Evidence briefing: Psychological needs of people with young-onset dementia

This briefing paper outlines key messages and evidence relating the occurrence and nature of young onset dementias and the experiences and needs of people living with or caring for someone whose dementia onset occurs before the age of 65 years. The paper does not contain specific recommendations for practitioners but does advocate a systemic approach to understanding and addressing the impact of these conditions.

Key messages

1. Dementia does not only affect older people.
   Whilst age remains the greatest risk factor for dementia, there are more than 40,000 people with early onset dementia (onset before the age of 65 years) living in the UK.

2. Rarer forms of dementia are more common in younger people.
   Alzheimer’s disease (AD) accounts for only around a third of individuals living with a young onset dementia, relative to approximately 60–80 per cent across all people living with a dementia. This imbalance reflects the greater prevalence of atypical dementias such as behavioural variant frontotemporal dementia, primary progressive aphasia and posterior cortical atrophy in the younger population.

3. Inherited forms of dementia are more common in younger people.
   Only approximately 1 per cent of people with AD have a directly inherited form of the disease, whilst in other conditions such as frontotemporal dementia, 10 per cent have a directly inherited disease with a further 20–40 per cent have some genetic component. Living at risk of dementia in a family with a mutation raises additional psychological, practical, legal and ethical issues for family members, and the development of interventions to help families talk about inherited conditions requires understanding of the family impact of the condition.

4. Diagnosis may be delayed
   Evidence suggests diagnoses of young onset dementia may be delayed by a variety of factors, including reduced expectations of encountering dementia in people under 65, attribution to life events of middle age, and the higher incidence of atypical dementia syndromes and non-memory complaints.

5. Some needs and challenges are specific to younger people with dementia.
   When someone under 65 develops dementia the challenges can be very different. For example if someone is still at work, and has children or teenagers when they develop a young-onset dementia this has implications for income, childcare and caring that are very different compared with an older person who is retired or engaged in more voluntary occupations. There is evidence that many of these needs go unmet and that professionals need specialist knowledge of young-onset and rare dementias in order to try to provide relevant psycho-education to these families.
6. Young onset dementia places a particular burden upon carers
Research shows that caregivers of younger people with dementia have higher levels of burden than their older counterparts, even when matched for severity of dementia and behavioural disturbance\textsuperscript{14,15}. There have been calls for specific interventions related to individual needs and circumstances for both young carers and their partners\textsuperscript{16}.

7. Children and young people are disproportionately impacted by a parental diagnosis of young onset dementia
Families in which one or more members develop a dementia at a young age (before 65) face very different challenges to those in which dementia develops later\textsuperscript{17,18,19,20}. Clinical psychologists and other healthcare professionals are often asked to help and support a range of family members, as young onset dementias impact on all the different generations and relationships in the family.

Calls to action
- **Ensure a systemic approach to dementia care**
  Attempts to address the needs of people with young onset dementia should acknowledge and integrate the concurrent needs of their children and families, with psychosocial support integrated into services for people with a dementia diagnosis.

- **Ensure services are age-appropriate**
  In line with the principles of the Memory Services National Accreditation Programme\textsuperscript{21}, people with dementia/suspected dementia and their carers should receive a service that is person-centred and takes into account their age and associated personal, psychosocial and physical needs. For people with young onset dementia, services should have a named lead within the team, and have access to in-depth assessment and advice relating to occupational functioning, neuropsychological assessment and other investigations/assessments/scans.

- **Ensure professionals are qualified to deliver dementia-specific psychoeducation**
  It is essential to ensure that the quality of therapy and support available to people with young onset dementia is not compromised by arbitrary divisions in training and expertise between healthcare professionals working in adult and older adult services.

- **Ensure availability of tailored support groups**
  Support groups have a constructive role to play in offering people the opportunity to acknowledge their diagnosis and its consequences alongside peers in a similar position who understand their predicament. Support groups provide a space in which to share one’s story, among listeners who understand and empathise, and, therefore, provide a setting in which acceptance of a diagnosis and the requisite adaptations is facilitated. Attendance at support groups is also positively associated with caregivers’ psychological wellbeing and social function\textsuperscript{22}.

- **Ensure communication aids for children and young people**
  Understanding and adapting to a diagnosis of young onset dementia in a parent is particularly critical for children and young people who may be living in the same home and often taking on a significant caring role.

- **Ensure a whole family perspective**
  Available evidence across both younger and older people living with dementia has stressed the importance of family and intergenerational relationships in dementia care\textsuperscript{23,24}. However there have been few attempts to look at the impact of dementia on the entire family system, on different generations and at different stages of the disease. What studies there are tend to focus on older-onset dementia or to conflate different dementia diagnoses, even though the impact of different dementias is likely to vary depending on the dementia symptoms and the age at onset. Taking a more systemic approach to service delivery is complex but necessary\textsuperscript{8}.
Examples of good practice

The Specialist Cognitive Disorders (SCD) Clinic at the National Hospital for Neurology and Neurosurgery is a nationally-renowned centre for the diagnosis and management of the wide spectrum of dementias, particularly the rarer and young onset forms. Recognising the need for specialised long term professional and peer-to-peer support, a series of support groups for individuals with rarer forms of dementia were launched, initially for those attending the clinic but latterly expanded to provide support nationally and internationally under the umbrella of Rare Dementia Support. In 2012, a Cognitive Disorders Specialist Clinical Psychology Clinic was launched. The psychological clinic accepts referrals from a range of sources, chiefly from the neurology team running the SCD clinic but also from other professionals within the Trust, and nationally from other specialist teams and GPs. The current service-model is short-term, usually entailing one assessment session followed by up to three intervention sessions. The specific aims of the psychology clinic are to: (i) Assess the client (who may be a person with dementia or family member) plus companion to identify presenting problems and goals for therapy; (ii) Deliver psychoeducation about dementia and the specific diagnosis; (iii) Offer short-term cognitive-behavioural or systemic interventions to address specific issues that are identified at assessment (e.g. anxiety, conflict about how to support the person with dementia); and (iv) Offer a person-centred approach and support around some of the broader issues linked with loss, grieving and end-of-life care.

Resources

- Young Dementia UK
  www.youngdementiauk.org/alzheimers-disease
- Rare Dementia Support
  www.raredementiasupport.org
- Alzheimer’s Research UK ‘Dementia Explained’
  www.dementiaexplained.org
- The Ally Bally Bee project
  www.allyballybee.org
- ADAD Forum
  Private forum for dominantly inherited Alzheimer network (DIAN) participants and families

Acknowledgements

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References