

# Services for younger people with Alzheimer's disease and other dementias

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## Members of the Working Group

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# Executive summary and recommendations

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## Summary

Younger people with dementia and their carers frequently fall through the net of the health and social care services.

During the 1990s an increasing number of these patients were being referred to old age psychiatry services. In response to this new pattern, the Faculty of Old Age Psychiatry, Royal College of Psychiatrists in conjunction with the Alzheimer's Society published a new policy paper in 2000 outlining the configuration of services for younger patients with dementia.

The document was well received. In 2002 a review showed that a start had been made in implementing its recommendations but no health area had put all its recommendations into practice.

The sponsors of the paper are encouraged by what has been achieved and remain convinced of the importance of the original document's two key recommendations:

- An incremental approach is advocated, with the appointment of two key players: at the commissioning level (primary care trusts or their equivalent), a named person responsible for planning, and a consultant clinician to act as a focus for referrals, initially with two programmed activities or sessional equivalents. An old age psychiatrist is well placed to undertake the clinical role.
- After these appointments have been made the rudiments of the local service is created. At all stages coordination and networking with people already involved with younger people with dementia is important; the composition and evolution of the new service will depend on existing local services and facilities.

Both organisations remain committed to these principles and consider that it is timely to publish this second edition of the policy paper so that the momentum of what has been started will be maintained. In this way this disadvantaged group of patients will have a modern dedicated service to meet their special needs.

The recommendations of this policy paper should be reviewed and audited in 2007. These findings should then be incorporated into another new edition of this policy paper, again under the auspices of the Faculty of Old Age Psychiatry, Royal College of Psychiatrists and the Alzheimer's Society.

## Recommendations

1. Commissioning agencies should have specific contractual arrangements for a specialised service for younger people with Alzheimer's disease and other dementias. There should be a named individual at the level of the commissioning authority with responsibility for these developments. The recommendations set out in this paper are in addition to the services currently available for patients with dementia.
2. For a population base of 500 000 at least one programmed activity or sessional equivalent should be allocated for planning, development and organisation and a minimum of one programmed activity or sessional equivalent for diagnostic and follow-up services. This service should have a named consultant, usually an old age psychiatrist with extensive experience of working with patients with dementia. For smaller populations, collaborative arrangements may be necessary across providers.
3. The number of programmed activities or sessional equivalents required would depend on the arrangements in place for managing these patients. In some areas rehabilitation services play an important part. Neuropsychiatry is a re-emerging discipline, which in some areas provides a service for acquired brain disorders; however, the boundaries of its responsibilities between degenerative disorders and the effects of trauma are not clearly defined. In areas where liaison psychiatry is well established, it provides a valuable service, particularly for patients with dementia associated with physical illnesses such as Parkinson's disease, multiple sclerosis and cardiovascular disease.
4. As dementia can be caused by many medical disorders, general practitioners and a range of specialists usually manage the early phase of the illness. Coordination and liaison between these groups and the new dementia service is therefore essential.
5. There should be much closer liaison between neurology and old age psychiatry services. This will assist in earlier, accurate diagnosis, referral to appropriate services and long-term management. More active links between professional agencies such as the Association of British Neurologists and the College is highly desirable.
6. As genetic factors are particularly important in younger people with dementia and other neurodegenerative disorders (for example Huntington's disease), easy access to the investigation of genetic factors and to genetic counselling is essential.
7. In a service of this nature, collaboration with neurology, neuropsychology, medical genetics, neuropsychiatry, liaison psychiatry, rehabilitation and learning disabilities is essential for establishing accurate diagnosis and dovetailing of services. In parallel, collaboration with social services departments, family doctors and other support services is important.

8. Substance misuse, particularly alcohol misuse, has been identified as a cause of dementia in 10% of younger patients. As a potentially preventable, and in some cases treatable, form of dementia, alcohol-related brain impairment represents an area of considerable concern. There should be close collaboration between substance misuse services and the dementia service for younger people. There should be multi-agency and multi-sector collaboration, especially in terms of support, social care, respite and day care. People with any form of brain damage should be screened for substance misuse in general and alcohol misuse in particular.
9. Particular mention should be made of other emerging areas of concern:
  - At present, people with HIV-related brain damage are usually catered for within the services for those with HIV, but as treatment improves, more of these people may be placed within mainstream services for brain damage and dementia.
  - Old age psychiatry and services for younger people with dementia have already been involved in the diagnosis and long-term care of patients with Creutzfeldt–Jakob disease (CJD). Although the incidence of new-variant CJD remains low, clinicians and planners should be alert to the potential significant increase in the number of cases in the future.
10. The needs of people with dementia from Black and minority ethnic groups are acknowledged but, in most cases, the relatively small numbers of younger people with dementia will preclude separate further provision for individuals from minority ethnic communities or from other minority groups. Any service development should be prepared to accommodate the individual needs of each person with dementia. Collaboration with appropriate external support services, where available, is advisable to ensure that the needs of patients from minority ethnic communities are being met.
11. For a population of half a million or more, a specialist multidisciplinary team is justified, and provider units should be encouraged to create such dedicated services. For a smaller population, service planners must prioritise which disciplines the multidisciplinary team should base their initial provision on, considering local variations in needs provision and workforce availability. This may start off with dedicated community mental health nurse and/or social worker sessions or posts.
12. People with dementia should be involved in the planning of services whenever this is appropriate – there is an emerging consensus that this is desirable. In addition, carers and voluntary organisations dedicated to patients with these disorders should be involved at every level.
13. The initial development of services should focus on the organisation of diagnostic and community services, to provide flexible and individualised care plans. Specialised services should be developed only where traditional services are deficient.

14. After the rudiments of a service have been established, the development of all essential parts of a comprehensive service should follow. A day hospital, respite care and long-stay provision are usual service requirements. Community-based services, such as community support workers, may also be considered appropriate. Separate provision is necessary, as these patients are physically robust and do not integrate easily with the frail older adults who make up a significant proportion of people using old age psychiatry services.
15. During the past few years there has been much emphasis on the treatment of Alzheimer's disease with cholinesterase inhibitors, but there is agreement that more effective treatments are needed. To assist this process clinicians must strive for accurate diagnoses, and after death every effort should be made to perform confirmatory neuropathological studies.
16. Every year the Alzheimer's Society organises a national conference on younger people with dementia to raise awareness and to increase contact among professionals from across the UK. This could be complemented by a similar conference with a focus for clinicians, organised by the Faculty of Old Age Psychiatry, Royal College of Psychiatrists and with the involvement of the Association of British Neurologists.
17. The impact of these recommendations should be audited in 2007 in a collaborative exercise involving the Alzheimer's Society, the Faculty of Old Age Psychiatry, Royal College of Psychiatrists and the Association of British Neurologists.
18. Although planners and commissioners are becoming aware of this statement, the value of pressure from patients, carers and non-statutory organisations cannot be overstated. Practitioners, the voluntary sector, carers and younger people with dementia must continue to educate the public, maintain the profile of the problems of younger people with dementia, and canvass the statutory authorities at every level for the creation of services. This is an essential preliminary phase before definitive plans can be drawn up. Persistence, commitment and a long-term agenda are the prerequisites for the development of plans and the allocation of funding.
19. During the preparation of this second edition of the report it has clearly emerged that neurologists, through the Association of British Neurologists, want to be more involved in the preparation of this policy paper, and ideally, would like to assume coauthorship. We recommend the setting up of a joint working group between the Faculty of Old Age Psychiatry, the Alzheimer's Society and the Association of British Neurologists so that the views of the latter can be more comprehensively included in the next edition. We further recommend that this is done as soon as possible and that once agreement has been achieved, the third edition should be published immediately afterwards.

## Introduction

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The management and care of younger people with dementia tends to be uncoordinated and variable throughout the UK (Barber, 1997). Several specialties play a part, sometimes reluctantly, but no single specialty has taken a lead to establish a coordinated policy for the development of services for this patient group.

Since the early 1990s, old age psychiatrists have increasingly been approached to assist in the management of younger patients with dementia, and attention was drawn to the need for appropriate policy in an open forum held by the Faculty of Old Age Psychiatry, Royal College of Psychiatrists in 1996. Three presentations were given: Dr Andrew J. Newens, senior lecturer at the University of Hull School of Health, spoke about the prevalence and incidence of early-onset dementia in the Northern Health Region; Carol Jennings presented a paper based on her perspective as the coordinator of services for younger people with the Alzheimer's Society; and Professor Ken Wilson, from the Department of Old Age Psychiatry, University of Liverpool, spoke about the service that had already been established in the Mersey Region.

The Faculty decided that it should respond to these emerging issues by preparing a forward-looking policy document. Dr D.D.R. Williams was asked to coordinate the initiative, using the presentations from the open forum as its basis. The resulting document was approved by the Executive Committee of the Faculty of Old Age Psychiatry in October 1999 and by the Council of the Royal College of Psychiatrists in January 2000.

A survey of Faculty members by the Alzheimer's Society in 2002 assessed the impact of the document and the extent to which new services had been developed for younger people with dementia. Although awareness of the report among Faculty members was comparatively high, no health area had yet met all the report's recommendations. However, there was evidence of tangible improvement in the provision of services, with a significant number of respondents reporting plans for future development.

The survey highlighted a number of concerns that have yet to be successfully addressed within most areas. In particular, the coordination of care and management in collaboration with other specialties, particularly neurology, remains a crucial factor (Allen & Baldwin, 1995; Cordery *et al*, 2002). Similarly, services for people with dementia due to alcohol misuse were very poorly developed across the UK at the time of the survey, as were specialist support services for people with familial forms of dementia or with learning disabilities and dementia.

It was felt that a revised and updated version of the original Council report could reflect the developments that have taken place in services for this patient group and at the same time reaffirm the need for development in a number of

key areas. The work was undertaken by Colin Cosgrove, on behalf of the Alzheimer's Society, and Don Williams, on behalf of the Faculty, during the summer of 2004.

## **The needs of younger people with dementia – The Alzheimer’s Society’s position**

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Although the symptoms of dementia are similar whatever a person’s age, younger people with dementia have different needs. The Alzheimer’s Society has long recognised this, and during the 1990s, in particular, campaigned to raise awareness and improve services for this group. The Society’s ‘Charter for younger people with dementia and their carers’, adopted in 1991, outlines the Society’s position on the needs of younger people with dementia: it states that all younger people with dementia, their families and carers should have access to comprehensive, specialist services from diagnosis to long-term care (see Appendix 1). Continuity of care in a multidisciplinary setting is a key constituent of a quality service, and the Society believes that younger people with dementia, their families and carers should be consulted at every level of planning.

As well as campaigning for recognition of the needs of this group, the Society provides support to anyone affected by early-onset dementia, whatever its cause. The Society’s carers’ contacts provide support at a regional level, offering practical information on services, as well as the personal experience of someone who has cared for a younger person with dementia. Likewise, the Society’s younger person’s network matches people in similar positions, and puts them in contact with each other for mutual support. Contact with others who understand their situation is invaluable for people who so often feel isolated and alienated.

Every year, the Society receives hundreds of calls from people affected by or working with early-onset dementia, and has developed comprehensive information about this topic. A national database of services in the UK can be used to direct people to centres and organisations that can offer dedicated care, and an annual conference on younger people with dementia continues to raise awareness and increase contact among professionals from across the UK. The Society’s own guide to service development and provision (Alzheimer’s Society, 2001) highlights the issues involved in planning services for this group, with examples of good practice.

The Society believes that adoption of the recommendations in this report would make progress towards the development of high-quality, comprehensive services for younger people with dementia. Current service provision across the UK is patchy, and although there are many very dedicated services offering excellent care, established protocols for service development and delivery are vital to encourage the more widespread improvement in care that is urgently required.

## Prevalence of dementia in younger people

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Dementia is relatively rare in people under the age of 65, with over 18 000 estimated cases in the UK in 2003 (Harvey *et al*, 2003). A comprehensive study of early-onset Alzheimer's disease, including prevalence, incidence, referral patterns and survival, was carried out by in the former Northern Health Region of England (Newens *et al*, 1993, 1994, 1995). This is a diverse geographical region with a total population of around 3 million, of whom almost 656 000 were aged between 45 and 64 years at the time of the study. All possible cases of early-onset dementia were identified, and an algorithm was followed to establish the clinical diagnosis of what was termed pre-senile dementia of Alzheimer type (PDAT). The total prevalence of PDAT was 227 cases, comprising 195 (86%) identified cases and an additional 32 (14%) estimated cases (Table 1).

There were 46 cases with miscellaneous causes; 26 were thought to be alcohol-related, with the remainder due to Pick's disease (4), obstructive hydrocephalus (5), Parkinson's disease (3), multiple sclerosis (2), and communicatory hydrocephalus, multisystem failure, myxoedema, cerebral tumour, trauma and CJD (1 case each) .

Research into early-onset dementia in the London boroughs of Kensington and Chelsea, Westminster, and Hillingdon elicited a different set of prevalence statistics (Harvey, 1998). For a combined population of around 567 500 people, of whom 193 493 were presumed to be between 30 and 64 years, a total of 227 cases of early-onset dementia were uncovered. When people who had passed their 65th birthday by the time the research had begun were excluded, 185 cases remained. This translates to a prevalence rate of 54.0 per 100 000 of the general population or 67.2 per 100 000 of the population aged 30–64. A later estimate of prevalence (Harvey *et al*, 2003) extrapolated the results of this research to the general

**Table 1** Estimated age and gender prevalence rates for pre-senile dementia of Alzheimer type per 100 000 population in the Northern Region of England

| Age range<br>years | Male<br><i>n</i> | Female<br><i>n</i> | Total<br><i>n</i> | Population<br>(000) | Prevalence<br>(per 100 000) <sup>1</sup> |
|--------------------|------------------|--------------------|-------------------|---------------------|--|
| 45–49              | 1                | 3                  | 4                 | 162.9               | 2.4                                      |
| 50–54              | 11               | 8                  | 19                | 161.0               | 11.8                                     |
| 55–59              | 26               | 33                 | 59                | 165.9               | 35.6                                     |
| 60–64              | 61               | 84                 | 145               | 166.0               | 87.3                                     |
| Total              | 99               | 128                | 227               | 655.8               | 34.6                                     |

1. The prevalence rates for vascular dementia and other types of dementia (*n*=46) were 11.7 and 7.0 per 100 000 respectively.

population and estimated a total of around 18 500 younger people with dementia in the UK.

Harvey further estimated the relative prevalence of the various causes of dementia in younger people (Table 3). It should be noted, however, that more comprehensive assessments of prevalence are available for other causes of dementia, such as frontotemporal dementia (e.g. Ratnavalli *et al*, 2002). Table 3 summarises Harvey's estimates.

The 'other' group consisted of Huntington's disease (9), dementia in multiple sclerosis (8), corticobasal degeneration (2), prion disease (CJD, 2), dementia due to carbon monoxide poisoning (1), dementia and Down's syndrome (3), dementia in Parkinson's disease (2) and dementia of unspecified cause (8).

The terms of Harvey's research were broader than those of Newens *et al*, which could account for the significantly higher rates of prevalence: whereas Newens *et al* were concerned primarily with the early onset of Alzheimer's disease, Harvey studied the full spectrum of heterogeneous diagnoses in early-onset dementia.

**Table 2** Estimated age and gender prevalence rates for early-onset dementia in the UK (data from Harvey, 1998)

| Age range<br>years | Male<br><i>n</i> | Female<br><i>n</i> | Total<br><i>n</i> | Population<br>(000) | Prevalence<br>(per 100 000) |
|--------------------|------------------|--------------------|-------------------|---------------------|-----------------------------|
| 30-34              | 3                | 3                  | 6                 | 47.3                | 12.7                        |
| 35-39              | 1                | 2                  | 3                 | 37.6                | 8.0                         |
| 40-44              | 1                | 5                  | 6                 | 38.6                | 15.5                        |
| 45-49              | 6                | 5                  | 11                | 33.3                | 33.0                        |
| 50-54              | 10               | 9                  | 19                | 30.4                | 62.5                        |
| 55-59              | 28               | 14                 | 42                | 27.6                | 152.1                       |
| 60-64              | 26               | 17                 | 43                | 25.9                | 166.3                       |
| Total              | 75               | 55                 | 130               | 240.7               | 54.0                        |

**Table 3** Distribution of diagnoses according to cause or type of 185 cases of early-onset dementia, as identified by Harvey (1998)

| Diagnosis                 | Cases    |    |
|---------------------------|----------|----|
|                           | <i>n</i> | %  |
| Alzheimer's disease       | 62       | 34 |
| Vascular dementia         | 34       | 19 |
| Frontotemporal dementia   | 23       | 12 |
| Alcohol-related dementia  | 19       | 10 |
| Dementia with Lewy bodies | 12       | 7  |
| Other                     | 35       | 19 |

The only diagnostic criterion explicitly excluded from the study was HIV-related cognitive impairment, a decision taken because of similar research being carried out in that particular area at the same time.

### **Non-Alzheimer's dementias**

Harvey's research illustrates the wide variety of diagnoses contained within the category 'early-onset dementia' and emphasises that there are differences between groups in terms of care required. Different conditions will require specific interventions, particularly those in which the development of dementia is secondary to another condition (e.g. HIV-related cognitive impairment) or those forms of dementia experienced by people with particular needs (e.g. people with alcohol-related problems or with learning disabilities).

Of particular note in the spectrum of diagnoses revealed by Harvey's research is the high number of cases of alcohol-related brain impairment. The prevalence of alcohol-related brain impairment is difficult to calculate, but studies suggest that admissions to psychiatric hospitals for this condition are increasing (Jacques & Stevenson, 2000). Some people with alcohol-related brain impairment can make a significant recovery with appropriate treatment. Services for this group require close collaboration with local drug and alcohol teams. However, research indicates that there is significant variation in service provision nationally, and that uncoordinated services lead to a fracturing of care pathways for this group (Cox *et al*, 2004). As a preventable, and in some cases treatable form of dementia, which represents a significant proportion of cases in younger people (10% according to Harvey), it is important that effective measures be taken to develop the provision of support and care for people with alcohol-related brain impairment.

Services are similarly limited for those individuals with learning disabilities who develop dementia. About 40% of people with Down's syndrome in their early 50s have been found to have dementia. The prevalence of dementia in people with learning disabilities other than Down's syndrome is also higher than in the general population. As increasing numbers of people with learning disabilities live to an older age, the corresponding increase in prevalence of dementia will create further pressure on care services (Wilkinson *et al*, 2004). Psychiatrists and other professionals working in specialist learning disabilities services usually provide diagnostic and management support, but value access to other expertise.

The incidence of HIV-related brain impairment appears to have fallen significantly since the introduction of zidovudine (AZT) and combination therapy, but many people with HIV remain at risk of developing dementia, particularly in the more advanced stages of their illness. HIV-related brain impairment can result from the direct effect of HIV on the brain or from opportunistic infections. Medication, alongside a structured rehabilitation programme, can help people with HIV-related brain impairment to relearn many of the skills required for daily living (Jamieson, 1999).

Prion diseases can also be a cause of dementia in younger people. In particular, the familial and variant forms of CJD affect people of a younger age. Although prion diseases are relatively rare, significant media attention in the past few years has been given to variant CJD and its links with bovine spongiform encephalopathy. It is not known as yet whether the number of cases of variant CJD has peaked or whether future increases are likely. Clinicians and planners should be alert to potential increases in the future (Donaldson, 1999).

The risk of developing a familial form of dementia is relatively higher in younger people, particularly as some hereditary conditions such as Huntington's disease can result in dementia symptoms. Specific services are required for people with familial dementias, in particular genetic counselling. In general, relations between old age psychiatry and genetic counselling services (where available) are good, and should be encouraged.

### **People from Black and minority ethnic groups**

The problems associated with dementia in people from Black and minority ethnic (BME) groups are beginning to be documented, and in many ways parallel the experiences of younger people with dementia (see Daker-White *et al*, 2002). People with dementia from BME communities experience difficulties in accessing health and social care services, or find mainstream services inappropriate to their needs. As a result, they do not make use of dementia care services, leading to a misapprehension that there is little need for support for people from these communities.

No national data exist on the prevalence of dementia in BME populations in the UK (Demirbag & Aldridge, 2003), but as this population ages it is to be expected that dementia will become an increasing concern for many people. In particular, genetic and environmental factors contribute to a high level of cardiovascular disease, high blood pressure, or diabetes in many people from BME communities – these are identified risk factors for the later development of vascular dementia (Alzheimer's Society, 2005). There are similarly no data on dementia in younger people from BME communities, which makes it difficult to assess the needs of people from minority ethnic groups within this already identified minority of those under 65 with dementia. However, a summary of the difficulties experienced by people of all ages from BME communities is appropriate, as it is likely that specialist services for younger people with dementia will face the need to provide for service users from BME communities.

As with younger people with dementia, people from BME communities face difficulties in accessing care at all stages. Brownlie (1991) reports the difficulties of engaging general practitioners – people who have difficulty speaking or communicating in English may depend on family members to translate, which can lead to a reluctance to disclose problems or mistranslation by the interpreter. It has been reported that sometimes children are used as interpreters who, although speaking English, will not be able to appreciate or convey the issues associated with dementia. In particular, problems in describing the nature of one's difficulties

or in understanding medical jargon, can be very frustrating. Difficulties in communication grow more complex as dementia progresses, as people who have learned English start to lose the language skills they had developed.

Assessment can also be a difficult experience, as assessment tools such as the Mini-Mental State Examination (Folstein *et al*, 1975) are not culturally sensitive and can produce skewed results, sometimes resulting in misdiagnosis (Forbat, 2003). Similarly, assessments for social services can demonstrate ethnic or cultural insensitivity, complicating access for people with dementia and their families (Demirbag & Aldridge, 2003). If people with dementia from BME communities are placed in mainstream dementia services, they and their families often complain that services are not appropriate – for example, they may not provide appropriate or familiar food, or demonstrate any cultural sensitivity in activities. Where one person from a BME community attends a centre used predominantly by White British people, they tend to be uncomfortable using the service (Brownlie, 1991) – this parallels the experience of younger people with dementia using a service along with much older people.

Research has demonstrated a desire among people from BME communities to use dementia care services, were they available and appropriate for their needs (Demirbag & Aldridge, 2003) – this is in contrast to the perception many people hold, that people from BME communities ‘look after their own’ and do not want to make use of mainstream services. As experience with younger people with dementia has shown, reluctance to use dementia services often has more to do with lack of information and inappropriate care, than with a desire to care for the person with dementia in isolation.

A number of local and national initiatives for older people from BME communities have been developed in recent years. However, experience shows that these groups or centres cannot provide specialist care to people with dementia. In addition, concern has been expressed that specialist dementia services for people from BME communities would relieve mainstream services of the need to adapt their provision (Brownlie, 1991). It is widely felt that BME organisations or agencies should provide a supportive role to mainstream services, but should not be seen as a substitute – rather, mainstream services should adapt to be accessible to people from BME communities. This is in line with the Royal College of Psychiatrists’ guidance on psychiatric services for older people from BME communities (Royal College of Psychiatrists, 2001).

The need to provide for people from BME communities applies equally to specialist services for younger people with dementia. However, as the level of need in these communities is currently not known, more research is needed to properly assess the numbers of younger people with dementia from BME groups, and to ascertain how their needs could be met in a specialist younger people’s service.

## Service provision

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### The need for specialist services

Traditionally, the allocation of responsibility for younger people with dementia has been haphazard, and has led to a situation whereby many 'fall through the net' of care services. Patients in the younger age-group have been largely the responsibility of general psychiatry services, but these services have little experience of working with people with dementia. Increasingly, more and more of these individuals are referred to old age psychiatry services because these services have expertise in the management of dementia. However, services for older adults are often inadequate, and only rarely does the responsibility for younger people with dementia have the protection of contractual agreements with service commissioners. Consequently, the needs of younger patients are often neglected.

Barber (1997) investigated the level of dedicated provision for younger people with dementia, and found that only 12 out of 284 (4%) hospital and community trusts in England had a dedicated service, and that only 39 (14%) had an identifiable consultant with responsibility for this group. However, Barber also found that investigation of prevalence and/or need invariably resulted in the development of specialist services: 10 out of 52 trusts who had surveyed the needs of younger people with dementia in their area had established some level of provision, with a further 33 either in the planning stages or deeming such development as necessary.

A large number of local surveys have been conducted to identify both prevalence and service requirements of younger people with dementia (see Alzheimer's Society (2001) for examples), and have generally highlighted the inadequacy of provision within existing dementia services and the need for specialist services for younger people. Surveys usually result in the establishment of a focus for referrals and the subsequent development of specific services catering for the needs of younger people with dementia and their carers (Alzheimer's Society, 1996). Sometimes services have developed from the establishment of an in-patient unit offering acute assessment and respite facilities, such as the Rowans Unit in Shropshire. However, many surveys have identified the need for appropriate diagnostic services, counselling, community support and many of the ingredients of good care planning to maintain people with dementia in the community. The Alzheimer's Society is actively involved in promoting all developments of this nature (Appendix 2).

Specialist age-appropriate services are frequently cited as a need in interviews with carers, and particularly as the views of younger people with dementia themselves are being heard (Beattie *et al*, 2004; Braudy-Harris & Keady, 2004; Shlosberg *et al*, 2004). Most surveys comment on the difficulties experienced by younger people with dementia in attending day care and respite facilities for older people. Specific services are valued by people with dementia and carers

alike as being responsive to their circumstances and providing the opportunity to meet with others who can relate to their situation. As with service-level surveys, therefore, the perceived need of younger people with dementia and their carers is also for specialist age-appropriate services that are responsive to the different needs of a younger age-group. The Alzheimer's Society's 'Charter for younger people with dementia and their carers' reflects this perceived need.

### **Management of dementia in younger people – the relationship between old age psychiatry and neurology**

Studies have shown a high level of functional and behavioural problems in younger patients with dementia (Baldwin, 1994; Ferran *et al*, 1996). Psychiatric follow-up by a consultant with expertise in dementia is strongly recommended. Consultants in old age psychiatry offer the most appropriate experience in this field, although in some cases a consultant with an interest in learning disabilities, neuropsychiatry or liaison psychiatry may be appropriate. However, few of these specialists have close working relationships with neurologists, contact with genetic counsellors and child liaison services, or ready access to general adult psychiatric wards for admission of patients. The increasing number of referrals to consultants in old age psychiatry reflects a growing recognition that they offer the most appropriate level of service to these patients.

Despite increasing reliance on old age psychiatry, there is a considerable lack of identifiable consultants with responsibility for this patient group, and there remains a persistent lack of consistency in referrals. As a result, many patients continue to be referred to neurology or adult psychiatry services. Identified consultants with a responsibility for this patient group would be beneficial in encouraging referrals to the appropriate services, but would be unlikely to eliminate inappropriate referrals: in areas where specialist early-onset dementia services have been established, inappropriate referrals remain widespread (Williams *et al*, 1999).

It is recommended, but not essential, that a specialist service for younger people with dementia should be developed with a lead from a consultant in old age psychiatry. However, a number of existing services run successfully with a lead from consultants in liaison psychiatry, and services with a neurological lead are relatively common, such as a cognitive function clinic in Liverpool.

The input of neurological services into the diagnosis and management of early-onset dementia cannot be underestimated: a study of referral patterns for younger people with dementia found that geriatricians and general practitioners were significantly more likely to refer patients to an old age psychiatry service than to neurology, whereas hospital physicians were more likely to refer to a neurology service. Referrals to neurology services tended to be for diagnostic purposes, whereas referrals to old age psychiatry were for other reasons, including behavioural assessment and long-term management (Allen & Baldwin, 1995). The

recognition of differing areas of expertise in the management of dementia is stressed by Cordery *et al* (2002) who note that younger patients may be under-investigated if managed solely by an old age psychiatrist, and may not receive adequate follow-up services if managed solely by a neurologist.

The study of Allen & Baldwin (1995) draws attention to the role of neurological and neuroradiological support in establishing a diagnosis of dementia in this age-group. The wide range of diagnostic categories makes differential diagnosis especially difficult (Ferran *et al*, 1996). This is particularly important in view of the high number of younger adults with depression who present with memory problems and of the need for specialised genetic counselling for specific disorders. Ferran *et al* recommended that where possible, diagnostic services should involve close collaboration between psychiatrists, neurologists and psychologists.

In order for younger people with dementia and their families to take appropriate steps towards planning treatment and care, early diagnosis is vital. The experience of receiving a diagnosis can be overwhelming, and reactions to the news can vary considerably. Despite this, studies confirm that the level of support offered by professionals at diagnosis can be very limited: Newens *et al* (1994) found that less than 20% of carers interviewed felt that they had been given sufficient information or advice about prognosis, management of symptoms, etc. Psychiatrists, however, were more likely to direct patients to domiciliary care services and support organisations such as the Alzheimer's Society, than were neurologists or other physicians. Support services such as community psychiatric nurses and social workers are highly valued by people with dementia and their carers in helping them to manage day-to-day issues (Delaney & Rosenvinge, 1995).

The goal of encouraging input from both neurological and psychiatric services would be to achieve early and accurate diagnosis, followed immediately by the initiation of plans for long-term management and referral to sources of ongoing support. This would obviously require considerable collaboration or, at the very least, effective communication, between all professionals involved in the care of younger people with dementia (particularly between neurology and old age psychiatry). Unfortunately, such close working can be very difficult to sustain, and the evidence would not suggest that this goal is being achieved in many areas.

The analysis of referral patterns between old age psychiatrists and neurologists by Cordery *et al* (2002) found that where a specialist early-onset dementia service was available, 80% of neurologists would refer patients to such a centre compared with 37% of old age psychiatrists. Where a specialist service did not exist, 21% of neurologists would refer patients to old age psychiatry, in comparison with 60% of old age psychiatrists who would refer to neurology. The situation appears to be one whereby consultants do not tend to involve other specialists in the management of younger patients with dementia. The resulting lack of coordination leads to a situation where, as in one specific example, 112 people can experience 38 different pathways through care services (Williams *et al*, 1999).

## **Development of services**

The principles of care planning should cater for the needs of this group of patients as for any other group. In contrast, surveys consistently report lack of appropriate counselling, carer support and community and respite facilities. In the absence of an organised service with a single focus for referral, younger people with dementia will be cared for by a wide variety of organisations with varying expertise and coordination. Service access is likely to be unsatisfactory, and poor organisation and planning of diagnostic and care services is common (Baldwin, 1994). If a clearly defined pathway of care is provided through one specific agency, service organisation is easier and subsequent use likely to be enhanced. This is illustrated by Ferran *et al* (1996) in their study of service use by 138 patients referred to a newly appointed consultant with special responsibility for younger patients. The service was oversubscribed even though the mean duration of symptoms at the time of referral was about 4 years.

A specifically identified district agency with responsibility for diagnosis of and care planning for younger people with dementia has the advantage of building up expertise in managing patients and their families. Familiarity with local services that cross age boundaries is particularly valuable. Close links can be cultivated with child support agencies, genetic counselling services, and statutory, voluntary and private organisations, with particular reference to the needs of young people.

It is therefore recommended that a single consultant in old age psychiatry be identified as having special responsibility for younger patients in any given commissioner-provider consortium. This responsibility should be incorporated in the contractual arrangements of the business plan, with an identified lead from commissioners, thus protecting the organisation should there be a shortage of appropriate consultants. It should be stressed, however, that close collaboration with neurological services, in particular diagnostic testing and neuroimaging services, should be encouraged at all times. The development of any service for younger people with dementia should benefit from multidisciplinary input.

## Developments in service provision

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Since the publication of the first edition of this document, the picture of service provision for younger people with dementia nationally has changed significantly. A review of developments since 2000 is appropriate, to acknowledge the achievements in the time between the first and this second edition, and to maintain the momentum of these achievements in the pursuit of further sustained improvements.

### Assessing the impact of the first report

The first edition of this document recommended a regular review of developments in services for younger people with dementia. The Alzheimer's Society carried out a postal survey of all members of the Faculty of Old Age Psychiatry in 2002, to assess members' awareness of the report and developments in service provision since its publication.

There were 241 completed surveys returned, and these highlighted some interesting points. Awareness of the report among respondents was high at 76%. However, at the time of the survey no health area had yet met all the report's recommendations:

- 22 respondents (11%) said that contractual arrangements for specialised services were in place and a further 15% reported that arrangements were under discussion
- 9% of respondents said that there was a named individual at the level of commissioning authority
- 15% of respondents reported that a named consultant responsible for younger people with dementia had been appointed.

Although these figures are low, they do reflect a gradual improvement in the development of services. For example, Barber (1997) found that only 12 out of 254 health trusts (5%) provided specialised services to younger people with dementia. The results of the 2002 survey do provide evidence of a developing recognition of the need for specialised services for this group. Furthermore, an encouraging 103 respondents (43%) reported that future plans for developing services did exist.

With regard to the recommendations that a range of professionals had a role to play in the provision of services, respondents referred to a wide range of professionals that had input: neurologists (75%), community psychiatric nurses (75%) and social workers (69%), followed by occupational therapists and neuropsychologists. Although this level of input from different professions is encouraging, respondents also noted that coordination and liaison between groups was variable, and that coordination with neurology services was particularly

difficult. It was felt that significant improvements in services could be achieved simply by improving the level of coordination.

Although the results of the survey indicate a trend towards improving services for younger people with dementia, responses indicated that a number of the report's key recommendations were not being met. For example, only 25 respondents (10%) reported that there was a named social worker with responsibility for younger people with dementia in their local authority area. Furthermore, services in key areas of concern, such as alcohol-related cognitive impairment, HIV-related brain impairment and CJD, were virtually non-existent.

Overall, nearly a fifth of respondents indicated that publication of the original report had improved the way services for younger people with dementia were delivered in their area. This represents an encouraging start and reflects the value of the document in improving services for this disadvantaged group. The authors of the report feel confident that the second edition will help to maintain the momentum of what has already been achieved.

### **Developments in services since 2000**

The Alzheimer's Society maintains a national database of services for younger people with dementia across the UK, which is monitored and updated regularly. An analysis of the services listed on the database was undertaken in November 2000, and the data from this analysis provide a useful base from which to trace developments in service provision since the publication of the first edition of this document.

In August 2004, analysis of the database showed that there were 121 projects offering a range of services for younger people with dementia, a significant increase in the provision of services since 2000. Community/home support services were the most common (52 services), closely followed by day centre/care (50). Respite care (21) and residential and nursing care (20) remain in short supply. There is a growing number of support groups and clubs for carers (36) and for younger people with dementia (17), as well as social and support groups designed for both younger people with dementia and their carers (12). Table 4 summarises service developments since 2000.

Although these figures are encouraging, services for younger people with dementia and their carers are still few and far between. Many areas have no provision for younger people with dementia. Where projects target younger people they may only provide one type of service and not provide for all the person's needs. Nevertheless, the number of projects is growing as the needs of younger people with dementia are increasingly recognised. The region in England with the highest number of individual projects is the North West (Lancashire, Merseyside, Greater Manchester and Cheshire) with 17 projects (14%). The South West has the lowest number of projects for an English region, just four (3%). There are seven projects (6%) in Wales, eight (7%) in Scotland and one in Northern Ireland. Two projects have a nationwide focus.

**Table 4** Types of services for younger people with dementia

| Services  | November 2000 | August 2004 |
|---|---------------|-------------|
|   | <i>n</i>      | <i>n</i>    |
| Assessment and Diagnosis                            | 13            | 23          |
| Carers support group/club                           | 26            | 36          |
| Support group for people with dementia and carers   | NA            | 12          |
| Support group/club for younger people with dementia | 13            | 17          |
| Community/home support/outreach /befriending        | 32            | 52          |
| Day centre/care                                     | 44            | 50          |
| Information and advice/advocacy /counselling        | 19            | 37          |
| Residential and nursing home/care                   | 15            | 20          |
| Respite care  | 14            | 21          |
| Others  | 6             | 11          |
| Total   | 182           | 279         |

NA, not available.

### **Policy developments: The National Service Framework for Older People**

The National Service Framework (NSF) for Older People (Department of Health, 2001: p. 106) contains an action point about younger people with dementia. The NSF directs the National Health Service and councils to 'review current arrangements, in primary care and elsewhere, for the management of dementia in younger people, and agree and implement a local protocol across primary care and specialist services, including social care'. In principle, this represents an important recognition of the needs of younger people with dementia. In practice, however, the NSF fails to make specific direction for the development of services. None the less, the inclusion of younger people with dementia in a document such as the NSF does represent a significant advance in achieving recognition of the complex needs of this group.

### **Services in Scotland**

In Scotland service development for younger people is also patchy. In general community-based services such as befriending or counselling groups are the most common type of development. There are very few specialist day facilities or residential facilities for primary degenerative dementias, although some areas such as Glasgow are able to provide residential accommodation for people with

alcohol-related brain damage. Some areas have begun to develop highly individualised care packages for small numbers of people with very complex needs, such as those with alcohol-related brain damage, those with combined learning disability and dementia, and those with acquired brain injury and dementia. Across Scotland, however, there is no consistency in the strategic planning of services for younger people with dementia.

### **Continuity in care: communication across disciplines and established care pathways**

Effective collaboration between disciplines is commonly cited as a key determinant of good practice in the provision of quality support to younger people with dementia. The establishment, in recent years, of a number of multidisciplinary teams providing specialised care to younger people with dementia is therefore an encouraging development.

The Birmingham Working Age Dementia Service has established the first dedicated full-time consultant post in this sub-specialty. Services such as the Teeswide Young Onset Dementia Team and the Coventry Young Onset Dementia team, have enabled greater coordination of services for younger people with dementia. Similar multidisciplinary services are also well established in Newcastle and Shropshire. The development of community-based teams such as ACCESS YPWD in Suffolk also provides an essential focal point for the care and management of this group.

Key achievements in the planning of care for younger people include the work of the West Midlands Regional Forum for Early Onset Dementia, which has produced two strategic documents for local and national reference: a set of commissioning guidelines for early-onset dementia services (Elliott & Read, 2002) and an integrated care pathway for early-onset dementia (Saad, 2004). Both documents will assist service planners and developers alike. A user version of the integrated care pathway (developed by carers and service users) is available to all individuals referred to the Coventry Young Onset Dementia Team.

Communication between disciplines and professions, as well as general awareness of younger people with dementia regionally and nationally, have been given a considerable boost from the emergence of regional forums for younger people with dementia. Regional forums meet regularly, usually on a quarterly or 6-monthly basis, and allow service providers or interested individuals to meet with others, share experience and good practice, and learn about developments within the region as well as nationally. Forums are not as yet available in all areas of the UK, but the achievements of existing forums in raising the profile of younger people with dementia in their localities indicate that similar models in poorly serviced areas might provide a useful platform for coordinated campaigning and the development of services. Further information is available from the Alzheimer's Society (see Appendix 2).

## **Service evaluation and user involvement**

Recent years have also seen the emergence of a number of evaluative exercises to assess how well dedicated services are meeting the perceived needs of younger people with dementia. The Alzheimer's Society's Younger People with Dementia Project, for example, was independently evaluated in 2002. The findings of the evaluation (Cantley *et al*, 2003) have been used as a basis for the Society to revise and update its strategy for younger people with dementia. Many local services for younger people have also carried out evaluations of their work to assess strengths and weaknesses.

In general, the recent profusion of evaluative exercises has given rise to an emerging knowledge base concerning good practice in specialist services. Recent reports have also demonstrated a growing awareness of the valuable input younger people with dementia themselves can have into such evaluations (see Coombes *et al*, 2004; Shlosberg *et al*, 2004) – this is indicative of a larger trend towards including the insights and opinions of younger people with dementia in any assessments of need (see Beattie *et al*, 2004; Braudy-Harris & Keady, 2004).

## **Services for people with non-Alzheimer's dementias**

From the information available, it would appear that, in addition to the inadequate provision of services for younger people with dementia, specific support for people with non-Alzheimer's dementias is very poor. In particular, services for people with alcohol-related brain impairment remain in very short supply. Early-onset dementia services may be able, to some degree, to accommodate people with alcohol-related brain impairment, but will usually have little or no experience in supporting people with alcohol-related problems.

However, recent years have seen the development of two national support groups for non-Alzheimer's dementias: the Pick's Disease Support Group, for people with frontotemporal dementia, and the CJD Support Network, for people with prion diseases. These organisations have succeeded in raising awareness and interest in these less common causes of dementia, and also provide information, advice and support to people living with these rarer forms of dementia, as well as the professionals working with them (see Appendix 2 for further details).

## **The need for continued pressure**

Progress has certainly been made towards comprehensive services for younger people with dementia, but the pattern of service development remains patchy – it is unacceptable that younger people with dementia find themselves in a kind of 'postcode lottery', with some regions of the UK relatively well serviced and others having virtually no specialist provision.

Notwithstanding the development of such services and key documents as described above, it remains clear that commitment is required at every level, from

commissioning to service delivery, if early-onset dementia services are not to remain dependent upon the efforts of isolated individuals or teams.

The lessons of the past few years, however, are such that it is evident that considerable effort is required to effect any improvement in service provision. A recent study in the Northern and Yorkshire region (Cantley *et al*, 2002) concluded that the development of services within that region was largely opportunistic and piecemeal, and also highlighted the importance of pressure from professionals, the voluntary sector, carers and people with dementia to keep this topic on the service development agenda. As well as institutional commitment, younger people with dementia still need 'champions' to maintain the pressure for improvements in support.

## Conclusions

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Although recent years have seen some developments in the recognition and management of early-onset dementia, it is evident that the provision of quality care to younger people with dementia requires the protection of contractual agreement and a firm commitment on the part of commissioners and care providers.

Arrangements for the incremental development of services, as recommended in this document, should be a reasonable means of achieving tangible benefits for younger people with dementia. Furthermore, new services should be established where necessary to complement and consolidate existing care pathways for this patient group – improved coordination between existing services, for example between neurology and old age psychiatry, has the potential to significantly improve the management of younger people with dementia.

The recommendations in this document do not require an unreasonable investment of resources, but they do require careful planning, with commitment from all parties involved. The College is in a strong position to take these recommendations to all parties concerned. The impact of the previous edition of this document, although appreciable, can be improved upon. The Alzheimer's Society, in association with the College, will assess the progress made in service provision in 2007. It is hoped that the management of early-onset dementia and the care of those affected will continue to see substantial improvement during this time.

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# **Appendix 1: Charter for younger people with dementia and their carers**

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All younger people with dementia, their families and carers should have access to comprehensive, specialist services from diagnosis to long-term care.

## **Early diagnosis, assessment and referral**

General practitioners should have the relevant skills, training and support to recognise the symptoms of dementia in all age-groups and refer people to a specialist consultant who can make a diagnosis and provide ongoing medical supervision.

## **Access to specialist services**

Younger people with dementia should have access to a full range of specialist support services including home, day, respite and continuing care which recognise the different life circumstances and environment of younger people and their carers. Specialist counselling should also be made available.

## **Adequate financial support**

There should be adequate financial support for younger people with dementia and their carers to enable them to meet the extra costs of caring for dementia.

## **Good employment practice**

Employers and the social security system should adopt good employment practices which recognise dementia as grounds for early retirement and which protect a person's entitlement to pension rights and other benefits.

## **Education, training and information**

There should be appropriate education, training and information for all health and social services professionals to ensure an effective and sensitive response to the needs of people with dementia and their carers.

Alzheimer's Society, 1991

## Appendix 2: Useful organisations

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### **Alzheimer's Society**

The Alzheimer's Society provides a range of specialist services for younger people with dementia:

- specialist information and support to people with dementia, carers and professionals
- a reading list on younger people with dementia
- a national database of specialist services
- trained carers' contacts providing regional support, including practical information on services and emotional support
- a support network enabling people with dementia and carers to be linked to others with similar needs
- an annual national conference on younger people with dementia.

Contact: Information Officer for Younger People with Dementia

Tel: 020 7306 0606

E-mail: [ypwd@alzheimers.org.uk](mailto:ypwd@alzheimers.org.uk)

Website: <http://www.alzheimers.org.uk/ypwd>

### **Pick's Disease Support Group**

The Pick's Disease Support Group provides support to carers of people with frontotemporal dementia. The services include:

- specialist information on frontotemporal dementia for carers and professionals
- a quarterly newsletter
- regular events
- regional contacts for local support
- an online discussion group.

Contact: Pick's Disease Support Group

Tel: 0845 458 3208

E-mail: [info@pdsg.org.uk](mailto:info@pdsg.org.uk)

Website: <http://www.pdsg.org.uk>

### **CJD Support Network**

The CJD Support Network provides help and support for people with CJD and other prion diseases, as well as their carers and concerned professionals. It provides:

- specialist information and advice on all forms of CJD
- education and training to promote good practice in care

- a specialist network linking affected families for mutual support
- caring grants for families in financial need.

Contact: CJD Support Network

Tel: 01630 673 973

E-mail: [support@cjdsupport.net](mailto:support@cjdsupport.net)

Website: <http://www.cjdsupport.net>