

# Services and support for people with early-onset dementia and their unpaid carers

**by Margaret Perkins**

*While dementia is usually associated with older people, it can affect younger people. If a diagnosis is made under age 65, this is referred to as so called early-onset or young-onset dementia. One estimate suggested that there were 15,000 younger people with dementia in the UK in 2007. This is likely to be a major underestimate by up to three times because of the way the data relies on referrals to services (Knapp and Prince 2007). Given the different place in the life course with family, financial and work responsibilities, the impacts can be particularly devastating and life changing for the whole family. A recent exploratory study undertaken in PSSRU investigated the current picture 'on the ground' from two differing perspectives: experiences of younger people diagnosed with a dementia and their unpaid carers, and of professionals (health, social and voluntary sector) in providing services and support for this group. We found that service availability and care pathways varied with degree of local service specialisation, and that client satisfaction was greatest where the family had an ongoing and supportive relationship with their local specialist clinical team. Financial constraints and low case numbers are the main barriers to establishing more specialist services.*

The **National Dementia Strategy** (DH 2009) sought to drive improvements in services and support for all people with dementia through better information, better understanding among all health and social care professionals of the needs of those with dementia and access to more timely assessment and diagnosis. Studies of younger people with dementia, where prevalence is low (around 2% of all dementia diagnoses), report the heavy burden on informal carers of caring for a younger person with a dementia (van Vliet et al 2010) and an increased length of time to diagnosis because the condition in younger people is often more complex (van Vliet 2011). Age-appropriate support is rarely available locally so families often have to rely on services targeted at much older people with dementia (Jefferies and Agrawal, 2009) and the knowledge base at primary care level may be low. The local **Alzheimer's Society** or **Frontotemporal Dementia Support Group** may offer valuable support specifically for younger people and their carers.

For our research, we chose three convenient sites – a London borough; a rural shire county and an urban shire county. We interviewed a small number of people with various forms of early-onset dementia and their unpaid carers as well as professionals providing services within the health, social care and voluntary sectors to explore care pathways, satisfaction with services and barriers to better provision.

## **Pathways to care**

The pathways to diagnosis and subsequent support varied across the sites.

- The London borough had a tertiary research centre and a clear pathway of referral for younger people with a suspected dementia into the centre. This pathway was well known to local GPs, enabling patients to be seen and diagnosed quickly by the specialist team.
- The rural shire county also had a tertiary centre and received complex and unusual referrals from a wide geographical area.
- The urban shire county did not have a specialist unit nearby. A community based old-age psychiatrist and a hospital neurologist, both with a particular interest in younger people with dementia, assumed responsibility for initial diagnosis in the local area with follow-up undertaken through the GP and community mental health team.



## ***Satisfaction with services and support***

Satisfaction with services appeared greatest in the rural shire site. Good relationships had been established with the highly specialist research team during diagnosis but additionally, these families lived close by and so were able to retain continuing contact with the team. In the London borough, although diagnosis took place within the tertiary centre, on-going support after diagnosis was passed back to local primary care services and the community mental health team. Unpaid carers felt that neither the person diagnosed nor they themselves were receiving the on-going support needed. In the urban shire site, where families relied on local non-specialist services for diagnosis, respondents said that GPs were unclear on which local specialist to approach and the person was often seen by several different specialists over a long period of time before a diagnosis was given.

Family support was usually the most important mechanism that enabled families to cope on an everyday basis. Across all sites, families reported difficulties in accessing the suitable respite and day care needed to balance their caregiving burden.

## ***The view of professionals***

Professionals in acute settings felt constrained in the service they could provide because of NHS tariff arrangements. In one site, financial constraints meant that plans by the local authority to develop specific services for younger people with dementia had been abandoned. Professionals in primary care and in the voluntary sector broadly reported a lack of dedicated services for this group but it was suggested that the new health commissioning arrangements may provide the chance to reconsider provision.

## ***Implications of our study***

This exploratory work demonstrated that, while it is clear that the individual needs of families living with early-onset dementia are very high, low prevalence means that the numbers of younger people living with dementia in any one area do not reach the 'critical mass' needed to provide targeted, effective services. While there is an on-going debate about whether specialised services should be provided, most younger people with dementia (apart from those within reach of tertiary research centres) are likely to continue to tap into existing services for older people with dementia, whether appropriate or not. Current financial constraints mean it is unlikely that developing services and support for this very small group will be a priority in the near future, but changes in commissioning of services may offer an opportunity to develop improved services and support for younger people with dementia.

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