEEP (2019), they are not an organisation, but a network of over 100 independent groups across the UK. These groups are run by people with young onset. DEEP 'engages and empowers people living with dementia to influence attitudes, services and policies that affect their lives' (DEEP, 2019). Informal discussions at a recent Dementia Congress revolved around *not* being a project, or even a network, but a social movement. There seems to be a recognition that people will have to organise themselves as best as they can, wherever they can, and for as long as they can to work towards reducing lingering stigma, and to support each other to create a sense of belonging, raise awareness and maintain quality of life. These developments are supported by charitable funding. Yet, whilst such activism may be necessary for change to be achieved, dementia is a progressive illness, and changing support and care requirements along the illness trajectory will need to be considered.

Community-based person-centred care planning: changing how systems of care think and respond

What is required for the younger group is not a mere tailoring of existing provision, but an integration of care needs of people with young onset and rare dementias. This requires flexibility, which is why the involvement of younger people diagnosed with dementia and affected families in the planning of care and support, in order to sustain quality of life and ultimately delay institutional care, is critical (Gove *et al.*, 2017; Pandya-Wood *et al.*, 2017; Charlesworth, 2018; Litherland *et al.*, 2018; Mayrhofer *et al.*, 2018). A recent study showed that the inclusion of people with young onset dementia and their care-givers in service design provided a pragmatic and realistic view of what is important and achievable for them (Mayrhofer *et al.*, 2018). Creating a model of responsive care may therefore be more effective through the development of locally available, community-based, co-ordinated services that emphasise integration and value individuals' endeavours, and rights, to live as well as they possibly can (Buckner *et al.*, 2019). An example of a local charity using a truly community-based approach to engaging with people with dementia and their families demonstrates how they can respond to issues as they present. This charity consists of people with dementia, care partners, volunteers and a small group of paid staff with experience in Social Services and the third sector. However, as the charity's founder pointed out:

...the main source of support for the activity groups we run comes from our approximately 70 volunteers, many of whom have formerly cared for a person with dementia. We currently run about 40 support groups for about 300 people each month. Whilst there is a dementia care pathway, it has become clear that people choose the time and the group with which it is right for them to engage. Our model is consciously and deliberately loose and fluid. People with young onset dementia in their fifties and early sixties fit quite happily into a group which suits them personally. (Service provider 11, charity)

This charity enables people living with dementia and their family carers to spend time in the company of people ‘who understand what it is like’ having to cope with a diagnosis of dementia, endeavouring to make a meaningful contribution to society despite a terminal illness, and to remain socially connected to counteract social isolation.

Whilst volunteering is identified as a pillar that community-based wellbeing relies on, in particular for people affected by dementia (South, 2015), volunteer turnover can be high, often due to other caring responsibilities, ill health, natural attrition or due to challenging behaviours that people with rarer forms of dementia may develop (Lowenberg-DeBoer and Akdere, 2018). This threatens many initiatives and affects people with dementia living at home, their care-givers and the networks of support on which they rely.

Volunteers are integral to support offered at the community level, but there is little evidence of how micro-level interventions based on volunteering can be sustained, and how locally relevant knowledge might be preserved when volunteers retire. This requires further research. We need to ensure that community-based support, care-giving and volunteering are adequately supported through capacity building across professions.

Implications for policy, practice and research

Community-based commissioning of integrated services between health care, social care and the third sector would provide not only the local ‘anchoring’ needed for younger people with dementia, but also the continuity and sustainability required for dementia support and care along the illness trajectory. A significant step would be for dementia policy to emphasise that dementia is not a ‘mental health’ issue *per se*, but a degenerative physical condition not dissimilar to other terminal conditions. This might go a long way towards a better understanding of young onset dementia and highlight the necessity for community-based commissioning for services that support individuals and families as the illness progresses.

The knowledge gained from recent studies is that approaches to care co-ordination and system navigation (Health Education England, 2016) are the starting point and not the solution. A co-ordinated approach to integrating health care and social care reduces the risk of missing unmet need (Royal College of Psychiatrists, 2018), but for younger people diagnosed with dementia this needs to be complemented by a much broader community-based safety net that can learn from existing initiatives and work to create DFCs and similar locally based provision. Such initiatives rely on volunteers. Little evidence exists of what enables volunteers to sustain their involvement and achieve a positive impact for people affected by dementia. Research is needed to explore how volunteering initiatives can provide sustainable support that reflects the needs and priorities of people affected by dementia as the illness progresses.

Concluding thoughts

This article argues that, whilst there is excellent support for people with young onset dementia in places, such support is not joined up at the systems level.

Post-diagnostic support at the community level relies heavily on volunteering. The challenge is to find ways to join up approaches that are known to work well, and to ensure that they are sustainable in the longer term to support individuals and families along the illness trajectory.

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