

# **An Action Plan for Dementia**



# **An Action Plan for Dementia**

Dr Eamon O'Shea and Ms Siobhán O'Reilly  
*National University of Ireland, Galway*

National Council on Ageing and Older People

Report No. 54

NATIONAL COUNCIL ON AGEING AND OLDER PEOPLE  
22 CLANWILLIAM SQUARE  
GRAND CANAL QUAY  
DUBLIN 2

REPORT NO. 54  
© NATIONAL COUNCIL ON AGEING AND OLDER PEOPLE, 1999

ISBN 1 900378 12 4

PRICE:     IR£8.50     E10.79

## Foreword

As Chairperson of the National Council on Ageing and Older People, it gives me great pleasure to introduce this *Action Plan for Dementia*.

Previous publications by the Council have pointed to the need for significant progress in the care of older Irish people with dementia. In this light, the former Minister for Health requested the National Council on Ageing and Older People to consider ways in which services for people with dementia and their carers might be improved. This report, a major piece of work developed in consultation with a wide variety of bodies from the statutory, voluntary and private sectors, is the outcome of that request.

The *Action Plan* takes as its guiding principle the recognition of the individuality of the person with dementia and of his or her individual needs. This principle has informed and influenced the development of the plan. The needs and uniqueness of the person with dementia must be paramount when we talk of care and service provision.

Action on the treatment of dementia can be delayed no longer. Given the increasing proportion of older people in the population and the higher prevalence of dementia in older age groups, action is needed now. This plan should serve as a model of best practice for the provision and planning of services to meet the individual needs of people with dementia and their carers.

On behalf of the Council I would like to thank the authors of the report, Dr Eamon O'Shea and Ms Siobhan O'Reilly. Thanks are also due to all those who gave of their time to the authors in the consultative process.

I would also like to thank Mr Christopher Domegan and his successor, Dr Margo Wrigley, who chaired the Council Committee which oversaw the preparation of the *Action Plan* in a consultative capacity. Our thanks go to all the members of the Consultative Committee for their guidance and advice. The members were Ms Winifred Bligh, Ms Janet Convery, Dr Murna Downs, Ms Mary Drury, Mr Martin Duffy, Ms Margaret Geary, Mr Frank Goodwin, Cllr Tim Leddin, Dr Aidan Meade, Dr John Murphy, Dr Des O'Neill and Sr Mary Threadgold.

Finally, the Council would also like to thank its Director, Mr Bob Carroll, its Research Officer, Ms Nuala O'Donnell and former Research Officers, Dr John Browne and Mr Frank Houghton who steered the project on the Council's behalf. Thanks are also due to Ms Catherine Mulvenna who prepared the report

for publication and to the Council's administrative staff for their secretarial assistance throughout the course of the project.

**Dr Michael Loftus**

*Chairperson, National Council on Ageing and Older People*

May, 1999

# Contents

## Executive Summary

- Introduction
- The dementia population
- The resource implications of dementia
- Policy background
- Balance of care issues
- The urgency of the problem
- Methodology
- Philosophy and principles
- Pathways to care: primary and community care services
- Pathways to care: secondary level care
- Pathways to care: residential and nursing home care
- Special need groups
- Policy implementation issues
- Costs and funding

## Recommendations

<b>Chapter One</b>	<b>Introduction</b>
1.1	Opening remarks
1.2	The objective of the plan
1.3	Realities and constraints
1.4	Methodology
1.5	Outline of the plan
<b>Chapter Two</b>	<b>The Nature and Prevalence of Dementia</b>
2.1	Introduction
2.2	Types of dementia
2.3	The symptoms and stages of dementia
2.4	<i>The Years Ahead</i> categorisation
2.5	Prevalence of dementia
2.6	Conclusion
<b>Chapter Three</b>	<b>The Cost of Dementia</b>
3.1	Introduction
3.2	Methodology
3.3	The burden of care in Ireland
3.4	Conclusion

<b>Chapter Four</b>	<b>Current Resources for Dementia</b>
4.1	Introduction
4.2	Primary and community care
4.3	Secondary care services
4.4	Residential care
4.5	Conclusion
<b>Chapter Five</b>	<b>Philosophy and Principles</b>
5.1	Introduction
5.2	The philosophical framework
5.3	Principles for the action plan for dementia
5.4	Conclusion
<b>Chapter Six</b>	<b>Pathways to Care: Primary and Community Care</b>
6.1	Introduction
6.2	Priorities for primary and community care
6.3	Primary care
6.4	Community care
6.4.1	Case management
6.4.2	Carers
6.4.3	Information and counselling
6.4.4	Day services
6.4.5	Respite care
6.4.6	Home support services
6.4.7	Other community care services
6.5	Conclusion
<b>Chapter Seven</b>	<b>Pathways to Care: Secondary Level Care</b>
7.1	Introduction
7.2	Psychiatry of Old Age
7.3	Geriatric medicine
7.4	The development of services
7.5	Conclusion
<b>Chapter Eight</b>	<b>Pathways to Care: Residential Care</b>
8.1	Introduction
8.2	Physical environment and design
8.3	Process of care
8.4	Conclusion
<b>Chapter Nine</b>	<b>Special Need Groups</b>
9.1	Introduction



9.2	Early onset dementia
9.3	Down's Syndrome and dementia
9.4	Conclusion

<b>Chapter Ten</b>	<b>Policy Implementation Issues</b>
10.1	Introduction
10.2	Monitoring and evaluation
10.3	Centre-local relationships
10.4	Statutory-voluntary relationships
10.5	Public-private relationships
10.6	Multidisciplinary working
10.7	Conclusion

<b>Chapter Eleven</b>	<b>The Social Economy</b>
11.1	Introduction
11.2	The nature of the social economy
11.3	Demand and supply issues
11.4	Conclusion

<b>Chapter Twelve</b>	<b>Costs and Financing</b>
12.1	Introduction
12.2	The cost of the plan
12.3	Current arrangements for financing care
12.4	Private insurance
12.5	Social insurance
12.6	Conclusion

<b>Chapter Thirteen</b>	<b>Conclusions</b>
-------------------------	--------------------

## References

## List of Tables

Table 2.1	EURODEM prevalence rates for dementia.
Table 2.2	The number of people with dementia in Ireland, 1996: based on an application of EURODEM prevalence rates to population.
Table 2.3	Estimated number of people with dementia by health board: based on an application of EURODEM prevalence rates to population; ranked by % of all ages with dementia in each health board.

Table 2.4	Estimated number of persons with dementia by county: based on an application of EURODEM prevalence rates to population; ranked by % of all ages with dementia in each county.
Table 2.5	The projected growth in the number of people with dementia in Ireland 1996-2026: population projections by EURODEM prevalence rates.
Table 3.1	Annual costs of dementia care (lower-bound estimate) 1997.
Table 4.1	Selected feedback from consultations: primary, community and secondary care services.
Table 4.2	People with dementia in residential care.
Table 4.3	Feedback from consultations on residential care services.
Table 12.1	Targets and costs

# **An Action Plan for Dementia**

## **Executive Summary**

### **Introduction**

Dementia as a disability is characterised by the following characteristics: impaired memory, impaired ability to learn, impaired ability to reason, and high levels of stress. The complexity and range of issues involved in the management of dementia emphasise the need for the development of co-ordinated, multi-layered, and well resourced services that are responsive to the individual needs of people with dementia and their carers. People with dementia are a heterogeneous group, which means that there is no single solution to the problem of dementia. An understanding of how the dementia population impacts on the care system is an essential part of the planning process. Equally, the level and quality of support provided to people with cognitive impairment will affect the degree and nature of the disability that results from that impairment.

The effective management of dementia in Ireland necessitates the development of an action plan, incorporating the viewpoints of all major stakeholders. The plan emphasises the uniqueness of the person with dementia. It places the individual with dementia at the centre of the planning process and goes beyond a neuropathological approach to understanding dementia to explore the concept of personhood in dementia within the framework of what Kitwood (1997) calls the 'new culture of dementia'. The plan outlines the approach to developing available, accessible and high quality services given existing resources and the public expenditure constraints that are likely to continue into the future. The need for a continuum of services is recognised and incorporated into the plan. Financing issues are explicitly considered along with new ways of funding and providing social care services for people with dementia and their carers. The intention is that the plan will serve as a model of best practice, which can guide policy-makers and others involved in planning service provision, and support the providers of local and flexible services for people with dementia.

### **The dementia population**

Estimates by Lawlor *et al*, (1994) suggests that there are just over 22,000 people with dementia living in the community in Ireland. The number of people with dementia in long-stay care in Ireland varies between 3,755 and 7,380, with the higher figure likely to be the more accurate indicator of prevalence in this setting. The number of people with dementia in psychiatric hospitals is estimated at just over 560 people (Moran and Walsh, 1992). Estimates of the

number of people with dementia in acute care hospitals are not available for Ireland, but estimates from one health board suggests that 18 per cent of acute medical beds are occupied by people with significant cognitive impairment (Clinch and Hickey, 1992). The number of people with dementia estimated from the aggregation of prevalence data from Irish sources corresponds closely to the numbers generated by the application of EURODEM prevalence rates to Irish population data. We can say with some certainty, therefore, that there are just over 30,000 people with dementia living in the country. The number of people affected by dementia is, however, different across counties and regions in Ireland, ranging from 1.31 per cent of the population in Leitrim to 0.55 per cent of the population in Kildare. This is because of the difference in the age structure of the population across counties and regions.

The focus on numbers should not distract us from the fact that dementia is likely to be experienced differently by different people. It is impossible to talk about average burdens, or normal symptoms, without doing damage to the complexity and uniqueness of the experience for people affected by the condition. These differences must be taken into account in the planning of services to meet the needs of people with dementia and their carers. The importance of an integrated and co-ordinated model of service provision that has the flexibility to adapt and respond to individual circumstances cannot be emphasised enough.

### **The resource implications of dementia**

The economic and social burden of dementia on society is the value of all the resources used to prevent, diagnose, treat, and generally cope with the illness. Dementia is a costly condition, drawing on a variety of public and private resources. Costs fall on the health services, the social care services, the psychiatric services, families, and the voluntary sector. There is increasing pressure to define the cost components with a view to improving resource allocation and accountability in this area in the future. Recent developments in drug therapy, particularly the availability of new acetylcholinesterase inhibitors, offer new opportunities for people with dementia and will increase the pressure for earlier and wider diagnosis of the disease, leading to increased costs in the future.

We have assessed the overall resource implications of dementia in Ireland using Rothstein's (1996) four category framework of: direct formal costs; direct informal costs; indirect formal costs; and indirect informal costs. Six main areas are covered in the cost analysis. These are as follows: mortality and life years lost, in-patient acute care, in-patient psychiatric care, residential long-stay care, family care, and primary and social care in the community. While the

study includes all of the main areas of provision, the data set is incomplete, most notably with respect to day care costs, drug costs and the marginal cost of treating elderly people with associated dementia in acute care. The overall baseline cost estimate of £247 million should, in the circumstances, be seen as a lower-bound estimate. While the results indicate that the cost of illness associated with dementia is substantial; the most important aspect of the work is the distribution of the burden. The critical role of carers in maintaining people with dementia in their own home is reflected in the results showing that family care accounts for almost 50 per cent of the overall resource burden, based on an opportunity cost valuation of carer time.

Two changes to the calculations would increase the cost significantly and provide an upper-bound estimate of the burden of dementia. First, valuing carer time on the basis of average home help remuneration of £3 per hour instead of an opportunity cost basis would more than double family care costs. Second, including an estimate for the marginal cost of dementia in acute care elderly populations would increase the cost of dementia in this setting. Dementia and other forms of cognitive impairment are common in older people admitted to the general hospital for other reasons. The difficulty lies in estimating the additional costs, in terms of service use and length of stay, associated with dementia in this group. A major element of the additional cost of care is associated with patients awaiting transfer to more appropriate forms of care. The problem is that we do not have data on the extent to which dementia increases the waiting time for patients awaiting transfer. However, if we assume a dementia prevalence rate of 20 per cent in acute care elderly populations (Hickey *et al*, 1997), and that 18 per cent of all bed days are additional dementia-related days<sup>1</sup> then acute care costs rise by £52 million. Including the revised estimates for family care and acute care would increase the overall cost of care to £450 million. Quite clearly, the consequences of dementia to society are serious and deserve more attention than they have received up to now. The purpose of this plan is to place the spotlight firmly on dementia services in this country.

## **Policy background**

For ten years now 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 (*The Years Ahead*, 1988). Not surprisingly, *The Years Ahead* recommended additional services for people with dementia in the following areas: screening programmes to identify early dementia; the development of nursing and home support services under the supervision of the

---

<sup>1</sup> This estimate has been provided by Dr. Desmond O'Neill.

senior public health nurse; the expansion of day care facilities for people with dementia; and the development of day hospital services for people with dementia. *The Years Ahead* also recommended special high support hostels and suitably adapted residential accommodation for people with dementia who could no longer be supported at home, linked to a multidisciplinary approach to care, under the direction of a consultant psychiatrist with special responsibility for the care of older people with severe dementia. Overall, *The Years Ahead* identified a significant gap between patient and carer needs and existing service provision in the area of dementia. Unfortunately, this gap has not been significantly bridged in the past ten years and services remain under-developed.

Despite the fact that the majority of people with dementia live at home, the emphasis on community care in official policy statements has not been matched by significant transfers of resources to the community sector during the past decade. If anything, community care services have become stretched in recent years as fewer long-stay beds have combined with binding financial constraints to place increasing pressure on the care system. Community care services remain patchy and variable across the country with no scientific or legislative relationship between need and provision. The implementation of the policies recommended in *The Years Ahead* has been slow and variable (Ruddle *et al*, 1997). The absence of a statutory mandate for community care services, apart from the public health nursing service, has had an inhibiting affect on the development of services for vulnerable older people in the past. Consequently, the critical element in bridging the gap between policy formulation and implementation is the establishment of a legislative basis for a greater number of community care services in the future.

### **Balance of care issues**

The ability of people with dementia to remain in their own home is determined by a number of different factors. Four factors are particularly important:

- the extent of disability and functional impairment
- the socio-demographic characteristics of individuals
- the availability of family-based care
- the availability and accessibility of relevant community services

While the balance of care between the community and institution is very sensitive to marginal changes in any of these factors, the availability of family care is critical for people with dementia living at home. Families continue to provide the bulk of care for dementia sufferers, sometimes being on call 24 hours per day (Ruddle and O'Connor, 1993). Structural changes in society may have made it more difficult for families to care, but these changes have not

necessarily diminished the basic willingness to care. Family care is not cheap, however, and imposes significant financial and emotional costs on carers. Community support services for people with dementia and their carers are under-developed and fragmented. 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. Late intervention is, in turn, more likely to lead to institutional care, as the carer may no longer feel that she or he is able to cope. The result is a system geared to providing substitute in-patient care for people with dementia rather than providing anticipatory and on-going community care in partnership with patients and their family carers.

The cost of long-term residential care for people with dementia is a serious problem in all countries. The annual cost of a bed in public long-stay institutions in Ireland is difficult to estimate, given the variety in long-term care provision in this country. Estimates from official sources suggest that the annual cost of a long-stay bed in an extended care unit in the Eastern Health Board is just over £20,000 (Department of Social, Community and Family Affairs, 1998). The annual cost of care in less technologically oriented long-stay units is likely to be lower, with one estimate suggesting annual per capita costs of approximately £15,000 (Blackwell *et al*, 1992). On the other hand, for long-stay institutions involved in comprehensive assessment and rehabilitation provision, the annual per capita cost of care may increase to over £30,000. Private fee paying accommodation is again very difficult to estimate given the wide variation in fee levels across the country, but residents and families can expect to pay between £15,000 and £20,000 per year depending on the location and type of accommodation. In the absence of private insurance, these costs can have devastating financial affects on patients and their families, and on the exchequer. Costs of this magnitude highlight the need for careful planning with respect to the placement of people with dementia. Given the high cost of residential care every effort must be made to keep people living at home. This can be done through increased spending for community care linked to the effective delivery of services to people with dementia. No one should be placed in residential care without first of all exploring whether a similar community-based budget might prevent admission, and allow them to continue living in their own home. For the most effective delivery of service, a case management approach to the organisation of care will be necessary to ensure that people with dementia get the services that they both need and value.

### **The urgency of the problem**

The ageing of the population, the inadequacy of community care, and ongoing and binding public spending constraints have combined to focus public

attention on pressing health and social care issues for people with dementia. Dementia poses particular challenges from both a clinical and policy perspective because of the heterogeneous nature of the condition, its multiple causes, the debilitating nature of the disease, and the absence of a cure. It has not, however, received the attention it deserves because it has largely been seen as 'tomorrow's problem'. This is now changing because the increasing proportion of the 'very old' within the population has placed the spotlight firmly on dementia, given the higher prevalence rates of dementia in older age categories. The accumulating evidence of unmet needs amongst people with dementia and the realisation that public expenditure constraints are likely to become even more binding within evolving Monetary Union strictures within the European Union has added to concern about future service provision for people with dementia and their carers. The reality is that the current system of care for older people with dementia is seriously under-funded, even if there is likely to remain strong resistance to any attempt to commit more public expenditure to this area in the future.

Future demographic projections point to an increase in the number of older people, particularly in the oldest age categories, a long-term decline in the pool of potential female carers, and a general decline in the proportion of the population of working age. The number of people over 65 years is projected to increase by 30 per cent by the year 2011, with the number of people over 80 years expected to increase by two thirds in the same period. These changes in population and labour market structures will lead to an increase in the number of people with dementia. By the year 2011 we will have over 7,000 more people with dementia than we have now. Demographic change, while unevenly spread, will place increasing pressure on public resources at a time when demands are likely to be high anyway, arising from the rising cost of welfare, pensions and other supports for older people.

There has been a lack of urgency in dealing with the problems of people with dementia and their carers that would not have been tolerated in other areas of the health services. Many patients with dementia fall between the cracks of the health care system, between purely medical provision and purely psychiatric provision. People with dementia may be discriminated against because of a lack of awareness and training amongst providers. In some cases the discrimination may be more perverse. A long-term care facility faced with a choice between a cognitively intact person and a demented one will generally choose the former. There is, however, an emerging consensus that the inadequate support available to dependent older people is no longer acceptable. Support for action has come from a number of different organisations, including the National Council on Ageing and Older People, various non-governmental



organisations, voluntary groups, the Alzheimer Society of Ireland, health professionals, and carers' representative groups.

This document is an attempt to put in place an action plan for dementia care in Ireland which reflects the genuine concern among the various providers and interest groups about service provision in this area. The aim of the plan is to strengthen the capacity of current programmes to provide dementia care services and to facilitate the development of new programmes in both community and secondary care settings. The emphasis is on providing high quality care geared to meet the individual needs of people with dementia. The concepts of health gain and social gain have been explicitly used in health care planning documents to emphasise the importance of quality of care for all patients and clients of the health services (Department of Health, 1994). Even if both of these concepts have often been poorly defined, and remain particularly elusive in the case of older people with neuro-degenerative conditions, they remain an important symbol of the importance of outcomes in the area of dementia.

## **Methodology**

The plan is a reflection of the views of health care professionals and policy-makers working in the area of dementia. We undertook extensive consultation with the national representative organisations associated with the professions relevant to dementia care. The following organisations were consulted over a six-month period:

- The Carer's Association
- Consultant Geriatricians
- Consultant Psychiatrists specialising in the Psychiatry of Old Age
- The Irish College of General Practitioners
- The Institute of Public Health Nursing
- Irish Senior Citizen's Parliament
- Sonas aPc
- Irish Association of Social Workers
- The Association of Occupational Therapists of Ireland
- The Psychiatric Nurses Association of Ireland
- The Alzheimer's Society of Ireland
- Western Alzheimer's Foundation
- Irish Registered Nursing Homes Association
- Irish Association of Older People
- Representatives of home help service providers
- Representatives of long-stay care providers
- Representatives from each of the health boards

- Dementia Services Information and Development Centre, St. James's

We met each of the groups separately and the interviews were, for the most part, unstructured. Prior to the meeting, people were sent a two page outline of the range and type of issues that we were likely to cover during the consultation, thereby providing a framework for the face-to-face discussions that followed. The main headings for the discussion were as follows: an overview of services, the diagnosis of dementia, community care services, support for carers, non-residential alternatives to home care, residential care, and co-ordination issues. Respondents were given the choice of following this agenda, or concentrating on the topic/s of most interest to them. People varied in how they responded to the interview, but most people valued the opportunity to explore the issues in a comprehensive manner. The consultations were followed, in October 1998, by a one-day seminar, at which people were given feedback on the progress of the plan and an opportunity to contribute further to its development.

### **Philosophy and principles**

The development of a philosophical framework is necessary in order to provide an enduring reference point for the planning of services for people with dementia. The philosophical framework proposed in the plan is based on respect for the autonomy of individuals suffering from the disease. It is easy to forget about the person with dementia in the search for optimal care strategies and efficiency in resource allocation. But, even if autonomy has to be qualified in the case of a person suffering from dementia, it is a good starting point, because it focuses on the person as the key to the whole process of care and not as an object of care. The person with dementia, by virtue of their very existence, their emotions, their senses, must take centre stage in any plan. The person remains sacrosanct even if the illness is difficult to both define and understand. Once we establish solidarity with the people we want to help, and their lives become part of some shared sense of humanity or community, it becomes relatively easy to derive principles for the provision of services.

The issue of resource allocation for people with dementia cannot be discussed in a vacuum. We must have principles against which progress can be measured to enable us to make informed comment about the advantages and disadvantages of different approaches to care. Any set of principles must acknowledge the primary role of the person with dementia in the process of care in keeping with the philosophy outlined above. This is very important as it confirms the resource allocation process as a means to an end, and not an end in itself. There is, of course, no scientific way of devising principles. Any set of principles will contain both normative and subjective elements. What follows, therefore, are

six principles, drawn from a variety of sources, which we believe should underlie the action plan for dementia care:

- respect for the preferences and rights of the person with dementia
- the comprehensive provision of care
- bias towards home care solutions, including support for carers
- care requirements to determine funding, not vice-versa
- access to services on the basis of need, not income or geography
- national quality targets and outcome targets to underlie provision

The purpose of these principles is to shape the action plan for dementia, with the overall objective of maximising the well-being of people with dementia. We want to close the gap between the quality of life that people with dementia currently experience and what they might optimally achieve with a more intensive, comprehensive, and co-ordinated approach to service delivery. For this to happen, the plan will have to nurture and develop the whole range of capabilities of people with dementia, thereby allowing them to reach full expression within the limitations imposed by their condition. This is a difficult and time-consuming task since it requires a detailed and intimate knowledge of the whole lives of people with dementia. But it is a task that must be done if we are to reach out to people with dementia as people and not as passive objects of care for whom concern is modulated by the decline in their mental powers.

### **Pathways to care: primary and community care services**

In the majority of cases, dementia can be dealt with at the level of primary and community care provision. Early diagnosis is critical for people with dementia. For that reason clinical standards and competencies for early diagnosis of dementia should be developed and people with dementia should be informed of their condition at the earliest possible moment, unless there are strong medical or social reasons for withholding such information. Early diagnosis allows for better planning, both in terms of care provision and in terms of personal issues. Early diagnosis facilitates more timely, and therefore more effective, community care intervention and leads to less crisis management for people with dementia.

To encourage and facilitate early diagnosis, information and training should be provided to general practitioners through opportunistic or targeted assessment using tools sensitive to the detection of dementia in primary care. Public health nurses should also receive training in dementia assessment and be given more resources to work with in order to make identification worthwhile. Early diagnosis would be facilitated by the launch of a public information campaign designed to raise awareness of dementia among the general public.

The current under-funding of community care services needs to be addressed without delay. This can be done through the provision of additional, flexible, and appropriate community care services, particularly in the areas of home support services, day care, day hospital, and respite care. To facilitate the effective delivery of services to people living at home new ways of co-ordinating services must be adopted. The most effective way of ensuring flexible and integrated care provision is through the introduction of a case management model to plan and co-ordinate services for people with dementia and their carers within geographically defined catchment areas in each health board. Within the case management model, the person with dementia should, where possible, play a major role in developing a care plan that suits his or her own particular preferences and circumstances. The case management model should be introduced on a pilot basis in two health boards as soon as possible.

Carers should also have a major input into placement decision-making and service delivery with respect to people with dementia. Carers require support from the moment of diagnosis. Carers are currently providing the bulk of care to people with dementia and they show no sign of reducing their current commitments in this area. What they want is a greater acknowledgement of their contribution to the care process and access to help and support from official sources. It is important to make the point that support from official sources must be flexible and must be available when and where carers value it most highly. Payment for carers is another issue that needs to be resolved. The current Carer's Allowance is too restrictive and should be replaced by a non-means tested Constant Care Attendance Allowance of £100 per week for carers. Eligibility for this allowance should be based on an assessment of care recipient needs and dependency made by the relevant case manager. This would significantly increase the numbers qualifying for the allowance and would be an important signal to carers of the value placed on their work by society. Carers should also receive training in the care of people with dementia, as well as counselling services, if required. Counselling should be available during the caring process and in the months following the death of the person being cared for by the carer.

Day services for people with dementia need to be expanded. Dementia-specific day care places should be provided in each district or community care area, in buildings suitable for people with dementia, and with staff who are trained in the care of people with dementia. We also recommend an increase in the number of respite beds in community hospitals to a norm of 1:10,000 elderly population. This should be accompanied by the development of in-home respite services for people with dementia as a mechanism for providing relief for

carers, thus ensuring their long-term ability to care for the person with dementia.

Home care services are very important in allowing people with dementia to continue living in their own homes. The problem is that home care services in many health boards are under-developed, while there is very little choice or flexibility on offer from existing services. A new approach offering comprehensiveness and flexibility is required, incorporating both 'twilight' provision of services and weekend coverage, if needs are to be met in this important area. People with dementia require the provision of flexible, continuous and legislatively based home help and home sitting services geared to meet individual needs and circumstances. The existing work of the voluntary sector in this area provides an important starting point for the expansion of both home care and day care services. There is also an important role for social workers in the care of people with dementia living in the community. That role needs to be acknowledged through the establishment of dedicated posts for social workers at community care level, working with chronic, frail, older people and their families.

In summary, the majority of the needs of people with dementia and their carers should be met by what is put in place at the level of primary and community care. This involves the provision of a flexible network of services that will meet the changing needs of those with dementia and their carers. The dignity and autonomy of people with dementia will be best served by the development of individualised care plans mediated through case management structures. General practitioners are critical agents in the process of care since they are often the first people involved in making a diagnosis of dementia. The public health nursing service is also important since nurses are likely to see most of the vulnerable people with dementia living at home, and provide a link to many of the support services that people with dementia need and value. Day centres are also an essential component of care provision for people with dementia. People with milder degrees of dementia, and who have no behavioural problems, can be managed in general day centres, which are available to all elderly people in a particular community. People with severe dementia, or who have problems with wandering, will require specialised dementia day centres at primary care level, as currently provided by the Alzheimer's Society in some parts of the country. Respite care, both in-patient and at-home types, is also important depending on the stage of the disease and the particular needs of patients and carers. Whatever the service, the key element in primary and community care is flexibility of supply in response to the expressed needs of people with dementia and their carers.

## **Pathways to care: secondary level care**

There are some people with dementia who will require the services of specialist dementia teams in response to the complexities arising from their condition. These specialist teams form the backbone of secondary level support services for the more complex cases presenting in the primary and community sectors. Secondary level services in this country are two in number: Medicine for the Elderly and Psychiatry of Old Age. The role of Medicine for the Elderly lies with both the diagnosis of dementia and the assessment and management of people with dementia who have medical problems. The cases seen by Medicine for the Elderly include people who have medical problems that are beyond the remit of the general practitioner and those who present with diagnostic problems. The continued development of specialist geriatric departments is a key element in the care of people with dementia. Psychiatry of Old Age is the mirror image of Medicine for the Elderly in that instead of dealing with physical problems, it deals with mental health problems in elderly people. About 50 per cent of the work of Psychiatry of Old Age services are in the area of dementia. The service has specific responsibility for people with dementia who have severe behavioural problems, such as aggression, associated with their dementia, or psychiatric symptoms, such as delusions, depression, or anxiety, associated with dementia. Like Medicine for the Elderly, Psychiatry of Old Age may also play a role in diagnosis but continued involvement in such cases only occurs where there are associated behavioural or psychiatric symptoms.

Psychiatry of Old Age services are under-developed in Ireland. Consequently, there is an urgent need to accelerate the development of Psychiatry of Old Age services beyond the limited, urban-based, services that are currently available in the country. We recommend the adoption of a planning norm of one consultant in old age psychiatry per 10,000 people aged 65 years and over. Each should be provided with an appropriate multi-disciplinary team, day hospital facilities based in a general hospital setting, acute psychiatric beds, and long-stay psychiatric facilities. For acute beds, the appropriate norm is 1:1,000 elderly population; for continual care beds, the appropriate norm is 3:1,000 elderly population. The service should also have good access to non-psychiatric day and residential care. Teams will require the direct involvement of community psychiatric nurses and a specialist social worker. Teams should also include psychologists and occupational therapists, as well as having access to speech and language therapists, physiotherapists and dieticians, depending on the specific needs of the patient. This plan allows for the introduction of five new Psychiatry of Old Age services per year over the course of the plan, in addition to the services already sanctioned but not yet in operation. By the end of the plan there should be twenty new posts in place.

Multi-disciplinary teamwork is an essential element of the shared approach to the delivery of services to people with dementia. So also is effective communication between the various specialities, and between secondary care services and primary/community care services. Currently, liaison between the geriatric and psychiatric services is mainly informal. To ensure effective secondary care provision, existing services must be linked through more formal models of co-ordination and co-operation, associated with evolving case management structures at the level of service delivery. A common training programme for all professionals working with people with dementia will help foster co-operation among the various professions in both the primary and secondary care sectors. The establishment of the Dementia Services Information and Development Centre at St. James's hospital as a national centre for training and development is an important step in developing appropriate and common training programmes for health professionals working in this area.

### **Pathways to care: residential and nursing home care**

The vast majority of people with dementia who are in residential care in Ireland are cared for within generic elderly care facilities. This is likely to continue in the future as people with easily manageable dementia will continue to be looked after in general category long-stay care, both in the public and private sector. However, the care needs of people with dementia, even those not suffering behavioural or psychiatric problems, are likely to be different to other patients. Indeed, given the heterogeneity of dementia, differences within the group of people with dementia may be greater than the differences between some older people with dementia and older people without dementia. Therefore, services in generic long-stay facilities must be augmented to ensure that people with dementia have access to appropriate care, and that appropriate referral procedures are in place should the care needs of residents change.

We recommend the development of effective training programmes for staff working in all types of residential care facilities. New initiatives in residential care provision will not succeed without the concomitant training of staff working in these units. Training programmes should be designed to facilitate a person-centred approach to care and service delivery, which recognises the uniqueness of residents with dementia. Generic long-stay facilities are unsuitable where there is serious or repeated behaviour disturbance. For people with severe and persistent dementia-related behavioural problems, we recommend specialist care in long-stay psychiatric units within Psychiatry of Old Age services. These units should be staffed by psychiatric nurses.

New investment in both generic and special residential care facilities is required if we are to follow the international trend towards small, safe, domestic-style,

accommodation for people with dementia in long-stay care. In many cases, this investment will take the form of adaptations to existing capital stock, but it may also require the provision of new buildings in some circumstances. Design features, such as colour, lighting, furniture, heating, and security, have largely been ignored in the provision of long-stay facilities in this country. There is an urgent need to invest in design features in long-stay accommodation, given the accumulating evidence on the affect of design on the well-being of people with dementia.

The process of care in residential accommodation is a very important aspect of good practice for people with dementia. Process is concerned with the form and delivery of care for dementia patients within residential facilities. More attention should be focused on the social and sensory needs of long-stay residents through the support of various psychosocial interventions such as reminiscence therapy, validation therapy and reality orientation for people in the early stages of dementia. There are many different approaches to overcoming communication difficulties in people with dementia. Music and touch are particularly important in stimulating a communicative response from people with dementia. Retained communicative abilities, if activated, will enhance the quality of life of people with dementia in three main ways: through increasing interactions with other people and with the environment; through having their needs better understood; and through being able to give some meaningful expression to their feelings. We recommend that social, psychological and sensory needs be given equal weighting to physical needs in residential care settings, and that management structures support a holistic and person-centred approach to care. Training for staff in the delivery of these types of interventions is an important aspect of more effective residential care for people with dementia. So also is the ongoing monitoring and dissemination of models of best practice leading to the eventual elimination of sub-standard accommodation and poor quality care. Training and quality of care issues should be more formally incorporated into existing regulatory structures for the long-stay sector.

### **Special need groups**

The application of EURODEM prevalence rates to Ireland suggests that there are approximately 2,000 people with dementia under the age of 60 in the country. Younger people with dementia do not fit easily into the services designed for their older counterparts. It is usually a case of choosing from a range of services set up with other needs, or age groups, in mind. Younger people with dementia are likely to react differently to the disease than people in older age categories. They tend to be more physically fit and active and to have more responsibilities in terms of employment and families. Sometimes early



dementia is associated with other conditions such as Down's Syndrome. There may also be difficulties with diagnosis, sometimes related to general practitioners having very little experience with early onset dementia. We are only now recognising that people with early onset dementia have needs which are unique and distinct from their older counterparts. Public awareness of early onset dementia is currently low and tolerance for younger people with dementia is likely to be less than for older people. More information on the specific characteristics of early onset dementia would go some way towards developing an understanding among the public of the difficulties of younger sufferers.

We need to develop appropriate and individual-specific community care services for younger people with dementia. Day care and respite care should play important roles in the care of younger people with dementia. We also need to be more aware of the needs of families given that early onset dementia occurs at a different stage of the family life cycle. Families and patients may need high levels of professional support at the time of diagnosis, particularly in the areas of counselling and emotional support. Early diagnosis is important because younger people with the disease are likely to have more commitments and early diagnosis may provide an opportunity for people to plan for the future.

Teamwork is an essential aspect of the approach to care for people with early onset dementia. For people with Down's Syndrome who also have dementia, there needs to be high levels of co-operation and understanding between the mental handicap services and the various services for people with dementia. Training in dementia care is necessary for people working in the mental handicap services to ensure that all staff working with people with Down's Syndrome who also have dementia should have the skills and competencies necessary to deal with both conditions. Similarly, health professionals from the various services for people with dementia should receive training in how to relate to people with a mental handicap.

### **Policy implementation issues**

For many years now the stated objective of public policy for vulnerable older people is to encourage and facilitate their independent living in their own home for as long as is possible and practicable. The emphasis on community care in official policy statements has not been matched by the significant transfer of resources to the community sector. Community care services remain patchy and variable across the country with no scientific relationship between need and provision. Consequently, it is at the level of policy implementation that most attention should be focused if the increase in resources to community care, which is critical to the success of this plan, is ever to become a reality. For that reason, the establishment of a committee to oversee the implementation of the

plan should accompany this document. The committee would monitor progress with respect to the attainment of service targets for people with dementia outlined in the plan.

There are three crucial relationships with respect to policy implementation: the relationship between the centre and the local; the relationship between the statutory and voluntary sector; and the relationship between the public and private sector. With regard to centre-local relationships there must be a renewed emphasis on meeting existing policy objectives for people with dementia and their carers, through legislatively based support for the provision of community care services. Providers should be involved in the formulation of policy, with respect to both planned provision and the resource implications of new forms of delivery. The role of the voluntary sector would also be enhanced by their more formal involvement in both the formulation and implementation of policy with respect to people with dementia and their carers. There also needs to be more consistent and longer-term funding arrangements between the health boards and the voluntary groups providing services to people with dementia.

Not enough is being done to release the considerable potential for complementary provision between the public and private sectors. We need to explore ways of developing co-operation between the public and private sector. Many nursing home proprietors feel cut off by the absence of any public services going into their homes. There is also concern among nursing home proprietors that subvention payments for people with dementia in private nursing homes are too low to support the type of services required by these patients. While there may be some substance to this claim, existing subvention funding for private nursing homes tends to crowd out spending on community care services, which, in turn, creates additional demand for nursing home places. For that reason, even if subvention payments are to be increased, no one should be granted a subvention for private nursing home care unless it has been established that a similar amount of money would not have enabled them to remain in their own home. This approach would lead to a more effective use of resources for people with dementia and would be more in line with current policy statements about the primacy of community care.

### **Costs and funding**

The recent comprehensive review of developments in care of the elderly is critical of the slow rate of progress towards the development of a genuinely community-based approach to the long-term care of dependent elderly people (Ruddle *et al*, 1997). While there remains a general consensus that the long-term care of dependent elderly people should be located in the community,

which is reiterated in this plan, not enough has been done to develop community care services in a comprehensive and integrated manner. There is uniform agreement that a major gap exists between the needs of elderly people with dementia and existing service provision. This plan contains a number of different recommendations designed to bridge the gap between need and existing provision for people with dementia. The overall cost of delivering the increase in services envisaged in the plan over a three-year period is £46 million, or approximately £15 million for each year of the plan. This is equivalent to an annual grant of £500 for each person with dementia in the country. When presented in this way, the cost is minimal relative to the potential gains to be had from the implementation of the plan.

We cannot, however, rely on increased public spending to solve all of the problems in this area, given the continuing constraints on social expenditure originating in our adherence to, and commitments arising from, the Maastricht criteria for Monetary Union. We will have to explore innovative ways of financing increased spending for people with dementia, through new forms of social insurance, and the nurturing and further development of the social economy. In the short term, we recommend additional resources for dementia care financed from general taxation; in the long-term we recommend moving to a social insurance system for the funding of long-term care, which would include services for dementia. We also see potential in the development of the social economy and suggest training and seed capital funding for the nurturing of social entrepreneurship at a local level as a means of meeting the needs of people with dementia and their carers in a flexible and innovative way.

## **Recommendations**

- 1.** We recommend that clinical standards and competencies for early diagnosis of dementia should be developed and that people with dementia should be informed of their condition at the earliest possible moment, unless there are strong medical or social reasons for withholding such information.
- 2.** We recommend that information and training should be provided to general practitioners to facilitate and encourage the early diagnosis of dementia through opportunistic or targeted assessment using tools sensitive to the detection of dementia in primary care.
- 3.** We recommend that public health nurses should receive training in dementia assessment and be given more resources to work with in order to make identification worthwhile.
- 4.** We recommend the launch of a public information campaign designed to raise awareness of dementia among the general public.
- 5.** We recommend the introduction of a case manager model to co-ordinate services for people with dementia and their carers within geographically defined catchment areas in each health board. The model should be introduced on a pilot basis in two health boards as soon as possible.
- 6.** We recommend that carers should have a major input into placement decision-making and service delivery issues.
- 7.** We recommend the replacement of the Carer's Allowance with a non-means tested Constant Care Attendance Allowance for full-time carers based on an assessment of care recipient needs and dependency made by the relevant case manager.
- 8.** We recommend the development of information and counselling services for people with dementia and their carers.
- 9.** We recommend that dementia-specific day care places be provided in each district or community care area in buildings suitable for people with dementia and with staff who are trained in the care of people with dementia.
- 10.** We recommend the development of day hospitals within each Psychiatry of Old Age Service for people with dementia who have associated behavioural problems or psychiatric symptoms.

- 11.** We recommend an increase in the number of respite beds in community hospitals to a norm of 1:10,000 elderly population and the development of in-home respite services for people with dementia as a mechanism for providing relief for carers and ensuring their long-term ability to care for the person with dementia.
- 12.** We recommend the provision of flexible, continuous and legislatively based home support services for people with dementia.
- 13.** We recommend the development of community-based occupational therapy services and social work services for people with dementia living at home.
- 14.** We recommend the adoption of a planning norm of one consultant in old age psychiatry per 10,000 people aged 65 years and over, each being provided with an appropriate multi-disciplinary team and psychiatric facilities, including a day hospital and acute and long-stay psychiatric beds together with good access to non-psychiatric day and residential care.
- 15.** We recommend the adoption of a ratio of 1:4,500 elderly population for community psychiatric nursing services within the framework of an expanded Old Age Psychiatry service.
- 16.** We recommend that geriatric medicine facilities be adequately staffed with full interdisciplinary teams, and encourage close co-operation between geriatric medicine and Psychiatry of Old Age services.
- 17.** We recommend dementia awareness training for medical and nursing staff in acute hospitals, particularly for people working in accident and emergency departments, to help them identify the symptoms of dementia in patients under their care.
- 18.** There should be undergraduate training in dementia for doctors, and chairs in geriatric medicine and the Psychiatry of Old Age in each of the universities.
- 19.** We recommend the provision of small-scale, domestic-oriented, specialist units attached to conventional long-stay facilities for people with dementia without significant behavioural problems, but who need long-stay care.
- 20.** We recommend that social, psychological, artistic and sensory/communication needs be given equal weighting to physical needs in

residential care settings, and that management structures support a holistic and person-centred approach to care.

**21.** We recommend the development of effective training programmes for staff working in all types of residential care facilities. These training programmes should be designed to facilitate a person-centred approach to care and service delivery.

**22.** We recommend 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.

**23.** We recommend specially designed and integrated care packages for people with Down's Syndrome and dementia, delivered within the mental handicap programme, with training in dementia care facilitated by the Old Age Psychiatry and/or geriatric medicine services.

**24.** We recommend the establishment of an implementation committee to oversee the development of this plan.

**25.** We recommend that the Dementia Services Information and Development Centre at St James's receives appropriate funding to allow it to function as a national centre for the identification and dissemination of information on best practice in dementia care in Ireland.

**26.** We recommend a renewed emphasis on meeting existing policy objectives for people with dementia and their carers, through legislatively based support for the equitable provision of community care services.

**27.** We recommend that services for people with dementia be delivered locally, in a flexible manner, within the framework of new case management structures, wherever possible.

**28.** We recommend that the voluntary sector should be more formally involved in both the formulation and implementation of policy with respect to people with dementia and their carers.

**29.** We recommend more consistent and longer-term funding arrangements between the health boards and the voluntary groups providing services to people with dementia.

**30.** We recommend an audit of the number of people with different types and severity of dementia in private nursing homes; an evaluation of the public

subsidy arrangements for these patients; and greater integration of public and private production in the care of people with dementia.

**31.** We recommend a more formal emphasis on multidisciplinary teamwork in the care of people with dementia within the integrative framework of a case management model of service delivery.

**32.** We recommend the development of the social economy and the nurturing of social entrepreneurship at a local level as a means of meeting the needs of people with dementia and their carers in a flexible and innovative way.

**33.** In the short-term, we recommend additional resources for dementia care financed from within existing health and social care budgets; in the long-term we recommend further exploration of moving to a social insurance system for the funding of long-term care.

# **Chapter One**

## **Introduction**

### **1.1 Opening remarks**

There are an estimated 30,000 people with dementia in Ireland. This number will increase along with the ageing of the Irish population in the second decade of the next century. Dementia provides an important challenge for everyone in Ireland, not just for policy-makers and providers with a professional interest in the area. How we organise and pay for the care and support of people with dementia will tell us something about how we view human existence and the role of the person in modern society. For a long time dementia was viewed as a hopeless condition, a disease characterised by fear and ignorance, with no possibility of a cure. Slowly, through the work of carers, dedicated health care professionals, and the Alzheimer Societies the status of dementia is being transformed from a topic of relative neglect to one of increasing concern to all sections of the community. This transformation is not complete, for there are many things yet to be done to improve the quality of life of people with dementia and their carers, as we will see in the pages to follow. The objective of this three-year plan is to create a positive and holistic environment for the development of dementia services in this country, heralding a new and sustained person-centred approach to the support of people with dementia and their carers. Dementia is sometimes referred to as tomorrow's problem, but it can be planned for by today's generation.

Dementia as a disability is characterised by the following characteristics: impaired memory, impaired ability to learn, impaired ability to reason, and high levels of stress (Marshall, 1997). The complexity and range of issues involved in the management of dementia emphasise the need for the development of co-ordinated, multi-layered, and well-resourced services that are responsive to the needs of people with dementia and their carers. People with dementia are a heterogeneous group, which means that there is no single solution to the problem of dementia. An understanding of how the dementia population impacts on the care system and vice-versa is an essential part of the planning process, for the level and quality of support provided to people with cognitive impairment will affect the degree and nature of the disability which results from that impairment.

Despite good intentions, much effort, and very considerable cost, existing care arrangements in Ireland are fragmented, with the result that the benefits for people affected by the disease are likely to be below what might optimally be



achieved. Indeed, for younger people with dementia, services are often not available within the traditional service boundaries, which are primarily designed to cater for the needs of older people with dementia. The effective management of dementia in Ireland necessitates the development of an action plan, incorporating the viewpoints of all major stakeholders, based on what Kitwood and Benson, (1995) refer to as the ‘new culture of care for people with dementia’. The new culture of care places the individual with dementia at the centre of the planning process and goes beyond a neuropathological approach to understanding dementia to explore the concept of personhood in dementia within the framework of what Kitwood (1997) calls the ‘new humanism’. The philosophy of the work will, therefore, be based on what O’Neill (1997) calls the ethics of hope and health.

The plan will consider ways to develop available, accessible and high quality services over the next three years given existing resources and the public expenditure constraints that are likely to continue over the period of the plan. The need for a continuum of services will be recognised and incorporated into the plan. Financing issues are explicitly considered along with new ways of funding and providing social care services for people with dementia and their carers. The hope is that the plan will serve as a model of best practice that can guide policy-makers and others involved in service provision, without undermining local and flexible support structures for people with dementia.

## **1.2 The objective of the plan**

The overall goal of the plan is to describe a best practice model for dementia care in Ireland. The plan will be based on a progressive philosophy that promotes the best interests of both people with dementia and their carers. A proactive approach to the potential of people with dementia will inform the plan. The emphasis will be on the person with dementia, on their needs, on their intrinsic value, and on their rights. The broad service philosophy of the plan is that home care is generally preferable to residential care. The plan will take explicit account of budget constraints, including cost estimates of any new proposals and suggestions for the overall funding of the care plan. The plan is targeted at policy-makers and professional groups, and elements of the plan may serve as a guide for health professionals working in the area of dementia.

## **1.3 Realities and constraints**

It is as well to begin by outlining the current realities with respect to the care of people with dementia in this country. The current system of care for older people with dementia is seriously under-funded, and there is likely to be strong resistance to any attempt to commit more public expenditure in this area in the

future. This is the reality facing social planners in Ireland today. Even when additional resources are sanctioned for care of the elderly the amounts are small relative to overall need, and minuscule relative to the growth in expenditure on acute hospital care services and pharmaceutical products. The vast majority of people with dementia live at home in the community and family care is the main bulwark of support for these people. The state usually intervenes when family care is absent, or breaks down, but is less willing to offer practical support to ensure the continuation of family care in a complementary sense.

Generic community care services, geared to meeting the needs of all older people, rather than meeting the distinct needs of people with dementia, provide the bulk of community support for people living at home. Consequently, the access of people with dementia and their carers to adequate assessment services, home care services, day care services and respite care is both limited and variable across the country. Dementia-specific community services, where they exist, tend to be localised and dependent on the existence of voluntary providers, mainly the Alzheimer Societies. There is also a shortage of dementia-specific, residential care beds, resulting in some people being cared for in inappropriate settings. The placement of disruptive, aggressive, or wandering patients is particularly difficult and causes most concern to providers, given the general reluctance to admit this type of patient into conventional long-stay units. The situation is exacerbated by the reluctance of the private sector to admit, or keep, disruptive dementia patients, making it even more difficult to find suitable accommodation for such people.

There is a serious supply-side problem in the provision of community and residential care services for people with dementia in this country. The main challenge is to find ways to stimulate the supply of community-based services both inside and outside of traditional statutory routes. On the assumption that all of the gaps in social services provision for people with dementia and their carers will not be met by the public sector, or the private sector, there is an imperative to explore ways to grow the social care system in the years ahead. Social entrepreneurship may be the key to expanding community care provision in the future. Social entrepreneurs are an important source of social innovation. They identify social need, but more importantly they identify new ways of addressing these needs, making use of existing social capital to create new forms of supply. Finding ways to stimulate social entrepreneurship at the local level will be an important part of any new strategy for dementia care in this country. Equally important will be strategies to stimulate demand for any new services from patients and families, and from the State. Innovation on the supply side will have to be matched by innovation on the demand side, linked to new funding arrangements, if community services for people with dementia are to be expanded.

## 1.4 Methodology

The plan is a reflection of the views of health care professionals and policy-makers working in the area of dementia. We undertook extensive consultation with the national representative organisations associated with the professions relevant to dementia care. The following organisations were consulted over a six-month period:

- The Carer's Association
- Consultant Geriatricians
- Consultant Psychiatrists specialising in the Psychiatry of Old Age
- The Irish College of General Practitioners
- The Institute of Public Health Nursing
- Irish Senior Citizen's Parliament
- Sonas aPc
- Irish Association of Social Workers
- The Association of Occupational Therapists of Ireland
- The Psychiatric Nurses Association of Ireland
- The Alzheimer's Society of Ireland
- Western Alzheimer's Foundation
- Irish Registered Nursing Homes Association
- Irish Association of Older People
- Representatives of home help service providers
- Representatives of long-stay care providers
- Representatives from each of the health boards
- The Dementia Services Information and Development Centre at St. James's

We met each of the groups separately and the interviews were, for the most part, unstructured. Prior to the meeting, people were sent a two-page outline of the type of issues that we were likely to cover during the consultation, thereby providing a framework for the face-to-face discussions that followed. The main headings for the discussion were as follows: an overview of services, the diagnosis of dementia, community care services, support for carers, non-residential alternatives to home care, residential care, and co-ordination issues. Respondents were given the choice of following this agenda, or concentrating on the topic/s of most interest to them. People varied in how they responded to the interview, but most people valued the opportunity to explore the issues in a comprehensive manner.

The focus of the exchanges was on best practice. Respondents were informed that resource constraints would be considered only on an ex-post basis, when the discussion turned to the funding of the best practice model adopted. People

were asked to rank the most important changes necessary to improve the quality of life of people with dementia and their carers. This question allowed some comparison of views expressed, and ensured homogeneity in the collection of information on overall priorities. People were also given an opportunity to respond to a pre-first draft document, which reflected on a best practice model for dementia, at a seminar in Galway in October 1998. All of the people interviewed earlier for the report were invited to this meeting. The seminar also included people who had expressed an interest in meeting with us, but whom we had not managed to meet prior to the seminar.

## **1.5 Outline of the plan**

The plan begins with a discussion on the nature of dementia and includes data on estimated prevalence rates for Ireland, broken-down by county. This is followed in Chapter Three by an estimate of the overall cost of dementia in society. Current resources for dementia are reported in Chapter Four. The philosophical framework and the principles for the action plan are set out in Chapter Five. It is only when we have a philosophy and set of principles against which progress can be measured that we will be able to make judgements about the advantages and disadvantages of different approaches to care for people with dementia.

Chapter Six brings together the primary and community care elements of a good practice model in the form of a pathways to care approach to services for people with dementia and their carers. The responses of the various groups interviewed for the work are interwoven into this chapter to provide the basis for the model of good practice. The needs and rights of the person with dementia form the basis of the model of good practice. The plan acknowledges that home-based care is the preferred and most suitable environment for the majority of people with dementia. Family carers are recognised as an indispensable part of the care team. The continuum of care, along which services adjust to meet the changing requirements of patients and carers, is an essential element of the model.

Secondary care services are examined in Chapter Seven. The importance of both Psychiatry of Old Age services and geriatric medicine services are highlighted in this chapter. This is followed in Chapter Eight by a discussion of the long-stay requirements of people with dementia. The optimal approach to dealing with dementia groups with special needs is set out in Chapter Nine.

The critical relationships for policy implementation are examined in Chapter Ten. This chapter also includes a call for structures to be put in place to monitor the implementation of the plan. The emphasis in Chapter Eleven is on

the potential of the social economy for delivering new and innovative approaches to both the funding and production of community care services for people with dementia and their carers. The cost of the plan is set out in Chapter Twelve. The cost of each recommendation is divided into a current and capital component and estimates relate to the three-year life of the plan. This chapter also includes a discussion of financing issues.

## **Chapter Two**

### **The Nature and Prevalence of Dementia**

#### **2.1 Introduction**

In medical terms, dementia refers to a group of diseases characterised by progressive and, in the majority of cases, irreversible decline in the mental functioning of sufferers. These diseases all result from damage to, or loss of, neurones in certain areas of the brain, particularly in the cortical (outer) area. These cortical areas are the areas responsible for functions such as thinking processes, planning, comprehension, organising, memory and abstract reasoning. The loss of cognitive abilities that results from damage to the neurones is often accompanied by deterioration in emotional control, social behaviour or motivation but there is no alteration in the level of consciousness. The effects of the damage to the brain intensify over time and are disabling and terminal.

There is no single cause of dementia, nor is there yet a cure for the vast majority of dementias. Control of blood pressure and other vascular risk factors will reduce the prevalence of dementia but it remains a devastating illness, exacting a huge physical, mental, and emotional toll on both patient and family (Cook-Deegan and Whitehouse, 1987). Research into the disease has been dominated by the clinical sciences (Bond, 1992), 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 (Harding and Palfrey, 1997). Certainly, simple causal relationships are difficult to establish for some dementias leading us to the view that a multi-disciplinary approach is needed for the identification, treatment, and care of people with dementia.

#### **2.2 Types of dementia**

Alzheimer's disease is the most prevalent dementing disease, accounting for more than half of all cases. It results from a gradual deterioration in the condition of the nerve cells in the brain, causing progressive deterioration of memory, intellect, learning, reasoning, language, judgement and perception. As described by Alzheimer (1907), this label was used only for dementia arising in middle age, but now the term is applied to the much more common primary degenerative dementia occurring in later life, formerly known as senile dementia.

Many conditions other than Alzheimer's disease cause dementia in older people, especially vascular dementia, formerly known as multi-infarct dementia, which accounts for about 20 per cent of cases (Miller and Morris, 1993). Vascular dementia is caused by a series of small strokes that cut off the blood supply to the brain. Some people may have mixed dementia caused by both Alzheimer's disease and multi-infarct dementia. As of yet there is no known cure for either condition, but control of vascular risk factors, and the use of anti-cholinesterase inhibitors may slow down, or temporarily improve, the decline in 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. 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 lobe dementias, Creutzfeldt-Jacob disease, Parkinson's disease, and Huntington's Chorea.

### **2.3 The symptoms and stages of dementia**

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 unyielding erosion of individual autonomy. The common symptoms and behavioural changes associated with dementia include the following:

- memory loss
- disorientation
- language difficulties
- wandering
- the failure to recognise people or objects
- impaired comprehension, reasoning and judgement
- the loss of ability to learn or initiate
- mood swings
- night-time wakefulness
- the 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

People with dementia will have various combinations of these symptoms, 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.

Dementia is often described in the literature in terms of a number of stages. This is a useful approach to try to gain some insight into the nature, general progression and impact of dementia. The caveat is, of course, the considerable variation in the symptoms that can occur during the course of the illness, which means that a person with dementia will not necessarily progress neatly from one stage to the next. As the disease progresses from stage to stage, the level of disability increases, the demand on carer's increases, and the range of medical and social supports required by the person with dementia also increases. Therefore, documenting dementia in terms of discrete changes in need during the course of the dementing illness allows us to consider the resource implications of the disease, even if the delivery of services is more likely to be on a continual and integrated basis.

### ***Stage 1      Early difficulties***

This stage is characterised by the following symptoms:

- forgetfulness
- reduced attention span
- lack of spontaneity
- lack of initiative
- disorientation of time and place
- depression and fear
- anxiety or suspiciousness about possessions, or about the behaviour of other people

At this stage, family members are unlikely to have noticed that anything is particularly wrong. The person with dementia may, however, become aware of trivial slips or lapses of memory. Rows and misunderstandings may occur due to deterioration in memory. The impact on resources is likely to be minimal at this stage of the illness. However, the work of a person with dementia, particularly younger people with dementia still in paid employment, may suffer as a result of reduced attention span, memory lapses and lack of initiative.

The following is an extract<sup>2</sup> from the experience of a person with dementia in the early stages:

---

<sup>2</sup> This extract, and the ones to follow, are taken from the experiences of people with dementia and their carers in Australia (Ministerial Task Force on Dementia Services in Victoria, 1997)



*The other day, I couldn't seem to find my wallet. I'm sure I left it in the... no it was the.... When I ask my wife to help me find things she gets annoyed, says she has more to do than waste time searching for my lost things. I'm sure she's hidden it. I know she's taking my money. I know my wife thinks I'm paranoid, but I'm sure she doesn't tell me everything.*

## **Stage 2      Emergence of significant difficulties**

This stage is characterised by the following symptoms:

- problems recognising close family and friends
- difficulties dealing with money
- restlessness and agitation especially at night
- repetitiveness in conversation and actions
- increased disorientation and forgetfulness

At this stage of the disease, the incidence of memory lapse increases to the point where the person with dementia can no longer ignore them. There will be a deliberate effort to hide difficulties from family and friends in an effort to maintain integrity. This is achieved by adopting a diverse set of coping behaviours. The new behaviours adopted may make little sense to others and can cause conflict in relationships. For example, the person with dementia may use lists or constantly repeat things to help him or her remember. Peculiar behaviours adopted, or errors made, will be noticed by others and can cause a great deal of embarrassment to spouses or other family members. The masking of difficulties by the person with dementia is an intensely private activity requiring a huge investment of emotional and physical energy. The person with dementia experiences feelings of fear, anxiety, bewilderment and uncertainty. This period may stretch into months or years. As the dementia progresses, the burden on carers increases. Difficulties arise in communicating with the demented person. Friends may withdraw as they do not understand the changes taking place or the carer may be reluctant to expose their dependant because of social embarrassment.

The following is an extract from the experience of a carer of a person with dementia:

*The onset of my partner's dementia was insidious, I didn't notice his increasing reliance on me, I didn't think the changes were anything more than "he was busy". "Could I look up a road directory and give him the most efficient route to go to a business appointment – street by street, it would save time. He appeared to have slight memory loss and confusion. How was I to know that this was not part of his growing old but the start of something more sinister.*

### ***Stage 3      Revealing and confirming***

This stage is characterised by the following symptoms:

- uncharacteristic mood swings and outbursts
- speech impairments
- wandering around home and away from home
- impaired judgement
- increased disorientation of time and place

This is the stage when the diagnosis is most commonly made. At this stage, a family member may confront the person, or the person with undiagnosed dementia may disclose his experiences. The mutual acceptance of the situation moves the coping behaviours into a different domain and the person with dementia is likely to feel a great sense of relief having shared the burden. The revealing stage may present particular problems to family members and the person with dementia. Family members dealing with the problem often feel frightened and disturbed about what is happening and may be reluctant to seek advice from their general practitioner because they feel unsure, and perhaps ashamed, about the changes taking place in a loved one. Tactics of concealment may still continue causing tension and conflicts within families. Sometimes the diagnosis will be made following an admission to hospital after an injury or an illness when the break in familiar routine and environment causes a crisis for the person with dementia. The advantage of a diagnosis, through whatever route, is that it allows people with dementia to make sense of what is happening to them.

Detailed information about the disease and the services available are essential at this stage to help those involved come to terms with the changes taking place in their lives. Unfamiliar surroundings can cause great anxiety in people with dementia and it helps if they are allowed to live as normal a life as possible in their own home. Respite services, home support services and access to specialist services, to assist in dealing with challenging behaviours, become necessary at this stage if the person with dementia is to remain in the community. Specialist provision would include access to neurological, geriatric, and psychiatric services, on their own, or in combination.

Normal and reciprocal relationships become uncertain. In particular, there is a loss of equality within the relationship between the person with dementia and a spouse who has assumed the role of carer. In the traditional bilateral relationship, partners form images of each other and come to depend on each other for emotional and spiritual development. Over the course of the relationship, everything is clear. Daily activities are clear and agreements with respect to intimacy, sexuality and physical aspects of the relationships exist.

When one partner gets dementia, the relationship moves from being a bilateral to a unilateral one, in which the healthy partner instinctively takes over responsibilities in an effort to neutralise increasing deficits. Old roles change as the healthy partner continuously adapts to increasing difficulties faced by a loved one. The changing nature of the relationship is emotionally very difficult. Children who are taking care of a parent with dementia also experience much the same feelings as spouses and they must adjust to the change in the traditional balance of power between parent and child.

The following is an extract from the experience of a person with dementia:

*I spend my whole life checking what I have done in case I've done something stupid or dangerous... I'm so afraid all the time. My husband and I have devised a checklist which we systematically go through before we can leave the house to go anywhere. It's a horrid feeling; I just only ever wanted to be happy and this thing just crept up on me. It didn't happen overnight and now it's ruling my life.*

#### **Stage 4      *Dependency and incapacity***

The fourth stage is characterised by the following symptoms:

- assistance with all the activities of daily living
- the person may no longer talk
- the person may no longer recognise family members
- inability to make decisions
- coexistence of other medical and physical conditions

In the final stage of the disease, decision-making abilities and awareness of actions may be lost. The person with dementia becomes completely dependent on others to manage his or her life. The level of statutory and family supports required to maintain the person in the community at this stage are huge and the person is often placed in residential care for the remainder of their life. A decision to admit a loved one into residential care is often accompanied by feelings of betrayal, guilt, loss and despair on the part of family carers. Staff in residential care play a pivotal role in supporting carers at this point. Carers need to be reassured that the admission to residential care is not a farewell but rather a guarantee of optimal treatment.

The following extract reflects a carer's experience of loss associated with looking after a person with dementia:

*The personal losses seemed endless, loss of companionship, loss of freedom to do things spontaneously, loss of a lover, loss of a*

*breadwinner, a role model for our children, loss of our future together. Learning to cope with wandering and my loss of sleep....*

### **Stage 5      End stage**

People with dementia who are in the final stages of the disease lose most, if not all, of their ability to communicate and respond. They are not able to speak for themselves or make decisions regarding medical treatments. They require palliative care that is responsive to their needs and that allows them to die with dignity, without pain and with as much comfort as possible. Carers need a lot of emotional support when the loss they have been experiencing over the course of the disease is finally bound by death.

The following extract comes from a carer reflecting on the death of a partner:

*In thinking of end of life decisions, I need to know that he will be treated with dignity and with gentleness, and be free from pain. I now accept that dementia has robbed us of the dignity and comfort of participating together in the dying process. There has never been an appropriate time to discuss death and to say 'goodbye'.*

## **2.4    The Years Ahead categorisation**

For the purposes of planning, *The Year's Ahead* (1988) report categorised dementia for older people in the following way:

- (i) those with mild dementia but not suffering from a significant physical disability or illness
- (ii) those with severe dementia but not suffering from a significant physical disability or illness
- (iii) those with dementia, whether mild or severe, and also suffering from a significant physical disability or illness.

This categorisation is useful in the planning process because the coexistence of other medical conditions as well as the severity of the dementia must be taken into consideration when devising appropriate care plans for people with dementia.

The family carer, with varying degrees of support from their general practitioner and the public health nurse will usually look after people in Category (i) at home. Specialist input may be required for early diagnosis, but care can usually be given in the home.

More comprehensive care, often involving the psychiatric services, is usually required for people in Category (ii), particularly if there are serious behavioural problems associated with the dementia. Whilst most people in the latter category can be helped by home-based or day hospital treatment, some of these patients will require in-patient psychiatric care; others will require care in specialist units attached to long-stay facilities.

People in Category (iii) usually require a mix of treatment involving an appropriate combination of medical, geriatric, and psychiatric care delivered in community and residential settings, depending on the nature of the dementia.

Once again, while categorisation of this type is useful in terms of helping us to understand the generally progressive nature of dementia, we must also acknowledge the uniqueness of the disease, in that no two individuals with dementia are likely to be affected in the same way. Moreover, the needs of people with dementia and their families are likely to change much faster than the above categories allow. For that reason, it may be better to characterise people with dementia on the basis of their performance in a number of domains, rather than on how long they have had the disease, or by their abilities in only one domain (Carr and Marshall, 1993).

Yet another complication is that the level and quality of support provided to people with cognitive impairment at each stage will affect the degree and nature of disability which results from that impairment. Finally, the categorisation of dementia into discrete stages is unhelpful if the policy emphasis is on continuity in care provision, linked to the notion of a care continuum, and the seamless provision of services. The more progressive approach in such circumstances may be to focus on the needs of the individual person with dementia, and their carer, drawing on many different types of services, even at the early stages of the disease. Case management and flexibility of service provision are not easily captured within the discrete categories outlined above. Notwithstanding these caveats, the notion of stages is a useful pointer to the resource implications of the disease, and remains, therefore, an important tool for the purposes of planning.

## **2.5 Prevalence of Dementia**

There has been a huge advance in our knowledge of the epidemiology of dementia in recent decades. 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 (Jorm *et al*, 1987). A meta-analysis of the results from a number of European prevalence studies done for

EURODEM (Hoffman *et al*, 1991) shows the highest rates in the oldest age categories, up to 95 years of age (Table 2.1).

**Table 2.1: EURODEM prevalence rates for dementia**

Age group	Males %	Females %	All persons %
30-59	0.2	0.1	0.1
60-64	1.6	0.5	1.0
65-69	2.2	1.1	1.4
70-74	4.6	3.9	4.1
75-79	5.0	6.7	5.7
80-84	12.1	13.5	13.0
85-89	18.5	22.8	21.6
90-94	32.1	32.2	32.2
95-99	31.6	36.0	34.7

*Source: Hoffman et al, 1991*

Although dementia can occur at any age, cases below the age of 60 years are far less common than in older age categories, as indicated by the data. However, when the disease does occur in younger age categories it poses different type of challenges for family carers and the health services. While changes in the prevalence of the disease across age categories tends to be consistent across European countries, country-specific prevalence studies tend to show different overall results depending on the methodology used to calculate rates, ranging between 4.3 per cent and 8.3 per cent of the elderly population aged 65 and over (Kay, 1980). There is no simple answer to the question of prevalence in various countries. Prevalence depends on how we define and measure dementia (Jorm *et al*, 1987).

The application of EURODEM prevalence rates to the most recent census of population data for Ireland (Central Statistics Office, 1997) suggests that there are just over 31,000 people with dementia in the country, made up of 18,000 females and 13,000 males (Table 2.2).

**Table 2.2: The number of people with dementia in Ireland 1996: based on an application of EURODEM prevalence rates to population**

Age group	Males	Females	All persons
30-59	1,321	663	1,984
60-64	1,099	346	1,445

65-69	1,326	732	2,058
70-74	2,306	2,434	4,740
75-79	1,761	3,274	5,035
80-84	2,550	4,684	7,234
85-89	1,492	3,873	5,365
90-94	669	1,852	2,521
95-99	134	487	621
<b>TOTAL</b>	<b>12,658</b>	<b>18,345</b>	<b>31,003</b>

*Source: Census of Population, 1996 by EURODEM prevalence rates*

The Western and North Western Health Boards have the highest percentage of people with dementia in their populations (Table 2.3). The Eastern Health Board has the lowest proportion of people with dementia in the population.

**Table 2.3: Estimated number of people with dementia by health board: based on an application of EURODEM prevalence rates to population; ranked by % of all ages with dementia in each health board**

<b>Health board</b>	<b>Population (all ages)</b>	<b>Persons with dementia</b>	<b>% of all ages with dementia</b>
Western	352,353	3,800	1.08
North-Western	210,872	2,274	1.08
Southern	546,640	4,946	0.90
Mid-Western	317,069	2,801	0.88
Midland	205,542	1,800	0.88
South-Eastern	391,517	3,414	0.87
North-Eastern	306,155	2,567	0.84
Eastern	1,295,939	9,401	0.73
<b>STATE</b>	<b>3,626,087</b>	<b>31,003</b>	<b>0.85</b>

*Source: Census of Population, 1996 by EURODEM prevalence rates*

Six counties have more than one per cent of the population suffering from dementia: Leitrim, Roscommon, Mayo, Cavan, Sligo, Kerry, and Donegal (Table 2.4). Kildare has the lowest proportion of the population afflicted by dementia, with a percentage of just 0.52 of the population. The differences in prevalence reflect differences in the age structure of the population across counties and regions.

**Table 2.4: Estimated number of persons with dementia by county: based on an application of EURODEM prevalence rates to population; ranked by % of all ages with dementia in each county**

<b>County</b>	<b>Population (All ages)</b>	<b>Females with dementia</b>	<b>Males with dementia</b>	<b>Persons with dementia</b>	<b>% of all ages with dementia</b>
Leitrim	25,057	179	149	328	1.31
Roscommon	51,975	357	289	646	1.24
Mayo	111,524	781	583	1,364	1.22
Cavan	52,944	318	249	567	1.07
Sligo	55,821	340	255	595	1.07
Kerry	126,130	759	574	1,333	1.06
Donegal	129,994	766	585	1,351	1.04
Longford	30,166	176	133	309	1.02
Tipperary N.R.	58,021	327	232	559	0.96
Clare	94,006	497	396	893	0.95
Galway	188,854	1,011	779	1,790	0.95
Monaghan	51,313	275	204	479	0.93
Tipperary S.R.	75,514	410	290	700	0.93
Kilkenny	75,336	382	286	668	0.89
Wexford	104,371	527	379	906	0.87
Laois	52,945	249	210	459	0.87
Waterford	94,680	483	334	817	0.86
Cork	420,510	2,164	1,449	3,613	0.86
Westmeath	63,314	309	227	536	0.85
Offaly	59,117	274	222	496	0.84
Limerick	165,042	805	544	1,349	0.82
Wicklow	102,683	484	320	804	0.78
Louth	92,166	438	281	719	0.78
Carlow	41,616	184	139	323	0.78
Dublin	1,058,264	4,962	2,896	7,858	0.74
Meath	109,732	462	340	802	0.73
Kildare	134,992	427	312	739	0.55
<b>STATE</b>	<b>3,626,087</b>	<b>18,346</b>	<b>12,657</b>	<b>31,003</b>	<b>0.85</b>

*Source: Census of Population, 1996 by EURODEM prevalence rates.*

Estimates by Lawlor *et al*, (1994) suggests that there are just over 22,000 people with dementia living in the community in Ireland. Estimates of the number of people with dementia in long-stay care in Ireland vary between 3,755 and 7,380, with the latter figure likely to be the more accurate indicator of prevalence in long-stay institutions. The number of people with dementia in psychiatric hospitals is estimated at just over 560 people (Moran and Walsh, 1992).



Estimates of the number of people with dementia in acute care hospitals are not available for Ireland, although estimates from one health board suggests that 18 per cent of acute medical beds are occupied by people with significant cognitive impairment (Clinch and Hickey, 1992). The number of people with dementia estimated from the aggregation of prevalence data from Irish sources corresponds closely to the numbers generated by the application of EURODEM prevalence rates to Irish population data. We can say with some certainty, therefore, that there are just over 30,000 people with dementia living in Ireland.

We do not know if the number of people with dementia is on the increase in Ireland. This is because we do not have the data to allow us to compare rates over time. What is happening is that more cases are now being detected at earlier stages. This is due, in part, to improvements in primary and community care diagnostic and assessment services linked to 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.

An extrapolation of the international incidence rates to the elderly population in Ireland suggests that approximately 4,000 new cases arise in the general community population every year (Keogh and Roche, 1996). This figure will increase in line with the ageing of the Irish population, beginning in the early decades of the next century. The projected growth in the number of people with dementia is shown in Table 2.5. In line with the ageing of the population the major increase in the number of people with dementia is likely to occur after the year 2006, with the numbers increasing by 10,000 between 2006 and 2016 and a further 10,000 up to the year 2026.

**Table 2.5: The projected growth in the number people with dementia in Ireland, 1996-2026: population projections by EURODEM prevalence rates**

<b>Age Group</b>	<b>1996</b>	<b>2001</b>	<b>2006</b>	<b>2011</b>	<b>2016</b>	<b>2021</b>	<b>2026</b>
30-59	1,984	2,067	2,269	2,447	2,566	2,602	2,612
60-64	1,445	1,513	1,792	2,139	2,252	2,357	2,319
65-69	2,058	2,010	2,169	2,587	3,111	3,296	3,473
70-74	4,740	4,465	4,532	4,923	5,929	7,186	7,688
75-79	5,035	5,354	5,131	5,263	5,784	7,060	8,662
80-84	7,234	7,637	8,165	8,021	8,415	9,441	11,777
85-89	5,365	6,308	6,916	7,604	7,672	8,255	9,492
90-94	2,521	2,874	3,452	3,928	4,411	4,578	5,063
95+	621	562	690	839	985	1,115	1,179
<b>Total</b>	<b>31,003</b>	<b>32,790</b>	<b>35,116</b>	<b>37,751</b>	<b>41,125</b>	<b>45,890</b>	<b>52,265</b>

*Source: Central Statistics Office (1995) projections by EURODEM prevalence rates*

## **2.6 Conclusion**

Dementia is likely to be experienced differently by different people. It is impossible, therefore, to talk about average burdens, or normal symptoms, without doing damage to the complexity and uniqueness of the experience for people affected by the condition. Similarly, the number of people affected by dementia is different across counties and regions in Ireland, ranging from 1.31 per cent of the population in Leitrim to 0.55 per cent of the population in Kildare. These differences must be taken into account in the planning of services to meet the needs of people with dementia and their carers.

Early diagnosis and intervention is necessary if people are to be maintained for as long as possible and practicable in their own homes. From assessment onwards, the level and quality of support that people with cognitive impairment receive at each stage will affect the degree and nature of the disability that results from the impairment. The categorisation of dementia in terms of discrete stages, even if somewhat of a caricature, helps the planning process, particularly if combined with the development of flexible response mechanisms to deal with the multi-faceted disability which evolves over the course of the illness.

## Chapter Three

### The Cost of Dementia

#### 3.1 Introduction

The ageing of the population, the high cost of institutional care, the inadequacy of community care, and ongoing and binding public spending constraints have combined to focus public attention on pressing health and social care issues for elderly people. Dementia is concentrated in older age categories and poses particular challenges from both a clinical and policy perspective because of the heterogeneous nature of the condition, its multiple causes, the debilitating nature of the disease, and the absence of a cure. Dementia is also a costly condition, drawing on a variety of public and private resources, and there is increasing pressure to define the cost components with a view to improving future resource allocation and accountability in this area. Recent developments in drug therapy, particularly the availability of acetylcholinesterase inhibitors (Rogers *et al*, 1996), offer new opportunities for people with dementia, and will increase the pressure for earlier and wider diagnosis of the disease, leading to increased costs in the future.

The burden of care on the families of people with dementia is also an issue. Family members very often assume the care-giving role and this can have a profound impact in terms of the financial and emotional strain it places on them. The opportunity cost of care for some carers may be high and the continued involvement of families in the caring process should not be taken for granted. Unfortunately, the allocation of resources to meeting the needs of people with dementia and their carers has not matched the rhetoric of support found in various policy documents and statements on the importance of such services. Many people with dementia fall between the cracks of the health care system, between medical provision, social provision and psychiatric provision. The value of this chapter is that it provides important baseline data on resource allocation and places the spotlight on current resource use, highlighting where, and on whom, the burden of dementia currently falls.

#### 3.2 Methodology

The economic burden of a disease on society is essentially the value of all resources used to prevent, diagnose, treat and generally cope with the disease. Rothstein *et al*, (1996) categorised costs into direct-formal, direct-informal, indirect-formal and indirect-informal.

Direct-formal costs are costs which relate particularly to the care for the disease and which can be directly determined from the market value of the resources. Such costs include initial diagnostic costs, physician services, acute and respite hospitalisation, long-term residential and nursing home costs, drug treatment costs, paid home-care, day care services and other social services.

Direct-informal costs refer to costs of care for the disease for which no monetary exchange takes place. These costs include costs of care provided 'free' by family and friends. Such costs are often assessed from opportunity costs, or from an imputed value for the service provided.

Indirect-formal costs are costs not immediately related to care for the disease. These costs include research costs, as well as physician visits by caregivers as a result of stress and other illnesses arising as a consequence of caregiving.

Indirect-informal costs refer to costs not directly related to the caring process and for which no monetary exchange takes place. These costs refer to the value of the days lost by the patient from productive activity due to illness and premature death. Intangible costs of the physical and emotional suffering experienced by patients and their families are also included in this cost category.

The economic and social burden of dementia has been assessed in only a small number of studies. Methodological approaches to the assessment of costs tend to vary from study to study, thereby giving rise to variations in reported findings. Some studies focus exclusively on Alzheimer's disease, while others focus on all dementias, including Alzheimer's disease. Variations in estimates also reflect differences in computational methods, including differences in the enumeration, quantification, and valuation of resources. Some studies have, for example, focused on a particular area of care provision and have estimated the economic burden of the disease in terms of the costs of this area of care only (Rice *et al*, 1993 ; Weinberger *et al*, 1993; and Stommel *et al*, 1994). Other studies have sought to estimate all types of costs for people with dementia (Kavanagh *et al*, 1995).

### **3.3 The burden of care in Ireland**

O'Shea and O'Reilly (1998) have assessed the overall resource implications of dementia in Ireland using Rothstein's framework referred to earlier. Six main areas are covered as follows: mortality and life years lost, in-patient acute care, in-patient psychiatric care, residential long-stay care, family care, and primary and social care in the community. While the study includes all the main areas of provision, the data in some of the areas covered is likely to be incomplete,

most notably with respect to the number of people with dementia in acute care. In addition, some elements of care are excluded, most notably day care provision and drug costs. The overall cost figure of £247 million (Table 3.1) should, in the circumstances, be seen as a lower-bound estimate. If we take the total population of dementia sufferers in Ireland as approximately 30,000 people, the cost of dementia spread across all those affected by the disease is just over £8,000 per person per year.

Two changes to the calculations would increase the cost significantly to provide an upper-bound estimate of the burden of dementia. First, valuing carer time on the basis of average Home Help remuneration of £3 per hour, instead of an opportunity cost approach, would more than double family care costs, while using the average industrial wage as a replacement cost would quadruple the costs. Second, including an estimate for the marginal cost of dementia in acute care elderly populations would increase the cost of dementia in this setting. Dementia and other forms of cognitive impairment are common in older people admitted to the general hospital for other reasons. The difficulty lies in estimating the additional costs, in terms of service use and length of stay, associated with dementia in this group. A major element of the additional cost of care is associated with patients awaiting transfer to more appropriate forms of care. The problem is that we do not have data on the extent to which dementia increases the waiting time for patients awaiting transfer. If we assume a dementia prevalence rate of 20 per cent in acute care elderly populations (Hickey *et al*, 1997), and that 18 per cent of all bed days are additional dementia-related days<sup>3</sup> then acute care costs rise by £52 million. Including the revised estimates for family care and acute care in Table 3.1 would increase the overall cost of care to £450 million.

**Table 3.1 Annual costs of dementia care (lower-bound estimate) 1997**

Care type	Annual cost per patient (£)	Number with dementia	Total annual cost of care (£m)	% of total cost
In-patient acute care	3,059	1,635	5	2
In-patient psychiatric care	23,489	596	14	6
Family care	5,360	22,761	122	49
Community care	1,054	22,761	24	10
Residential care	16,298	5,031	82	33
<b>Total</b>	<b>8,233</b>	<b>30,023</b>	<b>247</b>	<b>100</b>

<sup>3</sup> This estimate has been provided by Dr. Desmond O'Neill.

*Source: O'Shea and O'Reilly (1998)*

While the results indicate that the burden of illness associated with dementia is substantial the most important aspect of the work is the distribution of the burden. The critical role of carers in maintaining people with dementia in their own home is reflected in the results showing that family care accounts for almost 50 per cent of the overall burden of care, based on an opportunity cost valuation of carer time. It is quite clear from these findings that the burden of the disease would be considerably underestimated if we did not attempt to put a monetary value on family care. Dementia is also a leading disease in terms of the burden falling on residential long-stay accommodation, and, to the extent that it can be measured, on acute care facilities.

### **3.4 Conclusion**

The data presented here is the first attempt to estimate the economic and social consequences of dementia in Ireland, although dementia is a serious and distressing disease in our society. The chapter provides estimates of the cost of dementia, based on the best available secondary data. The data shows that the burden of care falls mostly on family carers. The task for planners should be to increase the level and type of statutory and other community-based supports for carers. This is the only way that the current policy emphasis on home care will be sustainable. The findings of the burden of illness study must be interpreted with caution since the data is secondary, and likely to be subject to some margin of error. Moreover, no attempt has been made to examine the cost-effectiveness of various treatment regimes for dementia so we cannot say anything about the optimal balance of care for patients in this area. Nevertheless, the consequences of the disease to society are serious and deserve more attention than they have received up to now. The purpose of this plan is to place the spotlight firmly on dementia services in this country.

## Chapter Four

### Current Resources for Dementia

#### 4.1 Introduction

*The Years Ahead* (1988) report described 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. Each stage of the continuum is important and the health and social services should be involved in the care process from the time of early diagnosis until the person's death. *The Years Ahead* report made a number of recommendations designed to improve services for people with dementia and their carers, and to move the care system in this part of the country closer to the ideal model of provision.

The reality for the vast majority of people with dementia remains, however, far-removed from this ideal model. Community care services for people with dementia are under-developed and fragmented. 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. 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.

#### 4.2. Primary and community care

*The Years Ahead* report recommended that 'general practitioners and public health nurses should be encouraged to screen elderly people at risk for early signs of dementia'. A screening methodology for primary care has, however, not been developed in a uniform manner across all health boards. Where screening does take place it is limited to a small number of general practitioners and public health nurses, but in no sense could screening be termed as adequate (Ruddle *et al*, 1997). The general practitioner is best positioned to detect dementia in its early stages. However, GPs vary widely in terms of their capacity and commitment to identifying patients with dementia. Some GPs may not be comfortable dealing with social, cognitive and behavioural problems. They may be reluctant to label someone with the diagnosis of dementia within the local community because of the negative attitudes and stigma associated with the disease. Others may not have the necessary training to allow them to detect dementia in their elderly patients. This may be a

particular problem for older doctors, who have not had exposure to the recent developments in the literature with respect to the assessment and diagnosis of dementia in the community. Awareness may also be a problem for doctors with patient lists comprising mainly younger people, in that they do not see that many elderly patients, let alone elderly people with dementia.

Although a large proportion of community care resources go towards the public health nursing services, the evidence suggests that the public health nurse is not always in a position to give people with dementia the level of service that they require. While the public health nursing service is valued by people with dementia and their carers, and reaches a substantial percentage of people suffering from dementia (Ruddle and O'Connor, 1993), visits are not frequent enough, or long enough. The public health nursing service is under considerable pressure with nurses facing very demanding caseloads. They also may have difficulties dealing with dementia-related psychiatric and behavioural problems, given the general nature of their nurse training. The community-nursing problem for people with dementia is exacerbated by the relative absence of community psychiatric nurses working in this area.

While the evidence with respect to the role of home support in delaying or preventing institutionalisation is equivocal (Downs, 1994), the majority of carers value these programmes highly. This is not surprising given that most home support programmes impact more directly on the carer than on the person with dementia. Despite the importance of home support services for carers, very few people have access to a comprehensive range of these services. There is, once again, evidence of considerable variability in the levels of provision of these services across the country. For example, home help services are available only to a small percentage of older people (Lundström and McKeown, 1994). Yet, carers of people with dementia have expressed a desire for more home help services above any other type of provision (Ruddle and O'Connor, 1993). The health boards are, however, not legally obliged to provide home helps, which means that existing services are inadequate, uneven, and fragmented. The fact that older people in need of home help services are not entitled to them by law explains why the service is poorly funded and thinly provided. Most of the existing services in this area are provided by voluntary organisations, albeit with some funding from the health boards. One of the problems with existing provision is that home helps deal with all elderly people and are not necessarily trained to deal with the dementia-related problems they may meet in their work. Training is a very important issue in the development of the home help service for people with dementia.

The home sitting service appears to be an extremely worthwhile service but has not been developed in any coherent or regular way across the country. Local



services have been developed by voluntary organisations, mainly through the support of FÁS programmes. The Alzheimer's Society of Ireland operate a home support service in association with FÁS, which currently caters for about 2,000 patients spread right across the country, albeit unevenly. The scheme currently funds about 400 people to go into the homes of people with Alzheimer's disease and act as alternative carers, thus providing important respite for carers who need a break from caring. The Western Alzheimer's Foundation also runs a home sitting service throughout the counties of Galway, Mayo and Roscommon. While no formal assessment has been done on the service, the Foundation has received very positive feedback from both carers and health care professionals about the benefits of this service. These are the types of services that carers say they want more of when asked to articulate their needs, but which remain sparsely provided, apart from the aforementioned programmes. For people in rural areas especially, a home sitting service may provide an important alternative to day care, which is often not accessible due to inadequate transport facilities.

*The Years Ahead* report recommended that 'a panel of people who are willing and available to care for elderly people with dementia be available in each district under the supervision of the senior public health nurse to help both the elderly person and the carer'. Currently only two health boards have such panels available (the Eastern and North Eastern Health Boards). The remaining health boards have reported that the lack of resources has prevented the implementation of the recommendation. The evidence from the recent review of the implementation of the recommendations of *The Years Ahead* (Ruddle *et al*, 1997) suggests that more resources are needed in this area.

*The Years Ahead* report recommended that 'day care facilities for the elderly with dementia be provided in each district' and that it should be the responsibility of the Co-ordinator of Services for the Elderly to develop such a service, either directly, or by agreement with voluntary bodies. Day care is one of the key elements of community-based services for people with dementia in Europe and the United States (Moriarty and Levin, 1993). The provision of day care facilities is under-developed in this country (Ruddle, 1994). Most of the existing facilities are provided by voluntary organisations, with some financial support from the respective health boards. However, arrangements between the health boards and the organisations operating these centres have been piecemeal and lacking in any overall coherent national strategy. Considerable inequities exist in relation to access to services, with geographical location the strongest predictor of the level of service received. Those in rural areas are at a particular disadvantage because of high transport costs and the length of travelling time to and from centres.

Another difficulty is that many day care centres are not able or willing to care for dementia patients. Voluntary organisations such as the Alzheimer's Association and the Western Alzheimer's Foundation have attempted to address this problem by providing dementia-specific day centres in some areas around the country. The Alzheimer Society of Ireland has pursued an active programme of development in this area in the past decade and currently has sixteen centres in operation serving more than 1,200 patients across the country. Even when services are available, the inadequacy of existing transport arrangements means that some older people cannot access the services. Evidence from Ruddle *et al*, (1997) suggests that while day care places for people with dementia exist in all health boards, existing provision is not adequate and the absence of dedicated places exacerbates the problem. Twelve years ago both the National Economic and Social Council (1987) and the National Council for the Elderly (Convery, 1987) identified a number of factors contributing to the low level of development of day care services. One important influence identified was the low priority assigned to day centres by the health boards. Unfortunately, a decade later, this is still the case, despite pressure from voluntary agencies and carer groups for more services.

Voluntary agencies also report difficulties in recruiting professional people to work in existing centres. This is not surprising given the discretionary and short-term nature of the funding of day centres. There is also the related issue of what constitutes optimal staffing and best practice in day care provision. There is considerable variation in the services provided within day care centres and very little evaluation on the effectiveness of care within this setting (Anders *et al*; Curran 1995). The absence of a standard definition of day care provision was raised numerous times during the consultation process. Day care services may vary even within health boards. The importance of matching day care provision to the needs of the local population was also raised during the consultation process. There are likely to be differences between rural and urban populations, which, in turn, must be reflected in models of provision. When planning day care in rural areas, standard urban solutions are unlikely to lead to best practice (Gibson, 1996).

Respite care provided by hospitals and nursing homes provides short-term and emergency relief for carers. Respite services are necessary to provide carers with time off from the continual demands of caring. It is one of the services that most carers consider to be necessary for them to continue caring (Gatz *et al*, 1990), yet there is a considerable amount of unmet need in relation to this service (Ruddle and O'Connor, 1993). Unfortunately, like most other services, marked variations exist in terms of provision across the country with ad hoc arrangements between health boards and voluntary organisations. Some respite services are not dementia specific, and are often not inclined to accept certain

categories of dementia patients whom they perceive to be troublesome. Not surprisingly, given the objectives of respite care programmes, carers tend to report high satisfaction levels with existing services (Levin *et al*, 1994).

However, respite care may not suit all people with dementia, or their carers. People with dementia can sometimes be disoriented and unsettled after respite care and become more difficult to manage. In some instances, respite care may hasten long-term residential care rather than delay it, contrary to the *a priori* expectation (Burdz *et al*, 1989). There is also evidence that for some carers the overall burden of care, including stress levels, is not reduced by respite care (Lawton *et al*, 1989).

Occupational therapists, physiotherapists and chiropodists also have an important role to play in the care of people with dementia. Community services in these areas are minimal for elderly people generally, and for people with dementia. Current provision is haphazard and the level of services in these areas varies across health boards. For many people with dementia, particularly those people living in rural areas, day care centres afford the only potential point of access to such services. However, shortfalls in day care provision means that the services are not available to the vast majority of dementia sufferers.

A similar situation exists with respect to social workers. With the exception of the North Western Health Board, and more recently the South Eastern Health Board, there are no social workers at the community level dealing with the problems of frail older people. Community social workers spend most of their time dealing with child protection cases. There are a number of hospital social workers whose main brief is the preparation of patients for discharge back into the community, but this is not community-based work. The social worker has potentially a very important role to play in supporting community-based living, particularly in providing information and advice to people with dementia and their carers, and in liaising between the various services and placement possibilities. Social workers also have a role to play in counselling people with dementia and their carers, in resolving relationship problems that sometimes develop with the onset of dementia, in protecting vulnerable old people from abuse and exploitation, and in organising support groups for carers. For any of this to happen, however, we need more social workers dedicated to care of the elderly.

The majority of elderly people with dementia depend on the care provided by family members in the community. It is very often the case that families will continue to care with very little outside help. The reason for this may reflect the difficulty carers have in acknowledging the need for services, or that they

simply do not know what services are available. More often than not, carers will not seek help until a crisis occurs. Late intervention may, in turn, lead to institutional care, as the carer may no longer feel that she/he is able to cope.

While it is essential that carers receive adequate support through the provision of early diagnosis, home support services, day services, and respite care they may also require on-going emotional and psychological support. The development of this type of support for carers has been left to carer groups themselves and the voluntary sector, mainly through the Alzheimer Societies. Consequently, not everyone who needs support of this kind gets it, depending on where they live and the extent of their contacts. This is unfortunate because, in many instances, carer isolation results from a lack of information, or an inability to share the information that exists among service providers. The provision of information is likely to be one of the most cost-effective responses to the emotional and psychological needs of carers. The role of the community social worker is much neglected in this area and needs to be developed if the social and emotional needs of carers are to be met on a comprehensive basis.

Our meetings and consultations with the various provider groups confirmed the inadequacy of existing community care provision for people with dementia and their carers (Table 4.1). There was uniform agreement about the need for more resources for community care. The message we received was that existing resources were only meeting very basic needs in the area of dementia. The policy was one of containment, of doing what was possible within the constraints. People were frustrated that their commitment to care was not matched by the provision of additional resources that would allow existing objectives to be met. There was a great desire to change existing structures, to move towards a comprehensive provision of services, which would facilitate the early diagnosis of dementia and provide good quality care in the home.

Existing providers were especially concerned about the burden of care experienced by carers. People stressed the need to provide families with the skills and resources necessary to cope with the problems of caring. There was a good deal of emphasis on the need for more training for both statutory and family providers of care for people with dementia. There was strong support for a person-centred approach to caring, which focussed on the individual needs of people with dementia. This support was common to both medical and non-medical providers of services. The other common response among the people we met was the desire for an integrated and co-ordinated response to solving the problems of people with dementia and their carers. People wanted a person, or persons, to bring the various strands of the care system together. There was an acknowledgement that existing provision was fragmented and this caused frustration among the providers and recipients of services. People felt that the

problem could be resolved quickly, without much additional resources, through the assignment of key workers with special responsibility for people with dementia.

**Table 4.1 Selected feedback from the consultations: primary, community and secondary care services**

Some GPs are inexperienced in dementia assessment, and training in this area receives little attention. They end up under-diagnosing the disease, or referring patients to more expensive secondary care specialists.

Even if it means more resources, we need to diagnose dementia earlier.

Respite care is not being adequately provided by the health boards.

The number of Psychiatry of Old Age services is totally inadequate.

Carers need counselling and coping skills. There is very little support from the structures that are already there. At the moment support is hit or miss.

Social worker support is crucial for people with dementia and their carers. Hospital social workers have been filling the gap left by the absence of community elderly-concentrated social workers.

There is nobody in community care at present who tends to the social and psychological needs of the person with dementia and their carer. The responsibility at present falls on the public health nurse. There is a need for social workers in the care of people with dementia in the community.

Transport to day centres is essential, even though it is expensive. For people living in rural areas, there is a need to experiment with mobile day facilities.

There are major gaps at the primary and community care level in terms of meeting needs. More use should be made of local community-driven services in meeting the needs that exist.

A major problem for public health nurses is the absence of appropriate referral services.

The potential of the community psychiatric nursing service is not being realised in dementia care due to a lack of resources.

Training is crucial at all levels.

Local care services are important; flexibility is the key element.

Family care is remarkably strong. Carer's expectations of services are low, but their expectation of themselves is exceptionally high.

The current opportunities for developing expertise and qualifications for nurses in the area of dementia are very poor.

There are tensions between service providers in terms of who is responsible for what in the care of people with dementia.

We need some way of integrating all that is happening at the moment.

Case management is the key to providing flexible services for people with dementia.

#### **4.3. Secondary care services**

Secondary level services for dementia have an important role to play in the diagnosis and care of people with dementia living at home. Specialist services may come from five specialities: Geriatric Medicine, Psychiatry of Old Age, Neurology, General Psychiatry, and General Medicine. In Ireland, academic medical development in dementia has occurred mainly in geriatric medicine and in Psychiatry of Old Age. While each has strengths to bring to dementia care, their most important attribute is that they are both multi-disciplinary and have developed strong links with community services. While improvements have been made in geriatric medicine in the past decade, progress has been slow in the Psychiatry of Old Age with only four services currently in place, with another five services approved for development in the near future. Given the strategic importance of both geriatric medicine and Psychiatry of Old Age more investment is needed in both areas, and particularly in the latter. The problems in this area will not, however, be solved by the appointment of more consultants in the Psychiatry of Old Age. This is a necessary condition for the development of services but it is not a sufficient condition. The effective provision of services also requires the expansion of community-based facilities, acute psychiatric beds, and long-stay psychiatric beds. Developments in each of these areas are critical to the success of the Psychiatry of Old Age service.

Domiciliary assessment is a very important part of the Psychiatry of Old Age service. The role of the community psychiatric nurse (CPN) is particularly important in this area. The CPN is the person on the psychiatric team who has the most regular contact with the people with dementia, thereby ensuring a

smooth functioning of the service. The work of the CPN involves monitoring the well-being of patients and offering advice and support within the catchment area of the service. Unfortunately, the slow development of the Psychiatry of Old Age services is reflected in the paucity of CPN provision across the country. Other important ancillary services such as occupational therapy and social work are similarly under-developed in Ireland.

*The Years Ahead* report recommended that ‘health boards develop day hospitals for the elderly with dementia in the main urban centres, under the direction of psychiatrists with an interest in this field’. A norm of two day-hospital places per 1,000 elderly people was suggested for planning purposes. The recommended norm with respect to day hospitals is not currently being met. The Eastern Health Board is the only health board with dedicated day hospital provision, linked to The Psychiatry of Old Age services in the region. Plans are underway in two other health boards, in the Midlands and North-East, to establish day hospitals for people with dementia. Day hospitals, within Psychiatry of Old Age services, play a very important role in the assessment and treatment of people with dementia with behavioural or psychiatric symptoms. Their success is heavily dependent on the complementary provision of comprehensive community care services and the availability of an efficient transport system for patients. In addition, a successful day hospital for people with dementia requires a multi-disciplinary staff who are trained to treat behavioural problems such as aggression and psychiatric symptoms such as depression. Day hospital provision is, therefore, a crucial component of Old Age Psychiatry services, rather than a stand-alone facility. Therein lies part of the reason for the slow development of day hospital provision for people with dementia, but this is no excuse for the current inadequacies in this area.

#### **4.4. Residential care**

Current policy in Ireland has focused on the importance of caring for all dependent elderly at home for as long as possible. While the policy of community-based care is an important starting point, the management of certain categories of people with dementia in their own home is not always appropriate. Therefore, in fulfilling their commitment to community-based care, policy-makers must not neglect the role of long-stay care facilities. There will always be a need for residential facilities, and, for this reason, there needs to be reassurance that high quality facilities, adapted to the needs of dementia patients, will be available when home care is no longer the most suitable option.

People with dementia currently live in a variety of institutional care settings in Ireland, mainly within conventional long-stay facilities. There are five types of long-stay non-psychiatric care facilities in Ireland:

- health board geriatric homes and hospitals
- health board welfare homes
- health board district and community hospitals
- voluntary geriatric homes and hospitals
- private nursing homes

Precise estimates of the numbers of people with dementia in each type of residential care facility is difficult to obtain because of the poor official recording systems currently in place. The estimates that are available (Table 4.2) suggest that the vast majority of people with dementia are cared for in private nursing homes and voluntary geriatric homes and hospitals (Browne, 1996). The figure for health board geriatric home/hospitals is likely to be significantly underestimated. In a survey of four long-stay hospitals, Blackwell *et al* (1992) found that 42 per cent of residents had poor mental health, 39 per cent were uncommunicative and 37 per cent were uncooperative. While not all of these people had dementia, the scale of the problem is likely to be greater than is suggested by the official figures. A minority of people with dementia are looked after within the psychiatric sector. These people are likely to have behavioural and emotional problems, which require special attention in psychiatric hospitals. While the number of people with dementia in psychiatric beds has decreased in recent years, there remains considerable variation across health boards in the numbers of people with dementia residing in psychiatric hospitals and units.

**Table 4.2 People with dementia in residential care**

<b>Facility type</b>	<b>Number of patients over 65 years</b>	<b>Number with dementia</b>	<b>% with Dementia</b>
Health board geriatric home/hospital	5,082	950+	19
Health board welfare home	1,200	133+	11
Health board district/community hospital	1,560	224+	14
Private nursing home	6,200	1,470-3,700	23-60
Voluntary geriatric home/hospital	2,936	478-1,800	16-61
Psychiatric hospitals and units	3,301	561	17

*Source: Browne, 1996*



There are no national guidelines for the placement of dementia patients in long-stay care facilities. As a result, there are marked differences across health boards in relation to policy on the placement of people with dementia. For example, the Eastern Health Board places strong emphasis on nursing homes while the North Western Health Board has a high number of community hospitals. The Mid Western, North Eastern and Midland Health Boards tend to rely on geriatric homes and hospitals while the Southern Health Board appears to have a mixture of all types (Keogh and Roche, 1996). Differences in health board policies in relation to the placement of dementia patients, and historical variations in the supply of facilities within each board, determine the type of care offered to older people with dementia in different parts of the country. Access to appropriate accommodation remains, therefore, an important and outstanding issue. The current situation has both efficiency and equity implications: people with dementia do not always get the care that they need in an appropriate residential facility; and there are considerable differences in the approach to placement across the country which leads to unacceptable inequities, of both horizontal and vertical types. People with similar needs are not treated equally, while people with dissimilar needs are not treated unequally.

The majority of people with relatively easily manageable dementia, but needing residential care, are found in general category health board homes and private and voluntary homes. However, it is fair to say that the majority of long-stay facilities are not designed to cater for the special accommodation needs of people with dementia. People with dementia are likely to be sharing accommodation with people who are not suffering from dementia. The physical environment of many existing general facilities fails to take account of the unique characteristics and needs of people with dementia. Providing a normal environment for people with dementia is difficult to achieve where facilities are not on a domestic scale. Only a small number of long-stay facilities have been developed or adapted to a scale and design which addresses the environmental needs of people with dementia. In addition, the majority of non-specialised long-stay facilities that are currently providing dementia beds do not have access to specialist services. In many facilities, the only treatment available is pharmacological, with limited access to other treatments such as physiotherapy, occupational therapy, speech and language, reminiscence, music therapy, or behaviour therapy (Keogh and Roche, 1996). There is also very little on-going training for people providing residential services for people with dementia.

While many people with dementia can be cared for alongside other people without dementia, in suitable accommodation, there are a small number of patients with dementia who exhibit behavioural problems that can upset, interfere with, or are dangerous to, other residents. The lack of appropriate

accommodation for people with dementia-related behavioural problems means that some of them may be sharing with other non-dementia older people, making it difficult to avoid the use of chemical and physical restraints in certain circumstances. The absence of appropriate accommodation for people with severe dementia and associated behavioural problems is a major gap in services.

*The Years Ahead* report recommended that specialist high support hostels be developed for older people with severe dementia but these have not been developed by the health boards as this type of accommodation is no longer considered suitable for people with dementia. Unfortunately, the funding recommended for the development of these hostels has not been reassigned for the development of more appropriate alternative accommodation in a long-stay psychiatric unit or ward, leaving a major gap in residential services for people with severe dementia. There has been a significant fall in first admissions (by 55 per cent) of people with dementia to in-patient psychiatric care over the past ten years (Keogh and Roche, (1996). Even if some of this decline reflects the new emphasis on community care in recent years, some people with dementia and associated behavioural problems are likely to be inappropriately placed given their condition and special needs. The problem is that we currently know very little about the fate of people who might previously have found accommodation in psychiatric hospitals.

The general consensus emerging from the consultations carried out for this report is that most people with dementia can be cared for in mainstream community hospital-type facilities provided there is a recognition that people with dementia have special needs (Table 4.3). This may mean some modifications to existing facilities to provide appropriate design and safe wandering areas for people with dementia. It will certainly mean more specialist training for existing staff, including consideration of the mix of staff between general and psychiatric nursing. Access to specialist services is also an important aspect of long-stay care for people with dementia, including full access to physiotherapy, occupational therapy, chiropody, and various types of diversional therapies. The general view among people interviewed for this study is that people with dementia-related behavioural problems should be accommodated in specialist dementia units, such as long-stay psychiatric units or wards. They should, however, be able to rotate between these specialised units and non-specialised units as the severity of their dementia changes.

There were a number of other issues raised during the consultations with respect to residential care services for people with dementia (Table 4.3). The most important of these was the view expressed by a number of people that therapeutic, communication, and behavioural programmes should be available

for people with dementia in residential care. Respondents were very much aware of the need to be proactive with respect to care in institutions and some regretted the fact that community therapists did not continue to have an input into the care of people with dementia in residential settings. There was also support for a continued link to general practice and the concept of shared care was mentioned as a possible approach to the medical care of people in institutional care. Private nursing home proprietors felt alienated from the general care system due to the absence of any health board services going into private nursing homes. This alienation needs to be addressed through the increased integration of the private sector into the public system, through shared provision arrangements for homes willing to accept public funding and regulatory procedures.

**Table 4.3 Feedback from consultations on residential care services.**

Support for people with easily manageable dementia can come from general category long-stay facilities.

The community hospital is the place to locate new units for people with dementia. Not enough is being done here.

There is a need for purpose-built residential facilities for people with dementia with special behaviour-related needs.

There should be ongoing special training in dementia care for the staff of community hospitals.

Staff in residential care settings must be trained to deal with people with dementia. In-service training is required for staff working in public and private long-stay care.

GPs lose patients when they enter long-stay care, particularly in public facilities. The concept of 'shared care' needs to be developed in long-stay institutions.

Services should continue when a person enters long-stay care. Quality of life should be maintained with links to geriatricians, the Psychiatry of Old Age services and GPs.

Quality of care controls, linked to process and outcomes, need to be built into nursing home regulations which are currently too focused on building specifications.

The individuality of each resident is the most important thing.

Many nursing home owners feel disenfranchised and disempowered because of the absence of any health board services going into private nursing homes.

There needs to be more transparency in relation to the admission of people with dementia into long-stay care.

We don't know enough about what happens to people once they are admitted to care.

There is an urgent need to develop long-stay emergency care beds in public institutions.

Group-living/hostels/sheltered accommodation is not an option in Ireland. They are likely to be costly, cumbersome and impractical.

There needs to be a stage between home care and institutional care. The gap between the home and some form of institutional care is too big and should be met by some type of supervised shared-living accommodation.

Another issue raised during the consultations was the need to focus more on quality of care for people with dementia in long-stay settings. Some people pointed to the lack of emphasis on process and outcome in existing regulatory instruments for long-stay care. Nobody denied the importance of technical issues associated with long-stay provision, such as standards of accommodation and fire regulations, but there was genuine concern about process issues in institutions. Some people worried about the excess use of drugs and the inappropriate use of other restraints in long-stay facilities. Other people were concerned about philosophical issues, pointing out how little attention is paid to the autonomy and dignity of residents, in pursuit of what was termed by one respondent 'the needs of the institution rather than the needs of the person with dementia'. All of these criticisms were at the level of the anecdotal, a fact that most people realised, but which pointed of itself to the need for more information than we currently have on what goes on within residential settings. We need more transparency with respect to both the admission of people into residential facilities and the approach to care once people are admitted.

People we spoke with were also critical of the lack of experimentation and innovation in residential care settings in this country. There is good evidence that changes in the process of care and the adoption of more person-centred models of provision can have positive affects on both patients and staff in

residential care (Gilloran and Downs, 1997). The Domus philosophy, for example, is based on greater expectation of resident functioning, more focus on the psychological and emotional needs of residents, more choice for residents, greater resident control, the availability of social and recreational activities for residents, and concern for staff needs (Lindesay *et al*, 1991). These were the very issues raised by many people during the consultations.

There was little support during the consultation process for group-living or sheltered accommodation for people with dementia. Group-living is a caring level between home and institutional care for demented patients which was developed in Sweden during the nineteen eighties. The main aim is to provide homely supervised care for a small number of patients outside of an institutional setting. The major advantage of group-living arrangements is likely to be the reduction in cost associated with reduced in-patient care, since the positive effects of group living on cognitive function, ADL capacity, and behaviour are likely to be small (Wimo *et al*, 1995). Only one respondent, whom we quote in Table 4.3, expressed support for group living, even though we raised the idea in all of the interviews during the consultation process. The prevailing view was that group-living arrangements were likely to be cumbersome and impractical, requiring high levels of supervision, and a framework for co-ordination which is not evident in existing community care structures in Ireland. One respondent felt that if people were to be kept out of institutions then they should remain in their own homes rather than be transferred to an alien group-home environment to live with strangers, under the supervision of people whom they equally didn't know. In general people felt that scarce resources should be directed to own-home care rather than to developing group-living arrangements which were unproven in the Irish system.

#### **4.5 Conclusion**

Services for people with dementia remain under-developed in Ireland. There are problems at each stage of the care continuum. Early diagnosis is critical for the development of an optimal care plan for people with dementia (Department of Health and Social Services, 1995) yet the reality is that early diagnosis is the exception rather than the norm in this country. While some screening for dementia is currently undertaken, early intervention strategies are not standardised, nor are they applied consistently across all health boards. For this to happen, additional resources will have to be allocated to a wide range of services, particularly to the area of domiciliary assessment. There is also a shortage of dedicated day care and respite care places for people with dementia living at home. These facilities provide important support for carers, allowing them to continue caring, but are currently not available for the majority of

people with dementia. Training must be developed for all the various providers of services for people with dementia, including family carers.

Secondary level services require significant investment, particularly in the area of Psychiatry of Old Age. Services in this area are currently under-developed and are confined to Dublin and Limerick. There are also problems in the area of residential care for people with dementia. The unique and specific caring and accommodation needs of people with dementia are not being met under present arrangements in general long-stay facilities. More attention must be paid to the mix and training of staff in both public and private care facilities looking after people with dementia. Design issues, including the scale of in-patient provision, are also important, but they have not been given the attention they deserve. Finally, the lack of suitable residential facilities for people with dementia with behavioural problems was raised by a number of people during the consultations phase of this plan. People with behavioural problems, who might have previously been treated in large psychiatric hospitals, need alternative, appropriately designed and staffed, small-scale accommodation in acute psychiatric wards or units.

## Chapter Five

### Philosophy and Principles

#### 5.1 Introduction

This chapter considers the philosophy and principles that should underlie the action plan for dementia. The development of a philosophical framework is necessary in order to provide an enduring reference point for the planning of services for people with dementia. The philosophical framework proposed in the plan is based on respect for the autonomy of individuals suffering from the disease. It is easy to forget about the person with dementia in the search for optimal care strategies and efficiency in resource allocation. But, even if autonomy has to be qualified in the case of a person suffering from dementia, it is a good starting point, because it focuses on the person as the key to the whole process of care and not as an object of care.

The person with dementia can never be treated as a means to an end, as defined by families, or by care professionals, or by bureaucrats. Instead the person with dementia, by virtue of their existence, their emotions, their senses, must take centre stage in any plan. The individuality, complexity and diversity of the dementia experience can only be addressed within a person-centred approach to care (Sixsmith *et al*, 1993). Once we establish solidarity with the people we want to help, and their lives become part of some shared sense of humanity or community, it becomes relatively easy to derive principles for the provision of services. Empathy with people suffering from dementia is only possible if we allow them, no matter what the circumstances, to keep intact and to demonstrate as much of their essential self as is possible, given the nature of the illness. Sometimes we will have to dig very deep to find that self, but dig we must. Only by doing that can we truly say that we have made progress in the development of services for people with dementia.

#### 5.2 The philosophical framework

Prior to the development of a service plan for people with dementia must come some discussion of the philosophical framework for the allocation of scarce resources. Normally we assume that individuals are sovereign in terms of decision-making and behaviour in their everyday life. The assumption is that both economic and social progress are enhanced by allowing self-interested autonomous individuals to choose rationally the best means to serve their usually given ends. The system works best when no obstacles are placed in the way of individual decision-making. It is only in exceptional circumstances that

deviations from consumer sovereignty are acceptable, *de facto*, if not *de jure*. For example, parents and guardians make decisions on behalf of mentally handicapped adults; health professionals make decisions on behalf of people suffering from mental illness; carers make decisions on behalf of elderly kin suffering from dementia.

In each of these examples, the decision-maker is assumed to either know more, or be more rational, than the person for and about whom decisions are being made. By and large, the examples given above are not contested, although concern is sometimes expressed about the potential for self-interested behaviour on the part of third party decision-makers, in the sense that decision-making may sometimes serve the interests of providers more than the recipients of care. Generally, however, for categories of people deemed irrational, emotionally immature, or with failing mental powers, the correctness of the procedure of referral is not contested. The consequent violation of the personal autonomy principle so highly prized by everyone is accepted as inevitable.

The situation of people with dementia is complicated by two factors. The first is the tendency to equate communication potential solely with mental capacity. People with early, or mild, dementia will normally be able to make decisions for themselves, at least under some circumstances. In such cases, it is inappropriate to deny people autonomy as long as they are in a position to exercise it. Early diagnosis is important since it can allow people with dementia an opportunity to express preferences about future care arrangements and to make other important decisions before their condition deteriorates. As the disease progresses, the ability of the person with dementia to reason, and to act in a truly autonomous way, is compromised. At this stage, under a rationality model of autonomy, the ability of the person with dementia to play a major role in the decision-making process about his or her own care is undermined. However, this does not mean that other forms of communication cannot be developed and nurtured. In particular, failing mental power does not diminish the capacity of individuals to communicate at the level of emotions and feelings, and through the various senses (Goldsmith, 1996). Communication is possible, although it is often a difficult and complex process. It takes time and patience, requiring an understanding and personal knowledge of people with dementia, which, unfortunately, is too often absent. The guiding philosophy of this care plan is respect for the autonomy of people with dementia, linked to a broad interpretation of communication, and a commitment to the primacy of the person with dementia in the decision-making process.

The second complication concerns the role of family carers in the care process. In the majority of cases, family carers are so directly involved in the care process that it is difficult to disentangle their needs from the needs of the person



under their care. This must be done, however, because carer and care recipient needs are different and must be treated as so. It is not good enough to equate care recipient needs with carer needs on the basis that what is good for carers must be automatically good for patients. In the desire to acknowledge and advance the role of family carers as partners in care, we should not forget that the person with dementia is also a partner in care, with separate needs and preferences.

One of the difficulties in this area is how little power, or control, people with dementia and their carers have in their dealings with health care professionals. Generally, both parties have to accept what is on offer from the health authorities, whether or not they consider the service offered to be appropriate to their particular needs, which partly explains why some services remain under-utilised. Services are not always provided in the form, or to the degree, required by clients; nor are services always delivered at the right time by the right person. People with dementia are encouraged to live in their own homes and families are expected to care, to keep their dependent kin at home, but neither are given the practical support and resources necessary to achieve such independence. It is, of course, very difficult to dismantle the old style paternalistic system associated with health and social care provision and there remains a strong element of provider and bureaucrat imperialism with respect to social care provision. If progress is to be made, choice will have to be restored to people with dementia and to their carers. The best way of doing this is to provide users and potential users of statutory services with a range of realisable opportunities to define the needs associated with their particular situation, and the type of services they require to meet these needs. Case managers may be required to give practical expression to these choices, and financial resources will have to be made available to support particular choices, but the key element remains the primacy of the consumer in social services provision.

The emphasis on individualism and the sanctity of personal autonomy and sovereignty is not to argue that society, and the social matrix within which individuals are embedded, has no influence on the way we treat people with dementia. Each of us lives our life within a social matrix comprising human interaction, language, custom, tradition and narrative (McIntyre, 1984). As a result of the fusion of these social forces, all individuals are constrained, to some extent at least, in how they act. The making of individual decisions is affected by the various collectivities to which we all belong. Our sense of community and solidarity with others is, therefore, a very important influence on the way we think about people with dementia and the respect we pay to the meaning and purpose of their lives. If people with dementia are not part of our ordinary social matrix, then we can never be affected by them, or understand their need for autonomy, respect and dignity. We allow ourselves to treat them

differently because we do not know anything about the lives they lead. The absence of people with dementia and their carers from everyday life is a denial of rights, but it also crucially affects the way we think about our social responsibilities towards them. The solution is to remove dementia from the private world into the public world so that the basic humanity of the condition can both be understood and transformed.

### **5.3 Principles for the action plan for dementia**

The issue of resource allocation for people with dementia and their carers is a problem in most countries. An action plan for dementia cannot, however, be discussed in a vacuum. It is only when we know the principles against which progress can be measured that we will be able to make informed comment about the advantages and disadvantages of different approaches to care (British Psychological Society, 1994). Any set of principles must acknowledge the primary role of the person with dementia in the process of care in keeping with the philosophy outlined above. This is very important as it confirms the resource allocation process as a means to an end, and not an end in itself. There is, of course, no scientific way of devising principles. Any set of principles will contain both normative and subjective elements. What follows, therefore, are six principles, drawn from a variety of sources, which we believe should underlie the action plan for dementia care.

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

The role and importance of the person suffering from dementia needs to be emphasised at all times, in keeping with what Kitwood (1997) calls 'the new culture of dementia care'. There is evidence that an individual's sense of self persists throughout the course of the disease. The care of people with dementia must always seek to protect and nurture the sense of self that remains with the patient. This should be done through careful monitoring of the affects of different types of care and stimuli on the patient in different types of physical and social contexts. The emotional, spiritual and psychological needs of people with dementia should be given due recognition in the care plan. The narrative of the lives of people with dementia must be protected through careful interventions and therapies that seek to connect with the wholeness of the person's life and not just the dementia component. An emphasis on patient experiences and patient rights should also extend into consideration of broader familial and social rights and responsibilities with respect to the disease.

***(ii) The action plan should be comprehensive.***

The action plan for dementia should be broad enough to cover the wide range of needs occurring in the dementia population. While the coverage of acute and medical care services is more or less complete, the coverage of community care and residential care for people with dementia is more restricted, and is often subject to means testing and various other qualifications. The action plan should, therefore, incorporate a holistic view of the needs of people with dementia, which transcends current preoccupations with health care needs and bio-medical interpretations of dementia. We must respond to people's needs whatever their origins, be they medical, psychological, psychiatric, emotional, economic, or social. For this to happen, the plan should include provision for both formal and informal support mechanisms from within and outside standard health care budgets. Interventions should be targeted to specific needs, and, where possible, specified standards and written protocols should accompany service plans in order to guarantee comprehensive provision of services. The plan should also be underpinned by the creation of a legislative framework to give effect to the delivery of the most essential services outlined therein.

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

Older people have, by and large, expressed a preference for care in the home rather than in institutions. This should be reflected in the action plan through a financial commitment to support home care solutions in the first instance. This means supporting family carers in their work, through payment, training and information. The needs of older carers must be explicitly recognised. Funds must also be made available for the development of the social infrastructure which is necessary to enable people with dementia to continue living at home. Respite care, day hospitals and day care are important parts of the social infrastructure, as are visiting services such as public health nurses and home sitting services. The voluntary sector also plays a major role in caring for people with dementia and should be better integrated with the statutory system. The plan should contain an integrated model for the delivery of services to people with dementia living at home that is capable of delivering appropriate care to the person with dementia when and where it is most needed.

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

The system of financing dementia care should not determine how funds are spent but should be structured in such a way as to respond in a flexible manner to the individual needs of older people suffering from the disease. The availability of personnel, buildings, or beds should not determine individual care plans. On the contrary, care requirements, as articulated by people with dementia and their carers, should determine the types of services and supports to be funded. This means that should home sitting services, day care, or respite care, be valued more than residential care, then finance should be available to support such preferences, *ceteris paribus*. People should not have to wait until they become very dependent, or enter an institution, before they receive attention from the health authorities. Existing supply structures should not be allowed to dominate, or determine, demand. Instead the emphasis in the future should be on developing flexible, community-based, responses to the clearly articulated needs and preferences of people with dementia and their carers.

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

Access in this context means access to basic care services in both the community and in institutions. Our first concern here is that a dual system of care does not emerge. This means that all older people, irrespective of social class or wealth, should be entitled to essential care services, unimpeded by their means, or their ability to pay. In the absence of a price mechanism, the assessment services bear most of the burden of controlling access to essential provision. To facilitate equal access, geriatric and Psychiatry of Old Age assessment facilities should be available on a comprehensive and national basis in order to establish common eligibility criteria for determining needs. Essential services should also be available in all areas and regions to overcome current geographical inequalities in provision. The problems, needs and challenges of people with dementia living in rural areas require special attention.

***(vi) National quality targets and outcome targets should be established.***

The tendency to equate efficiency with cost control must be avoided. The quality of care and the outcomes associated with care also need to be explicitly recognised. The concepts of health gain and social gain must be transformed into concrete measurable criteria, which can be used to monitor progress in both community care and residential care. Both

quality and outcome are multi-dimensional concepts, incorporating medical, psychiatric, psychological, social, and economic elements, and should be applied to both patients and carers. No single measure can encompass all the relevant domains for either people with dementia or their carers. Individual-based measures, for example measures of patient behaviour and mood changes, or measures of patient depression, must ultimately be combined with broader, services-based criteria to give a complete picture of quality and outcome in this area. Serviced-based process measures would include elements such as the awareness and understanding of dementing illnesses, continuity of care, patient dignity, carer recognition and aesthetic aspects of care. The plan should be accompanied by a commitment to monitor both process and outcome for people with dementia through the initial development of pilot projects within community and residential care settings

## **5.4 Conclusion**

The basic philosophy underpinning this plan is respect for the autonomy and personhood of people with dementia. We have outlined six principles to give effect to this philosophy. These principles will, in turn, shape the action plan for dementia, with the overall objective of maximising the well-being of people with dementia. We want to close the gap between the quality of life that people with dementia currently experience and what they might optimally achieve with a more intensive and co-ordinated approach to service provision. For this to happen the plan will have to nurture and develop the whole range of capabilities of people with dementia, thereby allowing them to reach full expression within the limitations imposed by their condition. This is a difficult and time-consuming task since it requires a detailed and intimate knowledge of the whole lives of people with dementia. However, it is a task worth pursuing because it will enrich the lives of people with dementia, thereby ennobling all of our lives.

## **Chapter Six**

### **Pathways to Care: Primary and Community Care**

#### **6.1 Introduction**

We have identified the gaps in existing services for people with dementia and their carers and the principles and philosophy that should underpin the future development of services in this area. Now it is time to discuss in detail the essential elements of an action plan for dementia in Ireland. The components of a good system of care for people with dementia is considered within the framework of a 'pathways' model (Ministerial Task Force on Dementia Services in Victoria, 1997) which is divided, for ease of exposition, into three constituent parts:

- primary/community care
- secondary/specialist services
- residential care.

Breaking down the model in this way allows us to develop the plan in line with current health board structures in this country. Notwithstanding these divisions, the importance of the continuum of care must always be acknowledged, reflecting the heterogeneity of people with dementia and their changing needs over time.

This chapter deals with primary and community level care. The emphasis is on care in the home for people with dementia who do not require secondary level care, or admission to long-stay residential facilities. In the majority of cases, dementia can be dealt with at the level of primary and community care provision. For more complex cases, involving early diagnosis, or challenging behaviours, or complex illness, assessment and care will be provided either by geriatric medicine services or by Psychiatry of Old Age services, or in combination, within a community setting, wherever possible. Both of these services are considered in the next chapter under the general heading of secondary level care. For people with dementia who need long-stay residential care, placement should, ideally, be provided in suitable, small scale, facilities, properly designed and staffed to meet the needs of people with dementia. Residential care is considered in more detail in Chapter Eight.

## **6.2 Priorities for primary and community care**

Good practice in primary and community care requires an early diagnosis of dementia and a careful assessment of the person's care needs and functioning (Commonwealth Department of Health and Family Services, 1997). Staff at all levels of provision must have a good knowledge of dementia and be aware of best practice in the area. Individualised care plans, tailored to the needs of people with dementia, and mediated by case management structures, are likely to give the best results in terms of health and social gain. The needs of carers must also be recognised and their voice must be heard in the development of individualised care plans. Families also require training to allow them to understand fully the needs of people with dementia. This is very important given the amount of time spent by family carers looking after people with dementia and the often high levels of stress involved in caring. To facilitate care in the home there must be a strong emphasis on local care and local provision and on the integration of all services.

The main priorities for primary and community care can be summarised as follows:

- early diagnosis and access to quality information on the disease and the support services available
- careful assessment of the person's care needs and functioning
- availability of and accessibility to a range of high quality community care services
- education and practical skills training for health care professionals working in this area
- flexible services which respond to the changing needs of patients and carers
- individual care plans that reflect the unique needs of each person with dementia
- continuity of care for the duration of the disease
- Constant Care Attendance Allowance for carers that is related to the needs and dependency of care recipients, but is not means tested
- public information and education programmes on dementia in each health board

In keeping with the philosophy outlined earlier, the autonomy and dignity of people with dementia must be respected at all times. It is very important, therefore, that people get the services they need, when and where they need them. The best way to ensure this happens is to develop a system of case management for people with dementia. Where appropriate, a case manager should be assigned to co-ordinate the individual care plans of people with

dementia, working closely with the person with dementia and their carers. Carers require a named contact to provide them with an assured link to appropriate services and the case management model is the best means of locating individual care plans within the existing health and social care fabric. The case manager should be able to draw on an expanded community care network of services to meet the particular needs of clients and their carers. For this to happen, additional resources will have to be directed to community care and the case manager will require expertise in both health and social services to ensure the delivery of appropriate services. The most likely candidates for the job of case manager are specialist public health nurses or medical social workers with training in gerontology and dementia, given the mix of skills required for the job. Case management can, and should, be accommodated within the existing framework of health services provision.

### **6.3 Primary care**

Early and accurate diagnosis of dementia is very important because it can help to identify treatable causes of dementia (e.g. nutritional deficiency) and help to distinguish dementia from other illnesses, such as depression, which can masquerade as dementia. Early diagnosis also allows the person with dementia and their carer to be linked with appropriate services and supports from the outset. It also allows the opportunity to inform the person of the nature of the condition and facilitates family decision-making with respect to future care plans (Brodaty, 1988).

While there are arguments for and against telling people in the early stages of dementia their diagnosis (Drickamer and Lachs, 1992), we believe that it is important psychologically for the person with dementia and their carer to be able to put a name on what is happening to them. In line with the practice in other areas, and for other conditions, people have a right to know what is the matter with them (Rice and Warner, 1994) and to be given the opportunity to participate, where appropriate, in decision-making with respect to the treatment of their condition. Dementia loses part of its threat if you can name, describe and understand it. Early diagnosis is also of great value to the carer, bringing with it the potential for increased understanding and tolerance (Schofield *et al*, 1998). An early diagnosis is, of course, of little benefit to those affected by the disease if the appropriate community-based services are not available from the outset. Therefore, early diagnosis must be complemented by the provision of additional resources for community care, including information and counselling services to support people who have been diagnosed with dementia, and their families. Counselling needs to be available throughout the course of the illness and both patients and carers require ongoing advice and support.



1. *We recommend that clinical standards and competencies for early diagnosis of dementia should be developed and that people with dementia should be informed of their condition at the earliest possible moment unless there are strong medical or social reasons for withholding such information.*

The general practitioner is best positioned to detect dementia in its early stages. However, family doctors vary widely in terms of their capacity and commitment to identifying dementing patients. While primary care guidelines exist for the detection of dementia in Ireland the likelihood is that these guidelines are rarely used by GPs. There is a perception that GPs are not always comfortable dealing with social, cognitive and behavioural problems. Sometimes, GPs are reluctant to label someone with the diagnosis of dementia within the local community because of the negative attitudes and stigma associated with this disease. Uncertainty about who to refer to and what services are available may also make the GP reluctant to make a diagnosis. It has also been suggested to us that younger patients with dementia may be picked up earlier and referred on to secondary care faster than older patients. Personalised and innovative education programmes are necessary to ensure that general practitioners understand the need for standardised cognitive testing in this area (Cheok *et al*, 1997). Communication between GPs and other community-based professionals also needs to be improved, particularly with respect to the assessment and management of the psychosocial aspects of dementia.

In summary, general practitioners need to have knowledge of the assessment process, knowledge about dementia itself, an awareness of carer stress, a route to sources of help and knowledge of reasons for seeking specialist assessment (Iliffe, 1994)

Inevitably, future developments in the drugs market will place GPs under increasing pressure to screen and diagnose dementia at an early stage so that the possible benefits of new drugs can be realised. In that context, it is important to monitor prescribing patterns very carefully to ensure that anti-dementia drugs are prescribed as one part of a holistic approach to supporting people with dementia and their carers. On the other hand, the trend towards increased prescribing is likely to be countered by pressure from the indicative drug prescribing initiative, which rewards GPs for not prescribing anti-dementia medications. We need to be equally careful in this instance to ensure that people get the drugs they need at the appropriate time.

2. *We recommend that information and training should be provided to general practitioners to facilitate and encourage the early diagnosis of dementia through opportunistic or targeted assessment using tools sensitive to the detection of dementia in primary care.*

The public health nurse also has a critical role in early diagnosis because of her regular contact with potentially at-risk elderly populations. Routine screening for dementia is not, however, occurring in any coherent or uniform manner across the country. The public health nurse service is already over-stretched dealing with the general health care needs of both children and general elderly populations. The time and opportunity to undertake additional screening programmes for dementia does not exist. In addition, public health nurse training is geared towards generalist nursing care which makes it more difficult for them to identify people suffering from dementia, let alone deal with their particular needs. In general, screening for dementia needs to be proactive and community-based, rather than in secondary or tertiary referral centres (Seymour *et al*, 1994). For this to happen, community nursing will have to receive more resources, together with dementia-specific training for nurses in order for them to identify the symptoms of dementia in elderly populations. It is also important to develop greater collaboration between GPs and community nurses in both the assessment and care of people with dementia.

3. *We recommend that public health nurses should receive training in dementia assessment and be given more resources to work with in order to make identification worthwhile.*

In the past two decades there has been wider appreciation of the way dementia, and, in particular, Alzheimer's disease affects the brain, and there is now much less stigma associated with mental health problems of all types. There remains, however, a good deal of ignorance and fear with respect to dementia. Voluntary organisations, such as the Alzheimer Society of Ireland, play a critical role in raising community awareness about dementia, helping to combat negative feelings about the disease. Awareness among the public makes the disease more acceptable and helps to foster positive attitudes towards the care of people with dementia. This, in turn, can help to encourage those experiencing the early signs of dementia to come forward for examination and diagnosis. Awareness of the disease can also be increased through public education campaigns designed to change attitudes and confront ignorance about the disease. Awareness can be fostered through the use of information technology in public spaces. For example, the location of touch screen information monitors in convenient public

spaces can provide general information on the disease, thereby providing an important and accessible service to the public.

One of the goals of the recent healthy ageing strategy, *Adding years to life and life to years* (National Council on Ageing and Older people, 1998), is to reduce the prevalence and severity of mental health illness in older people. Greater awareness of mental health issues is an important part of the strategy for the effective treatment of people with mental health problems. More awareness facilitates prevention and the early diagnosis of problems. Unfortunately, it is not possible to talk about primary prevention for the vast majority of disorders associated with dementia. However, primary prevention is possible for symptomatic dementias and involves the early detection and treatment of those physical illnesses or other psychiatric disorders that produce a dementia type syndrome (Keogh and Roche, 1996). For example, continuing improvement in the treatment and control of hypertension in older people will reduce the risk of dementia associated with stroke. For people with dementia, the availability of a good level of general medical care, allied to improved personal and social environments for the person, can influence the progression of the disorder. Health promotion is also important for carers, given the level of stress sometimes associated with the caring role. Information, training, and networking are important for carers in combating isolation and loneliness and in creating awareness of the nature of dementia and the effect it is likely to have on the carer. Public acknowledgement of the key role played by carers in the caring process may also be part of an effective health promotion strategy for carers.

4. *We recommend the launch of a public information campaign designed to raise awareness of dementia among the general public.*

## 6.4 Community care

The care of people with dementia is an ongoing process and may continue over many years. The majority of elderly people with dementia depend on the care provided by family members in the community. In general, most people with dementia can live successfully in the community given appropriate statutory, voluntary, and family support structures. The problem is that community care services are often poorly developed to meet the needs of people with dementia and their carers (Philip *et al*, 1995). In this country, community support services for people with dementia and their carers are inadequate, with considerable variation in existing provision across the country. While people with dementia and their carers value community-based services highly, they are

not provided with any consistency across the country. Not surprisingly, the result is that in many cases the full burden of care falls on families.

As the dementia progresses, the burden on carers increases, particularly when progression is associated with behavioural problems. Difficulties may arise in communicating with the demented person. Friends may withdraw, as they do not understand the changes taking place. Carers may feel isolated, left to deal with the problem on their own, and perhaps unable and unwilling to talk about the problem because of social embarrassment. For whatever reason, or combination of reasons, carers may not actively seek help until a crisis occurs. Late intervention may lead to institutional care, as the carer may no longer feel able to cope with the situation. The burden of caring is reduced if the carer knows that appropriate community-support structures are there should they require them. Very often they may not use the service but the knowledge that it is there is enough. Therefore, if living at home is to remain a realistic option, carers must be adequately supported by appropriate and accessible community services. The key element in community care provision is that services are comprehensive and flexible, with provision determined more by service users than by service providers (Barber *et al*, 1996). This is particularly important in rural areas where accessibility issues demand a more thoughtful response by providers to the provision of services.

Community care services are often categorised into core and non-core services to make the point that the services listed under the core heading should be provided as entitlements to people rather than on a discretionary basis. The argument is then made that core services should have the authority of legislative support and be available to older people whenever required, throughout the country. For people with dementia, core community care provision should be defined as those services which facilitate people remaining in their own home for as long as possible and practicable. The division of community services into core and non-core provision should not distract from the individual needs of community care recipients. The majority of community care services are, in any case, inter-connected, making it difficult to divide them in terms of overall worthiness. The development of community care services for people with dementia must, therefore, be on a comprehensive basis in line with the principles outlined earlier in the report. Services must be integrated and delivered in a person-specific way according to the needs of individual patients and their carers. The most useful approach is to leave it to people themselves and their carers, in consultation with the health professionals, to decide on what services best meet their requirements.

#### **6.4.1 Case management**

An effective integrated system of care requires that there are clear, co-ordinated and definite routes into a range of community services (Ovretveit, 1993). A mechanism by which this can be achieved is by the nomination of a key worker, or case manager, with responsibility for co-ordinating fragmented systems of community care for people with dementia. Ideally, there should be a number of case managers with small case-loads operating within each community care area, or district, each reporting to the overall Co-ordinator of Services for the Elderly. Dementia is lifelong and progressive and care plans must, therefore, be monitored and revised over the course of the disease. The key worker would act as a single point of reference. This is very important particularly for those with dementia living alone and becomes increasingly significant as the person with dementia becomes more dependent and his or her needs become more complex. The case manager should be linked to a multi-disciplinary team with regular meetings to discuss cases and review care plans.

Once a diagnosis of dementia is made, the overall co-ordinator for services for the elderly in the relevant community care area, or district, should be notified. The care co-ordinator would then assign a case manager to meet with the person with dementia and their family to discuss and assess the care needs of the patient. The plan would be devised in consultation with the family, the general practitioner and the relevant specialist services. Following the agreement of a plan, the case manager should be intensively involved in the process and delivery of care. The case manager would draw on the full range of community-based services, and be allocated a budget which can be used to purchase appropriate community care services from outside conventional public sources. Part of the job of the case manager would be to visit people on a regular basis to ensure that needs are being met and that services are introduced or modified as required. The overall goal of case management is to deliver tailored care packages suited to the specific needs of the person with dementia and their carer (Hunter *et al*, 1997). Ideally, the plan would be designed in such a way that it respects the competency of the carer and minimises professional involvement to the necessary provision of services.

The case manager should be a specialist public health nurse or a medical social worker with training in gerontology and dementia, depending on the local circumstances prevailing within each board. Whether specialist public health nurse or medical social worker, the case manager must have sufficient expertise, time, and resources to do the important co-ordination tasks associated with the post. Conceptual clarification and skills training will be needed before any new system of case management is put in place. Professional training is a necessary but not sufficient condition for effective case management. Case management will succeed only to the extent that the following conditions are met: resources are available to support case management decision-making; expectations are

realistic; and structural arrangements at the local level are satisfactory (Sturges, 1995). While the concept of the case manager is very important, it can only be introduced, in practice, within the framework of a more developed and comprehensive community care system. Case management is not about reducing costs, though this may happen, but about the more efficient and effective delivery of community care services (Kemper *et al*, 1987). This is the value added by case management practice.

The assignment of a case manager would also go a long way towards meeting the recent call for the assessment of carer and care recipient needs in the recent *Review of the Carer's Allowance* (Department of Social, Community, and Family Affairs, 1998). Intensive case management, linked to appropriate early intervention and the provision of dementia-specific services, can have a major impact on the quality of life of people with dementia and their carers (Killeen, 1998). Evidence from the Lewisham case management scheme suggests that intensive case management leads to benefits for patients and carers which less intensive interventions have not been able to achieve (Challis *et al*, 1997). The role played by the case manager in integrating specialist mental health support with intensive home-focused social care was critical to the success of the Lewisham scheme. The results were significant reductions in the needs of older people and clear gains experienced by the carers participating in the scheme. Given the numbers of people with dementia in the community not everyone can have this kind of service. For that reason, case management for people with dementia should, in the first instance, be concentrated on people with dementia living at home but on the boundaries of residential care. A pilot project based in two different health boards should be introduced as soon as possible to explore the potential of case management in this country. One of these projects should be based in an urban area, the other in a rural area.

5. *We recommend the introduction of a case management model to co-ordinate services for people with dementia and their carers within geographically defined catchment areas in each health board. The model should be introduced on a pilot basis in two health boards as soon as possible.*

#### **6.4.2 Carers**

The key worker recommendation does not mean that carers should be excluded from decision-making with respect to the care of people with dementia. Carers want to be directly involved in the process of care, including making decisions on the most useful services for their particular situation. There needs to be a high level of co-ordination between family carers and professional carers in order to maintain a high level of care. However, it is important that the formal

support being offered complements the care already being given by families. Family carers have much to contribute by way of diagnosis and treatment, as they are aware of the past history of the person in their care. They are the experts and they should be consulted when decisions are being made in relation to the person in their care. The ideal care plan would be designed in such a way that it respects the competency of the carer, minimises professional involvement, while at the same time maximises the benefits and impacts of services and enhances the quality of life of the person with dementia and their carer.

*6. We recommend that carers should have a major input into placement decision-making and service delivery issues.*

The issue of payment for carers also needs to be addressed directly. Current support for carers via the Carer's Allowance is inadequate and only a minority of carers satisfy the strict eligibility criteria for this scheme. Caring is a multi-skilled job, involving long hours and a significant degree of stress. It must be recognised as such through the provision of adequate remuneration.

Carers have consistently expressed a preference for direct payment, not because they are greedy, but because they would like some acknowledgement from the state of the job that they do. There are well documented opportunity costs associated with caring based on the sacrifices carers make in order to look after their loved ones. Caring can also be looked at using a replacement cost valuation of what it would cost the exchequer if family carers were not available to provide the care that they do. On the assumption that there are about 22,000 people with dementia living at home (Lawlor *et al*, 1994), with an estimated 60 per cent of these requiring full-time care (Ruddle and O'Connor, 1993), and assuming a replacement professional annual cost of care of £15,000 per person per year, the annual savings to the exchequer generated by carers is conservatively estimated at just under £200 million pounds per annum.

Not everybody with dementia living at home is in need of high levels of care. It is not reasonable, therefore, to give all carers the same level of payment for caring. Payment should be linked to the needs assessment carried out by the case manager assigned to the care recipient. The full-time carers of people of medium to high dependency should receive a 'continual care payment,' or 'constant care attendant allowance' of the type suggested by the Department of Social, Community, and Family Affairs (1998) and the National Council on Ageing and Older People (1997) respectively. The new payment would be recognition of the important role played by carers in community care and would

not be means tested. The allowance would be paid regardless of means, and should not be calculated in the means test for other social welfare payments. Assuming again that 60 per cent of people with dementia living at home can be classified as either medium, or high, dependency, the number of carers qualifying for a constant care attendant allowance would be approximately 13,000 people. The cost of the scheme, on the basis of an illustrative weekly payment of £100, which is linked to the 1998 level of the contributory old age pension plus an adjustment based on the government's commitment to raise this to £100, is equal to £68 million pounds annually. This is approximately one third of the savings to the exchequer generated by carers on the basis of a replacement cost valuation of their work.

*7. We recommend the replacement of the Carer's Allowance with a non-means tested Constant Care Attendance Allowance for full-time carers based on an assessment of care recipient needs and dependency made by the relevant case manager.*

#### **6.4.3 Information and counselling**

Information and counselling on all aspects of dementia is crucial, particularly at the time of diagnosis, as it helps both the person with dementia and the carer adjust to the new situation. According to one carer:

*Information about dementia helps me to manage his different moods and know that it is not his fault. I now know how to respond and what to do. In the beginning, I used to lose my temper all the time, which did neither of us any good.*

High quality, accurate, up-to-date information across a range of topics, from the availability of services in local areas to practical information about the progression of the illness, is crucial, but is not available at the moment. A combination of information and counselling in the early stages can lay the foundations for successful future caring and can help to alleviate carers' stress and any anxiety on the part of the person with dementia. Information can empower carers allowing them a sense of ownership of, and involvement in, the care process, which helps to validate and legitimise their role.

General practitioners, public health nurses, and other community-based health professionals should develop their skills in information giving and counselling and ensure that their knowledge is up-to-date. The recent involvement of the North Eastern Health Board in an EU home training project shows what can be achieved through information, skills and knowledge training for both formal



carers and family carers (North Eastern Health Board, 1997). The information needs of both formal and family carers identified as part of this project were broadly similar and focussed on three main demands: information on dementia, information and training on how to deal with behavioural problems, and information and training on stress management. The recently established Dementia Services Information and Development Centre at St. James's hospital has an important role to play in the dissemination of information to both health care professionals and family carers working in the area of dementia. The Alzheimer Society of Ireland provides a similar education role for the public. In general, voluntary organisations have an important role in the provision of information about dementia and need to explore innovative ways of providing this information. The information provided needs to be clear, easily understood and available in a variety of formats. The role of carer support groups in the exchange of information is also important. The information provided by carers in this type of setting should be valued and capitalised upon by the health care system.

8. *We recommend the development of information and counselling services for people with dementia and their carers.*

#### **6.4.4 Day services**

An effective day service is one that is well planned, accessible and responsive to the needs of its clients. Currently, there are six types of day care and day hospital services in Ireland:

- *Day Care Centres:* These centres tend to have a social function and cater for all elderly. The difficulty here is that people with dementia may become marginalised in this type of setting where staff levels are relatively low and there is a lack of expertise in the area of dementia. There is often a reluctance to accommodate people with dementia in generic centres.
- *Dementia-focused Day Care Centres:* These are day care centres that operate specific days for people with dementia or allocate a number of places to dementia patients in their normal service. This type of model of day care goes some way towards addressing the needs of people with dementia. Again staff in these centres need to be aware of dementia-specific issues.
- *Dementia-specific Day Care Centres:* These are day care centres that cater exclusively for people with dementia and generally develop as a

result of the initiative of voluntary organisations. Staff in these facilities tend to be more knowledgeable and more skilled in dealing with people with dementia.

- *Day Hospitals in Medicine for the Elderly Services:* These hospitals are not dementia-specific but will accommodate some dementia patients with a physical illness. They are staffed by multidisciplinary teams but, in general, they are reluctant to accept complex dementia cases such as those with severe behavioural problems, mood disturbances and very high dependency levels.
- *Day Hospitals in the Psychiatry of Old Age:* These day hospitals treat people with dementia who have associated behavioural problems, or psychiatric symptoms. They provide an alternative to psychiatric in-patient admission. They are staffed by a multidisciplinary team led by a consultant in the Psychiatry of Old Age.
- *Mobile Day Hospitals:* This type of day hospital model is useful for sparsely populated rural areas. In this model, a multidisciplinary team travels to a number of centres, on one day each week, to provide assessment, treatment and rehabilitation in a local environment for all elderly people.

In general, people in the early stages of dementia can be accommodated within a generic day centre. However, as their dementia progresses, attendance at a dementia-specific or dementia-focused day centre may be more appropriate. People with more complex dementia, and in need of medical treatment may require care in a day hospital. Regardless of which type of day service the person with dementia attends, it is very important that their needs are met by the service. The case manager should work closely with these services to ensure that the person is receiving optimal benefit from the service they are attending. Day services should only be provided in response to the assessed need of the person with dementia. Opening times should also be flexible in keeping with the emphasis on individualised provision of care for people with dementia.

There is a need to establish national standards for day care services for people with dementia. Standard quality of care issues need to be formalised. Small-scale centres in domestic settings with empathic, trained staff, appear best placed to provide good quality day care for people with dementia (Curran, 1996). A coherent transport policy for getting people to day care also needs to be developed. This will necessitate joint planning and co-operation between the health boards, the transport authorities, and the voluntary agencies. A greater investment of resources will be necessary to secure the expansion and provision

of high quality services. Voluntary agencies and local initiatives should be financially supported in their efforts to develop day services. Day care centres should be locally based. This will help promote contact between staff and carers, thereby promoting a sense of partnership and continuity in care. Local day care services not only encourage active involvement from the broader community but may also minimise transport time and costs.

Day hospitals for people with dementia who have associated behavioural problems or psychiatric symptoms should be developed as an integral part of each Psychiatry of Old Age service. This means additional resources and training for staff. The model of a travelling day hospital is a good model in some circumstances, and should be adopted to facilitate elderly people living in rural areas.

*9. We recommend that dementia-specific day care places be provided in each district or community care area in buildings suitable for people with dementia and with staff who are trained in the care of people with dementia.*

*10. We recommend the development of day hospitals within each Psychiatry of Old Age Service for people with dementia who have associated behavioural problems or psychiatric symptoms.*

#### **6.4.5 Respite care**

Respite services can refer to short-term placement in some form of residential setting, or to in-home provision of the service. Respite in the home of the person with dementia is highly valued (Downs, 1994), but is rarely provided, and we found no evidence of formal programmes of in-home respite in this country. Respite care outside the home allows the carer a complete break from the caring process and is one of the services most frequently rated by carers as being very necessary. While respite care is of benefit to the carer (Lawton *et al*, 1989), it is important that the person with dementia is not overlooked in the consideration of respite care. Respite care in a residential setting is not always a suitable option of care as it can lead to disorientation and behavioural problems for some people with dementia, particularly if respite is provided for only a very short period. The case manager and carer, taking advice from the specialist services that are available, should determine the appropriateness of respite care for each individual concerned. The challenge lies in ensuring that services have the resources and standards of practice to meet individual requirements (Levin and Moriarity, 1996).

Continuity of care is important for people availing of respite care. Staff in the residential facility should be given detailed written information on the patient's situation and past history. This will be of benefit to staff involved in the caring process during the period of respite and offer reassurance to carers that the individual needs of the person with dementia are respected. The facility in which the respite service is available should also be appropriately designed to ensure the safety and comfort of dementia residents. It must also have high levels of appropriately trained staff. Ideally, respite services should be locally based, in a small-scale homely environment, and available when they are needed.

*The Years Ahead* report recommended the development of community hospitals across the country providing a range of services including respite care at the community level. These hospitals have developed in a piecemeal fashion across health boards and it is not clear if all of them provide respite care as part of their service. In general, there is a great deal of variation in the quantity and quality of respite care across the country. The type of care provided in respite facilities varies from basic nursing care and hotel type services to full multidisciplinary assessment and special care programmes. Sometimes, appropriate respite care is not available locally, with the result that carers may accept services in inappropriate accommodation close by rather than in a suitable facility some distance from where they live. There is no support available to families wishing to avail of short-term respite care within private nursing homes. In the past, before the advent of *Nursing Home (Subvention) Regulations* 1993, a short-term grant was available from the health boards to partly cover such costs. Respite care can be extremely beneficial to carers of people with dementia who wander or exhibit challenging behaviours. However, it is often difficult to find appropriate respite care facilities willing to take people with behavioural problems. Residential facilities may also be deterred from providing respite care as the variability in demand that can occur during the year means that beds may be unoccupied at times. The uncertainty in relation to demand can threaten the financial viability of providing this type of service.

Respite care services should be expanded within the general framework of geriatric medicine and the Psychiatry of Old Age services. People with dementia should not be allowed to use respite care without prior adequate assessment. Plans for the expansion of residential respite services should be based on estimates of the aged population and dementia prevalence estimates, but a planning norm of 1 respite bed per 10,000 elderly population seems reasonable. Simultaneously, in-home respite care should be developed, starting with appropriate training for in-home respite carers. A more co-ordinated approach to the provision of respite care will also be necessary, involving joint

planning between all of the agencies involved. The choices and preferences of carers must be respected in this process (Levin *et al*, 1994). The Co-ordinator of Services for the Elderly should have detailed knowledge of respite options available in their area, and should assist the case manager in planning and implementing appropriate respite care strategies, based on the expressed needs of carers.

*11. We recommend an increase in the number of respite beds in community hospitals to a norm of 1:10,000 elderly population and the development of in-home respite services for people with dementia as a mechanism for providing relief for carers and ensuring their long-term ability to care for the person with dementia.*

#### **6.4.6 Home support services**

Home support services for people with dementia comprise community nursing services, home help services, and home sitting services. Although home support services exist to some degree in each health board area, it has been reported that 87 per cent of those caring for people with dementia in the home could be categorised as receiving a low level of domiciliary support (Ruddle & O'Connor, 1993). The public health nursing service is not adequately resourced, nor is the service adequately supported by back-up services. The public health nurse does not have the time or the special training to provide optimal care for people with dementia living at home. The paucity of community psychiatric nursing services also means that the public health nurse is often very much on her own in dealing with people with dementia with behavioural problems.

The home help service is regarded as a key service in home care for older people. Unfortunately, the home help service is still a discretionary service, which contributes to variability of provision and eligibility across the country (Lundström and McKeown, 1994). Existing services are also not flexible enough. The service is not always available out of hours, or on an emergency basis. A further problem in this area is that the services provided are generic, which means that few, if any, workers are trained in communication and management of people with dementia.

Home sitting services are very beneficial to people with dementia and their carers as they allow care and respite in the home with as little change to routine as possible. They are of particular benefit to people living in rural areas as they can offer an alternative to day care, or respite care, which is sometimes difficult to access from a rural area. They can offer structured periods of care and

support to people with dementia who can be managed better in the home setting. However, sitting services have yet to become part of mainstream service provision. At the moment only a minority of people with dementia are receiving home sitting services, despite evidence that carers value relief care very highly. Training for home sitters is a critical issue if the service is to be developed on a comprehensive basis. Low rates of pay make it difficult to recruit people to work in home care and home sitting services. Organisations who currently provide training for people working in home-based services report a high rate of turnover as workers are attracted to better paid jobs. The provision of all home support services on a statutory basis would permit a more co-ordinated response to the problems of people with dementia and allow services to be more easily monitored and evaluated. It would also help to alleviate regional disparities in service provision which currently exist across the country. There is a clear need for more resources for home nursing, home help and home sitting services. Some of the increase in resources should go towards investment in the training of home workers in the area of dementia. Trained personnel are crucial to the quality and success of this service.

There is also a need for additional resources for the provision of ‘twilight’ services and weekend coverage for people with dementia. ‘Twilight services’ would involve an evening call from a nurse or care attendant (depending on the situation) to ensure that the person with dementia is safe and secure, has his or her medication, is in bed and so on. This service may be especially valuable for people living alone with mild or moderate dementia. The appointment of case managers with responsibility for the monitoring and management of patient-specific services would contribute to a co-ordinated service and ensure flexibility and continuity in home support provision. Continuity of care is a very important issue. High turnover of workers leads to discontinuity and can be very confusing and upsetting for the person with dementia and their carer.

*12. We recommend the provision of flexible, continuous and legislatively based home support services for people with dementia.*

#### **6.4.7 Other community care services**

Occupational therapists, social workers, physiotherapists and speech and language therapists have an important contribution to make to the care of people with dementia. Occupational therapists focus on the treatment of the whole person with emphasis on activities of daily living, dressing, eating, grooming, and hygiene. Their main aim is to restore, maintain or lessen decline in the person’s functional abilities. Social workers have an important role in protecting the rights of older people, including guarding against exploitation or

abuse. They also play an important role in providing support and advice to the carers of people with dementia. A key aspect of the social worker's role and expertise is in the area of mediation and negotiation with families, particularly when conflict arises. Physiotherapists focus on recovering functional body movement and mobility. They can also design individualised therapeutic programmes to restore balance, strength, co-ordination and ability to walk. Their main aim is to maximise the person's abilities to allow the greatest level of independence possible within the limitations of dementia. Speech and language therapists focus on improving quality of life by maximising communication ability and cognitive function.

While each of these services are important, and should be accessible to people with dementia, occupational therapists and social workers should be included as part of multidisciplinary teams providing geriatric medicine and Old Age Psychiatry services. For this to happen, there needs to be a greater recognition of the potential contribution that occupational therapy and social work make to care for people with dementia. Access to both of these services in the home is currently very limited and there is an unwillingness to sanction elderly-specific provision for these services. Heavy caseloads also place huge demands on existing providers and restrict the amount of time that can be devoted to people with dementia. Social work should also be developed in its own right as an important community care service. The current limited provision of community-based social workers for elderly people is unsatisfactory and needs to be remedied as a matter of urgency.

*13. We recommend the development of community-based occupational therapy services and social work services for people with dementia living at home.*

## **6.5 Conclusion**

The majority of the needs of people with dementia and their carers should be met by what is put in place at the level of primary and community care. This involves the provision of a flexible network of services that will meet the changing needs of those with dementia and their carers. The dignity and autonomy of people with dementia will be best served by the development of individualised care plans mediated through case management structures. General practitioners are critical agents in the process of care since they are often the first people involved in making a diagnosis of dementia. The public health nurse service is also critical since nurses are likely to see most of the vulnerable people with dementia living at home, and provide a link to many of

the support services that people with dementia need and value. Day centres are also an important component of care provision for people with dementia. People with milder degrees of dementia and who have no behavioural problems can be managed in general day centres that are available to all elderly people in a particular community. People with severe dementia, or who have problems with wandering, will require specialised dementia day centres at primary care level, as currently provided by the Alzheimer's Society in some parts of the country. Respite care, both in-patient and at-home types, is also important depending on the stage of the disease and the particular needs of patients and carers. Whatever the service, the key element in primary and community care is flexibility of supply in response to the expressed needs of people with dementia and their carers.



## **Chapter Seven**

### **Pathways to Care: Secondary Level Care**

#### **7.1 Introduction**

In the previous chapter we have argued that the majority of the needs of people with dementia and their carers should be met by what is put in place at primary and community care level. However, there are some people with dementia who will require the services of specialist dementia teams in response to the complexities arising from their condition (Ely *et al*, 1997).

These specialist teams form the backbone of secondary level support services for the more complex cases presenting in the primary and community sectors. Secondary level services in this country are two in number: Medicine for the Elderly and Psychiatry of Old Age. The role of Medicine for the Elderly lies with both the diagnosis of dementia and the assessment and management of people with dementia who have medical problems. The cases seen by Medicine for the Elderly include people who have medical problems that are beyond the remit of the general practitioner and those who present with diagnostic problems.

Psychiatry of Old Age is the mirror image of Medicine for the Elderly in that instead of dealing with physical problems, it deals with mental health problems in older people. The service has specific responsibility for people with dementia who have severe behavioural problems, such as aggression, associated with their dementia, or psychiatric symptoms such as delusions, depression, or anxiety associated with dementia. Like Medicine for the Elderly, Psychiatry of Old Age may also play a role in diagnosis but continued involvement in such cases usually only occurs where there were associated behavioural or psychiatric symptoms.

#### **7.2 Psychiatry of Old Age**

Psychiatry of Old Age covers all psychiatric disorders in old age. Referrals to the service include people developing functional psychiatric illnesses, such as depression, for the first time over the age of 65 years and people with dementia and associated behavioural or psychological problems. The type of behavioural problems associated with dementia includes aggression, agitation, and disinhibited sexual behaviour. Psychological symptoms associated with dementia include anxiety, agitation and delusions. Both behavioural problems and psychological problems have major affects on the quality of life of sufferers

and their families, leading in some cases to premature institutionalisation. Most patients are referred by general practitioners, although referrals are also made by geriatricians, general hospital-based consultants, and psychiatrists. The management and treatment of patients is community-based whenever possible. Domiciliary assessment and day hospital treatment are important elements of the service. The community psychiatric nurse also plays a crucial role in supporting patients and carers in the home. Some patients will inevitably require admission to in-patient care, for instance the seriously depressed who are suicidal or not eating, or those with dementia who are extremely agitated or aggressive whose behaviour cannot be managed at home.

The first Psychiatry of Old Age service to be established in Ireland was the service for North Dublin, set up in January 1989. Since then, three more services have been established; Dublin South Central associated with the Martha Whiteway day hospital; Dublin South East based in St. Vincent's hospital; and a service for Limerick city based in St. Camillus' hospital. There are plans for the development of additional Psychiatry of Old Age services in five other centres across the country: Tallaght, Cavan/Monaghan, Donegal, Portlaoise and Waterford, but, at the time of writing, there are still only four services operating. With only four services, existing coverage is very weak amounting to approximately 15 per cent of the population aged 65 years and over. The concentration of existing resources in Dublin also leads to major inequities in terms of geographical spread of the service since only those people living in the catchment area served by a Psychiatry of Old Age service can avail of it.

The Psychiatry of Old Age services that do exist are described in some detail in Keogh and Roche (1996). Their activities are broadly similar and correspond to the general framework of provision outlined in previous paragraphs. It is useful to focus briefly, however, on the more important aspects of the service.

Domiciliary assessment is an essential ingredient of the service as it brings the service to people who need it. Assessment by the psychiatrist includes taking the history of the patient and a mental status examination. The coping skills of the patient and the family are assessed, and the adequacy of the home is established. The majority of patients receive home-based management. The role of the community psychiatric nurse (CPN) is very important in maintaining the person with dementia in his or her own home environment. The CPN monitors patients in the home, acts as a liaison person with family carers and the statutory services, and generally offers practical and emotional support for patients and carers.

Day hospital provision is also an important part of Psychiatry of Old Age services. The day hospital offers separate care and support for two groups of patients: people with functional mental illness and people who are disturbed secondary to dementia. Staffing in the day hospital usually includes psychiatric nurses, consultant psychiatrist, psychiatric registrar, occupational therapist, and psychology input. Social workers also play an important role in the provision of services. The role of the day hospital is critical in maintaining people with dementia in the community. Evidence from Corcoran *et al* (1994) gathered from the two-day hospitals associated with The North Dublin Psychiatry of Old Age service suggests that the day hospital provides a satisfactory process of care for patients with functional mental illness with low usage of beds. For optimal effectiveness, the day hospital must be part of a continuum of care, and must be linked to both community care and in-patient care in an integrated way. At present the CPN performs an important liaison role, backed up by the social worker. This task is critical to the current success of Psychiatry of Old Age services and must be protected and expanded within any new case management model of care.

There are patients with mental illness who are too unwell or disturbed to be managed at home. These patients will require in-patient treatment in an acute psychiatric unit sited ideally in a part of, or adjacent to, an acute general psychiatry unit. A critical component of existing Psychiatry of Old Age services is that patients have ready access to acute medical and psychiatric services when the need arises. People with dementia with severe behavioural problems who are not responding to treatment and who are not manageable elsewhere may need long-stay psychiatric care, with appropriate care on wards staffed by psychiatric nurses. The availability of acute and long-stay psychiatric beds is critical to the operation of the Psychiatry of Old Age service. Without them, the service is not properly resourced.

Psychiatry of Old Age services remove the element of crisis management from dementia care, allowing a more structured and considered approach to the care of people with dementia with behavioural and psychological problems. The multidisciplinary approach to care facilitates good management of patients and allows for a comprehensive provision of services. In areas where local psychiatric services have responsibility for older people, which is in most part of the country, services, although valuable, are not as complete or as comprehensive due to the limited input from psychiatric social workers, occupational therapists and psychologists. Neither are psychiatric services always as well integrated with other parts of the care system as is the case in areas served by Psychiatry of Old Age services.

### **7.3 Geriatric medicine**

Geriatricians have pioneered specialist care of dementia in Ireland with the first surveys of cognitive impairment in the community in the late 1980s (O'Neill *et al*, 1988; O'Neill *et al*, 1989) and the development of the first memory clinic for the assessment of dementia and related disorders in the 1990s. Dementia forms an important part of the training of geriatricians along with acute brain failure (otherwise known as delirium) and in many parts of Europe geriatricians form the front line of specialist dementia care. Departments of geriatric medicine play a major role in relation to diagnosis and have particular expertise in dealing with dementia occurring with other medical abnormalities. In Ireland, geriatricians work closely (where possible) with psychiatrists of old age and with general psychiatrists. The referral of patients between geriatricians and other specialities depends on local preferences and perceptions as well as on the presenting problems of the patient. Where referral and co-operation exists the gains to the patients and their families are immense. When the integration of medical and psychiatric services is less than optimal the quality of care is significantly reduced, much to the frustration of patients, families and staff.

#### **7.4 The development of services**

Sometimes people with dementia require access to more specialist services for an assessment of their condition. In Ireland, geriatricians tend to see dementia patients with medical problems, neurologists tend to see early onset cases of dementia, while psychiatrists tend to see dementia patients with behavioural problems. The Psychiatry of Old Age service is an important element of dementia assessment and care for certain categories of people, but there are currently only four old age psychiatrists in the country. Those involved in existing old age psychiatry services recommend that there should be one whole time equivalent consultant in the Psychiatry of Old Age per 100,000 population. Given that 11 per cent of the population is over 65 years, this ratio suggests that there should be 40 consultant posts in Psychiatry of Old Age in Ireland. The recent promise of five additional posts in this area is an advance on existing provision but the service currently remains underdeveloped, especially outside of the main urban centres.

Although the Psychiatry of Old Age service is hospital-based, it should be community-oriented. The service has a very important role to play in relation to diagnosis and specific treatment of behavioural and psychiatric problems. The behavioural problems associated with dementia are often temporary, making the provision of an assessment and treatment service in the home, backed up by the option of short-term admission to psychiatric care, if problems are very severe, preferable to residential care as the only option for these patients. Close relationships between the service and the GP can also help to increase GP

awareness of the benefits of an early diagnosis and appropriate treatment for behavioural problems in the community. A Psychiatry of Old Age service can further help to educate doctors in the management of dementia, and provide important support for doctors in decision-making about placement.

An effective Psychiatry of Old Age service must be adequately resourced and multidisciplinary in terms of the services available to patients. Each Psychiatry of Old Age service should be staffed by a multidisciplinary team headed by a consultant and comprising registrars, community psychiatric nurses, occupational therapists, psychologists and administrative support. The inclusion of psychiatric social workers on domiciliary assessment teams is also recommended as an important element of good practice. The service must be backed up by a day hospital and by appropriate outpatient facilities. Patients must also have access to acute psychiatric beds and long-stay beds, both psychiatric and non-psychiatric.

The structural requirements of the Psychiatry of Old Age Service are as follows:

- one acute dementia bed per 1,000 population over 65 years
- two day-hospital places per 1,000 population over 65 years
- three continuing care places per 1,000 population over 65 years

*14. We recommend the adoption of a planning norm of one consultant in old age psychiatry per 10,000 people aged 65 years and over, each being provided with an appropriate multidisciplinary team and psychiatric facilities, including a day hospital and acute and long-stay psychiatric beds together with good access to non-psychiatric day and residential care.*

The role of the community psychiatric nurse in providing psychosocial interventions in dementia is undervalued in this country, with an inadequate provision of resources in this area. Community psychiatric nurses have the special skills required to address the special needs of cognitively impaired older people living in the community. They enhance the capacity of people with dementia and associated behavioural problems to live independent lifestyles in their own home (Dellasega and King, 1996). Community psychiatric nurses also have an important liaison and co-ordination role in the community, as well as providing valuable support for public health nurses. The development of community psychiatric nursing services up to a ratio of one nurse per 4,500 people aged 65 years and over is recommended as a suitable planning norm for this service. It is also suggested that post-graduate nurse training courses in Old

Age Psychiatry be established to encourage nurses to move into Old Age Psychiatry.

*15. We recommend the adoption of a ratio of 1:4,500 elderly population for community psychiatric nursing services within the framework of an expanded Old Age Psychiatry service.*

There has been a significant increase in the number of specialist geriatric medicine departments in the past ten years, as reported in Ruddle *et al*, (1997). Unfortunately, the development has been somewhat uneven across the country, with little or no development in the Southern and North Eastern Boards. Similarly, the number of geriatricians who work full-time on the care of older people is not spread evenly across the country leading to differences in the type of care available across the different health boards. None of the health boards have reached the recommended norm for assessment beds and only two, the Midland and the Southern, have reached the recommended norm for rehabilitation beds. It is critical that departments of geriatric medicine are adequately resourced and have the ability to be truly interdisciplinary in terms of services available to patients. Not all of the existing departments are adequately staffed with full interdisciplinary teams, which dilutes their overall effectiveness, particularly with respect to the care and treatment of people with dementia. Geriatricians and psychiatrists of old age can, and do, work together caring for patients with different profiles of medical and behavioural problems, but they must have the multidisciplinary resources for maximum impact and the most effective delivery of services (Beck *et al*, 1998).

*16. We recommend that geriatric medicine facilities be adequately staffed with full interdisciplinary teams, and encourage close co-operation between geriatric medicine and Psychiatry of Old Age services.*

People with dementia may first come to the attention of the health services as in-patients in acute care hospitals, or as patients in accident and emergency units in acute care hospitals. More attention needs to be paid in acute care settings to the identification of people with dementia. Where dementia is suspected a formal assessment should be made by the appropriate specialist services, which in the majority of cases will be located in departments of geriatric medicine. People with dementia should continue to have the same access to acute hospital services as other patient groups, but their special needs must also be recognised and accommodated in the hospital sector. Training is

again critical in raising awareness about dementia in acute care settings. To facilitate developments in this area, there should be under-graduate training for medical students in the area of dementia with chairs in geriatric medicine and the Psychiatry of Old Age in each of the universities.

*17. We recommend dementia awareness training for medical and nursing staff in acute hospitals, particularly for people working in accident and emergency departments, to help them identify the symptoms of dementia in patients under their care.*

*18. There should be under-graduate training in dementia for doctors, and chairs in geriatric medicine and the Psychiatry of Old Age in each of the universities.*

## **7.5 Conclusion**

Secondary level care services, mainly in the form of Psychiatry of Old Age and geriatric medicine, are an important component of services for people with dementia. The problem is that Psychiatry of Old Age services are under-developed in Ireland. Consequently, there is an urgent need to accelerate the development of Psychiatry of Old Age services beyond the limited, urban-based services that are currently available in the country. This will require significant investment in community and residential facilities, including the provision of additional day hospital places. The care of people with dementia with complex behavioural and medical problems is ultimately a shared responsibility involving community and hospital-based professionals, including specialists in Old Age Psychiatry, geriatric medicine, Psychology, and in some instances Neurology. Multidisciplinary teamwork is, therefore, a critical element of the shared approach to the delivery of services to people with dementia. To ensure effective secondary care provision, existing services must be expanded and linked through more formal models of co-ordination and co-operation, associated with evolving case management structures.

## **Chapter Eight**

### **Pathways to Care: Residential Care**

#### **8.1 Introduction**

The emphasis in this chapter will be on the sizeable minority of people with dementia who receive care in residential settings in both the public and private sectors. The vast majority of people with dementia who are in residential care in Ireland are cared for within generic elderly care facilities. Unfortunately, due to budget constraints, we did not have the time to visit the range of long-stay facilities in the country. Consequently, we had to rely on the consultation process for information on best practice in the provision of residential care. What is clear from the people we talked to is that the residential care needs of people with dementia, even those not suffering behavioural or psychiatric problems, are likely to be different to other patients. Indeed, given the heterogeneity of dementia, differences within the group of people with dementia may be greater than the differences between some older people with dementia and older people without dementia. For these reasons, the type and scale of accommodation available to people with dementia is important, as is the process of care within long-stay institutions.

The emphasis in this chapter is on environmental and therapeutic issues in both public and private residential care. We will discuss the physical environment and design of buildings and the contribution each makes to the quality of life of residents and staff. Therapeutic issues are discussed within the framework of the process of care within residential facilities. Process is concerned with the delivery of care in residential settings, including training issues and the level of communication between staff and patients.

#### **8.2 Physical environment and design**

Long-stay care for people with dementia in Ireland currently occurs in five residential types: health board geriatric homes, welfare homes, district hospitals, private nursing homes and voluntary homes. While we have estimates of the number of people with dementia in each type of care, the figures that are available are likely to be significantly underestimated (Browne, 1996). Therefore, while we can speculate that somewhere between 6,000 and 9,000 long-stay residents, equal to approximately one third to one half of all residents (Ineichen, 1990), suffer from dementia we cannot be sure of the validity of these figures. The absence of hard information on this issue is surprising, given the availability of sophisticated assessment scales to measure cognition, and the



captive nature of the population under observation<sup>4</sup>. It is difficult to plan for care in residential settings, particularly in the area of nursing care and the skills mix of providers when the accuracy of population estimates remains an issue. This deficiency in data collection needs to be resolved immediately through a careful audit of dementia in long-stay care settings.

The majority of people with dementia who are in residential care in Ireland are looked after in generic long-stay facilities (see Table 4.2). Care in public institutions has evolved along workhouse lines, with the emphasis on physical and medical needs rather than on the needs arising from cognitive impairment. It is easy, therefore, to agree with the recent recommendation of Ruddle *et al*, (1997) that health boards should provide residential accommodation adapted to the individual needs of the person with dementia as a matter of urgency. The private sector has been equally reluctant to invest in special facilities for people with dementia. Very few private nursing homes have developed special accommodation, or design features, for people with dementia, due mainly to the cost of such adaptations. Environmental design is now widely regarded as crucial in the care of people with dementia. Some people have argued that design is as critical an ingredient in residential care as nursing care, or the approach to the organisation of care within the facility (Calkins, 1988). Good models in environmental design emphasise smallness, normal domestic facilities, appropriate decor linked to the memory of residents, appropriate stimulation, easy access, and opportunities to observe the daily life of the unit (Fleming and Bowles, 1987).

The focus on design, linked to consumer preference and empowerment, is evident in more recent residential developments for people with dementia in other countries. Marshall, (1993, 1997) is a good example of current thinking on design, emphasising as she does small-scale units, home-like environments, visual landmarks, controlled stimuli, single rooms furnished to the taste of residents, and safe outside and/or conservatory space. While most of the work on design has been centred on residential care it is important not to forget the role of home environmental modifications, given the fact that the majority of people with dementia live at home. This is a neglected area of enquiry but one which is very important given the impact of environment on the well-being of people with dementia wherever the location (Gitlin and Corcoran, 1996).

A growing trend in other countries has been the development of specialist care units (SCUs) for people with dementia, attached, more often than not, to

---

<sup>4</sup> It is acknowledged that assessment is broader than the application of cognitive assessment scales and requires longitudinal data on patient behaviour, including information on family history.

mainstream long-stay facilities (Woods, 1995; Downs and Marshall, 1997). This development recognises that some people with dementia require in-patient care geared to their particular needs. There is no standard definition of a special care unit, although experts in dementia care agree on the following five characteristics (Mentes and Buckwalter, 1998):

- admission of residents with cognitive impairment
- staff specification, selection and training
- activity programming for the cognitively impaired
- family programming and involvement
- segregated and modified physical and social environment

The scale of the operation is a very important consideration in SCUs. The emphasis is on smaller sized units, designed and fitted to resemble a home away from home, offering appropriate activities, a spatial layout to facilitate wandering, and attention to colour and sound. Existing SCUs vary in terms of size, structure, philosophy of care, staffing and organisation, and cater for very diverse populations (Lefoy *et al*, 1997; Williams and Trubatch, 1993). The heterogeneity of provision in this area makes it difficult to pass judgement on the overall effectiveness of these units. The development of a consensus on whether SCUs are effective, and if so, how and for whom, is, therefore, likely to be a slow process (Sloane *et al*, 1995; Mentes and Buckwalter, 1998).

Nevertheless, SCUs are an increasing feature of the residential landscape. The Confused and Demented Elderly units (CADE) in New South Wales cater for people with high levels of challenging behaviour in eight-bed units. In the United States, SCUs tend to be designed with the needs of the mid-stage dementia resident in mind (Kovach, 1996). In Sweden, group homes have been developed as an alternative to traditional residential care. Suitably adapted ordinary housing is used to promote the domestic and social abilities of people with dementia. In France, small units for dementia sufferers are also a feature of the care landscape, with the emphasis again on homely provision of care in a secure and safe environment. In the UK, the Domus Project facilitates new patterns of group living, where people with dementia largely fend for themselves, with support from appropriate care services. The results from the Domus Project are positive with evaluations showing more interaction among residents, less depression, and a lower rate of general decline, than for people with dementia in conventional residential settings (Dean *et al*, 1993; Murphy *et al*, 1994). There is strong international support for the positive impact of small scale residential settings, providing homely care in an appropriate physical environment, on the quality of life of people suffering from dementia (Carr and Marshall, 1993). This explains why the general policy trend in most countries

is for this size and type of structure, although the proportion and type of people with dementia in such settings varies from country to country.

There are some specialist dementia units in this country, but there is no universal approach to the care of people with dementia in residential settings. People with dementia without significant behavioural problems tend to end up in conventional generic long-stay facilities, both public and private, while people with challenging behaviours tend to be treated in psychiatric institutions. During the consultations process we heard many stories of the difficulty of getting ambulant dementia patients with only mildly disruptive behavioural problems into long-stay facilities, especially into private nursing homes. This is an unsatisfactory state of affairs and one that must be addressed immediately through the provision of small-scale, domestic-oriented, specialist units associated with mainstream long-stay facilities. Mostly, this will only require the modification and adaptation of existing buildings, but new investment may be required in some cases. Some people with dementia and associated behavioural problems will continue to require long-stay psychiatric care. Design and environmental issues are equally important in this setting.

The Alzheimer unit attached to Highfield in Dublin and the order of St. John of God nursing home in Shankill, Co. Dublin are good examples of what can be achieved when attention is given to the issues of staffing, environment and design for people with dementia. Similarly, the recent establishment of a dedicated dementia unit in St. Mary's long-stay hospital in Castlebar is a good example of what can be achieved through the fusion of geriatric and psychiatric services with the objective of an improved service for confused elderly people needing specialist care. Staffing and training, combined with physical environment and design, are the key ingredients for a more person-centred approach to residential care for people with dementia.

*19. We recommend the provision of small-scale, domestic-oriented, specialist units attached to conventional long-stay facilities for people with dementia without significant behavioural problems, but who need long-stay care.*

### **8.3 Process of care**

Process also matters in the care of people with dementia in residential care settings. That is why there should be more experimentation with different models of care for people with dementia in long-stay care. We need to explore and evaluate different psychological care strategies which highlight and nurture the resourcefulness of people with dementia in both residential and community

care settings (Chapman *et al*, 1994). The evidence with respect to the effectiveness of various strategies available is sparse, but there are an increasing number of therapies and activities which challenge what Downs (1994) calls 'the therapeutic nihilism commonly found in the care of people with dementia'.

Reality orientation was the first attempt to recognise the personhood of people with dementia and to deal with the orientation problems associated with dementia (Holden and Woods, 1995). This was followed by validation therapy (Feil, 1982) and resolution therapy, both of which seek to highlight the feelings and emotions of people with dementia, including their ability to communicate with other people. Reminiscence therapy for people with dementia is very popular in day and residential settings (Woods *et al*, 1992). While there is no evidence that reminiscence therapy improves cognitive function, it can, and does, bring a lot of pleasure to people with dementia and facilitates communication within groups (Gibson, 1994). Religion is an area which retains meaning for many people with dementia, and for these people old hymns, prayers and devotional rituals (of their own denomination) may be a very important element of reminiscence therapy. The spiritual needs of people with dementia are, of course, important in their own right and opportunities must be available for continued participation in religious observance.

There are also many different types of expressive therapies that seek to provide stimulation for some, or all, of the senses, as a way of addressing impoverished communication and interaction among people with dementia. There is good evidence of the positive affect on music on some categories of people with dementia (Holden and Woods, 1995; Kneafsey, 1997). The Sonas aPc approach provides stimulation for all the senses, using music and the sense of touch to create a relaxed and safe environment for participants, to encourage and activate the potential for communication in people with dementia. The feedback from residents, relatives and staff in the residential units where the programme has been run is unambiguously positive (Linehan and Birkbeck, 1996). There are positive affects for patients and staff during the administration of the programme and improvements in general spatial orientation, independent functioning, and the use of initiative were also identified in the three months following the programme.

To facilitate a greater emphasis on the social and emotional needs of patients in residential facilities, and to provide scope for the individualised provision of care to people with dementia, management and organisational structures will have to become more flexible (Gilloran and Downs 1997). A person-centred approach to care for people with dementia is a critical ingredient for good quality care provision. Good management practice is a necessary pre-requisite for a person-centred approach to care. So is a comprehensive training strategy

for all staff working with people with dementia. In-service training has been identified by Gilloran *et al* (1995) as contributing to overall high levels of staff morale which can only be good for patient care. The lack of suitably trained staff in both public and private residential care settings was reported many times during the consultation process. There was unanimous agreement among the people we spoke with that training for people providing care in residential settings should be a priority. New training programmes are needed which would focus on the attitudes and technical competence of staff, and on ways of promoting person-centred models of care delivery to people with dementia. The Sonas programme should become an essential component of new training programmes for people working in residential care. Recent advances in technology should also be examined for their usefulness in supporting habilitation, social and intellectual stimulation, care, security and surveillance.

The existing regulation of long-stay provision for elderly people, including people with dementia, is too concerned with technical issues, mainly related to infrastructure and finance, and not concerned enough about models of care provision within both the public and private systems of care. The individual needs of demented patients as people are often overlooked by care providers when the prevailing approach to care is based on a routine model (Downs and Marshall, 1997), or worse still, a rejective model of care (Liuokkonen, 1992). Kitwood, (1993) talks about the concept of the person in dementia care, and the need to move towards an interpersonal, genuinely communicative, and moral psychology of care. To achieve this objective we need to know much more about existing care relationships among health professionals, family carers and patients. We need better information systems for the routine generation and collection of data on process in both community and residential care facilities. Information about people with dementia learned while the person attended community care services, such as day care, should be transferred to residential care settings should that person have to enter long-stay care. This information will be very useful for staff in residential care settings in their efforts to treat the new patient as a unique person (Berenbaum, 1997). Finally, we need a more active role for patients and their families in the assessment and planning of services.

20. *We recommend that social, psychological, artistic and sensory/communication needs be given equal weighting to physical needs in residential care settings, and that management structures support a holistic and person-centred approach to care.*

*21. We recommend the development of effective training programmes for staff working in all types of residential care facilities. These training programmes should be designed to facilitate a person-centred approach to care and service delivery.*

## **8.4 Conclusion**

Residential care for people with dementia should be provided in small-scale homely environments. This has not been the case in Ireland in the past. New investment is required if we are to follow the international trend towards small, safe, domestic-style accommodation for people with dementia. There is also an urgent need to invest in design features in long-stay accommodation, given the accumulating evidence on the affect of design on the functioning of people with dementia. Design features have largely been ignored in the provision of long-stay facilities in this country. The process of care in residential care is equally important. More attention should be focused on the social and sensory needs of people with dementia through the support of various psychosocial interventions such as reminiscence therapy, validation therapy and reality orientation in the early stages of dementia. Expressive therapies, including music and touch, should also receive more attention as therapeutic approaches to care for people with dementia. Training for staff will be an important aspect of more effective residential care for people with dementia. So also will the ongoing monitoring and dissemination of models of best practice leading to the eventual elimination of sub-standard accommodation and poor quality care.

## **Chapter Nine**

### **Special Need Groups**

#### **9.1 Introduction**

The application of EURODEM prevalence rates to Ireland suggests that there are approximately 2,000 people with dementia under the age of 60 in the country. There was a lot of concern expressed during the consultations process about the special characteristics of early onset dementia and the absence of special programmes for people in this category. Younger people with dementia do not fit easily into the services designed for their older counterparts (Department of Health and Social Services, 1995). It may sometimes be the case of choosing from a range of services set up with other needs, or age groups, in mind. Younger people with dementia will more than likely react differently to the disease than people in older age categories. They tend to be more physically fit and active and to have more responsibilities in terms of employment and families. There may be difficulties with diagnosis, sometimes related to general practitioners having very little experience with early onset dementia. Public awareness of early onset dementia is also low, leading to potentially more stigma being attached to the problem in younger people. We are only now recognising that people with early onset dementia have service needs that are unique and distinct from their older counterparts.

#### **9.2 Early onset dementia**

There are a number of groups with dementia who fall into the category of early onset dementia. While early onset dementia mainly comprises people affected by Alzheimer's disease and cerebrovascular disease, a sizeable proportion of younger people with dementia have developed it alongside other disorders such as Down's Syndrome, Parkinson's disease, Acquired Immune Deficiency Syndrome (AIDS), Huntington's disease, Creutzfeldt-Jakob disease, and alcoholism. Early diagnosis of younger people is very important since up to 10 per cent of early onset dementia may be treatable. The diagnosis of early onset dementia is, however, challenging, and the symptoms may be often confused with other disorders and disabilities, such as depression, or migraine. Proper assessment and diagnosis is not helped by the fact that younger people with dementia do not fit easily into one medical speciality and may not always be seen by the right person.

The additional problems faced by younger people with dementia are many and varied (Cox and McLennan, 1994). Younger people with dementia are usually

still at work and many still have parenting responsibilities. People diagnosed with dementia may have to retire from work, while carers may also have to give up employment in order to care for them, leading to a double loss in income at possibly a critical stage in the life-cycle for both. The diagnosis is likely to come as a shock to all the family with considerable need for counselling and information on hearing the bad news. Younger people with dementia in the early stages of the disease are likely to remain partially aware of their impairments and depression, anxiety, and paranoid feelings are not uncommon (Whalley, 1997). The genetic implications associated with some of the causes of early onset dementia may also affect the abilities of families to cope with the situation.

There may also be an increased problem with regard to wandering and potentially aggressive behaviour in younger people with dementia given that they are likely to be fitter and more active than older people with dementia. This can cause huge strains within families trying to come to terms with the disease. Personal relationships may deteriorate, and friendships may come under strain. There may be much less tolerance for the behaviour of young people with dementia than there would for older people. Legal and financial affairs may also have to be dealt with immediately, given the suggestion that people with early onset dementia may have a more rapid deterioration in functioning than people diagnosed with dementia in later years. There may be a need to make arrangements for legal protection in the form of an Enduring Power of Attorney (EPA) to ensure that the wishes of the person with dementia are known and respected throughout the course of the disease. The main advantage of the EPA is that it enables older people to provide for the conduct of their affairs in advance of and in spite of mental capacity. For an extended discussion of the range of issues arising in this area the reader is referred to the recent publication by the National Council on Ageing and Older People, *The Law and Older People: A Handbook for Service Providers* (1998).

People with early onset dementia have great difficulty fitting into existing service provision. The evidence from the consultations for this report suggests that younger people with dementia fare worst of all when it comes to the appropriate delivery of services, both community-based and residential provision. Dementia-specific services, where they exist, are likely to be geared specifically towards people in older age categories. The existing services are, therefore, unlikely to provide for the specific needs of younger people with dementia. The services are unlikely to be sensitive to the age of the person, to take account of their emotional needs, or to pay much attention to the needs of younger family members who may also be carers. Early onset dementia cases are likely to fall through the cracks in the system, with people ending up in



inappropriate care settings following a placement crisis on foot of a breakdown in family caring structures.

The optimal response to dealing with the problems of people with early onset dementia centres on the delivery of person-centred packages of care designed to keep the person living in the community for as long as possible and practicable. In that sense the optimal approach is no different to the approach to care for older people with dementia. However, the special needs of younger people with dementia and their carers, discussed above, need to be formally recognised in the delivery of care packages, with special emphasis on diagnosis, family counselling and emotional support, clinical management, social functioning, and innovative day care and respite care planning. There is a strong argument for the assignment of a key person in each health board with responsibility for ensuring that the needs of younger people with dementia are addressed within the proposed case management structures.

22. *We recommend 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.*

### 9.3 Down's Syndrome and dementia

A significant proportion of people with Down's Syndrome develop dementia in their third and fourth decades. Prevalence may be as high as 45 per cent in individuals over 40 years of age (Prasher and Krishnan, 1993), though the data for Ireland suggests much lower rates of between 8 and 14 per cent (Tyrell *et al*, 1996). Oliver and Holland (1986) found that the average age of onset of clinical signs of dementia in Down's Syndrome populations to be 38 years and the duration of dementia to be 11 years. Given that most people with Down's Syndrome are now living longer as a result of earlier medical intervention, there will be a larger number of people with dementia in this category in the future. The combination of Down's Syndrome and dementia presents important multi-disciplinary challenges to the health and social services and to families.

Diagnosis is difficult because dementia may be masked by the existence of learning disability in the person and by the presence of other conditions and complications such as hearing and visual impairment, or depression (Holland, 1997). The key to providing an appropriate response lies in the ability of the mental handicap and geriatric services to combine to provide appropriate services to people with the two conditions. People with a mental handicap and dementia should remain within the mental handicap programme, but should be able to receive specialist care from the geriatric programme. People working in the mental handicap services should receive training in dementia care.

Likewise, training in dealing with mental handicap is necessary for staff from the dementia services called in to support mental handicap specialists. While we need much more information on the needs of people with Down's Syndrome and dementia, an integrated and flexible approach to service delivery would go a long way towards improving the quality of life of people in this category.

*23. We recommend specially designed and integrated care packages for people with Down's Syndrome and dementia, delivered within the mental handicap programme, with training in dementia care facilitated by the Old Age Psychiatry and/or geriatric medicine services.*

## **9.4 Conclusion**

Younger people with dementia have the problem of not fitting into a specific category. Their needs are not always the same as older people with dementia. We need to develop appropriate and specific services for people in this category. We also need to be more aware of the needs of families given that early onset dementia occurs at a different stage of the family life cycle. Early diagnosis is important because younger people with the disease are likely to have more commitments and early diagnosis may provide an opportunity for families to plan for the future. Diagnosis is sometimes problematic, however, and this can be a difficult area for general practitioners and families alike. Families and patients need high levels of professional support at this critical time. Public awareness of early onset dementia is also low and tolerance for younger people with dementia is likely to be less than for older people. More shared information on the specific characteristics of early onset dementia would go some way towards developing an understanding among the public of the difficulties of younger sufferers.

## **Chapter Ten**

### **Policy Implementation Issues**

#### **10.1 Introduction**

This chapter concentrates on the key issues and relationships with respect to the implementation of this plan. For many years now the stated objective of public policy for vulnerable older people is to encourage and facilitate their independent living in their own home for as long as is possible and practicable. The emphasis on community care in official policy statements has not been matched by a significant increase in resources for the community sector. As we have seen earlier, community care services remain patchy and variable across the country with no scientific relationship between need and provision. Consequently, it is at the level of policy implementation that most attention should be focused if the increase in resources to community care, which is critical to the success of this plan, is ever to become a reality. Clearly, if the objectives set out in this document are to be realised structures will have to be put in place to monitor and evaluate the implementation of the plan.

There are three crucial relationships with respect to policy implementation: the relationship between the centre and the local; the relationship between the statutory and voluntary sector; and the relationship between the public and private sector. Each relationship is considered separately in this chapter. Multidisciplinary working and the relationship between service providers is also important for policy implementation given the involvement of so many different services and service providers in the care of people with dementia. Co-ordination, communication, and goal-setting are all critical to the success of multidisciplinary working. Each of these issues are discussed in the plan, but ultimately it is the willingness of the various providers to work together to develop team-based multidisciplinary solutions to dementia problems that will be critical for policy implementation.

#### **10.2 Monitoring and evaluation**

There is clearly a need for the implementation of this action plan to be monitored. This is standard procedure in places where similar plans have been put in place (Ageing and Disability Department: NSW Health, 1996; Howe, 1997). An implementation committee should be established, comprising representatives from the main agencies working in the field. The National Council on Ageing and Older People should also be represented on this committee. The committee should have a monitoring and review role with

respect to the plan and should be allocated adequate resources to allow it to function efficiently and effectively. The committee should develop performance and milestone indicators for the implementation of the strategies set out in the plan. The committee should report annually on progress with respect to the targets set out in the plan and produce an overall report on outcomes at the end of three years. The committee should also have responsibility for the evaluation of pilot projects and demonstration projects funded to promote good practice. To assist it in the task of data collection, the committee should draw on the resources of the Dementia Services Information and Development Centre at St. James's Hospital.

There are a variety of different approaches used to treat people with dementia, and not enough information on the relative merits of various strategies of care. Good practice needs to be identified and replicated; bad practice should also be identified and then eliminated. In that regard, the Dementia Services Information and Development Centre at St. James's Hospital can play a major role in effecting improvement and change in services for people with dementia in this country through the dissemination of information on both process and outcome in the field. For the centre to function effectively as a national agency, it is important that it develops good communication links with all people working in the area of dementia, in all parts of the country. The centre should be multi-disciplinary in staffing and orientation, reflecting the importance and value of a holistic approach to dementia, in keeping with what we know about optimal care strategies for people with dementia.

Issues of quality pervade all aspects of the care of people with dementia. However, data on quality of care in the dementia services are difficult to obtain and the ability to measure outcomes and assess service efficacy is particularly limited in this field. The care of a person with dementia is multifaceted with care inputs from a variety of health and social care professionals making it difficult to construct a single outcome measure based on a generalised health state classification system. There are also special problems in measuring quality in this field. Primary among these difficulties is the fact that a person with dementia is often incapable of evaluating the quality of care and communicating concerns about it because of cognitive difficulties. Both depression and challenging behaviour in the person with dementia may, of course, be a reflection on the quality of care, but this is very difficult to establish with any degree of certainty. The impact of care-giving on family members also needs to be established since care is an interactive relationship between carer and patient containing the potential to confer both positive and negative affects on carers (Schulz *et al*, 1995).

Notwithstanding these difficulties, there have been a number of attempts to measure well-being in people with dementia. There are single-attribute outcome measures available for each of the different domains associated with dementia (Ramsay *et al* 1995; Higginson *et al*, 1997). These domains include: physical health, activities of daily living, instrumental activities of daily living, psychological well-being, cognitive decline, inappropriate behaviour, social functioning, behaviour and effect, and consumer satisfaction. For carers the domains include the following elements: physical health, psychological well-being incorporating stress, burden and coping, social functioning, satisfaction, knowledge and skills, and co-ordination/communication. Most of the scales used in these various domains have been developed for the purpose of assessment and diagnosis, or to measure the effect of particular programmes (Lawton, 1991). The difficulty lies in combining the scales used to measure these various domains into one single outcome measure for people with dementia and their carers (Lawton, 1994). This is the challenge facing us with respect to measuring health and social gain in dementia care. In truth, outcome measures in this area are still at a very early stage and it will be some time before we can combine these measures to make judgements on the quality of care for dementia sufferers. At the same time, we need to move beyond simplistic and vague generalisations about outcome which unfortunately characterises much of the discussion about health and social gain in the health services. This will only be achieved through more research into quality of care in dementia services.

24. *We recommend the establishment of an implementation committee to oversee the development of this plan.*

25. *We recommend that the Dementia Services Information and Development Centre at St James's receives appropriate funding to allow it to function as a national centre for the identification and dissemination of information on best practice in dementia care in Ireland.*

### **10.3 Centre-local relationships**

The key relationship in the system for policy implementation is the one between the centre and the local. The principle of subsidiarity implies that centre-local relationships should be so arranged as to maximise the efficiency and effectiveness of intervention. Ideally this would mean that overall policy objectives would be clearly set by the centre, leaving the local to execute policy

in a uniform, yet flexible way, in response to community needs and preferences. This has not happened with respect to services for dementia. The policy-making function with respect to care of the elderly has remained under-developed, and policy for dementia has been subsumed under the Department of Health's general policy on older people. Health boards have not always complied with stated policy objectives, particularly with respect to the development of community care services for older people. The result is an absence of specificity with respect to dementia services, allied to an absence of uniformity and equity in care provision (Ruddle *et al*, 1997); a state of affairs that is at variance with what one would have expected in such a small country.

The absence of binding legislative criteria for the vast majority of community care services has contributed to the slow progress in effecting a significantly increased allocation of resources to care in the community. We need to replace the current reliance on ad hoc rules and administrative guidelines with national eligibility criteria for service provision. Service objectives and eligibility criteria for access to them should be governed by legislation (Commission on Health Funding, 1989), especially for community care services, allowing flexibility in mode of delivery but none with respect to provision. The difficulty lies in devising an appropriate legal framework that combines obligation and flexibility with respect to service provision. Mangan (1998) outlines the difficulties of developing a general legal framework for the provision of services, particularly one that would allow for innovation and imagination in the provision of services. Yet, the legal route may be the only way to overcome the current inequity in the provision of community care services across the country. It is only when essential community care services are available to everyone on the same basis that we can begin to talk about the desirability of local autonomy in the application of national policies to suit local community preferences and needs.

There are likely to be major implementation gains from renewed efforts at co-ordination and integration at the local level. Evidence from two experimental projects, aimed at improving the co-ordination of services at local level, points to the large benefits to be obtained from an integrated approach (Browne, 1992). Improved communication, better understanding and a sense of mutual trust among the various providers of care are the main advantages associated with this approach. These benefits are not inconsequential, given the generally fragmented approach to caring for people with dementia in Ireland. The whole area of co-ordination is, therefore, of central importance for effective policy implementation. For that reason, case management has been put forward in this plan as a solution to the problem of fragmentation in service delivery for people with dementia. Case management offers the best hope of providing integrated service delivery to meet the unique and differentiated needs of people with

dementia, thereby facilitating the achievement of the stated policy objectives of this plan.

*26. We recommend a renewed emphasis on meeting existing policy objectives for people with dementia and their carers, through legislatively based support for the equitable provision of community care services.*

*27. We recommend that services for people with dementia be delivered locally, in a flexible manner, within the framework of new case management structures, wherever possible.*

#### **10.4 Statutory-voluntary relationships**

The relationship between the statutory and voluntary sector also influences the implementation of policy. The voluntary sector, mainly in the form of the Alzheimer Society of Ireland and the Western Alzheimer Foundation, plays a major role in the community care of people with dementia, particularly in the areas of home sitting services, day care provision, and respite care. Yet, the voluntary sector is not fully integrated into decision-making at the level of policy formulation or policy implementation. The sector has little influence on management decision-making either at health board or at national level. As a consequence, the expertise of the voluntary sector is under-utilised, their contribution marginalised, their potential not fully realised. Voluntary provision is crucial to the health and independence of older people with dementia and their carers and must be formally recognised as such.

The absence of the voluntary sector from the policy process affects policy implementation in a number of ways. The most obvious is that the vast potential of the sector remains under-utilised. The residualisation of voluntary activity leads to the fragmentation of service delivery, leading to greater pressure being placed on the family care system. Of course, as Mulvihill (1993) points out, when everything is discretionary there is little reason to engage in planning and partnership in the delivery of care. If there were a more systematic relationship between the needs of people with dementia and resource allocation then this problem would not arise. This brings us back to the importance of legislatively based guidelines for community care services. It is only with the introduction of more explicit service targets that it will be in the interests of the statutory authorities to engage in true partnership with the voluntary sector with a view to meeting the stated objectives.

The funding relationship between the public authorities and the voluntary sector are far from optimal. The ad hoc nature of funding arrangements means that voluntary groups are rarely sure of their allocations ex-ante, thereby making planning very difficult. Sometimes funding is provided on a retrospective basis, leading to an even more tenuous budgetary situation for voluntary groups. Without guaranteed funding, linked to provider contracts, it is well nigh impossible for voluntary groups to continue to provide services in a structured and consistent manner. Not surprisingly, voluntary effort tends to concentrate in those areas where there is a better chance of public funding as witnessed, historically, by the concentration of much voluntary activity in the residential care sector. Even allowing for budgetary restrictions, this sector has provided the best hope of consistent funding from the statutory authorities over the years. Consistent funding arrangements for voluntary providers and the setting of targets for service delivery, based on an accurate assessment of local needs, would lead to a more efficient use of scarce voluntary resources.

28. *We recommend that the voluntary sector should be more formally involved in both the formulation and implementation of policy with respect to people with dementia and their carers.*

29. *We recommend more consistent and longer-term funding arrangements between the health boards and the voluntary groups providing services to people with dementia.*

## **10.5 Public-private relationships**

The interaction between the public and private sectors in care of people with dementia is mainly confined to the nursing home sector. The *Health (Nursing Homes) Act*, 1990 and the *Nursing Homes Regulations* which came into effect on the 1st September, 1993 govern the regulation and public subsidisation of long-stay care in private nursing homes. In particular, new criteria, based on an examination of the means and dependency of old people, are now used to determine the extent of public funding for the private long-stay sector. This has resulted in a large increase in spending on nursing homes, at least compared to spending in other areas, of approximately £65 million between 1993 and 1997. The integration of the private sector into public systems of delivery is more pronounced in some boards than in others, with the sector playing a major role in long-stay provision in the Eastern Health Board.



The most recent survey of long-stay units estimates that 23 per cent of admissions to nursing homes are due to dementia, amounting to approximately 1,500 people. However, the total number of people with dementia in private nursing homes is likely to be closer to 4,000 people, if estimates by O'Neill *et al* (1991) are correct. There has been little if any public policy acknowledgement of the implications of such a large dementia population in private care, either in terms of necessary care supports, or with respect to financing arrangements. Current subvention arrangements are a cause of concern to nursing home proprietors, as the maximum public subsidy for a person entering a private nursing home is £120 per week, which is equivalent, at the very most, to 50 per cent of the cost of care. This leaves a significant gap, for a large number of people, between what they are asked to pay and what they can afford to pay, even with a public subsidy. This causes financial worries for both patients and nursing home proprietors, and ultimately becomes a problem for the public sector. We have already highlighted the accommodation and design needs of people with dementia in private nursing homes. We are not likely to see much progress in this area, given existing public subsidy arrangements and the prohibitive cost of investment in new facilities.

The potential for co-operation between the public and private sectors with respect to placement procedures has not been exploited fully under the new legislation. There is a strong argument for a more uniform and standardised approach to assessment and admission in both the public and private sectors. Otherwise, differences will continue to exist in the ways, and the circumstances in which, decisions are taken to admit older people with dementia into long-term care, both between and within each sector. An elderly person seeking a subvention to enter a private nursing home should be subject to the same assessment procedures as a person entering a public long-stay institution. One possibility in this regard would be to use the resources of existing public long-stay hospitals to make decisions of this kind, based on uniformly applied dependency criteria. Indeed one might go further and make the case for a common assessment procedure for all nursing home admissions, whether an application for a statutory subvention is received or not (National Council for the Elderly, 1991). An assessment of this type would determine whether an older person was seeking care in a private home voluntarily, or whether the decision was forced on the individual and family because of the limitations of the available community care services. This, in turn, might focus attention on the need to stimulate the development of the community care option across the whole social spectrum.

One of the unwelcome by-products of the new legislation on private nursing homes is that the implementation process has drawn down resources that might

otherwise have been used to improve the community care system. In general, the financing of nursing homes should not occur at the expense of resources for community care. Accepting this principle means that subvention for nursing home care should never be granted unless it is clear that a similar subsidy would not have succeeded in maintaining the elderly person with dementia in their own home. The subsidy, if applied to community care, could be used to fund additional services in the areas of community nursing, home helps, day care and so on, as well as perhaps making some financial contribution to family carers. These services are vital in slowing down or preventing entry into long-stay care. It is only after assessment has been completed and a recommendation is in place to the effect that the elderly person should be moved out of his or her own home that the subsidy should be transferred to residential care.

*30. We recommend an audit of the number of people with different types and severity of dementia in private nursing homes; an evaluation of the public subsidy arrangements for these patients; and greater integration of public and private production in the care of people with dementia.*

## **10.6 Multidisciplinary working**

At the level of provision, there is an awareness of the importance of a multidisciplinary approach to care. We have seen this approach work very well in the small number of Psychiatry of Old Age teams in this country where the emphasis is on a comprehensive and holistic approach to care. For effective policy implementation, this multidisciplinary approach needs to be replicated throughout the care system with the emphasis on co-ordination, co-operation, communication, and a common set of objectives among team members. Family carers, must also be included as part of the working team, to form what O'Neill (1998) refers to as 'the coalition against dementia'. Case management is likely to be the most effective element in the integrative process. The case manager should be given the administrative and financial capacity to allocate resources on behalf of the person with dementia in accordance with the particular circumstances of each case.

A multidisciplinary approach to care is of little value if the person with dementia is outside the decision-making process. People with dementia must be placed at the heart of the decision-making process and their voice must be both heard and respected. We have to be careful, however, about what we mean by autonomy and self-determination for people with dementia because, with dementia, a person's ability to understand, reason, and respond is diminished. This leads to problems in the interpretation of the wishes of people with

dementia as the disease progresses. In an ideal world, people who are diagnosed sufficiently early would establish an Enduring Power of Attorney to ensure that their preferences for future care arrangements and the handling of their estate are known and respected. The problem of legal provision is that the person with dementia is deemed either competent or incompetent, with little room for manoeuvre in between. This does not fit easily with the gradually progressive nature of most types of dementia (Jacques, 1997). In the absence of legal provision, and where there are disagreements about the best course of action, multidisciplinary decision-making may be the best way forward, involving consultation between all people involved in the case. This approach may be expensive, but it offers the best hope of protecting the autonomy of the person with dementia, while recognising the limitations of the autonomy model in particular circumstances.

*31. We recommend a more formal emphasis on multidisciplinary teamwork in the care of people with dementia within the integrative framework of a case management model of service delivery.*

## **10.7 Conclusion**

This chapter has largely been concerned with issues of policy implementation. Current policy is based on a philosophy of independent living for older people within the framework of an expanded community care system. The problem is that the implementation of the policies necessary to achieve given objectives with respect to community care has been painfully slow. To avoid a similar fate for this document we suggest the establishment of an implementation committee to oversee the introduction of the plan. One of the main reasons for this state of affairs is the absence of any legislative expression of health care objectives in the form of explicit criteria for service provision. Policy implementation is not only about additional resources, though more would help. The real issue is the absence of binding legislative and administrative structures to ensure the implementation of those policies that are already agreed. Until such time as these structures are put in place then progress towards the community care objective is likely to remain slow.

The absence of the voluntary sector from the policy formulation process, as well as the weakness of their relationship with the statutory sector, has exacerbated the policy implementation problem. Neither has enough been done to release the considerable potential for complementary provision between the public and private sectors. An additional problem here is the tendency for subvention funding for private nursing homes to crowd out spending on community care

services. No one should be granted a subvention for private nursing home care unless it has been established that a similar amount of money would not have enabled him or her to remain in their own home. For those assessed as needing nursing home care, the subvention may have to be increased to reflect the additional needs of people with dementia in long-stay care.

## **Chapter Eleven**

### **The Social Economy**

#### **11.1 Introduction**

The recent comprehensive review of developments in care of the elderly since the publication of *The Years Ahead* report (1988) is critical of the slow rate of progress towards the development of a genuinely community-based approach to the long-term care of dependent elderly people (Ruddle *et al*, 1997). While there remains a general consensus that the long-term care of dependent elderly people should be located in the community, which is reiterated in this plan, not enough has been done in recent years to develop community care services in a way that would significantly improve the quality of life of old people living at home. There is uniform agreement that a major gap exists between the needs of dependent elderly people and service provision. This plan has outlined a strategy for meeting the needs of people with dementia in this country. We cannot, however, rely on increased public spending to solve all of the problems in this area, given the continuing constraints on social expenditure originating in our adherence to, and commitments arising from, the Maastricht criteria for Monetary Union. We will have to explore innovative ways of developing entrepreneurial supply-side responses to the problem of social need in the area of dementia. This chapter highlights the potential of the social economy in bridging the gap between need and existing provision of services for people with dementia living at home.

#### **11.2 The nature of the social economy**

The gap between the needs of people with dementia and the public and private resources available to meet those needs has focused attention on the possibilities of bridging that gap through the development of the social economy. The social economy is difficult to define with different groups using different definitions depending on the particular context at any given time. Most definitions include some combination of the following to describe social economy activity: community ownership, local control and benefit, decentralised, people-centred, models, and social objectives.

The social economy is most relevant where market failure exists, but the state cannot, or will not, intervene. In such circumstances, needs and demands arising from the market failure are met through community, voluntary, or co-operative forms of organisation, rather than through conventional public sources. Latent needs are transformed into effective demand through local community-based

innovative responses to the problem of provision. Thus delineated, the social economy is related to the concepts of the 'third sector' which comprises the voluntary, non-profit, and co-operative sectors. For people with dementia and their carers, need exists in relation to community nursing services, home care services, day care services, respite care services, and transport to facilities. The social economy has the potential to respond to need in all of these important areas.

Social entrepreneurship may be the key to expanding community care provision in the future. Social entrepreneurs are an important source of social innovation. They identify social need, but more importantly they identify new ways of addressing these needs, making use of existing social capital to create new forms of supply. Finding ways to stimulate social entrepreneurship at the local level will be an important part of any new strategy for dementia care in this country. Equally important will be strategies to stimulate demand for any new services from patients and families, and from the state. Innovation on the supply-side will have to be matched by innovation on the demand side if community services for people with dementia are to be expanded.

There is a dearth of information on why some communities are better than others in developing social entrepreneurs and innovative projects within the social economy field. Civic leadership may play an important role in developing the social economy. There are also indications that the previous involvement of community groups in training and education projects may provide a fertile ground for the subsequent identification and development of innovative social projects. Most of the social economy experiments have so far concentrated on work for females within the social care sector. For the future, seed funding will be required to encourage social entrepreneurship within a broader range of activities and people. This funding could take the form of capital grants, start-up grants, loan/credit facilities, or it might be confined to help with information gathering and training supports. Training and managerial programmes for providers will certainly be necessary, if opportunities are to be realised and exploited. A legal framework will also have to be developed if organisations working in the social economy are to become fully integrated with existing statutory providers of social services. This will involve the establishment of social care contracts between the health board and local providers.

### **11.3 Demand and supply issues**

While there is agreement that genuine need does exist among older people living in the community, the critical question is how to transform that need into demands which can be met within the social economy. To some extent, this

depends on the willingness of care recipients and their families to pay for the services provided in the new social economy, since this will determine the level of state support required for any new initiatives. Willingness to pay is, of course, influenced by the amount of income available to people. For many elderly people, and their immediate families, the amount of money that they have available to spend on community care services which are not currently being provided by the health board is very small, even allowing for recent improvements in the income position of older people in this country. If consumer resistance to charges and personal payment is high due to inadequate income, then demand may have to be stimulated by third party agencies through the use of mechanisms like designated vouchers for social services, thereby offsetting some of the cost for clients. Home equity schemes may also play an important role in the development of the social economy through the release of funds tied up in housing assets. The funds released from such schemes would allow older people who wished to remain in their homes the opportunity to buy in home care facilities and services that would make living at home much easier.

The social economy contains the potential to address some of the social care problems facing people with dementia and their carers. The development of both sides of the social market will require careful nurturing if progress is to be made. As part of this development, the institutional rigidities associated with existing forms of social services provision will have to be tackled. Currently, social care production is, by and large, controlled by the state, and administered through the health boards. This control exerts a powerful conservatism on the organisation of social care and serves to dampen any sustained attempts at innovation and development by local and community groups. If progress is to be made in meeting the needs of dementia sufferers and their carers, the hegemony that has been established by the state in the area of community care provision must be diluted. Partnership between the health board and local providers needs to be developed and nurtured through the appointment of development officers in each health board to foster co-operation between the two sides. This officer could explore the capital and financial needs of the social economy sector and identify areas where the sector could make a contribution to meeting the care needs of people with dementia. Given the enormous gap between need and provision in this country, and the success of locally based projects elsewhere (Gibson *et al*, 1996) now is the time to think about new ways of providing social care services and new ways of financing that provision.

32. *We recommend the development of the social economy and the nurturing of social entrepreneurship at a local level as a means of meeting the needs of people with dementia and their carers in a flexible and innovative way.*

## **11.4 Conclusion**

The social economy contains the potential to make an important contribution to the community care of people with dementia. At the moment, the degree of support for locally based social care projects varies between health boards and even within health boards. The allocation of funding for social economy production is arbitrary, and operates on an ad hoc basis, leading to frustration among community groups seeking to integrate their services with existing statutory provision. Local community groups can meet some of the needs of people with dementia but they require consistent and medium-term funding arrangements in order to develop services. The negotiation of social care contracts between local social economy producers and the health board is the way forward in this area. Social entrepreneurship is the key to further developments in the social economy. Entrepreneurship can be nurtured by initiatives in business and management training for potential entrepreneurs, seed capital funding for pilot initiatives, and start-up capital grants for projects meeting specific social economy criteria in the area of dementia. These initiatives would encourage new forms of production to deal with the many gaps that exist in the provision of services for people with dementia.



## **Chapter Twelve**

### **Costs and Financing**

#### **12.1 Introduction**

This chapter outlines the cost of the various recommendations made throughout the report. The estimation of the costs is difficult given how little published information there is on the costs of the various services and facilities for people with dementia. The costs should be seen as best estimates in the circumstances and relate to both current and capital expenditure. In the short-term these costs will have to be financed out of general taxation. In the long-term there is a strong case for moving towards a social insurance-based system for the financing of long-term care for older people. The argument in favour of social insurance is made in this chapter.

#### **12.2 The cost of the plan**

The cost of care for the various recommendations is shown in Table 12.1<sup>5</sup>. The costs relate to the expenditure necessary over the next three years to improve services for people with dementia in this country. Cost is divided into current and capital items for the various services. Some of the recommendations have no cost implications. Continual care payment for carers is obviously the major revenue implication of the plan, amounting to £68 million. Under current arrangements this cost would be borne by the Department of Social, Community and Family Affairs. The current revenue implications of the service component of the plan amounts to £27.5 million over three years. Capital spending associated with health and social care facilities comes to £18.6 million. The basis of the current and capital estimates is projected investment in services and facilities multiplied by the appropriate wage and capital costs. The absence of much published information on costs means that some of the estimates are based on the personal communication of people working in particular services and, therefore, best placed to provide information on these costs.

The cost of developing Psychiatry of Old Age services is just under £1million per service. The costs shown in Table 12.1 are based on the assumption that five additional services will be introduced annually over the next three years, in addition to the five new services already sanctioned. Costs include the personnel costs and capital costs associated with day hospital provision, acute

---

<sup>5</sup> The costing rationale for each item is available on request from the author.

in-patient psychiatric beds and long-stay psychiatric beds. Nine million pounds has been allocated for the expansion of home support services for people with dementia over the next three years. This should allow services to be delivered to an additional 2,000 people each year over the course of the plan. The per capita cost of this expansion of services spread across recipients is just under £30 per week, which is very good value in comparison to residential care costs.

The importance of early diagnosis is seen by the allocation of £4.0 million, which covers staff time and diagnostic costs on the assumption of 4,000 new cases per annum. The overall information and training budget is close to over £5 million, reflecting the importance assigned to this area in the plan. Support for the social economy in the form of training, capital grants, and care contracts amounts to £1.5 million, including both current and capital spending. An estimate of £3 million has been included for the development of appropriately designed small-scale specialised units for people with dementia in long-stay care. The importance of process within residential care is reflected in an allocation of close to £1 million to encourage a holistic and person-centred approach to care in this setting. A budget of £0.4 million has been allocated for experimentation with case management for vulnerable people with dementia.

**Table 12.1: Targets and costs**

	<b>TARGETS</b>	<b>CURRENT (£M)</b>	<b>CAPITAL (£M)</b>
<b>1</b>	<b>Early diagnosis</b> Clinical standards and competencies for early diagnosis of dementia so that people with dementia can be informed of their condition at the earliest possible moment, unless there are strong medical or social reasons for withholding such information.	4.0	-
<b>2</b>	<b>Information and training for GPs</b> Information and training for general practitioners to facilitate and encourage the early diagnosis of dementia.	0.6	-
<b>3</b>	<b>Information, training and resources for nurses</b> Information and training in dementia assessment for public health nurses plus additional resources to work with in order to make identification worthwhile.	0.6	-
<b>4</b>	<b>Public information campaign</b>	1.0	-

	A public information campaign to raise awareness of dementia among the general public.		
<b>5</b>	<b>Development of a case management model</b> A case management model to co-ordinate services for people with dementia and their carers located within geographically defined catchment areas in each health board. The model should be introduced on a pilot basis in two health boards, one urban-based, the other rural-based, as soon as possible.	0.4	-
<b>6</b>	<b>Carer input into decision-making</b> Carers to have a major input into placement decision-making and service delivery issues.	-	-
<b>7</b>	<b>Constant Care Attendance Allowance for carers</b> The replacement of the Carer's Allowance by a non-means tested Constant Care Attendance Allowance based on an assessment of care recipient needs and dependency made by the relevant case manager.	68.0	-
<b>8</b>	<b>Expansion of information and counselling services</b> Information and counselling services for people with dementia and their carers.	0.6	-

<b>9</b>	<b>Development of dementia-specific day care</b> Dementia-specific day care places in each district, or community care area, in buildings suitable for people with dementia, and with staff who are trained in the care of people with dementia.	0.3	2.1
<b>10</b>	<b>Increase in day hospitals</b> Day hospitals for people with dementia to increase in line with the development of Old Age Psychiatry services	-	<i>See No. 14</i>
<b>11</b>	<b>Increase in respite beds</b> An increase in the number of respite beds in community hospitals according to a norm of 1:10,000 elderly population and the development of in-home respite services for people with dementia as a mechanism for providing relief for carers and ensuring their long-term ability to care for the person with dementia.	<i>See No. 12</i>	1.5

<b>12</b>	<b>Increased provision of home support services.</b> The provision of flexible, continuous and legislatively based home support services for people with dementia.	9.0	-
<b>13</b>	<b>More occupational therapists and social workers</b> The expansion of community-based occupational therapy services and social work services for people with dementia living at home.	0.6 <i>See also No.14</i>	-
<b>14</b>	<b>Expansion of Old Age Psychiatry services</b> A planning norm of one consultant in Old Age Psychiatry per 10,000 people aged 65 years and over, each being provided with a multidisciplinary team and psychiatric facilities, including a day hospital and acute and psychiatric beds together with good access to non-psychiatric day and residential care. The target is five new services per annum over the next three years ( <i>See No. 10, No. 11 and No. 15</i> ).	4.5	10.0
<b>15</b>	<b>Increase in community psychiatric nurses</b> The adoption of ratio of 1:4,500 elderly population for community psychiatric nurses.	<i>See No. 14</i>	-
<b>16</b>	<b>Development of geriatric medicine</b> We recommend that geriatric medicine facilities are adequately staffed with full interdisciplinary teams, and we encourage close co-operation between geriatric medicine and Psychiatry of Old Age services.	0.9	1.5
<b>17</b>	<b>Dementia awareness training for acute hospital staff</b> Dementia awareness training for medical and nursing staff working in acute hospitals, particularly for people working in accident and emergency departments, to help them identify the symptoms of dementia in patients under their care.	0.3	-
<b>18</b>	<b>Development of medical education</b> There should be under-graduate training in dementia for doctors, and chairs in geriatric medicine and the Psychiatry of Old Age in each of the universities.	1.0	-

<b>19</b>	<b>Development of small-scale special care units</b> Small-scale, domestic oriented, special care units, attached to conventional long-stay facilities, for people with dementia, but without significant behavioural problems.	-	3.0
<b>20</b>	<b>Appropriately staffed and managed residential care</b> We recommend that social, psychological, artistic and sensory/communication needs be given equal weighting to physical needs in residential care settings, and that management structures support a holistic and person-centred approach to care.	0.9	-
<b>21</b>	<b>Appropriate training for residential care staff</b> We recommend the development of effective training programmes for staff working in all types of residential care facilities. These training programmes should be designed to facilitate a person-centred approach to care and service delivery.	0.3	-
<b>22</b>	<b>Focus on early onset dementia</b> We recommend 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.	0.5	-
<b>23</b>	<b>Focus on people with Down's Syndrome</b> The introduction of specially designed and integrated care packages for people with Down's Syndrome and dementia, delivered within the mental handicap programme, with training facilitated by the Old Age Psychiatry and/or geriatric medicine services.	0.5	-
<b>24</b>	<b>Establishment of an implementation committee</b> The setting-up of a committee to oversee the implementation of this plan.	0.2	-
<b>25</b>	<b>National Centre for Dementia Services Information and Development</b> The Dementia Services Information and Development Centre at St James's to be consolidated as a national	0.3	-

	centre for the identification and dissemination of best practice in dementia care in Ireland.		
<b>26</b>	<b>Legislatively based support for community care services</b> A renewed emphasis on meeting existing policy objectives for dementia sufferers and their carers, through legislatively based support for the equitable provision of community care services.	-	-
<b>27</b>	<b>Local delivery of services</b> Services for people with dementia to be delivered locally, in a flexible manner, within the framework of new case management structures, wherever possible.	-	-
<b>28</b>	<b>Expanded role for voluntary sector</b> The involvement of the voluntary sector in both the formulation and implementation of policy with respect to people with dementia and their carers.	-	-
<b>29</b>	<b>Consistent and long-term funding arrangements for voluntary providers</b> Consistent and longer-term funding arrangements between the health boards and the voluntary groups providing services to people with dementia.	-	-
<b>30</b>	<b>Integration of public and private sectors</b> An audit of the number of people with different types and severity of dementia in private nursing homes; an evaluation of the public subsidy arrangements for these patients, and greater integration of public and private production in the care of people with dementia.	-	-
<b>31</b>	<b>Enhanced teamwork</b> A more formal emphasis on multidisciplinary teamwork in the care of people with dementia within the integrative framework of a case management model of service delivery.	-	-
<b>32</b>	<b>Nurturing of social economy</b> The development of the social economy and the nurturing of social entrepreneurship at a local level as a	-	-

	means of meeting the needs of people with dementia and their carers in a flexible and innovative way.		
33	<b>Development of a social insurance model for funding</b> In the short-term, additional resources for dementia care financed from within existing health and social care budgets; in the long-term we recommend further exploration of moving to a social insurance system for the funding of long-term care.	1.0	0.5

### 12.3 Current arrangements for financing care

When the continual care payment for carers is added to the care service and capital components of this plan, the total cost is £114 million. This cost is not inconsequential and the question immediately arises as to how even the care service component of the plan will be funded. Ireland, like many other developed countries, is facing the problem of providing an equitable, efficient and affordable system of financing for the long-term care of old people, including people with dementia.

Under the existing system, most of the public expenditure on both community-based and residential long-term care is financed from general taxation. Financing by the Voluntary Health Insurance (VHI) is minimal and is confined to convalescent care. There are currently no private long-term care insurance products on the market, nor are there any equity release schemes available to help cover the cost of care. Personal, out-of-pocket, contributions mostly arise when the individual is in a public or private long-stay institution, though nominal charges do exist in some areas for some community care services. In the case of public long-stay care, nearly the entire weekly pension of the elderly person is retained by the institution. Even with maximum subvention, (currently £120 per week), an older person in a private nursing home will still have to pay a significant component of the cost of care from their own resources.

The existing system of financing is biased towards residential care, despite the many recommendations contained in policy documents supporting community care (*The Years Ahead*, 1988; Ruddle *et al*, 1997). Dealing with this imbalance will require action to provide a more positive bias towards community care solutions, so that older people can be supported in their own home for as long as is possible and practicable. This will involve allocating additional resources to community care, giving better levels of support to carers, and assigning case

managers to take control of budgets and care strategies (Ruddle *et al*, 1997). The availability of additional resources is the most critical policy issue facing health policy-makers in the immediate future and will determine the success of this plan for people with dementia.

## **12.4 Private insurance**

Private insurance is sometimes put forward as the solution to the funding problem in long-term care, particularly by those who believe in personal responsibility, freedom of choice, and market-based solutions to health care problems. However, the main problem with private insurance is the capacity of insurers to deliver comprehensive coverage at affordable prices. Insurers worry especially about the potential for moral hazard and adverse selection in dementia care insurance. Moral hazard in community care may arise if old people and their families transfer much of the burden of care from the family to the now insured formal system. If, in turn, insurance is primarily taken out by those more likely to need care then, the resulting cost explosion may be too much for the market to bear. The higher premiums that inevitably result from both moral hazard and adverse selection problems reduces the potential market for insurance to such an extent as to make public intervention inevitable, even for relatively well-off, low risk, individuals.

Funding from private insurance sources is, therefore, unlikely to ever be the mainstay of care provision in this country. At the moment, residential care is by far the predominant type of insurance coverage on offer in countries where private insurers are involved in the market (Wiener *et al*, 1987). Home care, on the other hand, is not extensively covered. Home care needs are the most difficult to define and insurance companies recognise the substantial potential for increased utilisation. The problem for insurers is that expanding home care generally raises, rather than lowers, overall expenditure on long-term care. Thus, while private insurance schemes could technically be developed so as to bias the system towards home care solutions for dementia sufferers this would be unlikely to happen because of fears about the abilities of insurers to control demand and hence costs in this area.

## **12.5 Social insurance**

The most potent source of additional funding for services for older people, and for dementia care in particular, is the development of a new social insurance system designed specifically for long-term care (O'Shea and Hughes, 1994). Social insurance allows people to pool the risk of having to pay out huge sums of money for long-term care in the future. Individuals pay into a fund, over the life cycle, in return for automatic entitlement should they need benefits at some



time in the future. Unlike private insurance, there is no exclusion and ability to pay does not determine access. There is no welfare stigma associated with social insurance schemes. For people unable to make a contribution to the scheme the government could step in to provide coverage. Social insurance would also eliminate the problem of adverse selection since enrolment would be mandatory.

A designated social insurance fund for long-stay care would allow for more comprehensive cover for dementia sufferers than currently exists. The potential for attracting additional funding into the system is stronger in a social insurance system than in a public scheme financed from general taxation. A designated fund would encourage transparency in priority setting, service delivery, and the evaluation of outcomes. The potential for moral hazard that exists in all third-party payment systems would, however, remain a problem. To deal with this issue, access to services would be subject to strict dependency assessment procedures to establish eligibility and genuine need. The question of whether care is provided in the public or the private sector is immaterial to the funding question. The optimal solution would be to have a competitive supply-side, comprising elements of both private and public production.

Using cash transfers rather than in-kind provision for some services could further enhance flexibility. Transfers to older people and their carers, tied to specific long-term care services, would restore some element of choice to consumers. This choice could be exercised through case management structures. More choice for care recipients would also likely lead to the development of desirable social entrepreneurship on the supply side, leading to new and innovative ways of providing care through the development of the social economy. This would make the system more responsive to care requirements, rather than having the funding system determining those needs in the first place. This would be very important in the area of dementia care, where existing statutory services are limited to basic nursing and residential care, leaving the voluntary sector to provide whatever experimentation and innovation they can within their existing budgets.

*33. In the short-term, we recommend additional resources for dementia care financed from within existing health and social care budgets; in the long-term we recommend further exploration of moving to a social insurance system for the funding of long-term care.*

## **12.6 Conclusion**

People with dementia make considerable demands on public resources. We have identified a number of critical services that require extra resources. This should not be surprising given the weakness of existing dementia-specific services in both community and residential care settings. Sometimes the costing of plans like this is a cause of controversy; some people will argue that the cost is too much; others will say that not enough is being spent on services. The facts are that services for people with dementia in Ireland are under-developed. The consultations undertaken for this plan confirmed widespread under-provision of services, so to do existing data sources. The spending proposed in this plan will go some way towards alleviating the range of needs that exist, but it will not solve all problems. Some people look at services only in terms of costs; others view services only in terms of benefits. What we need to do is evaluate service provision from the point of view of both costs and outcomes. That is the only way of delivering value for money in this area.

## **Chapter Thirteen**

### **Conclusions**

This report deals with many of the issues critical to the development of an action plan for dementia. The emphasis is on meeting the health, social, psychological and emotional needs of people with dementia and their carers. Meeting those needs does not require a separate dementia care programme, but it does require developing and expanding existing care of the aged services in this country. We outlined six principles that should underpin the developments of services in this area:

- person-centred models of care
- comprehensive provision
- a bias towards home-care solutions
- care requirements to determine funding
- needs-based provision
- evidence-based practice

Additional resources are the key to the development of services in this area. The total cost of the services element of this plan is £46 million, spread over three years. Paying carers under a new continual care payment would cost an additional £68 million on an annual basis. These costs should not be seen as a burden on society, but as an opportunity to contribute to the enrichment of society through increased spending on people with dementia and their carers.

It is clear from these figures that the implementation of the plan, including an increased payment for more carers, will require imaginative thinking on funding, and ultimately some consideration of movement to a social insurance scheme for long-term care. This would provide a clear signal that dementia is a socially insurable risk, which can be planned for in an orderly fashion.

Dementia does not always happen to somebody else; it can happen to me, to you, to all of us. New services for people with dementia will also require the development and nurturing of the social economy in order to widen the scope and flexibility of local community care responses to the problem of dementia. First and foremost, however, the plan will require a commitment from us all that action is required to improve the quality of life of people with dementia and their carers. Once that commitment exists we can set about developing consistent, effective, and targeted services for people with dementia.

The plan puts forward a model of good practice in dementia care. The pathways to care model presented leaves scope for flexible and innovative responses at a local level to the provision of services. Dementia is a heterogeneous condition that requires careful assessment of the person's needs and functioning before a care plan can be formulated. We must allow scope for local services to respond in a unique way to the needs of the person, within, of course, the set of principles and philosophy outlined earlier in the report. There is strong evidence from demonstration projects in other countries that skilled assessment and a carefully designed and implemented individualised package of care leads to positive outcomes for people with dementia and their carer. This is the way forward in this country because it is an explicit recognition of the uniqueness of the person with dementia, and offers the best hope of individual and person-centred models of care delivery.

Training in dementia care is an essential part of the plan. Training programmes must be developed, not just for specialists working in the field but also for people working in generic elderly care services. Early diagnosis of dementia is also critical because it allows time and scope for the delivery of appropriate services, and facilitates the involvement of the person with dementia and their carer in decision-making with respect to services and placement. It also opens up the possibility of prevention in limited cases. The expansion of Psychiatry of Old Age services and the on-going development of geriatric medicine are essential elements in diagnosis and service delivery for people with dementia.

Family carers are the most important source of support for people with dementia. Consequently, we have an obligation to support the work that carers do through the development of information and counselling services for carers, the expansion of services such as home support and respite care, and through more generous monetary rewards. Case management is also a valuable source of support for carers because it provides an important contact point for service delivery, thereby removing the sense of isolation and loneliness that is sometimes associated with caring. While there remains some dispute in the literature about the effect of different services on carer strain levels, it is clear that different interventions are needed at different stages of the care-giving process. Carers must be supported from the beginning and through the different stages of the care process, including having access to bereavement counselling at the end of the process.

Although the emphasis in this plan is on developing primary and community care services for people with dementia, the needs of people with dementia in residential care are also important. We need to pay much more attention to the design and scale of residential facilities for people with dementia. This has been a much neglected area in Ireland. The care process within long-stay care

is also important. While purpose-built or adapted dementia environments can provide the stimulus for better care, the crucial elements for improved outcomes for residents are the care practices, staff attitudes and the social culture within institutions (Rosewarne *et al*, 1997). 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 the senses, through reminiscence, music, and therapeutic and diversionary activities. There has been much progress made in dementia care and the view that 'there is nothing that can be done' is now rightly seen as an unsupportable view. There is, however, much scope for improvement in developing communication skills for people caring for dementia patients. Training is again important for staff if they are to develop the skills necessary for an empathic delivery of care. Staff need training and support in the same way as family carers do, if they are to be able to perform the demanding job required of them.

The essential element of this plan is the importance of the person with dementia. We have made a number of recommendations designed to improve the quality of life of people with dementia. The emphasis is on primary and community care solutions to the problems that exist in this area. Strategies now need to be put in place for the implementation of the plan and the monitoring and evaluation of service delivery. The implementation of this plan will demonstrate that it is possible to build a society in which respect, empathy, and the concept of shared citizenship prevail over public indifference to one of the most vulnerable groups in our communities. In three years time we need to revisit this plan to see how far we have got in achieving the targets we set for ourselves. By that time, based on the best available estimates of incidence rates, there will be about 12,000 more people with dementia in the general community population. The time for action is now.

## References

- Ageing and Disability Department: NSW Health (1996). *New South Wales Action Plan on Dementia: Implementation Strategies*. Sydney: Ageing and Disability Department.
- Alzheimer, A. (1907). 'Über eine eigenartige Erkrankung der Hirnrinde.' *Allgemeine Zeitschrift für Psychiatrie*, 64, pp. 146-8.
- Anders, W., B. Mattsson, I. Krakau, T. Eriksson and A. Nelvig (1994). 'Cost-Effectiveness Analysis of Day Care for Patients with Dementia Disorders.' *Health Economics*, Vol. 3, pp. 395-404.
- Barber, B., L. Dormer and D. Prasadu (1996). 'Developing flexible responsive teamwork.' *Journal of Dementia Care*, Jan./Feb., pp. 26-27.
- Beck, C.K., M. Cody, and M. Zhang (1998). 'A multidisciplinary team approach to managing Alzheimer's Disease,' *Supplement to Pharmacotherapy*, 18 (2), pp. 33-42.
- Berenbaum, R.J. (1997). 'Transfer of information from adult day care to nursing homes: Bridging the gaps in the long-term care of dementia patients.' *Journal of Gerontological Social Work*, 27, (4), pp. 85-95.
- Blackwell, J., E. O'Shea, G. Moane and P. Murray (1992). *Care Provision and Cost Measurement: Dependent Elderly People at Home and in Geriatric Hospitals*. Dublin: Economic and Social Research Institute.
- Bond, J. (1992). 'The politics of caregiving: the professionalisation of informal care.' *Ageing and Society*, 12, pp. 5-21.
- British Psychological Society (1994). *Psychological well-being for users of dementia services*. Leicester: British Psychological Society.
- Brodaty, H. (1988). 'Minimal brain damage in the Adult II: Early dementia.' *Patient Management*, August, 127-150.
- Browne, M. (1992). *Co-ordinating services for the elderly at local level: Swimming against the tide*. Dublin: National Council for the Elderly.

- Browne, J. (1996). 'Mental disorders in long-stay care settings.' In F. Keogh and A. Walsh (eds.). *Mental Disorders in Older Irish People: Incidence, Prevalence and Treatment*. Dublin: National Council for the Elderly.
- Burdz, M.P., W.O. Eaton and J.B. Bond (1988). 'Effects of respite care on dementia and non-dementia patients and their caregivers.' *Psychology and Ageing*, 3 (1), 38-42.
- Calkins, M.P. (1988). *Design for dementia: Planning environments for the elderly and the confused*. Owing Mills, MD: National Health Publishing.
- Carr, J. and M. Marshall (1993). 'Innovations in long-stay care for people with dementia.' *Reviews in Clinical Gerontology*, 3, 157-167.
- Central Statistics Office (1995). *Population and Labour Force Projections 1996-2026*. Dublin: Stationery Office.
- Central Statistics Office (1997). *Census of Population 1996*. Dublin: Central Statistics Office.
- Challis, D., R. Von Abendorff, P. Brown and P. Chesterman (1997). 'Case Management and Dementia: An evaluation of the Lewisham Intensive Case Management Scheme.' In S. Hunter (ed.) *Dementia: Challenges and New Directions*. London: Jessica Kingsley Publishers.
- Chapman, A., A. Jacques and M. Marshall (1994). *Dementia Care: A Handbook for Residential and Day Care*. London: Age Concern England.
- Cheok, A.S., C.A. Cohen and C.A. Zuccherro (1997). 'Diagnosing and managing dementia patients.' *Canadian Family Physician*, 43, March, pp. 477-482.
- Clinch, D. and A. Hickey (1992). 'Cognitive impairment in hospitalised elderly – Limerick,' in Mid-Western Health Board Report titled: *The Elderly Mentally Infirm: Who cares?* Report of a review group.
- Commission on Health Funding (1989). Dublin: Stationery Office.
- Commonwealth Department of Health and Family Services (1997). *Future Directions in Dementia Care in Australia: A Report by the Reference Group of the National Action Plan for Dementia Care to the*

Minister for Family Services. Canberra: Commonwealth Department of Health and Family Services.

Convery, J. (1987). *Choices in Community Care: Day Centres for the Elderly in the Eastern Health Board*. Dublin: National Council for the Elderly.

Cook-Deegan, R.M. and P.J. Whitehouse (1987). 'Alzheimer's Disease and Dementia: The Looming Crisis', *Issues in Science and Technology*, Summer, pp. 52-63.

Corcoran, E., A. Guerandel and M. Wrigley (1994). 'The day hospital in psychiatry of old age – what difference does it make?' *Irish Journal of Psychological Medicine*, 11 (3), pp. 110-115.

Cox, S.M. and J.M. McLennan (1994). *A guide to early onset dementia*. Stirling: University of Stirling, Dementia Services Development Centre.

Curran, J.S.M. (1995). 'Current provision and effectiveness of day care services for people with dementia.' *Reviews in Clinical Gerontology*, 5, pp. 313-320.

Curran, J.S.M. (1996). 'The Evolution of Daycare Services for People with Dementia.' In R. Bland (ed.) *Developing Services for Older People and their families*. London: Jessica Kingsley Publishers.

Dean, R. and K. Briggs and J. Lindesay (1993). 'The Domus philosophy: A prospective evaluation of two residential units for the elderly mentally ill.' *International Journal of Geriatric Psychiatry*, 8, 807-817.

Dellasega C. and L. E. King (1996). 'The Psychogeriatric Nurse in Home Health Care: Use of Research to Develop the Role.' *Clinical Nurse Specialist*, Vol. 10, No. 2.

Department of Health (1994). *Shaping a Healthier Future. A Strategy for Effective Healthcare in the 1990s*. Dublin: Stationery Office.

Department of Health and Social Services (1995). *Dementia in Northern Ireland: Report of the Dementia Policy Scrutiny*. Belfast: Department of Health and Social Services.

Department of Social, Community and Family Affairs (1998). *Review of the Carer's Allowance*. Dublin: Stationery Office.



- Downs, M. (1994). *Dementia: A Literature Review*. Stirling: Dementia Services Development Centre.
- Downs, M. and M. Marshall (1997). *Scottish Need Assessment Programme. Priority Services Network: Dementia*. Glasgow: Scottish Forum for Public Health Medicine.
- Drickame, M.A. and M.S. Lachs (1992). 'Should patients with Alzheimer's disease be told their diagnosis?' *New England Journal of Medicine*, 326 (14), pp. 947-951.
- Ely, M., C. Brayne, F.A. Huppert, D.W. O'Connor and P. Pollitt (1997). 'Cognitive Impairment: a challenge for community care. A comparison of the domiciliary service receipt of cognitively impaired and equally dependent physically impaired elderly women.' *Age and Ageing*, 26, pp. 301-308.
- Feil, N. (1982). *Validation: The Feil Method*. Cleveland, OH: Edward Feil Productions.
- Fleming, R. and J. Bowles (1987). 'Units for the Confused and Disturbed Elderly: Development, Design Programming and Evaluation.' *Australian Journal of Ageing*, 6 (4), pp. 25-28.
- Gatz, M., V.L. Bengston, and M.J. Blum (1990). 'Caregiving families.' In J.E. Birren and K.W. Schaie (eds.), *Handbook of the psychology of aging*. New York: Academic Press, pp. 405-426.
- Gibson, F. (1994). *Reminiscence and recall*. London: Age Concern.
- Gibson, F., D. Whittington, D. James, A. Patenden and L. Rahim (1996). 'Responding to the needs of rural carers.' *Journal of Dementia Care*, March/April, pp. 15-17.
- Gilloran, A. and M. Downs (1997). 'Issues of Staffing and Therapeutic Care.' In S. Hunter (ed.) *Dementia: Challenges and New Directions*. London: Jessica Kingsley Publishers.
- Gilloran, A., A. Robertson, T. McGlew and K. McKee (1995). 'Improving work satisfaction amongst nursing staff and quality of care for elderly patients with dementia: some policy implications.' *Ageing and Society* 15, 375-391.

- Gitlin, L.N. and M.A. Corcoran (1996). 'Managing Dementia at Home: The Role of Home Environmental Modifications.' *Topics in Geriatric Rehabilitation*, 12 (2), pp. 28-39.
- Goldsmith, M. (1996). *Hearing the Voice of People with Dementia: Opportunities and Obstacles*. London: Jessica Kingsley Publishers.
- Harding, N. and C. Palfrey (1997). *The Social Construction of Dementia: Confused Professionals*. London: Jessica Kingsley Publications.
- Hickey, A., D. Clinch and E.P. Groarke (1997). 'Prevalence of cognitive impairment in the hospitalised elderly.' *International Journal of Geriatric Psychiatry*, 12, 27-33.
- Higginson I.J., P.M. Jeffreys and C.S. Hodgson (1997). 'Outcome measures for routine use in dementia services: some practical considerations.' *Quality in Health Care*, 6, pp. 120-124.
- Hoffman, A., W.A. Rocca, 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.
- Holden, U. and Woods, B. (1995). *Positive Approaches to Dementia Care*. Edinburgh: Churchill Livingstone.
- Holland, T. (1997). 'The risk of dementia in people with 'Down's Syndrome.' In S. Hunter (ed.) *Dementia: Challenges and New Directions*. London: Jessica Kingsley Publishers.
- Howe, A. (1997). 'From states of confusion to a National Action Plan for dementia care: The development of policies for dementia care in Australia.' *International Journal of Geriatric Psychiatry*, 12, pp. 165-171.
- Hunter, R., L. McGill, N. Bosanquet and N. Johnson (1997). 'Alzheimer's disease in the United Kingdom: developing patient and carer support strategies to encourage care in the community.' *Quality in Health Care*, 6, pp. 146-152.
- Iliffe, S. (1994). 'Why GPs have a bad reputation.' *Journal of Dementia Care*. November/December, pp. 24-25.

- Ineichen, B. (1990). 'The extent of dementia among old people in residential care.' *International Journal of Geriatric Psychiatry*, 5, pp. 327-335.
- Jacques (1997). 'Ethical Dilemmas in Care and Research for People with Dementia.' In Susan Hunter (ed.) *Dementia: Challenges and New Directions*. London: Jessica Kingsley Publishers.
- Jorm, A.F., A.E. Korten and A.S. Henderson (1987). 'The prevalence of dementia: a quantitative integration of the literature.' *Acta psychiatr. scand.*, 76, 465-479.
- Kavanagh, S., J. Schneider, M. Knapp, J. Beecham and A. Netten (1995). 'Elderly people with dementia: costs, effectiveness and balance of care.' In M. Knapp (ed.) *The Economic Evaluation of Mental Health Care*. Aldershot: Arena.
- Kay, D.W.K. and K. Bergmann (1980). 'Epidemiology of mental disorders among the aged in the community.' In J.E. Birren, R.B. Sloane (eds.) *Handbook of Mental Health and Ageing*. NJ: Prentice-Hall, Englewood Cliffs.
- Kemper, P., R. Applebaum and M. Harrigan (1987). 'Community Care Demonstrations: What have we learned?' *Health Care Financing Review*, 8 (4), pp. 87-100.
- Keogh, F. and A. Roche (1996). *Mental Disorders in Older Irish People: Incidence, Prevalence and Treatment*. Dublin: National Council for the Elderly.
- Killeen, J. (1998). 'Home Care: can it be a real choice?' *Journal of Dementia Care*. Jan./Feb. London: Jessica Kingsley Publishers.
- Kitwood (1993). 'Towards a theory of dementia care: the interpersonal process.' *Ageing and Society*, 13, 15-67.
- Kitwood, T. (1997). 'Personhood, dementia and dementia care.' In S. Hunter (ed.) *Dementia: Challenges and New Directions*. London: Jessica Kingsley Publications.
- Kitwood, T. and S. Benson (1995). *The New Culture of Dementia Care*. London: Hawker Publications.

- Kneafsey, R. (1997). 'The therapeutic use of music in a care of the elderly setting: a literature review.' *Journal of Clinical Nursing*, 6, pp. 341-346.
- Kovach, C.R. (1996). 'Alzheimer's Disease: Long-Term Care Issues.' *Issues in Law and Medicine*, 12 (1), pp. 47-56.
- Lawlor, B., A. Radic, I. Bruce, G.R.J. Swanwick, F. O'Kelly, M. O'Doherty, J.B. Walsh and D. Coakley (1994). 'Prevalence of mental illness in an elderly community dwelling population using AGE CAT.' *Irish Journal of Psychological Medicine*, 11, 4, 157-59.
- Lawton, M.P. (1991). 'A Multidimensional View of Quality of Life.' In J.E. Birren, J.E. Lubben, J.C. Rowe and D.E. Deutchman (eds.). *The Concept and Measurement of Quality of Life in the Frail Elderly*. New York: Academic, pp. 3-27.
- Lawton, M.P. (1994). 'Quality of Life in Alzheimer Disease.' *Alzheimer Disease and Associated Disorders*, 8, Supplement 3, pp. 138-150.
- Lawton, M.P., E. Brody and A. R. Saperstein (1989). 'A controlled study of respite services for caregivers of Alzheimer's patients.' *The Gerontologist*, 29, pp. 8-16.
- Lefroy, R.B., J. Hyndman and M.S.T. Hobbs (1997). 'A special dementia unit (hostel): review of the first eleven years of operation.' *Australian Journal of Ageing*, 16 (1), pp. 16-19.
- Levin, E., J. Moriarty and P. Gorbach (1994). *Better for the Break*. London: HMSO.
- Lindesay, S., K. Briggs, M. Lawes, A. MacDonald and J. Herzberg (1991). 'The Domus Philosophy: A Comparative Evaluation of a New Approach to Residential Care for the Demented Elderly.' *International Journal of Geriatric Psychiatry*, 6, pp. 727-736.
- Linehan, C. and G. Birkbeck (1996). *An Evaluation of Sonas aPc: A multisensorial approach to activate the potential for communication in the elderly*. Dublin: The National Research Agency Ltd.
- Liukkonen, A. (1992). 'Basic care of demented patients living in institutions.' *Journal of Clinical Nursing*, 1, pp. 345-350.

- Lundström, F. and K. McKeown (1994). *Home Help Services for Elderly People in Ireland*. Dublin: National Council for the Elderly.
- McIntyre, A. (1984). *After Virtue*. London: Duckworth.
- Mangan, I. (1998). 'Equity, consistency and comprehensiveness: The need for a legislative framework to govern the provision of essential services for older people.' In National Council on Ageing and Older People (ed.) *Conference Proceedings: Review of the Implementation of the Recommendations of the Years Ahead - A Policy for the Elderly and Implications for Future Policy on Older People in Ireland*. Dublin: National Council on Ageing and Older People.
- Marshall, M. (1997). 'Therapeutic design for people with dementia.' In S. Hunter (ed.) *Dementia: Challenges and New Directions*. London: Jessica Kingsley Publishers.
- Marshall, M. (1993). *Small scale, domestic style, long stay accommodation for people with dementia*. Stirling: University of Stirling, Dementia Services Development Centre.
- Mentes, J.C. and K.C. Buckwalter (1998). 'Dementia Special Care Units: Programming and Staffing Issues.' *Journal of Gerontological Nursing*, January 1998.
- Miller, E. and R. Morris (1993). *The psychology of dementia*. New York: John Wiley & Sons.
- Ministerial Task Force on Dementia Services in Victoria (1997). *Dementia Care in Victoria: Building a Pathway to Excellence - Final Report*. Victoria, Aged, Community and Mental Health Division, Victorian Government Department of Human Services.
- Moran, R. and Walsh, D. (1992). *The Irish Psychiatric Hospitals and Units Census 1991*. Dublin: Health Research Board.
- Moriarty, J. and E. Levin (1993). 'Interventions to assist caregivers.' *Reviews in Clinical Gerontology*, 301-308.
- Mulvihill, R. (1993). *Voluntary-Statutory Partnership in Community Care of the Elderly*. Dublin: National Council for the Elderly.

- Murphy, E., J. Lindsay, and M. Dean (1994). *The Domus Project*. London: The Sainsbury Centre.
- National Council for the Aged (1985). *Institutional Care of the Elderly in Ireland*. Dublin: National Council for the Aged.
- National Council for the Elderly (1991). 'Comments and Recommendations.' In E. O'Shea *et al.* *The Role and Future Development of Nursing Homes in Ireland*. Dublin: National Council for the Elderly.
- National Council on Ageing and Older People (1997). 'Comments and Recommendations' in H. Ruddle, F. Donoghue and R. Mulvihill (1997). *The Years Ahead Report: A Review of the Implementation of its Recommendations*. Dublin: National Council on Ageing and Older People.
- National Council on Ageing and Older People (1998). *Adding years to life and life to years...A Health Promotion Strategy for Older People*. Dublin: National Council on Ageing and Older People.
- National Council on Ageing and Older People (1998). *The Law and Older People: A Handbook for Service Providers*. Dublin: National Council on Ageing and Older People.
- National Economic and Social Council (1987). *Community Care Services: An Overview*. Dublin: National Economic and Social Council.
- North Eastern Health Board (1997). *Optimising support for informal and formal carers of people with dementia: Final Report*. Naval: North Eastern Health Board.
- O'Neill, D. (1997). 'Cognito ergo sum? Refocusing dementia ethics in a hypercognitive society.' *Irish Journal of Psychological Medicine* 14 (4), pp. 121-123.
- O'Neill, D. (1998). 'Completing the coalition against dementia.' *Irish Medical Journal*, 91 (2), pp. 46-47.
- O'Neill, D., L. Condren, F. O'Kelly, A. King, M. Young, J.B. Walsh and D. Coakley (1988). 'Cognitive impairment in the Elderly.' *Irish Medical Journal*, 81, (1), pp. 11-13.

- O'Neill, D., L. Andrew and F. O'Kelly (1989). 'Screening for dementia and delirium using an adapted Folstein mini-mental state examination.' *Irish Medical Journal*, 82, pp. 24-25.
- O'Neill, D., D. Begley, N. McCormack, J.B. Walsh and D. Coakley (1991). 'Dementia and Depression in a Nursing Home Population.' In D. O'Neill (ed.), *Carers, Professionals and Alzheimer's Disease*. London: John Libbey.
- O'Shea, E. and R. Corcoran (1990). 'Balance of Care Considerations for Elderly Persons: Measuring Dependency and Estimating Opportunity Costs.' *Applied Economics*, Vol. 22.
- O'Shea, E. and J. Hughes (1994). *The Economics and Financing of Long-Term Care in Ireland*. Dublin: National Council for the Elderly.
- O'Shea E. and S. O'Reilly (1998). *The Economic and Social Costs of Alzheimer's Disease and Related Dementias in Ireland: An Aggregate Analysis*. Working Paper No. 25, National University of Ireland, and Galway: Department of Economics.
- Oliver, C. and A.J. Holland (1986). 'Down's Syndrome and Alzheimer's disease: a review.' *Psychological Medicine*, 16, pp. 307-322.
- Ovretveit, J. (1993). *Co-ordinating Community Care: Multidisciplinary Teams and Care Management*. London: Open University Press.
- Perry, R.H., D. Irving, G. Blessed, A. Fairbairn and E.K. Perry (1990). 'Senile dementia of Lewy Body type.' *Journal of Neurological Sciences*, 95, 110-139.
- Philip, I., K.J. McKee, P. Meldrum, B.R. Ballinger, M.L.M. Gilhooly, D.S. Gordon, W.J. Mutch and J.E. Whittick (1995). 'Community care for demented and non-demented elderly people: a comparison study of financial burden, service use, and unmet needs in family supporters.' *British Medical Journal*, Vol. 310, June.
- Prasher, V.P. and V.H.R. Krishnan (1993). 'Age of onset and duration of dementia in people with Down's Syndrome.' *International Journal of Geriatric Psychiatry*, 8, pp. 915-922.

- Ramsay, M., C. Topan and I. Higginson (1995). 'Review: Measures to determine the outcome of community services for people with dementia.' *Age and Ageing*, 24, pp. 73-83.
- Rice, D.R., P.J. Fox, W. Max, P.A. Webber, D.A. Lindeman, W.W. Hauck and E. Segura (1993). 'The economic burden of Alzheimer's disease care.' *Health Affairs*, 12, 2, pp. 164-76.
- Rice, K. and N. Warner (1994). 'Breaking the bad news: what do psychiatrists tell patients with dementia about their illness?' *International Journal of Psychiatry*, 9, pp. 467-471.
- Rogers, S., L.T. Friedhoff and the Donepezil Study Group (1996). 'The efficacy and safety of donepezil in patients with Alzheimer's disease: results of a US multicentre, randomised, double-blind, placebo-controlled trial.' *Dementia*, 7, 293-303.
- Rosewarne, R., A. Bruce and M. McKenna (1997). 'Dementia Programme Effectiveness in long term care.' *International Journal of Geriatric Psychiatry*, 12, pp. 173-182.
- Rothstein, Z., I. Prohovnik, M. Davidson, M.S. Beeri and S. Noy (1996). 'The economic burden of Alzheimer's disease in Israel.' *Israel J. Med. Sci.*, 32, 11, 1120-1123.
- Ruddle, H. (1994). *Caring for the Carers*. Dublin: Soroptimist International.
- Ruddle, W., F. Donoghue and R. Mulvihill (1997). *The Years Ahead Report: A Review of the Implementation of its Recommendations*. Dublin: National Council on Ageing and Older People.
- Ruddle, H. and J. O'Connor (1993). *Caring without Limits? Sufferers of Dementia/Alzheimer's Disease. A Study of their Carers*. Dublin: The Alzheimer Society of Ireland.
- Schofield, H., B. Murphy, H.E. Herrman, S. Bloch and B.S. Singh (1998). 'Carers of people aged over 50 with physical impairment, memory loss and dementia: a comparative study.' *Ageing and Society*, 18, pp. 355-369.
- Schulz, R., A.T. O'Brien, J. Bookwala and K. Fleissner (1995). 'Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates and causes.' *Gerontologist*, 35, pp. 771-791.



- Seymour, J., P. Sanders, J.P. Wattis and L. Daly (1994). 'Evaluation of early dementia by a trained nurse.' *International Journal of Psychiatry*, 9, pp. 37-42.
- Sixsmith, A., C. Howley, J. Stilwell and J. Copeland (1993). 'Delivering Positive Care in Nursing Homes.' *International Journal of Psychiatry*, 8, pp. 407-412.
- Sixsmith, A., J. Stilwell and J. Copeland (1993). 'Dementia: Challenging the limits of dementia care.' *International Journal of Geriatric Psychiatry*, 8, pp. 993-1000.
- Sloane, P.D., D.A. Lindeman, C. Phillips, D.J. Moritz and G. Koch (1995). 'Evaluating Alzheimer's Special Care Units: Reviewing the evidence and identifying potential sources of study bias.' *The Gerontologist*, 35 (1), pp. 103-111.
- Stommel, M., C.E. Collins and B.A. Given (1994). 'The costs of family contributions to the care of persons with dementia.' *The Gerontologist*, 34, 2, pp. 199-205.
- Sturges, P.J. (1995). 'Care Management Practice: Lessons from the USA.' In C. Clarke and I. Lapsley (eds.) *Planning and Costing Community Care*. London: Jessica Kingsley Publishers.
- The Years Ahead (1988). *The Years Ahead: A Policy for the Elderly*. Report of the Working Party on Services for the Elderly. Dublin: Stationery Office.
- Tyrell, J.F., M.P. Cosgrave, M. McLaughlin and B.A. Lawlor (1996). 'Dementia in an Irish Population of Down's Syndrome People.' *Irish Journal of Psychological Medicine*, 13 (2), pp. 51-54.
- Weinberger, M., D.T. Gold, G.W. Divine, P.A. Cowper, L.G. Hodgson, P. Schreiner and L.K. George (1993). 'Expenditures in caring for patients with dementia who live at home.' *American Journal of Public Health*, 83, (3), pp. 338-41.
- Wiener, J.M., D.A. Ehrenworth and D.A. Spence (1987). 'Private Long-Term Care Insurance: Cost, Coverage and Restrictions.' *The Gerontologist*, Vol. 27, No. 4.

- Whalley, L. (1997). 'Early onset dementia.' In S. Hunter (ed.) *Dementia: Challenges and New Directions*. London: Jessica Kingsley Publishers.
- Williams, J.K. and D.A. Trubatch (1993). 'Nursing home care for patients with Alzheimer's Disease: An overview.' *Neurology* 43, (Supplement 4), pp. S20-S25.
- Wimo, A., R. Adolpson and P.O. Sandman (1995). 'Care for demented patients in different living conditions: effects on cognitive function, ADL-capacity and behaviour.' *Scandinavian Journal of Primary Health Care*, 13, (3), pp. 205-210.
- Woods, B. (1995). 'Dementia Care: Progress and Prospects.' *Journal of Mental Health*, 4, pp. 115-124.b
- Woods, B., S. Portnoy, D. Head and G. Jones (1992). 'Reminiscence and life review with persons with dementia: Which way forward?' In G. Jones and B. Miesen (eds.) *Caregiving in Dementia: Research and Applications*. London: Tavistock/Routledge.

## **APPENDICES**

### **Appendix 1**

#### **Authors' Acknowledgements**

A great number of people contributed to the production of this report. We would first of all like to thank the members of the Consultative committee set up by the Council to steer this project through to completion. We would like to thank people on an individual basis as follows: Mr Bob Carroll, Dr Margo Wrigley, Mr Christopher Domegan, Ms Janet Convery, Mr Martin Duffy, Mr Frank Goodwin, Cllr Tim Leddin, Dr Aidan Meade, Sr Mary Threadgold, Dr Des O'Neill, Dr Murna Downs, Ms Winifred Bligh and Ms Mary Drury.

I would also like to thank the following people who provided invaluable written comments on various drafts of the report: Sr Mary Threadgold, Ms Janet Convery, Dr Margo Wrigley, Dr Des O'Neill, Mr Moss McCormack, Mr Francis Rogers, Dr Murna Downs, Dr Cillian Twomey, Mr Joe Stanley, Mr Frank Houghton, Ms Mary Drury, Dr T Greally and Ms Nuala O'Donnell.

We met many people during the consultation process for the report and I would like to thank them for their time and for their commitment to the project. In particular, I would like to thank the following people: Dr Joseph Duggan, Dr Patrick Murphy, Dr John Gibbon, Dr John Lavan, Dr Christine O'Malley, Dr John Murphy, Dr Maureen Caffrey, Dr Davida de la Harpe, Mr Des Kavanagh, Ms Anne Doherty, Ms Maggie King, Mr John O'Brien, Mr Michael O'Connor, Ms Barbara Scully, Mr Norman Stuart, Ms Rose O'Keefe, Ms Sheila Simmons, Ms Francis Weir, Mr Andy Feeney, Ms Pauline Burke, Mr Michael Neville, Dr Terry Connors, Ms Barbara Bolger, Mr Bernie Haddigan, Ms Niamh Daly, Mr Pat Gaughan, Dr Kevin Kelleher, Ms Patricia Lane, Ms Kathleen Leavy, Mr Eddie Collins-Hughes, Dr Ruth Lohan, Ms Margaret Fitzpatrick, Mr Seamus Murphy, Mr Alan Aylward and Mr John Brady.

Many of the above also attended a seminar on dementia in Galway on 5<sup>th</sup> October 1998 at which a preliminary draft of the report was discussed. The seminar was very important to the authors in developing our thinking on dementia. Our special thanks to all who attended and contributed.

Our thanks also to those people who indicated an interest in discussing their ideas with us but, for a variety of reasons, we failed to meet up with them. This

category includes the following: Dr Sean Murphy, Dr Kieran O'Connor, Dr Ken Mulpeter, Dr Morgan Crowe and Dr De Souza.

To everyone we met during the consultations, and who contributed to the report, thank you.

## Appendix 2

### National Council on Ageing and Older People

The National Council on Ageing and Older People was established in March 1997 in succession to the National Council for the Elderly (January 1990 to March 1997) and the National Council for the Aged (June 1981 to January 1990).

*The functions of the Council are as follows:*

*1. To advise the Minister for Health on all aspects of ageing and the welfare of older people, either at its own initiative or at the request of the Minister and in particular on:*

- (a) measures to promote the health of older people;
- (b) measures to promote the social inclusion of older people;
- (c) the implementation of the recommendations contained in policy reports commissioned by the Minister for Health;
- (d) methods of ensuring co-ordination between public bodies at national and local level in the planning and provision of services for older people;
- (e) methods of encouraging greater partnership between statutory and voluntary bodies in providing services for older people;
- (f) meeting the needs of the most vulnerable older people;
- (g) means of encouraging positive attitudes to life after 65 years and the process of ageing;
- (h) means of encouraging greater participation by older people;
- (i) whatever action, based on research, is required to plan and develop services for older people.

*2. To assist the development of national and regional policies and strategies designed to produce health gain and social gain for older people by:*

- (a) undertaking research on the lifestyle and the needs of older people in Ireland;
- (b) identifying and promoting models of good practice in the care of older people and service delivery to them;
- (c) providing information and advice based on research findings to those involved in the development and/or implementation of policies and services pertaining to the health, well-being and autonomy of older people;

- (d) liaising with statutory, voluntary and professional bodies involved in the development and/or implementation of national and regional policies which have as their object health gain or social gain for older people.
- 3. *To promote the health, welfare and autonomy of older people.*
- 4. *To promote a better understanding of ageing and older people in Ireland.*
- 5. *To liaise with international bodies which have functions similar to the functions of the Council.*

The Council may also advise other Ministers, at their request, on aspects of ageing and the welfare of older people which are within the functions of the Council.

## **Membership**

**Chairman**            Dr Michael Loftus

Mr John Brady  
Ms Janet Convery  
Mr John A Cooney  
Mr Jim Cousins  
Mr Joseph Dooley  
Cllr Michael Finnerty  
Mr James Flanagan  
Ms Maragret Geary  
Dr John Gibbon  
Prof Faith Gibson  
Mr Frank Goodwin  
Dr Mary Hynes  
Mr Eamonn Kane  
Ms Betty Keith  
Ms Sheila Kennedy  
Mr Jack Killane  
Cllr Tim Leddin PC  
Ms Leonie Lunny  
Ms Mary McDermott  
Dr Diarmuid McLoughlin  
Ms Mary Nally  
Mr Pat O’Leary

Ms Mary O'Sullivan  
Mr Peter Sands  
Ms Sarah Scott  
Mr Bernard Thompson  
Mr Liam Walsh  
Dr Margo Wrigley

Director  
Research Officer  
Resources Officer  
Communications Officer  
Projects Officer

Mr Bob Carroll  
Ms Nuala O'Donnell  
Ms Catherine Mulvenna  
Mr John Heuston  
Ms Liz Leonard\*

\*Temporary replacement for Trish Whelan who is currently on a career break.