Early-Onset Dementia

The Needs of Younger People with Dementia in Ireland

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Table of Contents

Figures and Tables

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† Since the report was completed we received the sad news of the death of David Wolfe. His contribution to Services for Older People, especially, people with dementia, will be sorely missed.

Executive Summary

The *Action Plan for Dementia* (O'Shea and O'Reilly, 1999) provides a blueprint for the development of policies and services in the dementia field in Ireland. However, little is known about the specific issues confronting people with early-onset dementia and there are no special programmes for people in this category. The reality is one of choosing from a range of services that were originally set up with other needs or age groups in mind. The Action Plan recommends *'that particular attention should be paid to the needs of people with early-onset dementia with appropriate care packages drawn up to reflect the special circumstances of people in this group and their carers'*. This study was initiated by the Alzheimer Society of Ireland in an attempt to contribute to the discussion about how this recommendation might best be implemented.

Interviewing Younger People with Dementia

Despite our initial intention to carry out a study of younger people with dementia by means of direct interviews, this proved to be virtually impossible and we were therefore forced to collect information from the primary caregivers of those affected by dementia. As a result, this study, explores the most pertinent issues which emerged from our study of 61 cases of early-onset dementia in Ireland. The ten most important issues to emerge were: (i) the need for a timely diagnosis, (ii) informing the person with dementia about their condition, (iii) supporting flexible care arrangements, (iv) improving home help, (v) improving day care, (vi) improving respite care, (vii) improving residential care, (viii) improving medical care, (ix) providing counselling and (x) improving financial supports.

Timely Diagnosis

Diagnosis of early onset dementia is beset with considerable difficulties, as many of the early symptoms are not specific to the illness and may easily not be recognised, particularly if occurring in a younger person. Many GPs will see very few younger persons with dementia during their working life and are therefore not always aware of the prevalence of dementia in a younger persons. Getting a timely diagnosis is of utmost importance to the person with dementia as it affects the person's ability to actively arrange their family life and participate in the management of their own care for as long as they are still able to do so.

Recommendation 1:
We believe that an awareness campaign amongst GPs would have a positive effect, firstly by making GPs more aware of the prevalence of early-onset dementia and by encouraging multidisciplinary assessment and referral to specialists that are able to either confirm or refute the onset of dementia in a younger person.

Informing the Person with Dementia

In about half of the cases we studied, the individual with early-onset dementia had not been informed of their illness. In another quarter of cases, despite having been informed, the person is no longer aware of their illness due to its very effects. There remains a culture of not informing the person with dementia, partly out a fear that knowing about their illness may add to the person's anxiety and distress. Notwithstanding a person's right not to be told about their illness, good practice would dictate that a person generally should be told about their condition.

Overall, the 'window of opportunity' to tell a person that he or she has dementia is relatively short, thus limiting the possibility of responding actively to the early onset of dementia and the specific problems that this entails. The people we interviewed as part of this study indicated that, where it was possible to inform the person with dementia, this knowledge was valued by all those directly involved. The biggest obstacle to telling a person about developing dementia, particularly when concerned with a younger person is a degree of stigma about the illness.

Recommendation 2:
We recommend that the Alzheimer Society continues to raise the profile of early-onset dementia within their general dementia campaigns to highlight the specific issues that are of concern to younger people with dementia.

Supporting Flexible Care Arrangements

Most younger persons with dementia are cared for in the family home. In our study population, 59 per cent are living with their partner, a small proportion (8%), all of whom are in the early stages of dementia, live on their own, whilst about 15 per cent live with a son or daughter or other relative. Only 15 per cent are in a residential home. There is a strong preference by younger people with dementia and their caregivers to maintain such arrangements for as long as possible. It is also important to note that such arrangements are the most cost-effective for society as a whole. However, caring for younger people with dementia in their own home setting crucially depends on the availability of flexible care arrangements to facilitate this.

Recommendation 3:
The overall aim in the care for younger people with dementia must be to provide a sustainable set of care arrangements which respects the wishes of the person with dementia and their partner and closest family members.

Access to Home Help

Only 24 of the 61 people (39.4%) in our sample had access to home help and over 40 per cent indicated that their level of access to home help is either inadequate or completely inadequate. Even where they had access to this assistance, there is often a desire to avail of more hours per week, alongside a widespread dissatisfaction with the time at which the help can be provided.

Recommendation 4:
There is a need for the Health Service Executive to increase the overall level of home help available to younger people with dementia, to address the hours during which such help is available, as well as assuring that levels of support are equitable and not resulting in regional differences.

Special Supports Groups for Younger People with Dementia

Day care centres play an important role in facilitating people with early-onset dementia, enabling them to stay in the family home for as long as possible. However, besides the general lack of places, existing day care centres are far from adequately equipped to provide the services needed by younger people with dementia.

- Existing day care centres primarily cater for older people with dementia and tend to lack sufficient stimulus for younger people.
- Where those with early-onset dementia frequent day care centres, this can put considerable demands on staff, mainly due to their greater level of activity, strength and, at times, challenging behaviour.
- There is a need to bring together younger people with dementia in special groups to deal with issues specific to them (e.g. medical information about dementia, counselling, legal advice, etc.).

Recommendation 5:
It is recommended that at least in Dublin, Galway, Limerick, Cork and Waterford specific support groups for younger people with dementia be set up.

Improving Respite Care

The importance of respite care lies in that it enables regular caregivers to recover their energy levels and continue to playing a primary caring role. However, younger persons with dementia may frequently find it impossible to access respite care.

- There is a general shortage of respite facilities and there is no respite care unit in Ireland which specialises in supporting younger people with dementia.
- Even where a general respite facility exists, the nursing home may not accept individuals under 60 or even 65, thus automatically excluding those with early-onset dementia.
- People with early-onset dementia may not meet referral criteria, e.g. with regard to behavioural problems.

Recommendation 6:
There is an urgent need to improve respite facilities for younger people with dementia. Improvements are sought in three ways: (i) the setting up of at least one dedicated respite facility for younger persons with dementia, (ii) a review of access criteria to existing respite facilities, and (iii) a review of the benefit criteria of the Health Service Executive to include the direct provision of, or financial support towards respite care for younger persons with dementia; i.e. the explicit recognition that temporary residential care is allowable under the age of 65.

Improving Residential Care

Recommendation 7:
There is an urgent need to improve residential care facilities for younger people with dementia. Improvements are sought in three ways: (i) increasing the number of residential care places which are available for younger persons with dementia, (ii) a review of access criteria to existing residential homes, and (iii) a review of the benefit criteria of the Health Service Executive to include the direct provision of, or financial support towards residential care for younger persons with dementia; i.e. the explicit recognition that residential care is allowable under the age of 65.

Providing Counselling Services

In the absence of a general cure to Alzheimer disease, medical care is largely limited to the treatment of secondary symptoms, like e.g. depression or anxiety. However, counselling could potentially provide considerable help for the person with dementia and their partners and family members in dealing with anxiety, depression and, where present, aggressive behaviour and have a significant influence on the quality of life experienced.

Recommendation 8:
We recommend that counselling services specific to younger people with dementia be developed in co-operation between the Health Services Executives and the Alzheimer Society of Ireland.

Improving Financial Supports

People with early-onset dementia and their families experience a double financial strain: firstly, they frequently loose one of the income providers to the family and, secondly, they incur considerable costs in the care for the person. At the same time, there are no specific state benefits for younger persons with dementia or their families, as they do not fall within any of the recognised categories. Early-onset dementia is neither categorised as a disability, nor as a terminal illness and at the time of diagnosis the person with dementia is by definition not eligible for benefits aimed at older people. Thus, many existing care provisions and financial supports are either unavailable to younger people with dementia or are inappropriate, having been designed with other target groups in mind.

Recommendation 9:
There is urgent need for early-onset dementia to be acknowledged as a specific needs group with appropriate care packages to be drawn up to reflect the special circumstances of people in this group and their caregivers.

Recommendation 10:
There is an urgent need to review the financial supports that are available to persons affected by early-onset dementia and/or their caregivers.

Clarifying Departmental Responsibilities and Legal Rights

Early-onset dementia does not easily fall under the responsibility of any one section within the Department of Health and Children. It is largely dealt with as an adjunct to dementia more generally and is therefore closely associated with services for the elderly. However, as the study shows, the care provisions which are needed in response to early onset dementia differ significantly from those needed for older people with dementia and questions arise as to whether dealing with early onset dementia is best served in the context of developing services for older people. What is needed is a complete change in the care system towards a person-centred approach and individualised care plans which respect the wishes of the clients.

Recommendation 11:
Urgent consideration needs to be given by the Health Service Executive to create the necessary structures to overcome the current fragmentation of responsibilities between services for the elderly, disability services and mental health services, and facilitate the effective development of comprehensive dementia care, independent of age.

Furthermore, the consultants believe that the new disability legislation that is currently developing in Ireland includes some important milestones with regard to developing appropriate responses to people with special needs and that provisions for people with early onset dementia should be reviewed in light of such newly developing frameworks.

Recommendation 12:
Consideration should be given to afford younger people with dementia similar status as those identified under the new Disability Bill 2004.

A Pilot Project for Younger People with Dementia

The Health Service Executive East Cost Area is currently supporting a pilot project Slán Abhaile, which is targeted at targeted at older people who, in spite of their wish to remain living in their own homes, might be at risk of having to move into residential care in order to have their long-term care needs met. Slán Abhaile supports both the principles and the objectives of the National Health Strategy in that it offers:

- Person-centred care
- Coordinated planning between agencies/service providers
- Individual integrated service plans for older people
- Enhanced home support services (including evenings and weekends)
- Support for informal carers

We believe that it its an opportune time to develop a similar project specifically targeted at younger people with dementia. While the number of younger people with dementia will always be small compared to the potential older population in need of a person-centred care plan, the pilot project would have to have as an explicit aim to draw younger people with dementia as early as possible into the project such as to learn about their needs and have them participate in the planning of their own future to the maximum extent. The outcomes of such pilot project, if properly evaluated, would provide an invaluable platform for the development of adequate services for younger people with dementia which is currently missing in the health system.

Recommendation 13:
The Health Services Executive should establish a pilot project along the lines of Slán Abhaile, specifically targeted at developing person-centred care plans for younger people with dementia. Given the experience of the Alzheimer Society in pioneering responses to early onset dementia, we suggest that such project may be pursued in partnership between the HSE and Alzheimer Society.

1 Introduction

The *Action Plan for Dementia* (O'Shea and O'Reilly, 1999) provides a blueprint for the development of policies and services in the dementia field in Ireland. However, little is known about the specific issues confronting people with early-onset dementia and there are no special programmes for people in this category. The reality is one of choosing from a range of services that were originally set up with other needs or age groups in mind. The Action Plan recommends *'that particular attention should be paid to the needs of people with early-onset dementia with appropriate care packages drawn up to reflect the special circumstances of people in this group and their caregivers'* (ibid). This study was initiated by the Alzheimer Society of Ireland in an attempt to contribute to the discussion about how this recommendation might best be implemented.

2 Aims of the Analysis

The overall aim of the study is to carry out a needs analysis of people with early-onset dementia in Ireland.

The Terms of Reference outline the following objectives:

- To present a statistical analysis of persons with early-onset dementia, in particular a demographic profile including age, age of onset and diagnosis, gender, socio-economic and family status.
- To provide an insight into and understanding of the day-to-day lives of persons with early-onset dementia and their caregivers.
- To produce a profile of the services used by those with early-onset dementia.
- To evaluate current policies and available services from a number of stakeholder perspectives.
- To examine the service, economic, social, emotional and support needs of the target group (including caregivers).
- To examine and to present good practice models in other comparable jurisdictions and to identify the lessons for policy and service planning in Ireland.
- To offer a set of recommendations for the future development of policies and services for the target group.

3 Methodological Considerations

The key issue confronted by the present research is the lack of statistical data which might be used to develop a needs analysis of people with early-onset dementia in Ireland and a substantial part of the study had to deal with the problem of how to compile reliable data so that future policy considerations might be based on this evidence.

In ideal circumstances, the development of a reliable portrait of those with early-onset dementia in Ireland would have required to identify the full population of those with early-onset dementia and then draw a random sample from this population for in-depth interview. This, in turn, would have required the participation of all Health Service Executives, specialist consultants and GPs throughout the country and over a considerable period of time. Such an approach was unfortunately beyond the scope of this study and would not have produced results within the required time frame. The study therefore is much more limited in as much as it exclusively builds on the experience of those with early onset dementia who are in one way or another in contact with the Alzheimer Society of Ireland.

However, the Alzheimer Society is a key service provider in Ireland for people with dementia, including those with early-onset dementia. The Society has developed a contact database of about 2,000 people with dementia, either directly or via their caregiver. This represents a significant proportion of all those with dementia in Ireland, but obviously one cannot assume that the profile of those in contact with the Society is identical to that of the overall population of people with early-onset dementia. Nevertheless, given the limitations of the present research we must treat the Society's contact list as a valid proxy for the population of people with early-onset dementia in general.

The second problem to be overcome in the course of the study concerned the identification of people with early-onset dementia from amongst the Society's clients. People with early-onset dementia make up less than ten per cent of the Society's contacts, but the contact database does not contain information about the age of the person with dementia. We therefore had to adopt a three-step procedure: firstly, a short postal questionnaire which was sent to all of the Society's home services and day care centres. This was followed up by interviews with the managers of those services that indicated that they were in contact with younger people with dementia. Following this, the managers asked each of their younger clients with dementia (or their caregivers) whether they were willing to participate in the survey and arranged interviews thereafter. The face-to-face interviews were carried out in considerable depth mostly with the caregiver, and in two instances with the person with dementia. The results of this survey are reported in Part A of this study.

Finally, we added to the views expressed by the individuals with dementia, their careers and the managers of the Alzheimer Society's services the views of some key informants of the Department of Health and Children and the Health Service Executive. Together, we hope to have achieved the aim of providing first insights into the lives of people with early onset dementia in Ireland and the particular problems they face.

4 The Prevalence of Early-Onset Dementia

There are no precise estimates available of the number of people living with dementia in Ireland. Lawlor *et al.*[1] estimate that there are just over 22,000 people with dementia living in the community. If we add to this the number of people with dementia in long-stay care (the estimates vary between 3,755 and 7,380) and those in psychiatric hospitals (approximately 560), O'Shea[2] concludes that there are approximately 30,000 people with dementia in Ireland. Prevalence data from Irish sources correspond closely to the numbers generated by the application of EURODEM[3] prevalence rates when applied to Irish population data, which result in an estimate of 31,000 people with dementia in 1996 (*ibid)*.

Applying the EURODEM prevalence rates to the 2002 Census of Population data for Ireland suggests that there are currently over 33,000 people with dementia and that about 3,500 of these are under the age of 65 (Table 4.1). Ireland's population is set to increase dramatically over the next two decades. Furthermore, due to increased life expectancy and falling fertility rates, the population will also age, with a disproportionate increase in the percentage of people aged 50 to 70. The Central Statistics Office provides a number of population projections based on different fertility and migration assumptions. Taking the high growth assumption (Model M1F1), and the prevailing EURODEM parameters, the number of people with dementia in Ireland is likely to increase to 47,600 in 2016 and 66,600 by 2026. The number of people with early-onset dementia is thereby likely to increase to over 5,000 by 2016 and to nearly 6,000 in 2026 (Appendix 1).

It is important to point out that it is impossible to substantiate the prevalence figures for early-onset dementia in Ireland from the survey undertaken for this study. If the estimates based on EURODEM are correct, only three per cent of younger people with dementia are in contact with any of the services run by the Alzheimer Society and our sample population amounts to less than two per cent of the estimated population of younger people with dementia. Therefore the characteristics of people with early-onset dementia discussed the following

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[1] Lawlor B., Radic A., Bruce I., *et al.* (1994) 'Prevalence of Mental Illness in an Elderly Community Dwelling Population Using AGE-CAT'. *Irish Journal of Psychological Medicine, 11, 157-160.*

[2] O'Shea, Eamon (2000) *The Costs of Caring for People with Dementia and Related Cognitive Impairments.* Dublin: National Council on Ageing and Older People

[3] Hoffmann A., Rocca W.A., Brayne C., *et al.* (1991) 'The prevalence of dementia in Europe: a collaborative study of 1980-1990 findings'. *International Journal of Epidemiology*, 20, 736-748.

chapters is representative only of those who avail of services provided by the Alzheimer Society but are not necessarily representative of the total population of younger people with dementia.

Table 4.1: Estimated Number of People with Dementia Based on EURODEM Model

	Male	Female	Total	Male	Female	Total
	%	%	%	Numbers	Numbers	Numbers
30 - 59	0.16	0.09	0.13	1,238	695	1,932
60 - 64	1.58	0.47	1.03	1,225	360	1,586
65 - 69	2.17	1.10	1.62	1,417	750	2,167
70 - 74	4.61	3.86	4.21	2,384	2,332	4,716
75 - 79	5.04	6.67	5.99	1,884	3,498	5,381
80 - 84	12.12	13.50	12.98	2,701	4,937	7,638
85 - 89	18.45	22.76	21.40	1,758	4,697	6,455
90 - 94	32.10	32.25	32.21	788	2,246	3,034
95 - 99	31.58	36.00	34.97	158	591	748
Total	**1.30**	**1.84**	**1.58**	**13,553**	**20,105**	**33,658**

Part A: A Study of 61 Young People with Dementia

5 The Study Population

The empirical element of this study is based on interviews with 61 caregivers for younger people with dementia; i.e. where the onset of dementia occurred at age 65 or younger. Contacts were made through the Alzheimer Society Home Supports or Support Groups, involving an invitation to all such groups throughout the country. In total, twenty centres participated. Some centres were in contact with only a single person with dementia under 65; the highest incidence was in Donegal with six people who had developed dementia at a younger age. Table 5.1 shows the distribution of the study participants across the different Regions. The interviews were carried out between May and October 2004.

Table 5.1: Study Participants by Region and Gender

	Male	Female	Total	Male	Female	Total
	Numbers	Numbers	Numbers	%	%	%
Border	2	4	6	33.3	66.7	100.0
Dublin	5	8	13	38.5	61.5	100.0
Mid-East		3	3		100.0	100.0
Mid-West		3	3		100.0	100.0
Midland	3	8	11	27.3	72.7	100.0
South East	4	12	16	25.0	75.0	100.0
South West	3	6	9	33.3	66.7	100.0
Total	**17**	**44**	**61**	**27.9**	**72.1**	**100.0**

None of those who receive support from the Alzheimer Society are below the age of 50 and only two people are under 55 years of age. Those who developed dementia at an earlier age and are supported by the Alzheimer Society are thus more or less equally divided between those who aged between 56 and 65 years and those who are over 65 (Table 5.2).

Table 5.2: Study Participants by Age and Gender

	Male	Female	Total	Male	Female	Total
	Numbers	Numbers	Numbers	%	%	%
46 – 55		2	2	0.0	100.0	100.0
56 – 65	8	21	29	27.6	72.4	100.0
over 65	9	21	30	30.0	70.0	100.0
Total	**17**	**44**	**61**	**27.9**	**72.1**	**100.0**

The average age at which people with early-onset dementia experience their first symptoms is 55 years, with the age of onset being relatively evenly spread across the four five-year intervals leading up to 65 years of age. As pointed out earlier, no conclusions can be drawn from this with regard to the prevalence of early-onset dementia, as the sample size is far too small. Nevertheless, the age distribution observed here is important with regard to the age at which the clients of the Alzheimer Society initially develop symptoms.

Table 5.3: Participants' Age at Onset of Dementia by Gender

	Male Numbers	Female Numbers	Total Numbers	Male %	Female %	Total %
under 46		2	2		4.5	3.3
46 - 50	3	8	11	17.6	18.2	18.0
51 - 55	8	10	18	47.1	22.7	29.5
56 - 60	4	13	17	23.5	29.5	27.9
61 - 65	2	11	13	11.8	25.0	21.3
Total	**17**	**44**	**61**	**100.0**	**100.0**	**100.0**

On average, four years elapsed between the appearance of the first symptoms and diagnosis with Alzheimer. One in five people with early-onset dementia were diagnosed within one year of developing symptoms and two in five were diagnosed after two to three years. However, for one in five it took four to five years to be diagnosed, whilst for the remaining 20 per cent it took in excess of six years and up to ten years before they were diagnosed.

Table 5.4: Years of Symptoms before Diagnosis by Age Group

	up to 1 year	2-3 years	4-5 years	6-10 years	Total
Age Group					
46 - 55	2				2
56 - 65	6	14	5	4	29
over 65	3	11	7	8	29
Total	**11**	**25**	**12**	**12**	**60**
%					
46 - 55	100.0				100.0
56 - 65	20.7	48.3	17.2	13.8	100.0
over 65	10.3	37.9	24.1	27.6	100.0
Total	**18.3**	**41.7**	**20.0**	**20.0**	**100.0**

Exactly two thirds (67%) of the study group were diagnosed with Alzheimer disease and a further 13 per cent were diagnosed without identifying any specific form of dementia. In twenty per cent of cases, the diagnosis comprised other specific forms of dementia, including Lewis Body, Pick's disease, frontal lobe and mixed vascular dementia.

Once a diagnosis has been made, the question arises as to whether the person with dementia is being told that they have this disease. Just over half (56%) of our study sample have never been informed that they have dementia. The remainder are equally divided between those who are currently aware of this fact and those who were aware of this at an earlier time but who are no longer capable of appreciating the meaning of this diagnosis.

6 The Symptoms of Early-onset Dementia

In this chapter we will look at the main symptoms of early-onset dementia. Whilst dementia is primarily associated with memory loss, and particularly loss of short-term memory, the signs of early-onset dementia are more varied. No particular symptom or combination of symptoms can be identified as definitive, although those affected by early-onset dementia develop an increasing number of these symptoms over time, typically of increasing severity.

In and of themselves, the symptoms outlined below provide a powerful indication of the changes that the illness produces in people's lives and of the resulting hardship, both on the part of those directly affected as well as their partners, families and relatives. The results reported here also provide insights into the frequency of occurrence of different symptoms and are thus potentially of assistance in relation to the timely diagnosis of this disease and understanding its progression. It is important, however, to point out that none of these symptoms, in isolation, can provide proof of the onset of dementia. Medical diagnosis is complicated and, at times, difficult to achieve. Arguably, it is important to focus not only on symptoms, but also on the changes that occur in people's behaviour and personality. The dynamics of this change provide the key to understanding the process that is under way and in need of investigation and, where possible, treatment.

When reading the descriptions that follow, it must be remembered that our sample contains 61 people who developed early-onset dementia. Those concerned are at varying stages in the progression of their illness: whereas some have only recently been diagnosed and are still able to live a reasonably normal life with their families, others are no longer able to do so and are in full-time residential care. In two cases, the person concerned had died only a short time prior to the interview with the caregiver.

Thus the range of symptoms reported in the following sections partly reflects the degree to which the illness has progressed. At the same time, this is far from being a linear process. Indeed, some people develop certain symptoms early on and never develop others. This randomness is a critical feature of the illness, and must be borne in mind when studying the dynamics of early-onset dementia.

6.1 Remembering Things

Memory loss, and particularly loss of short-term memory is probably the most common symptom associated with the onset of dementia. All of those in our sample were affected by memory loss, at least to some extent, with nearly two thirds (62%) being profoundly affected. In practically all cases it was primarily their short-term memory which was most strongly affected, resulting in a gradual "slipping back" in time.

Initial experiences of dementia are frequently related to the failure to remember where one has placed one's belongings. This can, at times, be accompanied by refined methods of memory jogging and forms of deception such that no one notices the resulting difficulties. Other experiences relate to unreasonable behaviour when shopping (e.g. buying large quantities of chocolate bars several times a day and then denying who had bought them or losing track of what needs to be bought and what has already been brought home, or losing track of the money spent and not waiting for the change at a cash till).

Other experiences involve feelings of geographical disorientation, such as not being able to find one's way home from a familiar neighbourhood. This may occur when walking, but more often when driving: the person with dementia simply cannot recognise a street that used to be familiar to them.

All of those who participated in the study reported a growing inability to recognise people: first their neighbours and friends, then their children and finally their own partner. In some cases, they may no longer remember their own name. In other cases, their partner may be mistaken for a brother or sister, as long-term memory takes over and replaces more recent life experiences. It is this failure to recognise close family members that tends to generate the greatest distress amongst the latter.

Table 6.1 Remembering Things

	Number	%
not affected		
slightly affected	4	6.6
affected	8	13.1
strongly affected	11	18.0
profoundly affected	38	62.3
Total	**61**	**100.0**

Experiences Associated with Memory Loss: Individual Cases

slightly affected

- this person began to mislay keys and to devise systems to sort things and to conceal difficulties with memorising and finding things

affected

- this person was affected from the beginning, producing changes in his life, with the result that he was unable to go to the shop to buy a newspaper

strongly affected

- this person began to forget lots of things and could not find the way home, or recognise people he knew well
- this person has good long-term memory but no short-term memory at all
- another person with dementia remembers people but cannot handle everyday matters, such as responding to requests such as taking the butter out of the fridge
- a fourth person remembers names and people but does not know how to dress himself or shave.

profoundly affected

- the first person in this category cannot remember where the toilet is in their own home
- the next “used to have a memory like a computer” but now cannot remember anything
- another person initially only lost their memory on occasions, in a less serious way, although now they cannot remember anything
- a fourth is totally oblivious to his surroundings
- a fifth has completely lost their short-time memory and remembers things that happened a long time ago but not yesterday
- another person “could go to the oven to get the milk”, she has no idea where it might be
- another only remembers his early years, having lost his short-term memory
- another person with dementia cannot remember anything, including how to dress herself
- in another case the person affected has very little short-term memory and lives in their youth
- in another case the person with dementia can remember very few things and cannot dress
- in the final case, the person with dementia has been profoundly affected for the last three years and doesn't recognise her husband

6.2 Sense of Anxiety

More than two-thirds (71%) of people with early-onset dementia experience some level of anxiety. The person with dementia generally senses that there is something wrong with their memory and experiences frustration at their inability to remember things. They may deny this, both to themselves and to their family members, but it frequently gives rise to increased anxiety levels and sometimes even generates panic attacks. In severe cases, this can also lead to depression (see below).

There is a cyclical pattern associated with these heightened levels of anxiety, increasing during the early stages of the illness but subsequently declining as the person with dementia becomes more oblivious to their surroundings and as their self-perceptions change.

Table 6.2 Sense of Anxiety

	Number	%
not affected	8	13.1
slightly affected	10	16.4
affected	16	26.2
strongly affected	10	16.4
profoundly affected	17	27.9
Total	**61**	**100.0**

Experiences Associated with Anxiety: Individual Cases

not affected (note: effectively beyond the point of experiencing anxiety)
- not sufficiently aware to be anxious
- “nothing bothers her”
- has no awareness of day-to-day living

slightly affected
- normally in good spirits, easy to very quiet at times
- one outbreak, threatened suicide
- anxious if routine is interrupted, e.g. late collection disrupts the whole day
- she is “mellow”, but when asked to do something, resists (e.g. to wash up)

affected
- very few episodes, but involved extreme anxiety
- not being able to remember things gets to him
- covers up anxiety
- OK as long as husband is present

strongly affected
- gets panicky, e.g. about locking front door, very security-conscious
- initially very anxious and very aware of mistakes, trying to cover up
- anxiety became a problem, without others realising.
- person with dementia gets agitated, especially when speech is affected
- unable to sit easily for long periods: gets into a panic, works up a sweat, walks around at a quick pace - particularly if routine changes

profoundly affected
- a lot of frustration and panic attacks
- anxious all of the time, particularly if left somewhere on her own
- she gets stressed about the dinner or her purse - these are her fixations
- gets very anxious about small things
- he wanted to get out and was anxious about the farm, did not accept reassurance
- terrified all of the time

6.3 Feeling Depressed

Every second person with early-onset dementia (56%) suffers from depression. However, unlike anxiety, depression is not always as obvious to the partner and family, as it is more inwardly-oriented. Indeed, a significant number of caregivers were not sure about whether, and to what extent the person with dementia was actually depressed. In a significant number of cases, it was obvious that the person felt depressed and had been prescribed medication. Responses to prescribed medication varied considerably in our sample, with some stating a very positive response and other caregivers stating that they felt that the medication even made things worse. As in the case of anxiety, depression levels may sometimes improve as the dementia progresses and the person becomes more oblivious to their surroundings.

Table 6.3 Feeling Depressed

	Number	%
not affected	16	26.2
slightly affected	11	18.0
affected	13	21.3
strongly affected	11	18.0
profoundly affected	10	16.4
Total	**61**	**100.0**

Experiences of Depression: Individual Cases

not affected (note: effectively beyond the point of experiencing depression)

- not now, but was depressed at the beginning
- she is never on her own and now “forgets” to get depressed
- never depressed, as she does not have sufficient awareness
- not presently depressed - too unaware of surroundings

slightly affected

- she gets a little depressed when her husband leaves for work - medication helps
- must have been depressed early on, but never spoke about this - later some “weeping sessions” with son
- given extra medication against depression recently - now back to normal
- used to be a lot worse, but medication is helping a lot
- she was always good at covering up with a smile

affected

- she constantly refers to being sick and wanting to stay in bed
- always suffered a bit from depression, but even more so now - on medication
- sometimes very down and sad

strongly affected

- she has a defeated, sad look
- sleeps too much, eats too much or not at all, he looks depressed
- used to get depressed after noticing that something was wrong - now no longer depressed
- suffered during the early stages, now on anti-depressants, which are not working well, she gets annoyed with herself
- was depressed at times, now on anti-depressants, not a major issue any longer

profoundly affected

- was depressed for a long time – now no longer aware of anything

6.4 Keeping up with Close Relatives

Most people with early-onset dementia live in their family home and are cared for by their partners and children. However, as communication skills decline and memory lapses increase, it becomes increasingly difficult to keep up with relatives. The process is generally a gradual one, with the circle of relatives becoming smaller over time. This process also depends partly on the attitude adopted by relatives, as relationships tend to become increasingly passive as far as the person with early-onset dementia is concerned.

Typically, this involves a gradual reduction in the frequency of leaving the house, and possibly an increasing reliance on the phone; phone conversations then become too demanding (in terms of the concentration involved) and contact is reduced to visits by relatives. In many cases, the dementia progresses to the point where the person is no longer able to recognise their relatives, first forgetting their names and eventually not being able to recognise their faces. The younger the relatives, the earlier their identities tend to get lost, with siblings frequently being the last to be forgotten. Indeed, at times the person with dementia may mistake their partner for a brother or sister. Ultimately, communication may cease altogether.

It is important, however, to recognise that not being able to communicate verbally does not necessarily mean that the person concerned is beyond caring. There are a significant number of examples which document that the presence of a familiar person alone conveys considerable benefits and reassurance to the person with dementia, even if no meaningful conversation takes place. Agitation and anxiety often appear to increase when familiar people leave the room and one caregiver pointed out the importance of touch as a means of communication: “friends and relationships went out the window, but as much instigated by others. People think they can only communicate verbally, but it's not true.”

Table 6.4 Keeping up with Close Relatives

	Number	%
not affected	7	11.5
slightly affected	6	9.8
affected	12	19.7
strongly affected	15	24.6
profoundly affected	21	34.4
Total	**61**	**100.0**

Relationships with Relatives: Individual Cases

affected

- while they are there, she knows them, but she forgets when they are gone. She recalls some names, not others.

strongly affected

- would never think to ring a sister, but would chat on the phone
- relatives have to take the initiative, he would not take the initiative himself
- people talk to him, but he responds very little
- never took the initiative and family now stays away
- seems to just drift away from them altogether

profoundly affected

- recognises the sisters and brothers sometimes, but not always
- recognises his wife, but is no longer able to recognise his daughter (who he believes to be his sister)
- recognises familiar people but unable to put a name to the face
- unable to take the initiative any longer, unable to recognise them any longer

6.5 Relating to Other People

Losing contact with other people is almost inevitably the first step along the path to isolation, both for the person with early-onset dementia but also, significantly, for their family and primary caregivers.

Unfortunately, dementia is associated with a considerable stigma. Due to a lack of understanding of this illness, people tend to shy away from the awkwardness involved in meeting a friend or neighbour who has developed dementia. The stigma is possibly greater with regard to early-onset dementia than dementia amongst older people. Although older people sometimes lose their memory and communication skills, it is considerably more difficult to deal with a comparatively young person, particularly if they can respond in unexpected and even threatening ways. One caregiver, for example, described how it has become impossible to meet other people, as her husband has a tendency to grab things or people, e.g. by the arm. He has a very tight grip, which can obviously result in embarrassing situations. A progressive loss of contact with friends and neighbours generally precedes the decline in contact with family members, and may constitutes an early sign of onset.

Table 6.5 Relating to Other People

	Number	%
not affected	3	4.9
slightly affected	5	8.2
affected	13	21.3
strongly affected	16	26.2
profoundly affected	24	39.3
Total	**61**	**100.0**

Relationships with Friends and Neighbours: Individual Cases

slightly affected

- continues to play bridge, but comes back less and less relaxed, although she keeps winning!
- can get very quiet with people, especially with someone she is not familiar with

affected

- is growing more passive now, e.g. unable to use the phone
- recognises other people but merely repeats whatever they say
- started tormenting people in neighbourhood, calling in two to three times a day – she obviously did not want to be left on her own
- depends on the day: some days are good, but most days are bad

strongly affected

- does not converse, but answers when approached
- has become awkward and ill at ease when meeting people
- unable to converse any longer

profoundly affected

- was always a shy person, but got worse when the words started slipping
- up until last year, she continued to socialise - now she is withdrawn and pretends to be asleep - she gets tired early in the evening
- cannot take part in any conversation, only a yes or no every so often
- used to mix people up. Children in the neighbourhood were cruel
- unable to recognise other people from the early stages, unable to go outside gate
- “once communication goes, people stop coming, yet she likes people and remains interested! It is a pity that people don’t realise the importance of touch!”

6.6 Carrying out Everyday Tasks to the Same Standard as Previously

This is probably the change that most frequently raises suspicions amongst close relatives that something is wrong with the person concerned. Unlike the gradual loss of memory, the decline in communication skills or mood changes, this phenomenon is more easily observable and manifests itself more directly. It is not a question of whether a person is able to complete a task, but rather of how they do this compared to previously.

As the majority of people in this study are female, the most frequent observation relating to the early stages of the illness is that the person concerned no longer does the housework to the standard she was accustomed to. Starting with a gradual decline in relation to tasks like cooking, shopping and cleaning, this typically advances to include a loss of pride in the home and ultimately a complete neglect of and detachment from their surroundings.

As the defining characteristic of early-onset dementia is the early age at which people develop this illness, a significant number of people are either in employment or self-employment when they start to experience its symptoms. In this context, not being able to perform tasks to the previous standard is one of the earliest detectable symptoms. As the person concerned is employed to do a specific task, their inability to perform that task will obviously be noticed quickly. But before it is noticed by co-workers, employers or family members, it is likely to be perceived by the person themselves, who comes under increasing pressure to fulfil their commitments. This pressure may also be noticed by, or expressed to partners and family members.

This process inevitably culminates in the ending of the work career of the person with dementia. However, the way in which this occurs varies from case to case. It is evident from the interviews that little assistance is available to help people to keep up their working life for as long as possible, if they so wish. With few exceptions, once a diagnosis of dementia is made, this entails the end of the person’s working life. In some cases, this may be a voluntary decision, in order to spend as much time as possible with their partner and family. In other cases, however, termination of work became necessary as the individual can no longer be insured. In other cases, where the work contract is less formal, the person may simply be laid off. Finally, some people decide to leave their job due to their inability to handle the burden of work.

It is impossible to draw up any general guidelines for how to deal with the work situation of a younger person with dementia. Dementia can develop at different speeds and some people may wish to continue working for as long as possible, either because they love their work or because it provides them with important stimuli which may help to slow down the progression of the illness. It is therefore important that support mechanisms and flexible arrangements are put in place to facilitate the person to continue to work – either in the workplace or at home - for as long as they wish.

Another issue that affects many people with dementia is the loss of their sense of direction or geographical orientation. For some, this initially affects their driving, to the extent that they are unable to recognise the streets that they are in, even when near their home and following routes that are very familiar to them. Later on, this disorientation may become more profound, with people losing their way in front of their home. The tendency for people with dementia to ‘wander’ is a major aspect of their care management, as a person may get lost and effectively need an around-the-clock care plan.

If this wandering is occasional, it may be of considerable help if the person concerned has lived at their current address for a considerable length of time. Neighbours may be able to intervene discretely and guide them home, once they recognise the person concerned. They may be aware that they have dementia, although this is not helped by the considerable stigma attached to the disease, particularly where the person affected is still relatively young. Where people have lived in a particular place for a considerable length of time and have good neighbourly relationships, this has a beneficial effect on the length of time for which they can cope independently or with minimal supervision.

However, as the illness progresses, dementia becomes increasingly debilitating, making it impossible for the person with dementia to perform even the most ordinary tasks, from changing their clothes to washing, bathing, shaving and feeding themselves. Despite the fact that our sample comprises people at all stages of the illness, nearly three-quarters (72%) indicate that they are profoundly affected and another 18 per cent say that they are strongly affected by it. Only two persons in the sample (3%) were not yet affected in their ability to do tasks to the usual standard, making this one of the most striking symptoms of early-onset dementia.

Table 6.6 Doing Everyday Tasks

	Number	%
not affected	1	1.6
slightly affected	1	1.6
affected	4	6.6
strongly affected	11	18.0
profoundly affected	44	72.1
Total	**61**	**100.0**

Experiences Associated with Performing Tasks: Individual Cases

strongly affected

- she always remembers that the dishes have to be done and she still hangs out the washing, but forgets to buy paper or to pay the bills
- has gradually retreated from organising bridge rounds
- very house-proud previously, now the house does not matter
- got lost a few times, lost a lot of weight, has difficulty dressing himself, he once walked into a shop with his trousers half down, with people calling the police
- could shave himself three times, forgetting he has just done this

profoundly affected

- was very good before she went into long-term care nine months ago, now unable to do anything
- will not even cook for herself, as she cannot be bothered
- is finding it difficult to find places, has given up driving, dressing is becoming a problem, unable to do anything now beyond making a cup of tea, will not go out on her own, as she has got lost a few times
- in the beginning he always had to check to see if the cows had been milked - he made an effort to disguise it from us – but now he cannot do anything
- he needs to be dressed, needs assistance in personal care, but still does some things by himself
- used to be great at baking, can no longer do anything
- can do nothing, we have to watch him when he dresses himself
- cannot do anything like she did previously
- unable to do anything really on his own
- three years ago was able to wash and dress, now in need of full assistance
- everything has to be done for her, unable to dress herself or to feed herself
- has needed profound help for the past five years
- needs complete care, as he cannot do anything on his own
- incapable of looking after his own personal needs

6.7 Dealing with Money

Dealing with money could be viewed as just another task that may cause problems for persons with dementia, although it also introduces an objective measure of the degree of decline. Most other evaluations are influenced by the personal judgement of the observer. At times, these judgements may be open to interpretation, as the person concerned may simply have changed their attitude (e.g. regarding the importance of housework). With money, however, the inability to check that accurate change has been given is a highly visible and measurable change in personal ability. Furthermore, it seems that in many cases numerical ability is affected earlier than language skills. In a number of cases, for example, difficulties arising from operating a cash register or doing accounts provided the first indication that something was happening to the person involved. A change in the ability to manage money and accounts can therefore be viewed as an important early indicator of the development of early-onset dementia.

Table 6.7 Dealing with Money

	Number	%
not affected	1	1.7
slightly affected	2	3.4
affected	4	6.9
strongly affected	7	12.1
profoundly affected	44	75.9
Total	**58**	**100.0**

Experiences Associated with Money: Individual Cases

slightly affected
- “not too bad”
- gets confused with coins

affected
- cannot keep up with the counting of money

strongly affected
- not great, able to pay for lunch but needs to be checked
- got bad very rapidly, e.g. buying quantities unrelated to need – leading to arguments in the supermarket
- money means nothing, plays with coins and parcels up the notes

profoundly affected
- failure to take change in the shop was first sign of dementia
- cannot go shopping any longer
- loses money - has a purse which she has all the time with a few coppers
- she gets pocket money, but never uses it – so that she knows she has money when she opens her purse.
- cannot even hold money - Euro change complicated things immediately
- used to run the house finances, but can no longer handle this; started gambling, slot machines, scratch cards etc. - played away full holiday money
- a nightmare - he thought the banks were taking his money and could not handle it
- ability to deal with money was gone from early on
- no longer has anything to do with money
- used to be excellent, but now has not got a clue
- has no idea about money at this stage
- no longer able to deal with money - used to hide it
- has no concept of what it even means
- no understanding of it at all

6.8 Being Able to Concentrate

Dementia inevitably affects a person’s ability to concentrate. However, as is the case with the ability to remember things and to relate to others, this process tends to be a gradual one and is difficult to identify, at least at the beginning. There are many other reasons why a person may experience difficulty in concentrating and, taken on its own, this is by no means an unambiguous indicator of the onset of dementia. However, as the illness progresses, the inability to focus on what is happening around one becomes a profound and defining characteristic of the illness.

The scientific literature points to the importance of keeping one’s mind trained and attempting to slow down the progression of the illness by continually exercising one’s capacities. However, little emerged during the interviews that pointed to strategies of actively jogging the mind of the person with dementia. There may be a sense of resignation once a formal diagnosis has been made. This effect is accentuated by the lack of specialised care for younger people with dementia. Leaving work brings with it a dramatic reduction in mental challenges. The gradual withdrawal from friends and neighbours then leads the person with dementia to spend an increasing amount of time at home and alone. When attending a day centre, most likely designed for older people with dementia, the person with dementia encounters a relatively docile environment, at least relative to what the younger person with dementia might require. It is therefore apparent that new strategies must be found to develop appropriate responses during the early years of dementia, particularly where younger people are concerned.

Table 6.8 Ability to Concentrate

	Number	%
not affected	1	1.6
slightly affected	1	1.6
Affected	3	4.9
strongly affected	15	24.6
profoundly affected	41	67.2
Total	**61**	**100.0**

Experiences Relating to Concentration Levels: Individual Cases

affected

- reads the first ten pages of a book, watches TV

strongly affected

- is still able to watch TV and tries to read; the interest is still there
- not for very long, short periods only
- lost interest in reading newspapers, watching TV - wanders around a lot
- cannot concentrate on anything – the TV is on all day, but does not follow it

profoundly affected

- her mind wanders constantly, cannot sit still long enough to concentrate
- the ability to concentrate went right from the beginning
- this was one of the first things to go, writing was out of the question
- went at the beginning, e.g. holding newspaper upside down or ripping it – does not respond when addressed, looks elsewhere
- retreats into himself
- he went through a stage of reading the papers up to ten times a day, but nothing was registering, he would watch TV without any comprehension
- cannot even sit through half an hour of her previous favourite TV programme
- unable to read a book; only reads magazines with pictures

6.9 Finding the Right Words

Not being able to find the right words can be a very visible expression of dementia, but not all people are affected in the same way. Indeed, some people may maintain their ability to express themselves verbally, regardless of the progression of their other symptoms. In one case, for example, a person with dementia was still able to fluently converse through French, whilst having become completely dependent in other respects.

Finding the right words is essential to communicating one's needs. Being unable to express oneself inevitably leads to frustration and isolation. It is therefore important for those who are near the person with dementia to have the patience to listen and to wait for them to find the right words. It also means that being sensitive to a person's needs must not be relegated exclusively to the spoken word.

In the context of diagnosis, it is important to remember that not all people with dementia immediately show signs of diminished language skills. In one case, for example, one man suspected that his partner was developing dementia, whilst the person with dementia was able to deceive her GP for a significant length of time, thanks to her conversation skills.

Table 6.9 Finding the Right Words

	Number	%
not affected	2	3.3
slightly affected	3	4.9
affected	9	14.8
strongly affected	11	18.0
profoundly affected	29	47.5
does not talk any longer	7	11.5
Total	**61**	**100.0**

Experiences Associated with Verbal Communication: Individual Cases

slightly affected

- is able to find the right words, but is becoming very long-winded
- can sustain a good conversation: one could sit for half an hour with her and think that all is normal

affected

- has a good ability to communicate, does the crossword, knows that stimulation is very important
- she repeats herself constantly, but is very capable of communicating her needs
- fine with partner but finds it difficult with other people

strongly affected

- sometimes very good, but now increasingly jumbles her words, can no longer express herself, although she is still able to speak French
- knows what to say, but needs time to find the words
- is growing very quiet, retreating into himself

profoundly affected

- on rare occasions he can hold a conversation for a short period
- used to sing, now cannot find the words
- most of the time puts the wrong words together
- has great difficulties, talks constantly, throughout the night, without making sense
- does not talk any more

6.10 Repeating Things in Conversation

Repeating things in conversation is closely related to the previous two symptoms, although it occupies a special position, being the symptom most commonly associated with dementia. The inability to find the right words and a lack of concentration are, at least during the initial stages, first and foremost noticeable to those who are close to the person with dementia. By contrast, constant repetition during conversations is also noticeable to other people, providing an important indicator during diagnosis.

Table 6.10 Repeating Things in Conversation

	Number	%
not affected	5	8.2
slightly affected	5	8.2
affected	8	13.1
strongly affected	11	18.0
profoundly affected	25	41.0
does not talk any longer	7	11.5
Total	**61**	**100.0**

Experiences Associated with Repetition: Individual Cases

affected

- not too bad in each individual conversation, but goes to several people in a row telling them the same thing, is preoccupied with something
- clearly visible from the early stages

strongly affected

- repetition at all times
- repeats things, but stops talking when he realises
- sometimes repeats things that he hears others in the house saying
- he could ask the same question several times within ten minutes
- she talks to herself a lot, and continually counts
- natters, but does not make conversation

profoundly affected

- repeating things was the first clue to her dementia: e.g. asking five times what time it is, then denying she'd asked before
- repeats the same things, times, dates, questions for a long time
- from quite early on said the same things over and over again
- repeats the same thing over and over again
- “it drives us to distraction” - but she sings all day, she always has

no longer applicable

- is not able to converse at this stage
- does not really enter into conversation any longer
- does not talk any longer

6.11 Feeling Suspicious of Other People

Unlike memory and conversation problems, which everybody with dementia is likely to develop at some stage, not all people with dementia are suspicious of others. Where this does occur, however, it frequently leads to tension between the person with dementia and his or her closest relatives. In its mildest form, the person with dementia may simply need to be surrounded by familiarity, becoming suspicious of strangers who call to the house, or experiencing fear if someone familiar leaves the room. There is frequent fear of being watched, which is probably associated with an awareness that changes are taking place in the person with dementia, without being able to determine exactly what these are. The person with dementia is frequently also suspicious of their neighbours, for example, believing that someone is trying to steel the milk from in front of the house or taxi drivers, believing that somebody is stealing their car.

In more severe cases, the person with dementia may develop conspiracy theories, believing that everyone around them is “out to get them”. This is particularly distressing for those who care for persons with dementia, as the distrust is often directed most strongly at those who are closest to them. In other cases, this distrust is more specific, some relatives being viewed as ‘good’ and others as ‘bad’.

There is no rule as to how to deal with these suspicions. In the context of dementia amongst younger people, the most effective approaches are likely to emerge from timely discussions with the person with dementia about the illness and future care arrangements, whilst this is still possible, to dispel any underlying fears.

Table 6.11 Feeling Suspicious

	Number	%
not affected	19	31.1
slightly affected	7	11.5
affected	13	21.3
strongly affected	8	13.1
profoundly affected	14	23.0
Total	**61**	**100.0**

Experiences Associated with Suspicions: Individual Cases

slightly affected
- watches people, hides bag and other things and not able to find them afterwards
- does not want to be out of the presence of people she knows

affected
- knows when there is a stranger in the house and reacts differently
- afraid of going into certain rooms, refuses to take off his jacket
- feels suspicious if someone leaves the house with a gift we have given them
- sometimes develops conspiracy theories and the like

strongly affected
- is particularly suspicious of close relatives
- is very suspicious of son, but good feeling for partner
- happy if there are no changes in faces, but gets paranoid if visitors arrive
- is afraid that people are coming to take him to a home, which he does not want

profoundly affected
- when things go missing she blames the first person she sees
- very suspicious of neighbours, feels they are watching, but not of family members
- feels that people are talking about her, is very sensitive to changes in tone

6.12 Aggression (Verbal and/or Physical)

At the upper end of the emotional spectrum, the difficulties involved in coping with the advance of dementia may result in verbal and, at times, physical aggression. Little is known about the emotional life of persons with dementia, partly due to the fact that most studies – including this one – rely on interviews with caregivers. But from the moment of diagnosis onwards (indeed, from the very beginning of the diagnostic assessment process) emotional responses represent a vital element of the equation, influencing quality of life, coping attempts, behavioural disturbance and the whole care-giving process[4]. Exactly half of the persons with dementia in our study sample were described as being sometimes aggressive, mostly verbally, but in some instances also physically. What is common to the caregivers' observations is the underlying anger and frustration that they observe in the person with dementia. Whilst this may help to explain their behaviour, the latter nevertheless poses a substantial challenge for the caregiver, particularly as the anger is typically directed at those closest to the person with dementia. In one case, the person with dementia developed extreme physical violence towards his partner.

Aggression is probably a more common phenomenon amongst younger people with dementia than with older persons with dementia. The anger and frustration arising from the premature onset of dementia are likely to be greater and, due to their greater strength, have a greater likelihood of producing behavioural alterations. Generally, the anger and frustration recede as the dementia progresses, along with the accompanying aggression. As the person becomes less able to comprehend the world around them, they tend to withdraw more into themselves and to become more docile.

Where the person with dementia experiences bouts of aggression, the effects are likely to be exacerbated by the lack of specific responses to early-onset dementia. Existing services are poorly equipped to cope with challenging behaviour and, at times, are forced to withhold their services. In particular, many residential homes will not admit persons with challenging behaviours, which restricts the availability of respite care precisely where it is most needed.

Clear implications arise from this: firstly, there is a need for more dedicated residential services directed at younger people with dementia and there is a need to develop counselling services for persons with dementia, their partners and close relatives. Counselling can clearly contribute to gaining a better understanding of the illness and helping those directly affected to cope with the demands it poses on a day-to-day basis.

Table 6.12 Aggression

	Number	%
not affected	21	36.2
slightly affected	8	13.8
affected	9	15.5
strongly affected	11	19.0
profoundly affected	9	15.5
Total	**58**	**100.0**

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[4] Woods, B. "Younger People with Dementia: Psychological Interventions" in Cox, S. and Keady, J. (1999) cit. op.

Experiences Associated with Aggressive Behaviour: Individual Cases

slightly affected

- more angry with herself than with others
- generally calm, but can get slightly agitated
- with strangers she gets slightly aggressive, but nothing serious
- verbally aggressive if under stress - very different from in the past
- gets a little aggressive when annoyed with son

affected

- more stubbornness than aggression – refuses to comply and uses language she had never used – bold, really, like a child
- more frustrated with himself, but consequently gets angry with family
- verbally aggressive but never physically
- suspicion (on the part of the interviewer) that the person is verbally aggressive, although partner does not express this
- “in the area of personal hygiene he was frustrated when we insisted on a bath, but struck out only occasionally”

strongly affected

- used to be very inoffensive, but lately has developed agitation and verbal aggression
- “if she gets frustrated we would know the length of her tongue”
- “if she had no cigarettes, she would go berserk - I watch her all the time and take them away at night for safety”
- “when he wants to go places at night; i.e. work, he can't understand why he's not allowed to go and can get quite aggressive”
- more verbally than physically aggressive, although once or twice he went to hit his daughter because she locked him in
- could get aggressive, especially with his wife, e.g. not wanting to go to the toilet even when he needs to go – e.g. throwing a pillow at her for no obvious reason
- outbursts of violence, particularly in reaction to any mention of Alzheimer's

profoundly affected

- occasionally aggressive towards husband, out of frustration
- used to be very placid, but became very aggressive; strong feeling of lack of security, big arguments about money and accounts
- very grumpy, blaming people around him, particularly closest caregivers
- severe aggression towards partner, punching and pulling hair in bundles
- gets very aggressive verbally and physically

6.13 Ability to Live Independently

Inevitably, dementia leads to a situation where the person with dementia is no longer able to live independently. However, this process is gradual and there are many things that can be done to improve the quality of life of the person involved. As pointed out earlier in this study, most families would prefer to care for the person with dementia in the family home for as long as possible. The extent to which this can be achieved largely depends upon the existing support network and services available.

Initially, if the partner is at work, it may be sufficient for someone to visit once or twice during the day. Nevertheless, the risks are clear: the person with dementia may wander off, leave the front door open or forget to turn off the gas. Even if events such as these are infrequent, the mere possibility of them occurring leads quickly to the need for supervision.

The next stages relate to personal care increasingly becoming necessary: help with washing and dressing in the morning, making a meal during the day, undressing and going to bed in the evening. Although these periods of assistance themselves may be relatively short in duration, many home services are not tailored to providing this help when it is most needed. Befriending and home help with regard to housekeeping generally work well, but services are generally unavailable in the early morning and later evening, when they are most requested.

Looking after a person with dementia can quickly become a full-time occupation, exceeding what a single caregiver can provide. Care arrangements seem to work best where the burden is divided between a partner, for example, and several other family members, each taking part in supervising and assisting the person with dementia. It is vital for the caregiver(s) to have time off and to hold on to a life of their own, and this can only be safeguarded via high-quality and appropriate day care and respite care arrangements, as well as sharing between several family members.

Ultimately, the person with dementia may become unable to feed themselves and may become incontinent. At this stage the level of care needed generally exceeds what can be provided by the family and full-time residential care may become the only solution. However, the better the day care and respite care arrangements on offer, the longer the person with dementia can be cared for at home. This is not only the preferred option for most families, but it is also the most cost-effective way of providing services. It is of course vital that family members recognise when they are no longer able to cope, and when a place in a high-quality residential home must be located. Unfortunately, many families have to cope with considerable uncertainty about the availability, or affordability, of such a place, in addition to the burden that they already carry.

Table 6.13 Ability to Live Independently

	Number	%
not affected	1	1.7
slightly affected	2	3.3
affected	1	1.7
strongly affected	6	10.0
profoundly affected	50	83.3
Total	**60**	**100.0**

Experiences Associated with Living Independently: Individual Cases

affected
- generally able to cope for the moment, but cooking, cleaning and personal needs are affected

strongly affected
- sleeps four or five nights per week on her own: is used to it
- needs supervision for bath and shower, washing clothes etc. - would not think to change them
- already debilitated due to Parkinson's, but wasn't aware of this - everything had to be done for him from the beginning, even dressing
- no longer able to live independently

profoundly affected
- fell out of bed, spent three weeks in hospital
- could only be left if she were in bed asleep, and even this is risky
- in the beginning he wandered off and took long trips – he then required supervision
- is now at the point of needing residential care, he is very strong, and this is becoming a severe problem
- almost totally incapable – caregivers take turns to stay at night
- impossible to live independently - turns on the gas and forgets about it, goes at the fire and forgets to stop putting in more fuel - could burn the place down
- incapable of ordinary living, even when eating, he stuffs his mouth like a child
- for six years has needed somebody around
- cannot even be left on her own for five minutes
- would not be able to cope at all
- totally dependent on husband
- incapable – day-time and night-time make no difference to her
- totally dependent
- she is like a 24-hour watch

7 The Experience of Dementia

The defining characteristic of early-onset dementia is obviously the age at which it occurs. Younger people with dementia face different challenges, as they are affected at an earlier stage in the life cycle. We do not have comparable figures for the dementia population as a whole, but some inferences may nevertheless be drawn from the study sample.

The early onset of dementia generally means that the person affected faces four particular challenges with regard to their life: (i) as the person affected is younger, he or she tends to be in a more active phase of their life, thus experiencing a more dramatic change relative to their expectations, (ii) they are more likely to be married, (iii) they are more likely to have children who are younger and potentially dependent, (iv) they are more likely to be in gainful employment and might potentially be the main income provider, or the main caregiver in the home. In either case, the onset of dementia profoundly affects their relationships with other family members and their ability to work or to care for others.

In this chapter, we will document how the early onset of dementia changes people's lives, as well as those of other family members. The material that we draw upon is based on four questions included in this study, where the caregiver, and in two instances the persons with dementia themselves, were asked to summarise the most important aspects of the changes occurring in the person, in their relationship with a partner, in their relationship with their children and in relation to their work and employment.

To place these observations in context, we calculated the mean score for each of the fourteen symptoms discussed in the previous chapter, sorting them accordingly. Thus, the changes described in the following sections start with those relating to people with slight symptoms of dementia, the symptoms gradually increasing thereafter.

7.1 The Person with Early-onset Dementia

This study relates specifically to younger people with dementia, whose living arrangements differ from those who develop dementia at a later stage in their life. Notably, the vast majority (59%) are living with a partner in the family home. A small proportion (8%), all of whom are in the early stages of dementia, live on their own, whilst about 15 per cent live with a son, daughter or other relative. The same proportion (15%) are in a residential home.

Table 7.1: Participants' Living Arrangements by Age

	46 - 55	56 - 65	over 65	Total	46 - 55	56 - 65	over 65	Total
	Number				%			
on his/her own		2	3	5		6.9	10.0	8.2
with partner	1	19	16	36	50.0	65.5	53.3	59.0
with son/daughter			5	5			16.7	8.2
with other relative	1	1	2	4	50.0	3.4	6.7	6.6
residential home		5	4	9		17.2	13.3	14.8
other		2		2		6.9		3.3
Total	**2**	**29**	**30**	**61**	**100.0**	**100.0**	**100.0**	**100.0**

The strongest perceived change in the person with dementia is their loss of independence. Being at an earlier stage in the life cycle, people expect to be in full control of what they do. Yet the early onset of dementia changes everything: being able to carry out everyday tasks, to earn an income, to have an equal relationship with a partner and provide for one's children. All of these relationships are transformed by dementia and, at least during the initial stages, the person with dementia is fully aware of the gradual decline that is taking place in their abilities.

As already pointed out, the evidence of this experience is mainly provided through the carers and largely summarise the experiences as outlined in the previous chapter. But the loss of independence and thus change in relationship to their partners and other family members is clearly highlighted as the major experience for the person with dementia. As a whole, these changes are traumatic and pose a major challenge for the person with dementia, their partner and their caregivers. But it is interesting to note that some people also react with great courage: one of the two people with dementia that we interviewed in person, for example, described how, having being diagnosed with dementia she took a stronger interest in her life, getting rid of previous fears, gaining confidence and finding a new strength. This remarkable testimony shows that, if their condition is actively managed and adequately supported, persons with dementia can have an acceptable quality of life for a considerable length of time.

In another case, the caregiver describes how her husband is confused, unable to work or to look after their financial affairs, and cannot be left on his own. On the other hand, he is able to manage his own personal care and, although he does not understand all of the changes that are happening to him, he is very playful and funny. Again, providing a secure environment helps to alleviate fear and may make it possible to maintain an acceptable quality of life for the person with dementia.

Changes Experience by People with Dementia: Individual Cases

affected

- he is a different person, not necessarily in a bad way, but he has lost a lot, e.g. he was very affectionate, but used to be so independent
- a total change in life, which is now confined to the home, apprehensive about the future
- she has changed her whole life. Although her family encourages her, it is all subconscious and passive
- went from jolly to dependent person to child
- no social life, no work, no interest in anything, no interest in music anymore

strongly affected

- has completely retreated into himself
- started failing in daily tasks, not being able to cope, leading to depression and crying
- was very intelligent, extremely independent – it is difficult to cope with losing that
- used to be very active and proactive, did a lot of voluntary work - all that changed radically and suddenly
- had a very active social life which gradually disappeared
- erosion of her independence, her fields of authority robbed, did not verbalise anything but got into rows
- everything has changed, everything normal in life has gone
- her independence has gone – does not take any initiative
- he just got gradually quieter and more introverted
- became completely dependent, incapable of self-care, e.g. washing etc.
- a different person, like a child now
- has gone from totally self-sufficient to totally dependent
- he has lost interest in home, family, current affairs, football, TV etc.
- she doesn't socialise or go shopping or attend family functions anymore
- her freedom to come and go has disappeared
- her social life and sense of independence have gone
- is now a completely different person - cannot remember anything, gets very cross, which was never the case before

Changes Experience by People with Dementia: Individual Cases (continued)

strongly affected

- can no longer do anything for herself or remember anyone; “but every so often her old self shines through”
- never goes out any more, but some friends still call and sometimes he recognises them
- his independence, his status in society (as a farmer) are gone - he is in full-time care now and is still young
- has lost all confidence, has lost weight and interest in the house and cooking
- cannot do anything for herself, has lost all major adjustments to life and home
- this has changed her completely, with a loss of confidence and independence, completely dependent on husband now
- has lost his independence, does not communicate with anybody, nor does he care what anyone does
- loss of confidence, with depression and quietness – does not participate with company, even though he enjoys it
- has lost interest in shopping and general appearance
- quieter, very dependent on others

profoundly affected

- mother is like a shell - like looking after a child - roles completely reversed
- profound frustration, used to be very active, now cannot do anything
- she is like a stranger, not fit to cope with life, does not understand what is going on around her
- no conversation for four years
- feeling fed up with life, has lost his independence

7.2 Relationship with Partner

Three quarters (77%) of people with dementia in the study group were married at the time of the onset of dementia. In four cases, the partner had died since the onset of dementia, in one case a separation took place and in another case the person with dementia himself is deceased. Thus, 41 of the 61 study participants (67%) are married, 13 (21%) are widowed and 5 (8%) are single.

Table 7.2 Marital Status at Time of Diagnosis and Now

Marital Status at time of diagnosis	Present Marital Status					
	single	married	widowed	separated	deceased	Total
single	5					5
married		41	4	1	1	47
widowed			9			9
Total	**5**	**41**	**13**	**1**	**1**	**61**

Those affected describe the profound changes that take place within their relationship with their partner as the dementia progresses. During the early stages, the main symptoms are the gradual withdrawal of the person with dementia into him/herself and their detachment from other family members, resulting frequently in an inability to even recognise their partner. Particularly during the early stages, relationships may become strained as the person with dementia becomes irritable in their attempts to cope with their inability to live an ordinary life.

Most younger people with dementia are, at least during the earlier stages, aware that something is happening to them. The frustration of not being able to remember things, and the fear generated by not knowing what is happening to them can, at times, lead to depression and cranky or even violent behaviour. Where the latter occurs, it tends to be most strongly directed at the person closest to the person with dementia; i.e. the partner.

As the dementia progresses, the person with dementia is likely to become more subdued and docile, with the result that their challenging behaviours, where developed in the first instance, recede. However, at this stage, the relationship is also likely to have moved towards one of increasing dependency. Many caregivers describe how their relationship has changed from being an equal relationship between two adults to being a kind of parent-child relationship, where the caregiver increasingly takes over decision-making for the person with dementia and ultimately provides even the most basic care, like assistance in washing, dressing and eating. Generally, these relationships remain characterised by love, affection and care and, albeit asymmetrical in form, continue to provide considerable reassurance and satisfaction for both the person with dementia and their caregiver.

Throughout this process there are constant changes in the degree of communication between partners, and it would naturally be a mistake to underestimate the difficulties that this entails. While not necessarily affected in the early stages, communication gradually becomes more one-sided, as the person with dementia gradually becomes less responsive. In practically all cases, communication first ceases with outsiders, than with family members.

It is important to note that whilst verbal communication may become more difficult, this does not mean that the person with dementia is insensitive or indifferent to those around them. Many caregivers described their calming effect on the person with dementia and the importance of non-verbal communication, for example through touch, where meaningful conversation has ceased to be possible.

Changes Experienced in Relationship with Partner: Individual Cases

affected

- relationship seemed to improve after diagnosis. Before diagnosis she felt a lot of pressure, unable to cope, now there's an explanation
- first he followed her everywhere; he would rely on her for everything and she (the partner) would get cranky as she lost her social life. Then she became ill. Now he (the person with dementia) was happy, whilst she was tired and cranky
- most of the time she does not really recognise her partner – thinking it’s her daddy or brother. The biggest problem for her partner is that he cannot discuss anything with her: "if I want to buy or change anything in the house – I wasn't used to having to make such decisions”

strongly affected

- partner strongly affected, doesn't go out any more, no drives, mass etc.
- developed extremely aggressive behaviour towards partner
- is losing any sense of who is around
- aggressiveness is a major problem, permanently testing partner's loyalty
- became argumentative once Alzheimer's was acknowledged, partner ‘treading on eggshells'
- sometimes he doesn't even know who they (partner and children) are
- he asks his partner: "where is (partner)", not aware that she is there, although later on he might acknowledge her. Partner feels she's in limbo.
- can communicate, thinks relationship is excellent, but not an adult relationship, almost like caregiver is adult and he is a child
- “thankfully, my father has been a rock with regard to mum and looks after her to the best of his ability”. However, father goes on drinking binges

Changes Experienced in Relationship with Partner: Individual Cases (continued)

strongly affected

- relates to partner as a four-year old child would relate to his mother
- they are the best of friends, they still share their lives
- great relationship – he would be lost without her and frets if she is not there
- person with dementia no longer has any relationship with partner, they are now like brother and sister, not sure if she knows whether he is her husband or not
- he now calls her mummy and she has become his full-time caregiver
- the relationship has changed – she used to be quite critical of him, but they are now like love-birds - she's more childlike now, he's more her father
- now relaxed with husband, things do not bother her as before
- had to give up a lot of socialising but "still loves her to bits"
- made her relationship more loving because of dependence on person
- relies on partner, shows more affection

profoundly affected

- broken-hearted
- partner (wife) now in wheelchair and daughter (who cares for both) now in a state of fear in relation to father, who is difficult to handle
- extremely stressful for partner

7.3 Relationships with Children

In many ways, the changes in the relationship between the person with dementia and their children mirrors the changes that occur in their relationship with their partner. However, whereas the relationship with the partner moves from one of equality to one of dependency, the relationship with children involves effectively a reversal in roles.

Not all children are able to cope with this reversal. Unlike the partner, who made a conscious decision to share their life with the person with dementia, the children of a comparatively young person with dementia may be at a stage in which they are still establishing their own independent life. In 15 per cent of the study group, for example, there were children under 18 years of age in the family home, and a further 34 per cent were between the ages of 18 and 25. The responses that we received varied widely as to how well children were able to cope with the changes in their relationship with their parent with dementia. Whilst some were coping well, others were unable to cope and, at times, completely withdrew from the parent concerned, or indeed from both parents.

The latter process may, in some instances, be encouraged by the other parent, as they do not wish their children to be "tied down with their own burden". As a result, the care provided by children can be extremely unevenly divided between siblings and, where none of the children are available or willing to share in this, this can result in an extremely heavy burden for the partner.

Table 7.3 Children at Time of Diagnosis

	Families with Children		Families with Children living at home	
	Number	%	Number	%
under 18	9	14.8	9	14.8
18 to 25	26	42.6	24	34.4
over 25	42	68.9	11	18.0
Total	**52**	**85.2**	**31**	**50.8**

Changes Experienced in Relationship with Children: Individual Cases

affected

- he asks how they are and likes having them home
- the relationship is just the same because wife played role of main caregiver
- total change, previously completely looked after children, now "no longer the same mum"
- she recognises all of the children except one daughter-in-law whom she had only met at a wedding - all relatives have been home in the past six weeks

strongly affected

- everyone just chips in, trying to help
- she is growing estranged from the children as communication is fading out
- less problems with children, more with partner, taking out aggression on him
- initial deterioration - children had to learn to accept idiosyncrasies - once that was the case, the relationship improved
- no relationship - oblivious to their presence
- would not recognise the children – who are no longer living at home – but knows one grandchild and calls him by name
- comes and goes - might have a good spell every six to eight weeks and then deteriorates again
- with two of the children, she was fine – but became very hostile towards one
- as always, except he can't initiate conversation - will appear normal, but really isn't
- the roles are now reversed
- due to her inability to do anything independently, she has become closer to her children, who adore her
- very close to the children - she follows them around, is dependent - still knows who they are and remembers names
- as a mother, growing up she was always there for them, but now there is no real interaction - she can, however, on occasions name the girls
- totally different - she is now the child and her children are the caregivers - but she still has the power to rule - elements of strength still come through
- cannot remember any of their names and thinks she has 13 children, not five, as she had 13 brothers and sisters
- cannot hold a conversation with children, everything is gone
- unable to recognise her children

profoundly affected

- may represent a hazard for grandchildren
- no communication or means of communication, can get very aggressive, verbally and physically
- deeply affected and very stressful as children have no normal childhood, their needs come second – the caregiver (daughter-in-law) and her partner (son) do not really have a life or time for each other

7.4 Changes in Work and Employment

The fourth aspect which is specific to early-onset dementia is the fact that the dementia develops at a time when the person may be gainfully employed or be the main caregiver in the home. In about 40 per cent of the study group, the person with dementia was employed or self-employed at the time of onset and in another 34 per cent they were the main carer at home. In all but one case, they had to give up employment, as they were no longer able to fulfil their work commitments. In some cases, this process was speeded up by the inability to retain work-related insurance after a diagnosis of dementia was made.

Our insights into what it means for somebody to have dementia - first having to cope with their developing illness at work, then having to give up work - is limited due to the constraints on interviewing persons with dementia. Particularly in light of the demands in caring for people with dementia, caregivers have relatively little to say about what it means for the person with dementia to have to give up employment. The focus of attention radically shifts to the home and to the personal sphere, and the observation most frequently made relates to the financial difficulties involved in providing adequate care due to the loss of income of the main earner.

Table 7.4 Principal Economic Status at Time of Diagnosis and Now

	Employment Status - present				
Employment Status - at time of diagnosis	**self-employed**	**unable to work due to illness**	**retired from employment**	**unable to look after home/family**	**Total**
employed full-time		5	8		**13**
employed part-time		1			**1**
self-employed	1	7	2		**10**
unable to work due to illness		2	2		**4**
retired from employment			11		**11**
looking after home/family				21	**21**
Total	**1**	**15**	**23**	**21**	**60**

In exactly half of all cases, the person with dementia was either the main or joint income provider. With only a few exceptions, this generally remained the case even after employment had ceased. It appears that, in these cases, the partner generally takes on the role of full-time caregiver and it is the pension of the person with dementia which continues to provide the main family income. This, however, obviously contributes to the financial burden faced by the family, which we will explore in greater detail at a later stage.

Table 7.5 Main Income Provider at Time of Diagnosis and Now

	Main Income Provider - present				
Main Income Provider - at time of diagnosis	**the person with dementia**	**his/her partner**	**jointly**	**other**	**Total**
the person with dementia	16	3			19
his/her partner	1	21	1	1	24
jointly		6	6	1	13
other	1			3	4
Total	**18**	**30**	**7**	**5**	**60**

Changes Experienced in Work and Employment: Individual Cases

affected

- had to give up employment as no longer able to deal with money
- she was very dedicated to and liked her work, but had to give it up and now misses work colleagues
- had to retire early (from teaching)
- worked at a till, could not keep account of money
- she still thinks she is able to work – it is very awkward, because she isn't

strongly affected

- lost last job due to unacceptable behaviour
- working became a problem and had to give up two years after diagnosis
- had to give up self-employment
- had to opt for early retirement
- developed difficulties with work around the home long before retirement age - employment was sporadic any way
- had to give up work as soon as Alzheimer's was diagnosed – no insurance
- had to retire after diagnosis
- completely unable to do any of the things he had done before

profoundly affected

- had to resign
- had to give up work
- had to cease because of Alzheimer's
- unable to do anything

Part B: Critical Issues for Younger People with Dementia

In this part of the study, we will explore the most pertinent issues which emerged from our study of 61 cases of early-onset dementia in Ireland. The ten most important issues to emerge were: (i) the need for a timely diagnosis, (ii) informing the person with dementia about their condition, (iii) supporting flexible care arrangements, (iv) improving home help, (v) improving day care, (vi) improving respite care, (vii) improving residential care, (viii) improving medical care, (ix) providing counselling and (x) improving financial supports.

8 Timely Diagnosis

As is well documented, the diagnosis of dementia is fraught with difficulties, frequently leading to a diagnosis only at a time when the patient is already showing advanced symptoms of dementia. This situation becomes exacerbated when concerning younger people. Firstly, as is the case at all ages, the first symptoms are not necessarily specific to dementia and may therefore suggest other illnesses. Secondly, as dementia is generally age-related, doctors do not contemplate the onset of dementia to the same extent when facing a younger patients as amongst older patients. Thirdly, because of their younger age, those affected may be more inclined to conceal their symptoms. As a result, the onset of dementia in a younger person is frequently misdiagnosed, and an accurate diagnosis may be delayed for several years.

Table 8.1 shows the numbers of doctors and specialists involved in the diagnosis of early-onset dementia in the study sample. All persons in our sample went at some stage to their GP after developing symptoms. However, in only 10 cases (16.4%) did the GP make a definitive diagnosis. In two-thirds of cases (63.9%), one specialist was involved in the diagnosis, while in one fifth of cases (19.7%) two or more specialists were visited. The specialists most frequently consulted were either Neurologists (39.3% of cases), Psychiatrists (16.4%), Geriatricians (14.8%) or other medical staff specialised in memory issues (8.2%).

Table 8.1: Doctors and Specialists Attended

	Number	%
GP	61	100.0
Neurologist	24	39.3
Psychiatrist	10	16.4
Geriatrician	9	14.8
Memory Clinic	5	8.2
Other	15	24.6

Note: People may have attended more than one doctor/specialist.

Generally, it is the GP who refers the younger person with dementia to a specialist. However, in over one third of cases (37.7%) this happened only either after the person affected (or their family) requested this specifically, or after a considerable delay. There is strong anecdotal evidence that GPs frequently fail to recognise the early symptoms of dementia in people under 65 years of age. This is of considerable concern, as it delays recognition of the onset of this disease and prevents those affected from exploiting to the full this extremely important period, when they can still comprehend the consequences of their illness and indicate their care preferences and priorities.

It is worth noting that the most frequent misdiagnoses arise from the failure to see depression as a symptom of underlying dementia. The second, less frequent form of misdiagnosis occurs where doctors interpret symptoms as part of menopausal changes. Depression in the context of the onset of dementia accounts for only a very small proportion of the total number of people suffering from depression and many GPs may never come across a single case of early-onset dementia. By contrast, doctors are more likely to encounter dementia in older people, and it is legitimate to ask to what extent GPs are actually aware of the incidence of dementia amongst those under 65 years of age.

Examples of Delayed Diagnosis: Individual Cases

- GP first thought it was depression (for six months) and than that it was menopausal, referring the person with dementia to the Well Woman Clinic. A different GP again thought that it was depression (for one year), and then referred her to a Memory Clinic (for one year). Finally, following a new visit to the GP, the symptoms of dementia were immediately recognised.
- GP referred to Neurologist (eleven months waiting for an appointment), although in the meantime the person with dementia deteriorated and was admitted to hospital. The first doctor did not pay any attention to the symptoms, whilst the second doctor arranged for diagnosis. If intermittent hospitalisation had not occurred, the patient would have waited one and a half years for diagnosis.
- The person with dementia stayed for 39 weeks in a Psychiatric Hospital, was visited by the Psychiatrist almost every day, without receiving any specific diagnosis. Doctors explicitly excluded dementia but suggested long-term care in another hospital. Once admitted to the other hospital, doctors immediately identified Alzheimer's.
- Partner noticed changes and complained to GP for at least four years before diagnosis. Partner had to insist as the GP did not find anything wrong with the patient (who hid symptoms during hours of conversation). Finally, referral to a Neurologist, the brain scan showing frontal lobe to be dead.
- Symptoms developed as long as ten years ago. The person with dementia forgot people's names, even those of the neighbours, and driving the car became a problem, due to absent-mindedness. Things deteriorated progressively, and GP finally referred the patient to a Psychiatrist, who made the diagnosis. Relatives feel that the GP should have made the diagnosis much earlier.
- First diagnosis by GP was depression. Friends and neighbours suggested alternative diagnosis and encouraged referral to a Geriatrician.
- The individual started to show symptoms six years ago, and was treated for fluid on the brain and depression. Doctors excluded Alzheimer’s, although the family suspected this was the cause. Only years later was diagnosis achieved, following hospitalisation and scans.
- First seen by a GP, who diagnosed depression. Three years later, after developing seizures, an MRI in hospital provided a definitive diagnosis of Pick's disease.
- Doctors first attributed symptoms to drunkenness. GP very persistent and supportive, but diagnosed Parkinson’s. Geriatrician eventually provided correct diagnosis.
- Partner requested CAT scan, but consultant contradicted partner's suspicion. Neurologist after MRI could not name the problem. A UK Hospital, after further MRI, provided a final diagnosis.
- The person with dementia first saw a Psychiatrist, then repeatedly went to their GP, and finally got a CAT scan. Pre-senile dementia was diagnosed, but this took four years, which was very frustrating for all those involved.
- The person with dementia experienced periods of depression for three to four years, and was finally seen by a Neurologist and diagnosed.
- Treated for years for depression by GP, after which the individual deteriorated and became hospitalised. 'Head to toe’ investigation generated concerns about bowel cancer, and only later was dementia diagnosed.
- GP treated person for years for depression. Then a private consultant made diagnosis.
- GP treated person for depression for 18 months. Husband suspected Alzheimer’s but patient had to see two specialists in UK and a further specialist in Ireland before diagnosis was made.
- GP put individual on pills for depression. Friend told husband to go to Neurologist who, in turn, sent for scan. Scan showed up problem immediately.
- Patient noticed something happening for years on a very slow basis. Doctors did not find anything wrong. Patient went downhill after car accident, but doctors still did not accept that anything was wrong. Later, they needed a hearing aid and had a number of related operations, when doctors noticed changes and finally diagnosed dementia.

Even if a case of dementia is suspected, GPs rarely deal with younger people with dementia, and do not have sufficient experience with the extensive investigations required to establish a diagnosis, particularly where the cause is uncommon[5]. Referral of the person with their partner / close relative to either a psychiatrist, a neurologist, or, if available, a memory clinic or specialist centre is recommended. However, when looking at the evidence from the survey, the main question that arises is whether the GP takes the possibility of early-onset dementia into consideration in the first place when presented with some of the less specific symptoms (e.g. depression). Once the consideration is there, referrals to specialists and diagnosis are likely to follow within reasonable time.

In light of the survey findings, and the small numbers of younger people with dementia who are in contact with the Alzheimer Society in Ireland in general, we suspect that a significant number of people with early-onset dementia are never diagnosed, or at least not at a time when they could still assert an active input into managing their own future.

Recommendation 1:

We believe that an awareness campaign amongst GPs would have a positive effect, firstly by making GPs more aware of the prevalence of early-onset dementia and by encouraging multidisciplinary assessment and referral to specialists that are able to either confirm or refute the onset of dementia in a younger person.

9 Telling the Person with Dementia

The second issue of particular concern is whether a person who is developing dementia should be informed of their condition. Good medical practice dictates that the diagnosis should be communicated to the person with dementia, their partner and their family, although there are no general rules as to whether the person with dementia should actually be told.

In our survey of younger people with dementia, a significant proportion did not currently know about their condition and had never been informed. In fact, over half (57.4%) of those with dementia were never told of their illness. The main explanation that was offered for this was that either the diagnosis was made at such a late stage that the person would not have been able to comprehend it any way or that the partner and/or family felt that the diagnosis of dementia would have added to the anguish they already experienced. Only 13 out of 61 persons (21.3%) were aware of their diagnosis. The same number had been told at some stage that they were developing dementia but no longer retained this knowledge due to the advanced stage of their illness.

It is important to note, however, that in cases where the person knew about their diagnosis, we did not find any cases where the person with dementia regretted having this knowledge. In most cases, particularly during the early stages of the illness, the level of anxiety and depression experienced by younger people with dementia is strongly related to their increasing inability to cope with the demands of everyday life, and the awareness that "something is happening to them" requires a response. Being informed about their diagnosis can have a positive effect on the life of the person with dementia, as it at least provides an explanation for the changes that occur and allow the conscious use of time for as long as possible. Particularly where the onset of dementia is accompanied by aggressive feelings towards their partner or other family members, the knowledge that this is due to the developing illness makes these changes more bearable both for the person with dementia, their partner and close relatives.

Perhaps the most important aspect of being informed of the diagnosis is that it gives the person with dementia the chance to take an active interest in the management of their condition for as long as this is possible. Because of the inevitability of symptom progression,

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[5] McLennan, J. "Assessment and Service Responses for Younger People with Dementia" in Cox, S. and Keady, J. (1999) op. cit.

the greater speed with which this may occur, and the fact that the person involved is still at an active stage in the life cycle, makes it all the more important to be actively involved in the forward-planning.

A joint approach to the changes necessary in order to manage everyday life contributes significantly to relieving anxiety and stress. This includes practical solutions to cope with cognitive impairment, planning for the future and providing reassurance in relation to future care plans. It also involves developing an understanding that the nature of the intimate relationship must change (from one of equal partners to one of dependency) and, where there are children, a pro-active approach towards acceptance of the gradual reversal of roles.

The decision to inform an (older) person with dementia about their illness is frequently left to their partner or family. Where the diagnosis relates to a younger person who is still able to fully comprehend the meaning of this, the question of informing the person with dementia primarily involves the medical practitioner and patient. To our knowledge, there are no specific guidelines for doctors with regard to early-onset dementia in Ireland, and it may therefore be useful to raise this issue in conjunction with a campaign aimed at GPs. More generally, the question of sharing the diagnosis with the person affected appears to be influenced by the stigma attached to the development of dementia, particularly with regard to younger persons. This discussion must therefore become the subject of a wider debate about awareness about the illness.

Recommendation 2:

We recommend that the Alzheimer Society continue to raise the profile of early-onset dementia within their general campaigns in order to highlight the specific issues that are of concern to younger people with dementia.

10 Flexible Care Arrangements

Earlier in this report, we described the general living arrangements of the study population. The majority (59%) are living with their partner in their family home. A small proportion (8%), all of whom are in the early stages of dementia, live on their own, whilst about 15 per cent live with a son or daughter or other relative. Only 15 per cent are in a residential home. Hence, it is one of the defining characteristics of younger persons with dementia that they continue to live in the family home. There is also a strong preference on the part of most caregivers to maintain such arrangements for as long as possible, and the availability of flexible care arrangements to facilitate this must be seen as a major issue with regard to early-onset dementia.

To facilitate the person with dementia to continue to live at home for as long as possible is not only their own preferred option and that of their caregivers, but also represents the most cost-effective solution from a societal perspective. However, this obviously depends upon the supports that are made available, including home care, access to day and respite care and regular medical visits by GPs and Public Health Nurses. Caring for a person with dementia places great strain on the caregivers, both physically as well as mentally. Indeed, many caregivers reported that, since caring for their partner or family member, their own social lives have gradually come to a halt, and that they are increasingly unable to go out, whilst friends and neighbours gradually stop calling to the home.

To enable people to be successfully cared for in the family home therefore depends on the support network that allows the burden of care to be shared. This includes sharing care between family members, which, at time, fails to take place. Successful care arrangements may also need to include counselling for both the person with dementia and/or their partner and caregiver(s). Gaining an understanding of the illness and the changes that occur for the person with dementia helps them and their caregivers and/or family members to be prepared. Counselling becomes particularly important where the person with dementia develops challenging behaviour, as it may help to reduce anxiety and fear.

In a significant number of cases, successful care arrangements depend on either direct care provision or adequate financial support to access independently provided services. To this end, the person with dementia and/or their family may need support in accessing services.

Most importantly, for care arrangements to be effective they need the active involvement of people with dementia in their design and delivery. It is time that specialist responses to early onset dementia are being developed which foster the active involvement of people with dementia in the development of their own person-specific care plans. We will return to this topic in the final Section on the Reform of the Health Services.

10.1 Support Networks

We will start with some reflections about overall care arrangements. Table 10.1 shows the extent to which each form of support is viewed as a significant contribution to overall care. At home, the partner and family members provide the backbone of support. In most cases where the partner is still alive, the partner is the primary caregiver. However, in some cases, as the partners themselves become older, the primary care may gradually roll over to one of the children. Friends and neighbours are usually still around during the early stages of the illness, but play an increasingly smaller role as the cognitive abilities of the person with dementia recede. Medical care by local GPs varies greatly, with some caregivers reporting excellent support and many others remaining considerably dissatisfied. Only one-third (34.4%) cite the local GP as a source of significant support. The situation with regard to availing of support through a Public Health Nurse is even lower and social workers play only a marginal role.

Table 10.1 People Providing Significant Support

	Number	%
Partner	39	63.9
Children	44	72.1
other relatives	20	32.8
friends/neighbours	16	26.2
doctor/GP	21	34.4
public health nurse	19	31.1
social worker	5	8.2
home help (cleaning/care assistant)	24	39.3
(Alzheimer) home support (befriending)	24	39.3
(Alzheimer) dementia support group	10	16.4
(Alzheimer) day care centre	24	39.3
respite care	19	31.1
full-time residential care	8	13.1
Total	**61**	**100.0**

The most important support structures outside the family are home help (cleaning and personal care, 39.3%) home support (generally organised by the Alzheimer Society, 39.3%) and access to an Alzheimer's day care centre (39.1%). It is, however, striking that each of these provide significant support for less than two fifths of those included in the survey, leaving the majority of younger persons with dementia without these supports. Respite care is available to less than one third of our sample, leaving two-thirds without access. Finally, full-time residential care generally only becomes relevant in the final stages of the illness, and applies to 13 per cent of the sample.

We have already highlighted the fact that the most important forms of care for younger people with dementia are provided by the immediate family. In exactly half of all cases in the study sample, the support provided by family members is described as excellent and in a further 25 per cent this is described as either very adequate or adequate. However, in 15 per cent of cases, family support is insufficient and it is worth noting the circumstances in which this may arise.

Table 10.2 Support from the Immediate Family

	Number	%
excellent	28	50.0
very adequate	8	14.3
reasonably adequate	11	19.6
inadequate	8	14.3
completely inadequate	1	1.8
Total	**56**	**100.0**

Support by the partner and other family members can typically only be sustained where the burden of care can be divided between several family members. At a minimum, this requires that, additional to the primary caregiver, other family members be regularly involved. Ideally, care should be provided on a rotation basis so that the primary caregiver can get time off to relax, socialise and recover their sense of self.

At times, however, family circumstances may arise that lead to an over-burdening of the primary caregiver (see textbox below). In some cases, family members live too far away to provide regular support. In other cases, children have families of their own and are unavailable due to family and work commitments. Interestingly, this is sometimes accepted and excused by the person with dementia and their main caregiver, as they do not want to burden their children with their own problems. However, it generally tends to result in an excessive burden for the partner. At times, the lack of support from other family members may be rooted in a lack of understanding about the illness and its progression and an inability to cope with increasingly awkward situations. In such cases, counselling might provide an additional axis of support.

Finally, and before turning to other support structures, it is worth making a few observations in relation to friends and neighbours. There is evidence that, even where initially available, support by friends and neighbours gradually disappears as the dementia progresses. Particularly as cognitive impairment increases and verbal conversation becomes increasingly awkward, there is a tendency for friends and neighbours to withdraw, resulting not only in an increasing isolation of the person with dementia, but also of their caregivers. Yet, as one caregiver emphasised, it is not only conversation that is important, as the mere presence of a familiar person can have a calming effect on the person with dementia, and may therefore be a considerable help.

Having started with family support structures, it is perhaps important to state that we do not believe that the family should be given exclusive responsibility for care provision. Nevertheless, this is the preferred option of most persons with dementia and caregivers alike. It is important to respecting the wishes of those with dementia and their families, but it is also necessary to understand the constraints on what the partner and family are able to provide. This should be the measuring-stick used to gauge the capacity of other support systems to provide an integrated set of sustainable care arrangements.

Reasons for Inadequate Family Support: Individual Cases

reasonably adequate support

- unevenly divided, as one (much younger) brother provides a lot of care, whilst others fail to contribute significantly
- husband is very supportive (giving up work to care), but does not have any other family in Ireland
- son and daughter live near by, but both work
- a high level of care provided by some family members, none from others
- immediate family have their own commitments

inadequate support

- the rest of the family are not involved, do not want to put up with it
- only her husband looks after her. Children have own life to lead
- other family members come to visit but offer no support. They do not realise what a help it would be if they cared for the person with dementia for a few hours. One brother sits with him for a few hours once a week
- this is a real problem as only two daughters help out, male members of family offer no support
- has three sisters and three brothers, but only one sister comes once a month
- other family members tend to avoid the situation, they do not like seeing the person with dementia in his present condition

Recommendation 3:

The overall aim in the care for younger people with dementia should be to provide a sustainable set of care arrangements which respect the wishes of the person with dementia, their partner and close family members.

11 Access to Home Help

Besides the care provided by the partner and/or other family members, home help provides the most important form of support. Home help may be provided in two ways: firstly, in the form of a Care Assistant who provides direct assistance to the person with dementia, in terms of personal hygiene, eating and dressing as well as providing general household help. This service may be provided by the local Health Service Executive (HSE) or may be purchased privately by the family. The number of hours needed invariably depend upon the stage of progression of the illness and the availability of other caregivers.

Depending on whether the partner works outside the home, there may initially be a need for someone who looks into the home once a day for a short period. However, as the dementia progresses, the period of help and supervision is likely to grow and eventually result in the need for ongoing supervision. This process can accelerate where the partner or main caregiver is older and finds it increasingly difficult to cope with the care burden.

Only 24 of the 61 people (39.4%) in our sample had access to home help and over 40 per cent indicated that their level of access to home help is either inadequate or completely inadequate. Even where they had access to this assistance, there is often a desire to avail of more hours per week, alongside a widespread dissatisfaction with the time at which the help can be provided. Possibly the most important hours are in the morning and evening, when the person with dementia is getting up or going to bed. At least with regard to home help provided through by the HSE, access is generally restricted to regular working hours, thus leaving the family without support when it is most needed.

A number of families decided to privately engage a Care Assistant. However, privately-hired support is very expensive and financial support to employ private help is cited by many caregivers as a major problem.

Table 11.1 Support with Regard to Home Help and Home Support

	Number	%
excellent	13	25.5
very adequate	6	11.8
reasonably adequate	11	21.6
inadequate	7	13.7
completely inadequate	14	27.5
Total	**51**	**100.0**

Table 11.1 shows the degree of satisfaction with home help arrangements within the sample. Satisfaction varies greatly with one quarter of caregivers citing arrangements as excellent and an equal share citing it as completely inadequate. Where home help is excellent or very adequate, this usually points to the quality of service provided, though it is still frequently held that more hours are needed. At medium levels of satisfaction, there are usually misgivings about the quality of support in terms of providing hands-on help, the lack of availability outside regular working hours and the amount of hours provided. Dissatisfaction is directly related to the complete lack of access to home help, either due to services not being available or not being affordable.

Recommendation 4:

There is a need for the Health Service Executive to increase the overall level of home help available to younger people with dementia, to address the hours during which such help is available, as well as assuring that levels of support are equitable, particularly in terms of regional disparities.

12 Improving Day Care Provisions

Day care centres also play an important role in facilitating people with early-onset dementia, enabling them to stay in the family home for as long as possible. This is particularly the case where the partner and/or primary caregivers have full-time work or family commitments. However, besides the general lack of places, existing day care centres are far from adequately equipped to provide the services needed by younger people with dementia.

- Existing day care centres primarily cater for older people with dementia and tend to lack sufficient stimulus for younger people. They are thus of limited relevance to people with early-onset dementia, particularly during the early stages of their illness.

- Where those with early-onset dementia frequent day care centres, this can put considerable demands on staff, mainly due to their greater level of activity, strength and, at times, challenging behaviour. Centres are often under-resourced to cope with these demands.

- There is a need to bring together younger people with dementia in special groups to deal with issues specific to them (e.g. medical information about dementia, counselling, legal advice, etc.). The development of such groups is still in its infancy in Ireland, with only one such group in the Dublin area.

- There is a need to improve counselling provision for all those involved. An emphasis should be placed on understanding early-onset dementia, the personality changes involved and how to cope. This can facilitate a second aim, namely to share the burden of care more widely.

It is extremely difficult to make recommendations on the basis of the present study with regard to the existing day care centres. Taken together, the Alzheimer's day care centres are in contact with possibly only three per cent of the estimated population with early-onset dementia. This, in itself, provides evidence that the centres do not provide a focal point of service for the wider population of younger people with dementia. At the same time, it should be said that the Alzheimer's day care centres are the only service of this kind which exist at all.

On balance, it appears that the most promising approach involves setting up specific support groups for younger people with dementia and developing further responses as needs become apparent. This approach would initially centre on a relatively small number of people, as the time span during which people with dementia are aware of their diagnosis and can be actively involved in their own social and care arrangements is relatively short. Therefore, there may at least initially not be many clients able to avail of such service, and setting up such groups may initially be confined to Dublin and other major cities. However, once such groups exist, and their existence becomes known and recognised, a wider group of younger people with dementia is likely to make use of such facilities.

Recommendation 5:

It is recommended that at least in Dublin, Galway, Limerick, Cork and Waterford specific support groups for younger people with dementia be set up by the Alzheimer Society.

13 Improving Respite Care

The third form of support comprises respite care. The importance of respite care lies in that it enables regular caregivers to recover their energy levels and continue to playing a primary caring role. However, younger persons with dementia may frequently find it impossible to access respite care.

- Firstly, there is a general shortage of respite facilities and there is no respite care unit in Ireland which specialises in supporting younger people with dementia.
- Secondly, even where a general respite facility exists, the nursing home may not accept individuals under 60 or even 65, thus automatically excluding those with early-onset dementia.
- Thirdly, people with early-onset dementia may not meet referral criteria, e.g. with regard to behavioural problems.
- Finally, excessive financial costs for the family may rule out respite care.

The recommendations with regard to respite care are therefore immediately apparent:

Recommendation 6:

There is an urgent need to improve respite facilities for younger people with dementia. Improvements should include: (i) setting up at least one dedicated respite facility for younger persons with dementia in Ireland, (ii) reviewing access criteria for existing (non-dedicated) respite facilities, (iii) reviewing the benefit criteria used by the Health Service Executive to include direct provision of, or financial support towards respite care for younger people with dementia, including explicit recognition that temporary residential care is admissible prior to the age of 65.

14 Improving Residential Care

Many people with early-onset dementia will, at some stage of their illness, require residential care. Like day care centres and respite care units, existing residential care places are often unsuitable for people with early-onset dementia as they cater predominantly for older people. Those with early-onset dementia can pose major difficulties for residential centres, as they are younger, stronger, have greater will-power, are less placid and more resentful of the environment in residential care centres aimed at older people with dementia.

People with early-onset dementia may also display challenging (aggressive) behaviour, mostly of a verbal nature, but may also become physically threatening. Most residential homes are ill-equipped to deal with such clients.

Table 14.1 Respite and Residential Care

	None	Respite	Resident	none	Respite	Resident
	Number			%		
Excellent		2	3		33.3	50.0
very adequate		2	3		33.3	50.0
reasonably adequate	1	2		20.0	33.3	
inadequate	1			20.0		
completely inadequate	3			60.0		
Total	**5**	**6**	**6**	**100.0**	**100.0**	**100.0**

When we examine satisfaction levels with respite and residential care, we find, predictably, that those who have access to respite or residential care typically rate this service as reasonably adequate to excellent, whilst those who have been unable to access respite or residential care rate their service access as inadequate or completely inadequate.

Experiences of Respite and Residential Care: Individual Cases

excellent support
- respite care is excellent – the person with dementia would go there any time - very happy there
- everything is OK now because she is in a nursing home, but it was horrendous what the family went through before that

very adequate support
- well cared for, but very challenging
- respite care for 2 weeks every 8 weeks

reasonably adequate support
- new centre which is brilliant, but for respite only. It is a relief to have such a facility

inadequate support
- it was not a suitable place for him because of his age and mobility. A top floor facility, not enough space for activity, although he was well-minded

completely inadequate support
- respite would be a help, but has not been able to avail of this
- completely inadequate, cannot get any information on residential care
- It is hard to get residential care cover for respite because of high dependency

We have concentrated, until now, on the ability to place a person in respite or residential care at an advanced stage of their dementia, when care at home is no longer an option. However, an interesting case emerged in this respect: is there a need for residential homes for people who are difficult to care for, in order to provide caregivers with temporary respite? This question arose during an interview with a nurse who is in charge of caring for a young person with dementia within a permanent residential setting. As the young person was going through a phase of challenging behaviour, this created a considerable burden for her nurses. However, after arranging regular respite care arrangements with another residential home, this situation was considerably alleviated. Non-specialised residential centres, which care predominantly for older persons, may themselves need to avail of respite arrangements for staff. If such structures were available, it might allow residential homes to be less restrictive in their intake.

Recommendation 7:

There is an urgent need to improve residential care facilities for younger people with dementia. Improvements should be sought in three different areas: (i) increasing the number of residential care places which are available for younger persons with dementia, (ii) reviewing access criteria for existing residential homes and (iii) reviewing the benefit criteria of the Health Service Executive to include direct provision of, or financial support towards residential care for younger persons with dementia, including an explicit recognition that residential care is permissible under the age of 65.

15 Overall Support from Alzheimer Society

This study was carried out amongst 61 caregivers of younger persons with dementia, all of whom were in contact with the Alzheimer Society of Ireland. As pointed out earlier in the study, there are up to 3,500 younger people with dementia in Ireland and no more than 100 (3%) are in contact with the Alzheimer Society. Yet the Alzheimer Society is the largest service provider for people with dementia in Ireland. One would therefore assume that those who are in contact with the Alzheimer Society derive benefits from this and, in the overwhelming absence of other dedicated services for people with dementia, and younger persons with dementia in particular, are grateful for its services. Unsurprisingly, about 80 per cent of the caregivers we interviewed expressed satisfaction with the services provided by the Alzheimer Society, and half judge these services to be excellent. However, at the opposite end of the scale, about 20 per cent expressed dissatisfaction.

Table 15.1 shows the overall satisfaction ratings with the support given by the Alzheimer Society of Ireland to younger people with dementia and the comments that follow show that negative ratings are not actually a reflection on the quality of any particular service, but merely reflect dissatisfaction with the relative scarcity of a service, and a desire to receive additional hours of support.

Table 15.1 Support from Alzheimer Society

	Number	%
excellent	22	41.5
very adequate	8	15.1
reasonably adequate	12	22.6
inadequate	10	18.9
completely inadequate	1	1.9
Total	**53**	**100.0**

Satisfaction with Alzheimer Society's Services - Comments

excellent support

- excellent but under-funded: no couch for nap - only chairs - no quiet room
- has made all the difference
- cannot speak highly enough
- superb
- excellent day care centre
- getting lots of support and help
- provides a great break, she's collected and stays there for a few hours a day
- caregiver gives brilliant care, comes three days a week, brings her to town and takes her out for dinner. Person with dementia goes to day care centre the other 2 days.
- caregiver from the Alzheimer Society was unbelievable, she even gave her home phone number to ring if needed
- excellent caregiver comes into the home
- they provide 6 hours befriending and 2.5 days of day care - it gives us a sense of relaxation knowing she is cared for
- can call support group at any time
- the day care centre was excellent, as was the bus driver. The Alzheimer's Support Groups are very valuable
- goes to day care 5 days a week and is happy going there
- could not survive without their support
- terrific
- completely relied on day care centre. Only for them would be in the river.

very adequate support

- now past it, didn't know of existence of support group early enough
- a volunteer from Alzheimer's calls 2 days a week for a couple of hours each time
- I can ring them if I need anything
- 2 hours per week

reasonably adequate support

- goes twice a week to day care centre, also good to know one can call by phone when help is needed
- day care centre is 15 miles away
- support is there from Alzheimer's Group, has been offered service but 2 hours is not enough
- it is there when needed, has used it, but no need for it at the moment
- should not be means-tested. The group is very good, but it has to be paid for
- was in Alzheimer day care centre – just ordinary, but good
- cannot allocate more time due to lack of funding

inadequate support

- only 2 days per week
- day care centre was good, but only available 1 day per week
- they were willing to help, but person with dementia is unwilling to accept help
- only 1 hour per week of home help
- very limited resources, can only provide 3 hours per week, inadequate funding
- the help is very good, but is not enough: two 2-hour sessions a week
- doesn't suit because person is too young
- only 1 day per week, would like 2 days

16 Improving Medical Care

In Chapter 8, we discussed in detail the difficulties faced by younger people with dementia in terms of obtaining a timely diagnosis. In this section, we will look at the care provided by doctors, and particularly GPs, after a diagnosis of dementia has been made.

From the outset, it should be acknowledged that dementia is not a treatable illness and there are therefore limits to the services that medical practitioners and specialists can provide. Moreover, any serious consideration of the adequacy of medical treatments would be beyond the scope of this study. We will therefore concern ourselves exclusively with satisfaction ratings in relation to the medical care that is available to younger people with dementia, as indicated by their caregivers. The majority of these people are cared for by their partner and/or family members within the family home. Good quality care by their GP is therefore an important part of the overall care plan.

Table 16.1 Satisfaction with Medical Care and Advice

	Number	%
excellent	17	29.8
very adequate	10	17.5
reasonably adequate	12	21.1
inadequate	8	14.0
completely inadequate	10	17.5
Total	**57**	**100.0**

About two thirds (68.4%) of caregivers deem the medical support that they receive (primarily the services of their GP) to be at least reasonable, while one third find their services to be inadequate or completely inadequate.

Looking at the individual comments made by caregivers, perhaps the most important service a GP can provide in this context is to offer good advice about dementia in order to help those involved to prepare for the future. However, presumably because doctors can offer little in the way of medical treatment, there is a tendency for many doctors to take a less active role in caring for the person with dementia and those around them. A number of caregivers complained that their doctor is only available when called out and that neither the doctor nor the Public Health Nurse ever call in on their own initiative. This is probably symptomatic of more general trends in the development of medical services and of the lack of primary care provision in Ireland. It raises questions, however, about the need for more pro-active approaches in the care for younger people with dementia.

Our main recommendation in relation to this issue therefore focuses less on the medical needs which, in the absence of a cure to Alzheimer's disease are limited to the treatment of secondary symptoms in anyway, but on the need for appropriate counselling services to be developed for people with dementia and for their partners and family members. In the earlier chapters of this study we discussed the anxiety and depression experienced by people with dementia as well as the feelings of suspicion and potential aggression towards their caregivers. Counselling is believed to be an important element in reducing anxiety and fear and is likely to have a beneficial impact on the quality of life for persons with dementia, as well as those who are near them.

Recommendation 8:

We recommend that counselling services specific to younger people with dementia be developed in co-operation between the Health Services Executives and the Alzheimer Society of Ireland.

17 Improving Financial Supports

This study does not attempt to estimate the cost of caring for younger people with dementia. A detailed analysis in relation to dementia in general was undertaken in Ireland in 2000 and published by the National Council on Ageing and Older People.[6] We will, however, address one particular aspect, namely the right of a younger person with dementia to have access to services where a need arises.

Younger people with dementia and their families usually find themselves in a financial dilemma: in about half of all cases, access to an income from work is placed in jeopardy by the illness. Secondly, as other family members (primarily the husband or wife) take on the role of caregivers, their earning capacity is also restricted. Table 7.5 shows that in only 2 out of 18 cases (11%) where a person with dementia was the main income provider at the time of diagnosis, another family member was able to take over that role. In most cases, this means that that the family has to survive on disability benefit or, once they reach retirement age, on a disability pension or other provision. Finally, families face high costs in providing even the most basic care for the person with dementia.

In addition to this financial squeeze, younger people with dementia face the additional difficulty that early-onset dementia does not bestow specific state benefits for persons with dementia or their families, as they do not fall within any of the available categories. Early-onset dementia is not categorised automatically as a disability, nor as a terminal illness and at the time of diagnosis the person with dementia is by definition not eligible for benefits aimed at older people. Thus, many existing care provisions and financial supports are either unavailable to members of this group or are inappropriate, having been designed with other target groups in mind.

Recommendation 9:

There is an urgent need for early-onset dementia to be acknowledged as a specific needs group with appropriate care packages that reflect the special circumstances of people in this group and their caregivers.

Table 17.1 Financial Assistance (CA/CB) by Age Group of Caregiver

	yes Number	no Number	Total Number	yes %	no %	Total %
26 – 35	3	7	10	30.0	70.0	100.0
36 - 45	2	9	11	18.2	81.8	100.0
46 - 55	2	4	6	33.3	66.7	100.0
56 - 65	7	10	17	41.2	58.8	100.0
over 65	3	11	14	21.4	78.6	100.0
Total	**17**	**41**	**58**	**29.3**	**70.7**	**100.0**

Just under one third (29.3%) of caregivers in our sample receive Caregiver's Allowance (15) or Caregiver's Benefit (2). Most of those in receipt of these benefits are under 65 years of age as upon reaching 65 years the Caregiver's Allowance is typically replaced by a non-contributory pension. In some cases a Caregiver's Allowance was withdrawn when the person with dementia turned 65 and began to receive a pension, as this allowance is means-tested.

The costs which arise from home help as well as day respite and residential care provision do not only depend on the level of services required, but also on what is available. Costs may vary from one region to another or from one urban centre to another as the Alzheimer's centres have no strict guidelines about how to structure their costs. Most centres request a contribution towards the provision of services, although this is generally considerably below the true cost of providing the service. Also, if people are unable to make this payment, they will seldom be refused a minimal level of assistance. However, the ability to provide services

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[6] *ibid*

is limited and availing of additional hours or days of assistance may either be restricted by the resources available to the centre or by those available to the person with dementia. This survey indicates that a significant number of caregivers cannot afford an adequate level of support due to financial constraints.

Recommendation 10:

There is an urgent need to review the financial supports that are available to persons affected by early-onset dementia and/or their caregivers.

Part C: The Reform of the Health Services

18 The Lack of Reform of Dementia Services in General

It is nearly twenty years ago that the Working Party on Services for the Elderly delivered its report *The Years Ahead: A Policy for the Elderly*[7]. The report describes an optimal model of best practice for people with dementia in terms of a continuum of service provision, with increasing levels of support as the level of dependency increases. The report is still widely regarded as the principal work outlining the care requirements for the elderly in Ireland.

However, despite its wide acknowledgement, the reality for the vast majority of people with dementia remains far removed from the model outlined in the report. As O'Shea and O'Reilly state more than ten years later: *"Community care services for people with dementia are underdeveloped and fragmented. Generally, people with dementia do not come into contact with the health and social services until crisis occurs, involving the person with dementia, their carer, or both parties. Late intervention is, in turn, more likely to lead to institutional care, as the carer may no longer feel that she is able to cope. The result is a system geared to providing substitute care for people with dementia rather than providing anticipatory and ongoing care in partnership with patients and their family carers*.[8]

In the light of the little changes that had occurred since the publication of *The Years Ahead,* the National Council on Ageing and Older People once more highlighted the key principles that should inform the care for older people in *An Action Plan for Dementia*:[9]

(i) Respect for the preferences and rights of the person with dementia should be at the core of the action plan.

(ii) The action plan should be comprehensive.

(iii) The action plan should be biased towards home care solution.

(iv) Dementia care requirements should determine funding, rather than have funding determining care needs.

(v) Access to services should be on the basis of need and should not be impeded by an inability to pay, or by geography.

(vi) National quality targets and outcomes targets should be established.

The reform of the health services with respect to dementia services thus effectively requires a major shift from the currently prevailing crisis management towards a preventive or 'whole systems' approach based on person-centred care plans. As the country, like any other developed country, is gradually shifting towards an ageing population, dementia needs to be viewed as a major public health issue of the coming decades, requiring significant planning and investment.

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[7] The Years Ahead (1988) *The Years Ahead: A Policy for the Elderly.* Report of the Working Party on Services for the Elderly. Dublin: Stationary Office.

[8] O'Shea, Eamon & Siobhán O'Reilly (1999) *An Action Plan for Dementia.* Dublin: National Council on Ageing and Older People, p49.

[9] *ibid.* p63-68.

19 Additional Problems in Responding to Early Onset Dementia

The need to develop a person-centred and preventative care approach is by no means unique to dementia care, or indeed to the care for younger people with dementia, but applies across a wide spectrum of health care. However, the problems in the current health services provision become particular heightened when concerned with early onset dementia. The reason for this is the sectional organisation in the current health services, whereby services for a younger person with dementia may be situated in a variety of sections within the Department of Health and Children, including A & E services, services for the elderly, disability services, or mental health services, with no one section having an overall responsibility to develop person-specific health plans for the persons concerned. Indeed, the younger person with dementia may frequently 'fall between all stools' and may have no access to services at all, or at least not in a timely and planned fashion. Some examples may illustrate the current dilemma for younger people with dementia:

- Dementia is not classified as a long-term illness or disability. Indeed there are only very few illnesses included under the Long Term Illness and Disability Scheme (LTI/DS)[10]. Those classified under the LTI/DS are eligible to free-of-charge drugs, medicines and certain approved appliances prescribed for the treatment of their condition, irrespective of their means. Despite the fact that early onset dementia will, except in very few cases, invariably lead to a premature death, it is not included under this scheme.

- Older people - aged 70 and over - have universal access to a medical card and are thus eligible to free (prescribed) medication. By reason of age alone, however, this is not available to the younger person with dementia.

- Whilst some younger persons with dementia may be eligible to a medical card (subject to a means test), the main expenses in the early stages of dementia primarily relate to the funding of appropriate care arrangements and thus are not covered by the medical card.

- Indeed, the current health system is completely void of any rights-based approach to social care, as opposed to medical care and any support towards social care is entirely discretionary. As the study shows, support for younger people with dementia strongly focuses around establishing sustainable care arrangements in the family home, thus systematically lying outside the provisions of the current system.

- The Department of Health and Children provides a limited number of Home Help Grants, a significant number of which are to support clients with dementia. However, Home Help Grants are entirely restricted to those over 65 years of age and thus systematically exclude younger people with dementia.

- Due to the chronic hospital bed crisis, there is a strong political pressure for additional health spending to have a maximum effect on freeing up acute hospital beds, and any additional expenditure is therefore likely to be targeted at chronically disabled patients, the vast majority of whom are older people. As effectively all of these patients have care needs which require institutional care, additional funding is thus likely to be used entirely to fund additional institutional care places, rather than extending any home care packages.

- There are other gross inequities in the system. For example, a considerable number of people with Down's Syndrome are likely to develop early onset dementia in their later life. As they are falling within the disability legislation, they are eligible to medical care, including the care needs arising out of the dementia.

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[10] The Long Term Illness and Disability Scheme only applies to the following conditions: Mental Illness, Mental Handicap, Phenylketonuria, Cystic Fibrosis, Spina Bifida, Hydrocephalus, Haemophilia, Cerebral Palsy, Epilepsy, Diabetes Mellitus, Diabetes Insipidus, Multiple Sclerosis, Acute Leukaemia, Parkinsonism, and Muscular Dystrophy.

- On the other hand, the disability condition, and hence their right to a needs assessment, applies only to people under the age of 65, while people over 65 are no longer classified as disabled.

- Finally, there are gross regional differences as to whether, and to what extent, people may have access to Home Care Grants and the extent to which they have to contribute to the financial cost of Home Help Services.

As can be seen from the above examples, the structures and funding arrangements under the current health system systematically undermine the development of effective care arrangements for younger people with dementia according to need. Furthermore, it is clear that no section within the Department has an overall responsibility to oversee the effective delivery of health services for younger people with dementia. The development of effective care for people with early onset dementia thus remains in a policy vacuum and there are no appropriate structures within the Health Services Executive under which appropriate policies may be developed in the future.

Recommendation 11:

Urgent consideration needs to be given by the Health Service Executive to create the necessary structures to overcome the current fragmentation of responsibilities between services for the elderly, disability services and mental health services, and facilitate the effective development of comprehensive dementia care, independent of age.

20 Towards a Rights-based Approach to Social and Medical Care

As the empirical part of this study has shown, early-onset dementia differs from dementia amongst older people due to the different life cycle at which the younger person is affected, and requires different responses. To date, few responses specific to early-onset dementia have been developed, and there is a need to consider how provisions for younger people with dementia might be improved.

To suggest some framework for the development of services for younger people with dementia, it is useful to look at recent changes in the (still evolving) disability legislation in Ireland. The *Disability Bill 2004* proposes, for the first time, to establish a system for the assessment of individual health and education needs for people with disabilities in Ireland. If the Bill is passed into legislation, people with disabilities (or their representatives) will have a statutory entitlement to:

- apply for an independent assessment of their health and education needs
- receive a statement of the services (Service Statement) which are available
- pursue a complaint about the failure to provide these entitlements through an independent redress mechanism.

Any individual who feels that he or she may have a disability is entitled to apply for an independent Assessment of Need. The assessment is undertaken without regard to cost or capacity to provide services identified in the assessment. Arising from this assessment, the person concerned receives an Assessment Report, indicating:

- whether they have a disability
- the nature and extent of this disability
- the health and education needs that arise from the disability
- the services considered appropriate to meet those needs and the timescale ideally required for their delivery
- a date when this assessment should be reviewed.

There are provisions for relatives, guardian or personal advocates to apply for assessment on behalf of a person with a disability. Each individual with a disability is encouraged to participate in their own assessment, whilst also taking account of the nature of their disability and their age.

Leaving aside the shortcomings of the *Disability Bill*, notably the fact that the Bill currently under discussion does not confer a right to services for people with disabilities, but makes the provision of services dependent upon the resources available, it nevertheless begs the question of why younger people with dementia – or indeed any person with special care needs - are not given similar consideration.

If one moves away from a narrow interpretation of ‘disability’ to a wider consideration of ‘people with special needs’, than it becomes readily apparent that younger people with dementia form part of this group and that their needs should be acknowledged accordingly.

Recommendation 12:

Consideration should be given to provide younger people with dementia with a similar status to those identified under the new Disability Bill 2004.

21 Slán Abhaile – A Pilot Project for Older People[11]

To get some idea of how better care and support could be provided for younger people with dementia, it is worth looking at a recent pilot project targeted at older people who, in spite of their wish to remain living in their own homes, might be at risk of having to move into residential care in order to have their long-term care needs met. The project supported 62 older people during the first 18 month of its duration, and service recipients’ needs ranged from moderate to high physical dependency with a significant minority with dementia related or other mental health problems.

Slán Abhaile is a project undertaken by Health Service Executive East Coast Area in Partnership with The Royal Hospital Donnybrook, St. Vincent’s University Hospital and Rehabcare. The project was developed with strong support from the Health Service Executive Eastern Region in the context of growing pressure on acute hospital beds, the sometimes inappropriate placement of older people in long-stay residential care facilities, and an increasing evidence that older people wish to remain living in their own homes and have their needs met at home for as long as possible.

Slán Abhaile supports both the principles and the objectives of the National Health Strategy in that it offers:

- Person-centred care, including Home Support, occupational therapy, social work, respite care, day care, meals on wheels and physiotherapy
- Coordinated planning between agencies/service providers
- Individual integrated service plans for older people
- Enhanced home support services (including evenings and weekends)
- Support for informal carers

An Evaluation of the project undertaken by University College Galway[12] demonstrates that Slán Abhaile is cost effective when the public expenditure costs are compared with the cost of nursing home and hospital care. The qualitative benefits of Slán Abhaile, as reported by health professionals, service recipients and their families in the course of the research include: provision of needed personal services, security of knowing someone is visiting every day, improvements in quality of life, reduction in stress on carers, being consulted before decisions are made, flexibility of home support services and better coordination of services.

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[11] Health Service Executive East Coast Area (2005) *Slán Abhaile – The Pilot Phase*
[12] The research was undertaken by Aoife Callan as part of her Master thesis at the Department of Economics UCG.

We believe that it its an opportune time to develop a similar project specifically targeted at younger people with dementia. While the number of younger people with dementia will always be small compared to the potential older population in need of a person-centred care plan, the pilot project would have to have as an explicit aim to draw younger people with dementia as early as possible into the project such as to learn about their needs and have them participate in the planning of their own future to the maximum extent. The outcomes of such pilot project, if properly evaluated, would provide an invaluable platform for the development of adequate services for younger people with dementia which is currently missing in the health system.

Recommendation 13:

The Health Services Executive should establish a pilot project along the lines of Slán Abhaile, specifically targeted at developing person-centred care plans for younger people with dementia. Given the experience of the Alzheimer Society in pioneering responses to early onset dementia, we suggest that such project may be pursued in partnership between the HSE and Alzheimer Society.

Appendix 1: EURODEM Projections

Table A.1: Estimated Number of People with Dementia, 2006

	Male	Female	Total	Male	Female	Total
	%	%	%	Numbers	Numbers	Numbers
30 - 59	0.16	0.09	0.13	1,238	695	1,932
60 - 64	1.58	0.47	1.03	1,225	360	1,586
65 - 69	2.17	1.10	1.62	1,417	750	2,167
70 - 74	4.61	3.86	4.21	2,384	2,332	4,716
75 - 79	5.04	6.67	5.99	1,884	3,498	5,381
80 - 84	12.12	13.50	12.98	2,701	4,937	7,638
85 - 89	18.45	22.76	21.40	1,758	4,697	6,455
90 - 94	32.10	32.25	32.21	788	2,246	3,034
95 - 99	31.58	36.00	34.97	158	591	748
Total	**1.30**	**1.84**	**1.58**	**13,553**	**20,105**	**33,658**

Table A.2: Estimated Number of People with Dementia, 2016

	Male	Female	Total	Male	Female	Total
	%	%	%	Numbers	Numbers	Numbers
30 - 59	0.16	0.09	0.13	1,653	924	2,577
60 - 64	1.58	0.47	1.02	1,909	573	2,482
65 - 69	2.17	1.10	1.63	2,305	1,197	3,501
70 - 74	4.61	3.86	4.22	3,633	3,235	6,867
75 - 79	5.04	6.67	5.92	2,651	4,095	6,746
80 - 84	12.12	13.50	12.92	3,866	5,940	9,806
85 - 89	18.45	22.76	21.32	2,845	6,987	9,832
90 - 94	32.10	32.25	32.21	1,275	3,341	4,617
95 - 99	31.58	36.00	34.90	255	879	1,134
Total	**1.41**	**1.82**	**1.62**	**20,392**	**27,171**	**47,563**

Table A.3: Estimated Number of People with Dementia, 2026

	Male	Female	Total	Male	Female	Total
	%	%	%	Numbers	Numbers	Numbers
30 - 59	0.16	0.09	0.13	1,751	982	2,732
60 - 64	1.58	0.47	1.02	2,345	703	3,047
65 - 69	2.17	1.10	1.63	2,804	1,466	4,270
70 - 74	4.61	3.86	4.22	4,942	4,400	9,342
75 - 79	5.04	6.67	5.90	4,224	6,296	10,520
80 - 84	12.12	13.50	12.89	6,084	8,559	14,643
85 - 89	18.45	22.76	21.16	4,506	9,429	13,935
90 - 94	32.10	32.25	32.20	2,021	4,509	6,529
95 - 99	31.58	36.00	34.76	405	1,186	1,590
Total	**1.77**	**2.20**	**1.99**	**29,080**	**37,530**	**66,610**

Source: CSO (2004) Population & Labour Force Projections 2001 – 2036 Model M1F1 and EURODEM op. cit.