THE ALZHEIMER SOCIETY of IRELAND

# Implementing Policy for Dementia Care in Ireland

## The TIME for ACTION is NOW

### by Prof. Eamon O'Shea

ICSG
Irish Centre for Social Gerontology

**The Alzheimer Society of Ireland** is the leading dementia specific service provider in Ireland. It was founded in 1982, by a small group of people who were caring for a family member with Alzheimer's disease or a related dementia. Today it is a national voluntary organisation, with an extensive network comprising 26 branches, 31 Day Care Centres, 20 Home Care/Support Services, 28 Carer Support Groups, 5 Social Clubs and one Overnight Respite Centre. The Society also operates the Alzheimer National Helpline offering information and support to anyone affected by Alzheimer's disease / dementia.

**The vision of The Alzheimer Society of Ireland is:**

- to want a world where dementia can be prevented and cured
- where stigma of the person with dementia is challenged and overcome
- where those who live with dementia have all they need to live happy and fulfilling lives.

**What we do:**

- campaign for better services
- provide a confidential, freephone Alzheimer National Helpline: 1 800 341 341
- run nearly 90 local specialist services for people with dementia and their carers across Ireland including day care, home respite, overnight respite, social groups, support groups, advocacy and counselling services
- provide carer information and support
- provide an information service and website: www.alzheimer.ie
- raise public awareness through national and branch activities and campaigns
- innovate and pilot new specialist services and supports
- commission and collaborate on social and therapeutic research projects
- fundraise to support our work
- provide opportunities for volunteers.

**For further information** about membership or any other of our activities please contact:
The Alzheimer Society of Ireland, Alzheimer House, 43 Northumberland Avenue,
Dun Laoghaire, Co. Dublin. T: (01) 284 6616. F: (01) 284 6030.
E: info@alzheimer.ie.

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## Introduction

Dementia is a relatively new area of policy focus, despite the expanding number of people worldwide affected by different dementia disorders. Few countries have specific health and social care policies for the condition and where there is a policy it is mostly encompassed in wider generic policies and statements on ageing. In addition, discussions of public policy issues in respect of dementia are relatively rare in the research literature (OECD, 2004). Similarly, the health economics of dementia is in its infancy. This too is surprising, given that dementia is one of the most devastating and costly group of diseases and its impact on the care systems of all countries will increase in the future due to population ageing.

In Ireland, the stated objective of public policy for people with dementia is to encourage and facilitate their continued living in their own homes for as long as is possible and practicable (Report of the Working Party on Services for the Elderly, 1988). The Action Plan for Dementia (APD) (O'Shea and O'Reilly, 1999) reinforced the need for a social model of dementia that is focused on care in the community and on maintaining and developing, what Kitwood, (1997) called, the 'personhood' of the person with dementia. The APD emphasises the need for the development of co-ordinated, multi-layered and well-resourced services, which are responsive to the individual needs of people with dementia and of those who care for them. The APD also describes a model of best practice for the provision and planning of dementia care in Ireland that seeks to maximise the autonomy and capabilities of people with the disease. Unfortunately, progress has been slow in embracing this person-centred, holistic model of care for people with dementia. The medical model is still dominant.

There is a great ethical challenge in dementia care since the diseases themselves influence the person's capacity to advocate for their own interests. A person-centred approach would facilitate people with dementia having their voices heard both in public awareness work and in policy formulation and implementation. This is now possible due to improvements in the diagnostic process which for many people is happening at an earlier stage in the condition. The involvement of people with dementia in policy and service planning would be a radical shift in the traditional approach to dementia care and would represent a new paradigm; one which places rights and advocacy at the centre of decision-making. This will be a challenge for the future direction of dementia care in all countries, irrespective of how services are organised and financed. The challenge will have to be faced, however, if people with dementia are to play a central role in the planning and delivery of their own care.

The Government's 2001 Health Strategy: Quality and Fairness: A Health System for you (Department of Health and Children, 2001) accepted the general thrust of the APD and committed to its implementation over a seven year period. However, despite some improvements in recent years in enhanced training and education for staff, increased at-home respite care, additional specialised dementia units and more old age psychiatry consultants, progress has been slow in implementing the Action Plan. A reluctance to commit significant additional resources to dementia care is at the heart of the problem. The original APD was modest in terms of its demands on the Exchequer, requiring less than €20 million per year over a three year period for its full implementation. This is equivalent to an annual grant of just over €500 per person with dementia. When presented in this way, the cost is minimal relative to the potential gains to be had, but not everyone appreciates the returns from investing in dementia care. Even caregivers and members of the general public do not have sufficient information about the benefits of treatment and care (Bond et al, 2005). This paper makes the case for a significant public investment in dementia care as part of a new strategy of making dementia a national health priority.

## Explaining Dementia

In medical terms, dementia refers to a group of diseases characterised by progressive and, in the majority of cases, irreversible decline in mental functioning. The loss of cognitive abilities resulting from damage to the neurons in certain areas of the brain is often accompanied by deterioration in emotional control, social behaviour and motivation. The effects of the damage to the brain intensify over time and are disabling and terminal.

Alzheimer's disease is the most prevalent dementing disease, accounting for more than half of all cases. Many conditions other than Alzheimer's disease cause dementia in older people, especially vascular dementia, formerly known as multi-infarct dementia, which account for about 20 per cent of cases (Miller and Morris, 1993). Some people may have mixed dementia caused by both Alzheimer’s disease and multi-infarct dementia. Lewy Body dementia accounts for a further 20 per cent of dementing illness (Perry et al., 1990), while the remainder are accounted for by a range of uncommon conditions including Pick's disease and other frontal dementias, Creutzfeldt-Jacob disease, Parkinson's disease and Huntington’s Chorea.

There is no single cause of dementia, nor is there yet a cure for the vast majority of dementias. The control of vascular risk factors, such as blood pressure, and the use of anti-cholinesterase inhibitors may slow down, or temporarily improve, the decline in some people due to these illnesses. In addition, many of the symptoms of Alzheimer’s disease, particularly those related to depression, agitation, hallucinations and delusions, can sometimes be controlled or alleviated by taking medications. However, dementia remains a devastating condition, exacting a huge physical, mental and emotional toll on both patient and family.

Research into the disease has been dominated by the clinical sciences and prevailing definitions of dementia and descriptions of people with dementia are nearly all based on a medical model. This trend has drawn criticism from some quarters concerned about the dominance of the bio-medical paradigm in this area (Bond, 1992; Harding and Palfry, 1997). There has also been criticism that the individuality and personhood of those with dementia has not always been recognised, with consequent negative affects on their rights as people and citizens (Kitwood, 1997; Innes and Capstick, 2001).

## Symptoms and Stages

Dementia is largely, although not exclusively, a disorder of old age. It has an insidious onset and gradually progresses. The rate of progression varies between individuals, but death usually comes within a decade of the original diagnosis. All dementias are characterised by a range of signs and symptoms. The signs and symptoms tend to progress in stages and vary with the different types of dementia. While people with dementia are a heterogeneous group with respect to their level of cognitive impairment, the disease is consistent in its erosion of individual autonomy. The common symptoms and behavioural changes associated with dementia include the following:

- Memory loss
- Confusion
- Disorientation
- Language difficulties
- Wandering
- Failure to recognise people or objects
- Impaired comprehension, reasoning and judgement
- Mood swings

- Night-time wakefulness
- Gradual failure to perform daily living tasks
- Hallucinations and delusions
- Challenging behaviours, such as verbal and physical aggression, suspicion, agitation and repetitive acts, inappropriate sexual behaviour, stealing and hiding things and the use of abusive or obscene language

While dementia is often described in the literature in terms of a number of progressive stages, from pre-diagnosis, diagnosis and early stage, through middle to late stage (Brodaty and Lie, 1998), considerable variation in the symptoms can occur during the course of the illness, which means that not everybody with the disease necessarily progress neatly from one stage to the next.

The uniqueness of the disease must, therefore be acknowledged, in that no two individuals with dementia are likely to be affected in precisely the same way. People with dementia are likely to have various combinations of the symptoms listed above, and possibly other complications as well, making it clear that there is no one solution to the provision of care for these people and their families. The most progressive approach may be to focus on the needs of the individual person with dementia and their carer, drawing on many different types of services and expertise, even at the early stages of the disease. Some of these needs will be social in character, which are not easily captured within the dominant medical model of care in place in Ireland today.

## Prevalence of Dementia in Ireland

Studies on the prevalence of dementia, which seek to estimate the number of people with dementia at a given point in time, show a sharp rise in the prevalence of dementia with age. Prevalence of dementia increases almost exponentially with age, nearly doubling every five years, but the increase is much more rapid for females for whom prevalence is much greater in the oldest age categories (OECD, 2004). There is, however, no simple answer to the question of prevalence in various countries. Prevalence depends on how we define and measure dementia (Jorm et al., 1987). Not surprisingly, therefore, dementia prevalence estimates are very different across countries, mainly due to methodological differences in the various studies that have taken place (Fratiglioni, 1998), none of which have occurred in Ireland.

Prevalence rates for the Irish population have been mostly based on EURODEM data (Hoffman et al., 1991), which provide a statistical integration of age-based rates from a number of different prevalence studies (Table 1). We use EURODEM rates to estimate prevalence rates in this paper, supported by meta-analysis data from Jorm et al (1987), which we use to estimate prevalence rates by county. Our prevalence estimates for younger people with dementia are based on Harvey (1998).

**Table 1: EURODEM Prevalence Rates for Dementia**

| Age Group | Males | Females |
|---|---|---|
| 30-59 | 0.2 | 0.1 |
| 60-64 | 1.6 | 0.5 |
| 65-69 | 2.2 | 1.1 |
| 70-74 | 4.6 | 3.9 |
| 75-79 | 5.0 | 6.7 |
| 80-84 | 12.1 | 13.5 |
| 85-89 | 18.5 | 22.8 |
| 90+ | 31.9 | 34.1 |

### *Applying EURODEM Rates to Ireland*

The application of EURODEM rates to the most recently available published Census population data for Ireland (Central Statistics Office, 2003) suggests that there were just over 34,000 people with dementia in the country in 2002, made up of 20,000 females and 14,000 males (Table 2). Western counties tend to have the highest share of the population with dementia, with Leitrim having the highest share at 1.36 per cent. (Table 3). Eastern counties tend to have the lowest share of the population with dementia, with Kildare having the lowest share at 0.53 per cent. Even in such a small country as Ireland there are clear regional differences in prevalence rates for dementia, reflecting imbalanced age distributions across the country, underlining the importance of age structure for prevalence estimates.

**Table 2: Estimated Number of People with Dementia in Ireland 2002**

| Age category | Males | Females | Males with dementia | Females with dementia | Persons with dementia |
|---|---|---|---|---|---|
| 30-59 | 773421 | 771706 | 1547 | 772 | 2319 |
| 60-64 | 77559 | 76693 | 1241 | 383 | 1624 |
| 65-69 | 65290 | 68184 | 1436 | 750 | 2186 |
| 70-74 | 51719 | 60410 | 2379 | 2356 | 4735 |
| 75-79 | 37377 | 52438 | 1869 | 3513 | 5382 |
| 80-84 | 22283 | 36574 | 2696 | 4937 | 7633 |
| 85-89 | 9444 | 20185 | 1747 | 4602 | 6349 |
| 90+ | 3042 | 9055 | 970 | 3088 | 4058 |
| Total | | | 13885 | 20401 | 34,286 |

Source: Census of Population (2002) by EURODEM prevalence rates

**Table 3: Estimated Number of People with Dementia by County 2002**

| County | Population (All Ages) | Persons with Dementia | % of Total Population |
|---|---|---|---|
| Leitrim | 25,799 | 351 | 1.36 |
| Roscommon | 53,774 | 689 | 1.28 |
| Mayo | 117,446 | 1,473 | 1.25 |
| Cavan | 56,546 | 642 | 1.13 |
| Longford | 31,068 | 352 | 1.13 |
| Kerry | 132,527 | 1,467 | 1.11 |
| Sligo | 58,200 | 638 | 1.10 |
| Donegal | 137,575 | 1,471 | 1.07 |
| Tipperary | 140,131 | 1,426 | 1.02 |
| Monaghan | 52,593 | 522 | 0.99 |
| Clare | 103,277 | 992 | 0.96 |
| Galway | 209,077 | 1,975 | 0.94 |
| Kilkenny | 80,339 | 734 | 0.91 |
| Cork | 447,829 | 3,952 | 0.88 |
| Waterford | 101,546 | 905 | 0.89 |
| Offaly | 63,663 | 558 | 0.88 |
| Westmeath | 71,858 | 628 | 0.87 |
| Wexford | 116,596 | 1,000 | 0.86 |
| Laois | 58,774 | 507 | 0.86 |
| Limerick | 175,304 | 1,460 | 0.83 |
| Wicklow | 114,676 | 921 | 0.80 |
| Louth | 101,821 | 818 | 0.80 |
| Carlow | 46,014 | 361 | 0.78 |
| Dublin | 1,122,821 | 8,637 | 0.77 |
| Meath | 134,005 | 939 | 0.70 |
| Kildare | 163,944 | 870 | 0.53 |
| Ireland | 3,917,203 | 34,286 | 0.88 |

Source: Census of Population (2002) combined with Jorm et al, EURODEM and Harvey rates

Table 4 shows the projected growth in the number of people with dementia. In line with the ageing of the population (Central Statistics Office, 2004), the major increase in the number of people with dementia is likely to occur after the year 2021, with the numbers increasing to over 100,000 by the year 2036. The projections suggest that there are currently 38,000 people with dementia in Ireland.

**TABLE 4: Projected Growth in the Number of People with Dementia in Ireland**

| Year | Persons with Dementia |
|---|---|
| 2006 | 37,746 |
| 2011 | 42,441 |
| 2016 | 49,153 |
| 2021 | 58,044 |
| 2026 | 70,115 |
| 2031 | 85,847 |
| 2036 | 103,998 |

Source: CSO projections (2004) by EURODEM and Harvey (1998) Prevalence Rates
Overall, the number of people with dementia estimated from the aggregation of fragmented prevalence data from Irish sources corresponds to the numbers generated by the application of EURODEM prevalence rates to Irish population data. For example, estimates by Lawlor et al. (1994) suggest that there were approximately 23,000 people with dementia living in the community in Ireland in the early 1990s. The number of people with dementia currently in residential care in Ireland is estimated officially at just under 5,000 people (Department of Health and Children, 2004), although international experience suggests that this figure is likely to be much higher, up to a maximum of 40 per cent of all people with dementia in the country (Gordon and Spicker, 1997; Gibson et al, 1999). Estimates of the number of people with dementia in acute care hospitals are not available for Ireland, although estimates

from one former Health Board suggests that 18 per cent of acute medical beds are occupied by people with significant cognitive impairment (Clinch and Hickey, 1992), which would include people with dementia.

Calculating the incidence of dementia is even more problematic than calculating prevalence (Alzheimer Scotland, 2000). Incidence refers to the number of new occurrences of the disease in the population over a period of time. Dementia is difficult to recognise, as people often confuse the symptoms of dementia with the signs of normal ageing. However, more cases are now being detected at earlier stages, due to improvements in primary and community care diagnostic and assessment services and increased public awareness about the disease. Incidence rates are also rising because more and more people are living to the age when dementia usually strikes. Although there are a number of international studies of incidence, few have similar results, with the range between 2.5 new cases per 1,000 people over 65 to 26 new cases per 1,000 people over 65 (Alzheimer Scotland, 2000). A tentative extrapolation of lower middle-range international incidence rates to the elderly population in Ireland suggests that approximately 4,000 new cases arise in the general Irish population every year.

## Family Care

There are an estimated 50,000 carers in Ireland looking after someone with one of six specified symptoms of dementia: for example 25,000 carers are looking after someone with marked forgetfulness on a regular or occasional basis, while 15,000 people are looking after someone with confusion to the point of interfering with everyday life (O'Shea, 2000). The overall median daily provision of care provided by these carers to people with dementia is 10 hours. This estimate is in line with results from other surveys on care provision for people with dementia (Ruddle and O'Connor, 1993). When carers were asked if they would prefer to provide less care hours, the majority opted for less care provision, but only by about 2 hours per day. It is clear, therefore that carers want to care, but would like more relief and more support from the ongoing burden of care.

Given the high levels of care provided it would be surprising if some carers did not experience some stress and strain as a result of caring. This is confirmed in international studies which suggest that caring for a person with cognitive difficulties gives rise to high levels of stress, all the more so if that person is suffering from dementia. In Ireland, over 90 per cent of carers of people with dementia experience feelings of confinement due to caring (Table 5). Four out of five carers report emotional adjustment due to caring, while 75 per cent feel some degree of upset due to the behaviour of the person under their care. Almost two thirds of carers of people with dementia report that they feel completely overwhelmed by caring. Significantly, in terms of the opportunity cost implications, 61 per cent of respondents have made some adjustment to work as a result of caring, while more than two thirds of carers report financial strain. The application of the General Health Questionnaire (GHQ) to carers of people with dementia in Ireland confirms the high personal costs associated with caring. The overall mean score on the GHQ for the carers of people with dementia is significantly above the accepted cut-off point for mental well-being among carers (O’Shea, 2003).

## The Economic Impact of Dementia

Cost-of-illness studies describe the economic burden of a given illness by estimating the value of all goods and services consumed in order to prevent, diagnose, treat and otherwise cope with the illness for a given period. Cost of illness studies for dementia are scarce in most European countries (OECD, 2004) with most studies emanating from the United States, but even where studies have been done cross-country comparisons are difficult due to methodological differences, particularly with respect to the monetary valuation family care costs. In addition, the range of formal resource items included in cost calculations has varied between studies, which also limits comparability.

**Table 5: Caregiver Strain Index for Carers of People with Dementia**

| Strain Index | Carers of People with Dementia % |
|---|---|
| Upsetting because of changes in elderly person | 96 |
| Confining | 91 |
| Change in personal plans | 88 |
| Adjustment for family | 84 |
| Physical strain | 79 |
| Emotional adjustments | 78 |
| Upsetting because of changes in elderly person | 75 |
| Disruption of sleep | 73 |
| Financial strain | 70 |
| Demanding because of other demands on time | 67 |
| Completely overwhelming | 65 |
| Adjustment to work | 61 |
| Inconvenient | 40 |

O’Shea (2004) estimated the baseline cost of dementia for Ireland at the beginning of this decade at €344 million, based on an opportunity cost valuation of informal care. Adjusted for inflation, the 2006 baseline estimate is just under €400 million. While the analysis for Ireland suffers from the usual problems associated with cost of illness studies - the lack of good quality data - the distribution of the burden of care is clear enough. Family care accounts for 57 per cent of the overall burden of care, rising to

76 per cent if family care is valued using substitution labour costs (applying the national minimum wage) rather than on an opportunity cost basis.

The contribution of family care is in contrast to the relatively low provision of community care for people with dementia. Community support services for people with dementia and their carers are under-developed and fragmented in this country. Generally, people with dementia do not come into contact with the health and social services until a crisis occurs, involving the person with dementia, their carer, or both parties. It is not surprising, therefore, that only 6 per cent of the cost of dementia in Ireland is attributable to community care services. In contrast, nearly, one third of the burden of care is attributable to residential care. It should be pointed out that we do not have any official published data on public expenditure on older people with dementia to allow comparison with other vulnerable groups or over time. The generation of this data should be a priority in the development of any new information strategy for older people.

Table 6 below shows comparative cost estimates in Euros (2004) derived from an analysis of a number of dementia cost studies across Europe, including Ireland (Jonsson and Berr, 2004). Per capita cost estimates range from about €6,000 to about €19,000 annually, reflecting the aforementioned differences in methodological approaches to the collection and estimation of the data. Ireland is at the lower end of the estimates at just under €10,000 per capita per annum. Costs would be higher for Ireland if the community care sector was properly resourced to provide a comprehensive service to people with dementia and their families. In general, the accumulating evidence suggests, notwithstanding differences in methodology, that the costs of care for people with dementia are very high across European countries. Equally consistent, according to Jonnson and Berr (2004), is the finding that the costs of care increase with successive loss of cognitive and physical function as dementia progresses.

**Table 6: Annual Per Capita Cost of Care for People with Dementia (2004)**

| *Country* | *Annual Per Capita Cost €* |
|---|---|
| Finland | *19,458* |
| Norway | *16,415* |
| Belgium | *15,435* |
| Germany | *12,583* |
| Sweden | *11,321* |
| Denmark | *10,610* |
| Ireland | *9,856* |
| France | *5,981* |

Source: Jonsson and Berr (2004). Estimates are adjusted for Purchasing Power Parities (PPP).

## Current Policy

This section briefly reviews current strategic thinking with regard to planning for dementia in this country. The stated objective of public policy with respect to the long-term care of older dependent people in Ireland since the end of the 1980s has been to allow people to live in their own homes for as long as is possible and practicable. Unfortunately, the ability of dependent older people to remain in their own homes has been compromised by the failure of successive governments to allocate sufficient resources to community care. The weakness of community care has affected the wellbeing of people with dementia living at home and affected the lives of their families in a very real way. Indeed, the financial and psychological strains on carers, as outlined earlier, are significant and would in any other area of the health service lead to public outrage.

The APD was instituted in 1999 to address some of the failures of policy in the field of dementia care identified at that time. It set a strategic direction for dementia care designed to strengthen the capacity of the health and social care system to meet the needs of people with dementia and their families and carers in the new century. The emphasis was on finding better ways of meeting the health, social, psychological and emotional needs of people with dementia and their carers. The APD was based on six core principles as follows:

- Person-centred models of care which respect the preferences and rights of the person with dementia
- Comprehensive provision
- Bias towards home care solutions
- Care requirements to determine funding
- Needs-based provision
- Evidence-based practice linked to national quality and outcome targets

It was recognised that securing additional resources would be the key to the success of the APD. The Action Plan made 33 recommendations for change at a total cost of approximately £45 million in 1999 prices. Translated to euros and adjusted for inflation means that the current investment required would be €73m. It was envisaged that this investment would be made over a three year period to bridge the gap between need and existing provision for people with dementia. The main targets were as follows:

- Increased public awareness about dementia
- Increase in early diagnosis through enhanced training and education for primary care workers, especially for general practitioners
- Development of a care management model of integrated care

- Expansion of dedicated community-based services, for example, day care services, occupational therapists, community psychiatric nurses
- Expansion of dedicated old age psychiatry services
- Development of new and expanded psychosocial approaches to complement existing medical and neurological models of service delivery in the community and in residential care units
- Development of small-scale, appropriately designed, special residential care units
- Development of new services for people with early onset dementia, including people with Down's Syndrome.

The Government's 2001 Health Strategy: Quality and Fairness: A Health System for you accepted the general thrust of the Action Plan and committed to its implementation, but over a seven year period. However, despite some initial improvements in enhanced training and education, increased at-home respite care, additional specialised dementia units and more old age psychiatry consultants, progress has been slow in implementing the Action Plan. The additional resources necessary to fully implement the APD have not been forthcoming. It is clearly time for a restatement of our commitment to provide for people with dementia in the country.

## Future Strategies and Priorities

A new deal for people with dementia requires more than promises to implement APD over the long-term. Because of the impact of demographic ageing in the coming decades and the importance of dementia in overall health and social care costs and disease burden, dementia must be accorded much higher priority in national health. For real progress to happen, dementia must be made a national health priority. It is already linked to existing priorities, for example, cardiovascular disease, but it needs to be accorded special status and have a national strategy of its own. The recent NESF report on care of the elderly called for an investment of €500 million in services for older people generally to bring Ireland up to OECD average expenditure in this area. People with dementia should be targeted as part of this new investment in ageing in the country. The first task should be the immediate implementation of APD as part of the national prioritisation of dementia.

The national prioritisation of dementia should encompass four key strategic elements, each of which have their origins in the APD:

- Early intervention, education and training
- Enhanced community-based services for people with dementia and their carers
- Co-ordination and integration of multi-disciplinary care provision
- Quality residential care that is centred on the person with dementia

The vast majority of people with dementia live at home in the community. However, most of these have never been formally diagnosed with dementia and, for the most part, are not known to the health and social care services. Similarly, there are many older people in long-stay care who suffer from dementia but have not been diagnosed as such, or treated accordingly. While early diagnosis is critical for the development of an optimal care plan, the reality is that early diagnosis, and sometimes even late diagnosis, is the exception rather than the rule. Even when the symptoms are obvious, there may well be a reluctance to label someone with dementia because of the negative attitudes and stigma sometimes associated with the disease within families and communities. There may well also be an erroneous attitude that as nothing can be done for the patient in terms of a cure, it may be best not to create false expectations on behalf of patients or future demands on existing community care resources, which are already scarce.

Doctors, public health nurses, community psychiatric nurses and social workers are key to early diagnosis, assessment and the care planning process. GPs should especially be encouraged to learn more about how to recognise the first signs of dementia and to participate actively in accessing specialist medical and social services on behalf of older people with dementia. Early diagnosis is particularly important now to facilitate decision-making on the suitability of patients for new cholinesterase inhibitor treatments. Health and social care staff in all facilities where older people receive care, including acute care, should also be provided with information and training on how to recognise the first signs of dementia in patients and clients and what to do in such circumstances. Equally, families are important in facilitating early diagnosis, underlying the importance of public information campaigns on the nature and form of the disease.

Information, education and emotional support are very important for people with dementia and their carers. Education can be especially important in the early stages to facilitate the participation of the person with dementia in the decision-making process, when they are still capable of making informed decisions. While there are many ways to provide information and education support, it should be provided at local level through the development of new information and advice centres that could be combined with counselling services, where appropriate. At the moment, there is an information vacuum about the disease, about services and about potential support structures for carers. These new information and advice centres have the potential to reach out to people with dementia and their families at a personal level while, at the same time, providing a link to both specialist and community-based services through referral and advocacy. These centres could also be used to increase public awareness and understanding of the needs of people with dementia and their carers.

Information and education are, of course, useless and possibly counter-productive unless community-based services actually exist. Much has already been written about the weakness of community care services for older people in Ireland. It is worth restating again, however, what services are needed for people with dementia to enable them to live well in their own homes. People should be provided with home support services that they need and value, when they need them most. Home care services include personal care, social support and domestic assistance. We have been much better at providing domestic assistance through the home help programme than in providing personal care or social support at the times that people need them most. Day care and respite care provided at home or in an appropriate setting are also important. It is also critical that the provision of aids and adaptations and new technologies to support independence and reduce risk is included within service plans to enable people with dementia to remain in their own homes.

Community-based provision needs a radical overhaul if services are to be responsive to the needs of people with dementia. The new Home Care Grants scheme may bring much-needed flexibility, innovation and imagination into community care provision. For that to happen, however, the allocation process will have to be much more person-centred than in the past. This means widening the set of choices available to people living at home, in terms of both provision and timing of services. It also requires that people be given the opportunity to make the choices that matter for them.

The estimated number of highly dependent people with dementia living at home and requiring intensive packages of care in Ireland is 1,300 people. This estimate is based on the application of the care intervals formula used by Alzheimer Scotland in planning services in that country to Irish population data. Assuming a conservative cost per Home Care package of €350 per week, this works out at an annual cost of €23 million for people with dementia living at home. While some of this expenditure is part of current funding allocations, it demonstrates the importance of additional investment on top of the resources required for the implementation of the APD.

Dementia care is provided by a variety of sources making co-ordination and integration critical for efficient and effective delivery of services. The review of the implementation of The Years Ahead report concluded that, while some collaboration and integration was evident at national level, procedures remained, on the whole, informal and unstructured (Ruddle, et al. 1997). By and large, this is still the case, despite everyone agreeing that co-ordination of services is a good idea (NESF, 2005). The provision of new information and advice centres would go some way to addressing concerns and frustrations with the current fragmented system. Something more is needed however to ensure that people with dementia receive timely and appropriate services that are embedded in their own local communities.

Care management is an approach to more integrated care planning and delivery of services, particularly for people with dementia with complex care needs. The international experience of care management for highly vulnerable older people is that it can reduce institutional care placements, improve quality of care and enhance quality of life for older people and for their carers, even if the cost of keeping people at home can sometimes be higher for people with dementia (Challis et al, 2002). In this country, very few people with dementia have been allocated a care manager or even a key worker to directly represent their interests as consumers and citizens. A care manager would facilitate needs assessment, oversee the development of a care plan, co-ordinate the delivery of services and monitor outcomes. She/he might also nurture local supply-side responses to need among people with dementia from private and voluntary providers, thereby expanding the range and variety of services in local areas.

Advocacy would be an important part of the work of the care manager. The care manager as advocate would support the person with dementia to represent themselves where possible; otherwise the care manager would represent the person’s best interests, in consultation with families, in relation to service provision and placement decision-making. Workers performing this advocacy role could come from a variety of different disciplines and agencies, depending on local circumstances. Whatever their origins, without them person-centred and flexible services for people with dementia will remain under-developed and fragmented.

Although the emphasis in this paper has been on developing primary and community care services for people with dementia, the needs of people with dementia in residential care are also important. While dementia special care units in long-term care institutions have been shown to be effective in some studies (OECD, 2004), it is not always possible to have dedicated units. Some dementia-specific provision is however, necessary in all long-stay units accommodating people with dementia. Connectedness to family and friends remains important for people with dementia at all stages of the disease, so people should be able to access good quality care in local generic long-stay units. Accommodating people with dementia in generic units may require the hiring of new specialist staff, dementia training for existing staff and improved design of the built environment.  In general, more attention should be paid to the design and scale of any type of residential facility accommodating people with dementia. When regulating quality of care for people with dementia in long-stay facilities, the design of the interior and exterior environment should form part of the assessment process.

The care process within long-stay facilities is also important. Psychosocial approaches are needed to complement medical and neurological models of service delivery. There should be more emphasis on developing meaningful communication with patients, using all of the senses, through reminiscence, music and various therapeutic and time-intensive activities.  Quality of life for people with dementia is a complex issue, but it is influenced by many things other than conventional nursing and medical care.  Some progress has already been made in this area and the view that 'there is nothing that can be done' is rightly now seen as unsupportable. There is, however, scope for improving the communication skills of people caring for dementia patients at all levels. If health professionals are to develop the skills necessary for an empathic delivery of care, information and staff training is essential.

## Conclusion

The message of this paper is the importance of making dementia a national health priority, beginning with the full and accelerated implementation of the APD. The emphasis in the paper has been on primary and community care solutions to the problems that exist in this area. Families continue to provide the bulk of care for people with dementia, but they need more support if the current high level of provision is to be maintained. Support structures must be collective and public if the full potential of older people with dementia and their carers is to be realised. Intergenerational solidarity at all levels of society is the key to achieving full citizenship rights for all older people. That solidarity cannot be taken for granted but must be continually renewed and nourished through dialogue and greater public awareness and discussion of dementia. The Action Plan for Dementia concluded with a simple statement as follows: the time for action is now. While that moment has passed, the time for a renewal and enhancement of our initial commitment has arrived through making dementia a national health priority.

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