

Dementia Gateway: Young onset dementia

This summary highlights key messages from the research on young onset dementia.

Key messages

- Although there is not much research on younger people with dementia, autobiographical accounts by younger people living with this condition means that more is known about their experiences.
- A small number of people diagnosed with dementia in the United Kingdom are younger people (around two per cent)¹ although this may be slightly higher (six to nine per cent).³
- There are many different causes of young onset dementia. Alzheimer's disease is the most common^{2,3,4} and substance misuse, particularly alcohol misuse, is a cause of dementia in 10 per cent of younger people.⁶
- It can be difficult to diagnose dementia in younger people – between 30 and 50 per cent of cases are either diagnosed wrongly or the diagnosis is uncertain.⁴
- People with young onset dementia may have different needs and commitments compared with older people with dementia^{2,5} and they may also need different forms of support.⁹ For example, they may need some changes to be made to their job.¹¹
- Family carers have an important part to play. It is not uncommon for children of young people with dementia to find themselves in a caring role alongside the person who mainly provides care to the person with dementia.⁴
- There has been some increase in the provision of specialist services for younger people with dementia in the United Kingdom, but generally this has been slow and access to good-quality care and support varies across the country.^{2,12,13}

Introduction

This summary highlights key messages from the research on young onset dementia. It is not intended to be a comprehensive review of the literature on this topic. The material on which this summary is based was identified through focused searching of the literature published from 2008 to 2012. Some material pre-dating 2008 is also referred to in order to illustrate a point that was not covered in the literature.

The status of research

Young onset dementia refers to dementia that happens before the age of 65.^{2,3,22} It is now seen as a considerable medical and social problem^{5,7} because more and more cases are being reported.⁴ Until about 20 years ago, medical professionals and the public assumed that dementia mainly affected people over the age of 65,⁴ and this is why research is usually focused on this age group.^{4,8}

There is not much research on young onset dementia in the following areas in particular: the treatment of dementia with drugs and other approaches;⁴ care services that are provided in the person's own home;⁴ following people over time, from diagnosis to treatment;⁴ and issues affecting families¹⁰ and caregivers.⁴ Also there is no national or international research that looks at things like the causes of dementia in younger people and how common it is (so-called 'epidemiological research').¹⁰ Because of this, we do not know very much about people with young onset dementia and what we do know is based on old information.

Epidemiological research

Epidemiological research looks at the prevalence (existing cases of a disease in a population), incidence (new cases of a disease in a given time period), causes, distribution (where on a map the cases are) and control of disease in populations. Because national and international research of this type on younger people with dementia does not exist, this makes it difficult to plan and commission services that are suitable for younger people with dementia.¹⁰

How common is young onset dementia?

There are no national studies of the number of people with young onset dementia because such studies depend on a large number of people taking part to produce an accurate estimate of that number.³ This is not possible because, of all the people diagnosed with dementia in the United Kingdom, only around two per cent have young onset dementia.¹ To get round this problem, researchers usually carry out studies in local areas to find out the numbers of people with young onset dementia in those areas and then use these figures to estimate the number nationally.¹

There are only a handful of local studies on the prevalence of young onset dementia,^{4,14} one being a study on three London boroughs in 2003.¹⁵ This found that the prevalence rate of young onset dementia in those aged between 30 and 64 was 54 per 100,000 people; and in the 45 to 64 age group it was 98 per 100,000 people¹⁵. Using these figures to estimate the number of people with young onset dementia in the United Kingdom, the study estimated

that in 2003 there were 18,319 cases of young onset dementia in the UK.¹⁵ But the findings from studies such as these can be inconsistent.⁴

A later prevalence estimate published in 2007 is that there were at least 15,034 people with young onset dementia in the United Kingdom¹. However, the actual figure could be three times more than this, given that the research on which this estimate was based was looking only at referrals of young people with dementia to services – this means that those who were not receiving services will have not been picked up.¹ More recent figures suggest that the percentage of people with young onset dementia in the United Kingdom is around six to nine per cent of all people with dementia.³

Causes of young onset dementia

The causes of young onset dementia have been linked to various diseases and conditions, including Alzheimer's disease, vascular dementia, fronto-temporal lobar degeneration (FTLD), lewy bodies dementia, Parkinson's disease, Huntington's disease, chronic alcoholism, HIV and chronic drug abuse.^{4,12} Alzheimer's disease is the most common dementia diagnosis in both younger and older people with dementia^{2,3,4} and more common in women than in men.² Drug and alcohol misuse, especially alcohol misuse, is a cause of dementia in 10 per cent of people with young onset dementia.⁶ People with Down's syndrome and other learning disabilities can also develop dementia at a young age.⁹

The younger the person is when they develop dementia, the more likely it is that the cause of their

dementia is genetic or to do with their body's metabolism.^{5,14}

Getting a diagnosis of dementia

Getting a diagnosis of dementia at the right time when you are younger can be difficult^{7,14,16–18} because the condition is usually associated with older people.¹¹ Between 30 and 50 per cent of cases of young onset dementia are reported as being diagnosed wrongly or having an uncertain diagnosis.⁴ It can take years to get a diagnosis.^{5,19} This may be because of a combination of things, such as: health professionals being less likely to consider a diagnosis in a younger person⁴, and the person with dementia and their family being in denial about the symptoms⁴, although they are often the first to know when something is not right.²⁰

Recognising the symptoms of young onset dementia is difficult because the types of dementia seen in younger people are more varied than those seen in people over the age of 65, and symptoms may be put down to other illnesses or conditions rather than dementia.² For example, some of the most common of these are depression, stress, the menopause, burnout and relationship problems.^{4,9,18}

Because dementia is usually associated with old age, doctors may be less likely to diagnose it in a younger person.⁴ In the same way, people and their families are less likely to think that there is a possibility of young onset dementia⁴ or may be in denial.¹⁶

Few studies follow people with young onset dementia over the period from diagnosis to treatment, indicating although this type of study can identify

causes of deterioration.⁴ It is very important that young onset dementia is diagnosed as early as possible, for many reasons. For example, it can start the process of getting access to treatment and the right kind of support.² It can help people with young onset dementia and their families to come to terms with the condition.² It helps people to get information that will help them to make the right decisions about finances, welfare, work and legal matters.^{5,21} However, there is a delay in seeking help if people with young onset dementia and their families do not think about such a diagnosis in the first place.⁴

The impact of the condition on people with young onset dementia and their families

There are very few studies that have looked specifically at the issues that affect younger people with dementia and their families¹⁰ and caregivers.⁴ Research that includes people under the age of 65 in their sample, and autobiographical accounts by younger people with dementia can provide this information.

People with young onset dementia may have different needs and commitments^{2,5} and need different kinds of support compared with older people with dementia.^{9, 22} This includes having children at home, being employed and having major financial commitments.^{2,5} However, younger people with dementia can articulate a clear understanding of their needs and experiences, so service providers should talk to them about the kinds of services that should be offered to them.²²

Experiencing the psychological and emotional impacts

Because people do not expect to be diagnosed with dementia at a relatively young age, people who get such a diagnosis and their families can find the psychological and emotional impact on them to be especially severe.^{4,14,23} Younger people with dementia may find it hard to grasp the idea that they are losing cognitive skills (thinking, knowing and reasoning skills) at such a young age.⁵ Being generally physically healthy and active, and aware of their problems, they can feel frustrated and in distress.^{2,11} The feeling of frustration and helplessness can be particularly strong if the younger person with dementia is also the main person who looks after their ageing parents or young children.¹⁸ Also, there is stigma associated with dementia,²⁴ particularly at a young age.¹¹ Even so, it is possible for a younger person with dementia to adjust to these changes with the right support and if they are able to look at their situation in a positive way.²⁵

Maintaining social networks

Because dementia in younger people is relatively rare, it can be difficult for the person with young onset dementia to find other people who identify with their situation and they can feel isolated and unsupported.⁹ This isolation may be reinforced because the illness is usually associated with old age.¹⁸ Isolation and loneliness can affect both people with young onset dementia and their family.¹¹

Employment and financial commitments

By definition, younger people with dementia are of employable age,¹⁴ they may be working or the main earner in the household,^{2,4,14, 22} have large financial commitments such as a mortgage,^{2,5} be caring for ageing parents¹⁸ and they may be a parent of young children.^{2,5,14,18} For younger people with dementia still at work, changes in their ability to do their job may not be understood by employers or colleagues and changes to their job that are needed may not be approved,¹¹ though would have been welcomed.²⁶ Where people have lost their job, as well as lost income and work roles¹¹ they may lose their self-esteem and a sense of value for themselves, among other things.⁴

Coping with daily challenges

The psychological factors that people may face can produce stress.¹⁸ They may need to change the roles that they had in the past or find new ways of coping or ways to do even relatively simple tasks such as using a digital watch or audiobooks in place of 'standard' versions.^{18,21} More often than not, tasks take longer to do or may not be done at all, and it is important that families, carers and staff are patient with younger people with dementia and try to understand the challenges they face.²¹

Threat of inheriting dementia

Families may experience fear and insecurity about children inheriting dementia from a parent because of their genetic relationship to the person with dementia.¹⁸ The parent with dementia may harbour feelings of guilt that their child may develop the

disease.¹⁸ Predictive genetic testing is available to at-risk adults for the mutated genes that cause young onset familial Alzheimer's disease, but the procedure is not simple and can itself be a cause of anxiety and depression.^{4,5}

The impact on families: adopting the role of carer

Adult carers

The main carers of people with young onset dementia are often relatively young, usually in their fifties and not ready to manage the role of caregiving.²⁷ They can experience a sense of grief for the person they feel they have lost and are often having to come to terms with their own changed identity as the son/daughter or spouse role becomes a carer role.^{5,21,23} If the right services are not provided, such as support groups, this can increase any feelings of isolation and exclusion.^{2,4,11} Anxiety and depression are quite frequent⁴ as are financial insecurity, stigma, stress and physical burden and there can be a negative impact on relationships with a partner.^{2,4,5,11,16} For example, a carer may find it difficult to respond to the sexual needs of a sexually active partner.⁵ Carers can face added pressure if they also have a job or are raising small children while caring for a spouse with young onset dementia.¹¹ In some circumstances, a carer may have to leave their job so that they can carry on caring.⁵

Child carers

As daily tasks become challenging for the younger person with dementia and their ability to be

independent changes, relationships between them and other members of their family are likely to change.⁴ One example is role reversal, where it is not uncommon for children of young people with dementia to become carers to their parents.⁴ Whether or not they are carers, children of younger people with dementia can experience problems that include: embarrassment about socialising with friends at home;⁵ fear of their parent being aggressive;⁵ extreme distress about their parent's worsening condition;⁵ feelings of grief for the parent they have lost;⁵ and anxiety about leaving home because of concern for their parent.¹⁸

Specialist provision

Younger people with dementia have specific needs, which general dementia services may not be able to address.^{2,18} Their continuing care and support needs and that of their families are challenging and should involve a team of professionals from a variety of different disciplines.^{2,7}

Services for people with young onset dementia include residential and nursing care, day care and community/home support such as respite care.^{4,6} But there is not much age-appropriate provision for younger people.^{2,4,6, 22,28} and for non-Alzheimer's dementias such as that resulting from alcohol abuse.⁶ Carers have said that services need to be coordinated better and there needs to be access to welfare advice, support and respite care.²

National recommendations

In 2000, guidelines from the Royal College of Psychiatrists included a recommendation that every area in the country has a named old-age psychiatrist responsible for younger people with dementia who would work in partnership with other specialists.^{6,29} In 2002, a survey of the Faculty of Old Age Psychiatrists stressed that partnership working, especially with neurology services, is essential.⁶

In 2006, joint guidelines from the National Institute for Health and Clinical Excellence and the Social Care Institute for Excellence promoted the need for the development of specialist multidisciplinary services linked to existing dementia services for the assessment, diagnosis and care of younger people with dementia.³⁰ In the same year, the Royal College of Psychiatrists and the Alzheimer's Society introduced recommendations for the development of services, which included having a named lead professional for planning services for younger people with dementia and a named consultant responsible for providing medical input.^{2,6, 12} As a result, there has been some growth in the provision of age-appropriate services for younger people with dementia in the United Kingdom, but generally progress has been slow and varies from area to area, making access to good-quality care and support variable across the country.^{2,12,13}

Implications from the research

Among professionals and members of the public, there is not much recognition of the distinct and complex needs of younger people with dementia.² Delivering effective services is dependent on accurate epidemiological data.¹⁵ Without national or international epidemiological research on younger people with dementia, it is difficult for service planners, policy makers and commissioners to plan the right services.¹⁰

Such research should also include information about younger people with dementia from specific groups such as: people with hereditary forms of dementia; people with learning disabilities; and black and minority ethnic people. Carers are also often overlooked and the special problems and challenges that they face, including developing services for this group of people, should be looked at further.⁴ Further research is also needed about the diagnosis, experience and treatment of young onset dementia to improve the knowledge and training of professionals.⁴

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