

Conference Proceedings

Planning for Dementia Care in Ireland

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Planning for Dementia Care

Edel Murphy (Rapporteur) and Eamon O'Shea (Editor)

National Council on Ageing and Older People

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22 CLANWILLIAM SQUARE
GRAND CANAL QUAY
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PRICE

Foreword

As Chairperson of the National Council on Ageing and Older People, it gives me great pleasure to present the Proceedings from the Conference, “Planning for Dementia Care in Ireland”.

The Conference, which took place on 4th June 1999 in the Royal Marine Hotel, Dun Laoghaire, marked the publication of the Council’s latest report – *An Action Plan for Dementia*. Officially opened by Dr Tom Moffatt TD, Minister of State at the Department of Health and Children with special responsibility for older people, the conference attracted almost 300 delegates from across the statutory, voluntary and private sectors.

The Action Plan, prepared by Dr Eamon O’Shea and Ms Siobhan O’Reilly, Department of Economics, National University of Ireland, Galway, is the result of extensive consultation with national organisations of older people, carers, and with health care professionals and policy makers working in the area of dementia. It builds on previous work undertaken by the National Council on Ageing and Older People which highlighted the need for significant progress in the care of older people with dementia in Ireland.

In June 1993, the Council organised a seminar to consider the setting up of a Dementia Services Information and Development Centre. This was followed, in 1996, by the publication of the report, *Mental Disorders in Older Irish People: Incidence, Prevalence and Treatment* and a conference which focused on priorities for mental health services for older people. The publication of the Action Plan, and the conference on planning for dementia care, are the latest steps taken by the Council in seeking to bridge the gap between the needs of dementia sufferers and their carers and the services actually provided.

The Action Plan takes as its guiding principle the recognition of the individuality of the person with dementia and of his or her needs. It outlines an approach to developing available, accessible and high quality services in the context of existing resources and public expenditure constraints. Its aim is to describe a best practice model of dementia care in Ireland – a model which may inform and guide policy makers and others involved in planning service provision, and which may give support and assistance to those who endeavour to provide flexible services at the local level.

The Conference provided the opportunity for delegates to discuss and focus attention on issues necessary to the successful implementation of the Action Plan. Dr Eamon O’Shea, one of the report’s co-authors, presented a summary of the report. This was followed by a response from a health board perspective and by a range of stimulating presentations on good practice in dementia care. The Keynote Address, delivered by Mr Malcom Goldsmith of the Dementia Services Development Centre, Scotland, focused on hearing the voice of the person with dementia and on overcoming

obstacles to communication. Parallel sessions during the afternoon concentrated on some of the key issues identified in the Action Plan, while the final part of the conference discussed setting priorities for the future – a crucial step in the effective planning for dementia care.

I would like to express my appreciation to Dr Tom Moffatt TD for opening the conference, to each of the speakers for presenting such excellent papers and to all the conference participants for their contribution to the day.

Dr Michael Loftus

Chairperson

National Council on Ageing and Older People

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Dr Michael Loftus
Chairperson, National Council on Ageing and Older People

In 1994, the National Council organised a seminar to explore the need for a Dementia Services Information and Development Centre. In 1996, it published a report and organised a conference on '*Mental Disorders in Older Irish People: Incidence Prevalence and Treatment.*'

For a number of years, the National Council on Ageing and Older People has been examining issues of policy and practice relevant to the welfare of older people suffering from mental disorders and, in particular, dementia. This is because such people are among the most vulnerable in the population and yet provisions and services for them and for their family carers remain inadequate.

The National Council On Ageing and Older People is pleased to present *An Action Plan for Dementia* prepared with his usual thoroughness, and following extensive consultation, by Dr Eamon O'Shea, expertly assisted by Ms Siobhan O'Reilly. The Council are greatly indebted to the authors for their work and to all those who assisted with information and advice, both individually and at a consultative seminar organised in the National University of Ireland, Galway in 1998 to discuss the draft Action Plan. The Council also thanks Dr Margo Wrigley, Chairperson, and the members of the Consultative Committee who worked so closely with the authors of the Action Plan. A particular tribute is paid to Mr Christy Domegan for his generous commitment to addressing the needs of those suffering from dementia and, in particular, for chairing the Consultative Committee until he became ill himself.

Opening Address

Dr Tom Moffatt, TD
**Minister of State at the Department of Health and Children with Special
Responsibility for Older People**

Introduction

I was delighted to receive an invitation from the National Council on Ageing and Older People to officiate at the opening of this Conference to mark the publication of the latest report, *An Action Plan for Dementia*.

I have always had the greatest admiration for the high quality of the Council's reports and believe that this Action Plan is equally enlightening. There has been wide consultation with various groups over a considerable period and this has resulted in a comprehensive report with a clearly defined set of recommendations. I would like to pay tribute to the authors, Eamon O'Shea and Siobhan O'Reilly, who have put forward a blueprint for the development of dementia services in Ireland.

There are over 60 million people in the European Community who are aged 60 and over. One in five of the population of the Community is an older citizen. The ratio is set to rise to one in four quite rapidly. In Ireland, the expected increase in the number of older people reaching advanced old age is dramatic. It has been estimated that between 1991 and 2026, there will be an increase of approximately 75% in the number of people aged 75 and over. Inevitably, this will give rise to an increase in the numbers of people with dementia.

Policy for Managing Dementia

The underlying philosophy of Government policy in the care of older people is that people should be maintained with dignity in their own homes for as long as possible by providing appropriate services for them and for their carers. This policy recognises the essential role of families and carers of dependent older people and the necessity to support them by providing a variety of services.

Similarly with regard to dementia, Government policy is based on the premise that most sufferers prefer to stay in their family surroundings. This approach works well where there are family members who are able and willing to be involved in the care of their relative. Professional input can then be directed to helping families by offering both practical and emotional support, for example, by the provision of respite care which gives families a break from the caring role.

However, we must recognise that, for the most part, dementia is a progressive and incurable condition where brain function deteriorates causing impairment of memory,

disorientation and gradual loss of skills. As a consequence, people lose their independence and require help from others in the basic tasks of daily living.

The emphasis on a community care model does not, of course mean that residential care facilities are not required. Such facilities are needed and should be provided in easily accessible, small, local units in a homely atmosphere. As far as possible, these facilities should be close to the persons home so that relatives and friends can maintain contact, thereby improving the quality of life of the person with dementia.

I note that the Action Plan reports that family care accounts for almost 50% of care provided to persons suffering from dementia. The Government is very much aware of the enormous contribution of family carers to looking after dependent older people and other people with disabilities in the home. Dermot Ahern, Minister for Social, Community and Family Affairs, is taking measures to improve assistance to carers through the Carer's Allowance. He has increased by £6 the Care Allowance for carers over 66 years and by £3 the allowance for carers under 66 years. There will also be a once-a-year payment of £200 towards the costs of respite care. On the Health side, I have allocated a sum of £1 million as part of the Budget allocation for older people to health boards, specifically for the support of carers. This fund can be used for the benefit of carers in a flexible manner, based on local needs. The improvement of liaison and support for individual carers and local voluntary groups who promote the interests of carers are examples of the type of support envisaged. Additional funding has also been provided to enable more paramedical and nursing staff to be recruited and assigned to home care of older people which, in turn, will also assist carers. A sum of £800,000 is earmarked for this purpose.

Dementia Services Information and Development Centre

The dissemination of information on all aspects of dementia is recognised as being an integral feature of a properly structured service for this condition. A Dementia Services Information and Development Centre has been established at St. James' Hospital, Dublin in association with The Mercer's Institute for Research on Ageing and Trinity College, Dublin. The main objectives of the Centre are:

To provide information, education and training for all those working with dementia sufferers and their carers.

- To establish and maintain databases on dementia services and dementia related research in other countries.
- To identify and highlight service developments to meet changing needs and circumstances.
- To increase public awareness of the nature and prevalence of dementia in Ireland and to liaise with all relevant agencies concerned to improve the welfare of dementia sufferers and their carers.

The Centre is now getting into its stride and substantial funding has been provided.

The Action Plan

It is fair to say that, up to now, action for the care of people with dementia has been fragmented. There has not been the investment of adequate resources in the community sector and, as the Action Plan states, “the service has fallen between the cracks of the health care system, between purely medical provision and purely psychiatric provision.” I want to place on record that Minister Brian Cowen and I regard the dementia issue as one of the top priorities for services for older people. In our negotiations with the Department of Finance for additional resources in year 2000 and beyond, the needs of dementia sufferers will be clearly flagged. This Government is committed to improve the lot of older people and this is clearly evident by improvements in the 1999 Budget in the areas of Social Welfare, Health and Taxation. I am confident that significant progress can be made on implementing the large number of recommendations contained in the Action Plan. The cost is considerable but the hope is that progress can be made on a phased basis.

Conclusion

I agree with Dr Mick Loftus that action on the treatment of dementia can no longer be delayed, even if there is no single solution to the problem of dementia. The proceedings of this Conference and especially what emerges from the workshops will be of tremendous assistance to me in planning future service developments. I wish those involved in the conference well in the day’s deliberations

Introduction to Conference Proceedings

Dr. Eamon O'Shea

Co-Author of *An Action Plan for Dementia*

The Proceedings deal with a range of issues critical to the implementation of the Action Plan for Dementia. Four main issues emerge as critical to its success:

- Additional resources in all areas of dementia care.
- Information and training for both statutory and family carers.
- Care management.
- Implementation procedures.

The proceedings begin with a summary of the Action Plan by its co-author, Eamon O'Shea. He highlights the principles upon which the Action Plan is based, the range of additional services required and the overall cost of the Plan. The cost is £46 million over three years or £500 per person with dementia in Ireland. When placed alongside the gains to be had from the introduction of the Action Plan, the cost is modest, suggesting a high level of return from investment in dementia. The potential for gains from investment is taken up by Pat Gaughan in his response to the Action Plan, where he outlines the advantages of continued and appropriate investment in the area of dementia, drawing on the experience of the North Western Health Board. The case for additional resources is also made later on by both John Grant and Maurice O'Connell, particularly in relation to the critical interface between statutory and voluntary provision of services.

The need for information and training in dementia care is central to the development of high quality services for people with dementia. All of the contributions on "good practice" in dementia care emphasise the relationship between training and education and the quality of care for people with dementia. Maureen Caffrey highlights the importance of meeting the expressed needs of carers through effective training programmes; Anne Hutton emphasises the importance of good process in day centres for people with dementia; while Celine Phelan outlines models of good practice in residential care.

Training and education is also essential if we are to provide a person-centred model of care to people with dementia. Malcolm Goldsmith explores the commitment to person-centred care and the need to communicate effectively with people with dementia. This is a skilled and demanding task, which requires patience, understanding, empathy, and above all, the continued renewal of our intrinsic humanity through education and practice. Murna Downs discusses the need to improve the quality of primary care responses to dementia through training and information and through the provision of guidelines for general practitioners.

Care management is identified as critical to the success of the Action Plan. David Challis provides evidence of the success of care management in the United Kingdom and its potential for use in this country. There is a strong feeling that the time is now right for experimentation with care management in the area of dementia. Des O'Neill emphasises the importance of care management as an integrating mechanism in the care of people with dementia, particularly its potential to bring together the various elements of primary and secondary care services. Anna Buckley outlines the need to have flexibility and continuity in community care services and highlights care management as important in this regard. Support for care management is evident throughout the contributions, with the qualification that good care management schemes will require investment in resources if they are to be successful.

Policy implementation is critical to the success of the Action Plan. Ruth Loane emphasises the importance of implementation and the ongoing evaluation of service provision through an implementation committee. This theme is taken up by Michael Loftus, chairman of the National Council on Ageing and Older People who argues for the implementation of the Action Plan without delay. John Cooney encourages those working in the area of dementia to lobby for additional resources and to make an effective case outlining the returns from investment in dementia. This call echoes the comments of Eamon O' Shea, who argues for ongoing monitoring of resource allocation for dementia and a review of the Action Plan after three years.

The Proceedings are an important record of peoples' commitment to bringing about an improvement in the quality of life for people with dementia in Ireland. The proof of the commitment of those who control resources for health and social care in Ireland will be the phased implementation of the recommendations contained in the Action Plan. The time for action is now.

Session 1: Action Plan for Dementia

Planning for Dementia Care in Ireland

Dr Eamon O'Shea

**Department of Economics, National University of Ireland, Galway
and Co-author of Action Plan**

Introduction

There are just over 31,000 people with dementia living in Ireland, three quarters of whom live at home in the community. 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 plan that is responsive to the individual needs of people with dementia and their carers. The *Action Plan for Dementia* is a response to the needs of people with dementia and their carers. It is a reflection of the views of health care professionals and policy-makers and was put together after extensive consultation with representatives of the various agencies working in the area of dementia.

The Action Plan details the need for significant investment in the area of dementia care. The emphasis is on the uniqueness of the person with dementia. The intention is that the Action Plan will serve as a model of best practice, to guide policy-makers and others involved in planning service provision, and to support the providers of local and flexible services for people with dementia. For a long time 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. Unfortunately, despite stated policy objectives, services for people with dementia remain under-developed. Community care services are patchy and variable across the country, with no scientific or legislative relationship between need and provision. People with dementia are not getting the services and support that they need to continue living in their own homes.

The *Action Plan for Dementia* contains 33 different recommendations designed to bridge the gap between the needs of people with dementia and the existing provision of services. The Plan proposes that these recommendations should be implemented over a three year period.

The Need for Action

The high personal and social cost of dementia, the gradual ageing of the population, the inadequacy of community care, and the ongoing and binding public spending constraints have combined to focus public attention on 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, the absence of a cure and ignorance about the disease amongst the general public. Patients with dementia may also fall between the cracks of the health care

system, between purely medical provision and purely psychiatric provision. People with dementia may also be discriminated against because of a lack of awareness and training amongst service providers.

There is an emerging consensus that the inadequate support available to people with dementia is no longer acceptable. The aim of the *Action Plan for Dementia* 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.

Principles for the Action Plan

The issue of resource allocation for people with dementia cannot be discussed in a vacuum. It is essential to have principles against which progress can be measured to enable informed comment to be made about the advantages and disadvantages of different approaches to care. In keeping with the philosophy of the Action Plan, the principles must acknowledge the primary role of the person with dementia in the process of care.

The Action Plan for Dementia is based on six principles as follows:

- 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, 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 Action 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 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.

Planning for Primary and Community Care Services

In the majority of cases, dementia can be dealt with at the level of primary and community care provision. The key areas requiring action are:

- **Supporting early diagnosis of dementia**

Early diagnosis is critical for people with dementia. It facilitates more timely and, therefore, more effective community care intervention leading to less crisis management for people with dementia. To encourage and facilitate early diagnosis, information and training should be provided to general practitioners and public health nurses through opportunistic or targeted assessment using tools sensitive to the detection of dementia in primary care. Early diagnosis would be facilitated by the launch of a public information campaign designed to raise awareness of dementia among the general public.

- **Funding of flexible community care services**

If we are to encourage early diagnosis then 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 legislatively-based community care services, particularly in the areas of home support services, day care, day hospital, and respite care. Community care services are very important in allowing people with dementia to continue living in their own homes. The problem is that community 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. For example, home help and home sitting services should be geared to meet the individual needs and circumstances of people with dementia. The dignity and autonomy of people with dementia will be best served by the development of individualised care plans mediated through case management structures.

- **Introduction of Case Management**

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. The case management model should be introduced on a pilot basis in two health boards as soon as possible. For case management to be successful caseloads must be small, services must be targeted and integrated and resources must be available to provide the intensive level of supports necessary to keep vulnerable people living at home.

Support for carers

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. 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,

based on an assessment of care recipient needs and dependency made by the relevant case manager. Carers should also receive training in the care of people with dementia, as well as counselling services, if required.

Planning for Secondary Level Care

There are some people with dementia who will require the services of specialist dementia teams, based in Medicine for the Elderly services or in Psychiatry of Old Age services, to deal with 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. There is a need for significant investment in Psychiatry of Old Age services, which are currently under-developed in Ireland. To deal with the existing need in this area and to overcome the obvious regional disparities in provision, five new Psychiatry of Old Age services per year are required over the course of the Action Plan, in addition to the services already sanctioned but not yet in operation. There should be twenty new services in place by the year 2003. Each new service 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. The continued development of specialist geriatric departments is also a key element in the care of people with dementia and ongoing investment is required in this area.

Planning for 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 sectors. 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.

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, are an important part of this investment, 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, psychological and sensory needs of long-stay residents through the support of various psycho-social interventions for people in the early stages of dementia. 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 poor quality care. The Dementia Services Information and Development Centre at St. James's hospital will play an important role in developing appropriate and common training programmes for professionals working with people with dementia. To facilitate and accelerate change, 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 other 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. 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. 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.

Policy Implementation Issues

The emphasis on community care in official policy statements has not been matched by the significant transfer of resources to the community sector. Consequently, most attention should be focused on policy implementation, if the increase in resources to community care, which is critical to the success of this Action Plan, is ever to become a reality. For that reason, a committee should be set up to oversee the implementation of this Action Plan. The primary task of this committee would be to monitor progress with respect to the attainment of service targets for people with dementia outlined in the Action Plan and to undertake a review of the Action Plan after three years.

There are three critical relationships with respect to policy implementation:

- **The relationship between the centre and the local**

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 relationship between the statutory and voluntary sector**

The role of the voluntary sector would 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.

- **The relationship between the public and private sector**

We also need to explore ways of developing co-operation between the public and private sector in the provision of care for people with dementia. 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 is substance to this claim, existing subvention funding for private nursing homes also 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 existing policy on the primacy of community care.

Costs and Funding

There is uniform agreement that a major gap exists between the needs of elderly people with dementia and existing service provision. This Action Plan contains 33 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 Action 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 Action Plan.

We cannot, however, rely on increased public spending to solve all of the problems in this area. 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 supply side of the social economy. In the short term, the development of additional services for people with dementia must be financed from general taxation; in the longer term, the introduction of a new social insurance system for the funding of long-term care, which would include services for dementia, should be seriously considered. The potential of the social economy can be developed through training programmes and seed capital funding for the nurturing of social entrepreneurship at local level. The development of the local social economy can make an important contribution to meeting the needs of people with dementia and their carers in a flexible and innovative way.

A Health Board Perspective on the *Action Plan for Dementia*

Mr Pat Gaughan
Programme Manager, North Western Health Board

Introduction

Based on a solid foundation of wide consultation and research, the *Action Plan for Dementia* brings a focus to the provision of services for those suffering from dementia, a focus that is overdue. This impressive publication will become an important national steer for all organisations, both statutory and voluntary, involved in the planning and delivery of services to those suffering from dementia. This paper presents the initial reaction to the Action Plan and discusses some of the issues raised, primarily from the perspective of the North Western Health Board.

Services in the North Western Health Board

The North Western Health Board provides services to 211,000 people, in Counties Sligo, Leitrim, and Donegal and a small part of West Cavan. Approximately one in seven people (14% of the population) in this region are elderly (aged over 65), the highest proportion in the country, and this figure rises to 17% in Co. Leitrim. Specific dementia services in the North West are quite limited, although the health board does have designated social workers for older people. Dementia-specific residential accommodation is provided in three 30-bed units. There are many community hospitals, day care centres and day hospitals in the region and the Alzheimer Society runs an Alzheimer-specific day centre. The community hospitals provide a respite service, which, although not dementia-specific, does cater for dementia patients. Almost 50% of admissions to the two acute hospitals in the region are patients over 65, almost twice the national average.

The Mental Health Services in the region are largely community-based, centred on a network of supervised residential units and hostels. There is also a network of mental health day centres and a psychiatric day hospital. Many of these provide respite care as well as long-term care. The North Western Health Board is currently recruiting a Psychiatrist for the Elderly. There are also two acute Mental Health Units in the region.

Early Diagnosis and Assessment

The Action Plan correctly emphasises the importance of early diagnosis of dementia. Early diagnosis allows the patient and the family/carer to come to terms with the illness while it is still in a mild form. The continued stigma attached to dementia, as well as other mental illness, often prevents people from presenting at an early stage of the illness. In the past, dementia patients were not visible in our community, but were cared for quietly in the home or in distant institutions. Visibility can be an important

factor in removing some of the stigma attached to dementia, especially for younger people, but this should be balanced with the need to maintain personal dignity of both the patient and the carer.

The General Practitioner (GP) is correctly identified in the Action Plan as the key to early diagnosis of dementia. Continued medical education and specialist input is vital if the GP is going to be able to contribute significantly to early diagnosis. The role of other professionals in this process also needs to be supported: in particular, the need for more postgraduate gerontology training for nurses. A number of initiatives currently underway in the North Western Health Board are addressing the needs of the GP and of nurses, with regard to their role in early diagnosis of dementia. Recent work carried out with Care Focus Groups in Sligo/Leitrim supports the point made in the Action Plan that carers need to have a greater understanding of dementia – this will require a more proactive dissemination of information both to individuals and through support by the health boards for carer networks.

Care in the Community

The emphasis in the Action Plan on domiciliary-based care is very much in keeping with the philosophy of the health boards. A recent survey, by Marie O’Grady, of carers in Sligo/Leitrim, showed that out of 469 respondents, none wanted to cease providing care. All the indications are that a partnership approach to caring involving carers, the patient, the voluntary sector and statutory organisations, is the desired way forward. The challenge, as set out in the Action Plan, is to adequately resource support for carers and to provide it in a manner that is flexible and adaptable. A more proactive approach to seeking the views of patients and their carers will create a dynamic for change within the system. To this end, the North Western Health Board has recently adopted a Strategy and Plan for Furthering Consumer Involvement in Services.

The Action Plan recommends a flexible case management approach for the delivery of domiciliary-based care. The challenge for the Health Boards is to structure the service at a local level on the basis of an area which is big enough to make it economical to deploy a range of resources and small enough to ensure that those managing those resources have detailed knowledge of their area and are responsive to the particular needs of individuals. Whether a Case Manager as put forward in this Action Plan should be dementia-specific or should have a wider range of responsibilities is something that requires further consideration.

Three important aspects must be addressed if case management is to be provided on a flexible basis:

1. Devolved budgets must be in place so that decisions can be made on a local basis in response to local needs.
2. The Case Manager must be the single point of reference and access for the patient and the carer to all relevant services in the health care system.

3. The Case Manager must have the freedom to provide a range of responses to particular situations, depending on the most appropriate solution.

Establishing the trust and confidence of the patient and carer is essential to the success of this approach.

In the North West, the home help service is one of the most valued services by patients and their carers. Demand for this service grows each year, putting considerable strain on resources – but additional resources for this service is a vital requirement. Indeed, this service should be expanded to provide for home sitting and to provide an element of specialist home self-help service.

In the North West, there has been increased emphasis on respite care for the elderly in recent years, and a home-based respite care pilot is currently underway. When planning respite care, the Action Plan correctly identifies the need to address the issue of disorientation of dementia patients. This supports the current plans in the North West to extend home-based respite care. Greater and more imaginative use of the existing locally-based mental health facilities can enhance the range of options for the provision of a more flexible service at community level.

The Action Plan recognises the value of Day Centres, both dementia-focused and dementia-specific. In rural areas, taking transport issues into account, integrating dementia-focused facilities with existing Day Care centres makes most sense.

Specialist Services

Undoubtedly, the development of Psychiatry of Old Age in each of the Health Boards will be a major boost to services for people with dementia, as outlined in the Action Plan. However, in focusing on bringing services closer to local communities, it will be necessary to keep demographic and geographic issues in mind in each region when allocating resources for Psychiatry of Old Age services. Some counties and regions may have greater needs than others and this should be reflected in the allocation of scarce resources.

Residential Care

The recommendation in the Action Plan to develop small scale domestic-oriented specialist units attached to conventional elderly long-stay facilities is both pragmatic and practical. The North Western Health Board has recently opened two purpose designed dementia units attached to existing Community Hospitals. While these units are larger than recommended in the Action Plan, the strategy is to develop a number of small-scale, 8-10 bed units. Some of these will be associated with existing community hospitals but at least two will be provided in association with the private sector, in areas where there is currently no health board community hospital or nursing home. The emphasis in the North West is on providing care as near as

possible to the patients' own communities, for all dependent older people including dementia patients. There is no reason why a mixture of public and private provision cannot work, provided the health boards have the freedom to engage in appropriate contractual arrangement with the private sector, in a context where standards of care and funding are explicit, agreed, and monitored.

Funding and Resource Allocation

Community care is not inexpensive care and substantial additional resources are required if this Action Plan is to become a reality. However, the transfer of resources from acute hospitals to community care is not a realistic source of additional funding. There is an onus on everyone in the public sector to maximise the service provision from the resources that are available. There has been a considerable increase in the number and range of resources based in local communities over the years – including GP practice nurses, palliative care nurses, nurses in public and private nursing homes and supervised residential units in the psychiatric services, as well as the public health nurses. There is scope to explore imaginative deployment and working arrangements at district level to maximise the combined contribution of all of these professionals and to increase the level of service available to the community. A pilot project to explore such options is currently underway in the Inishowen area. The development of the social economy through official support for social entrepreneurship at a local level can also play an important role in maximizing the potential of community care services. This will involve a paradigm shift on the part of those involved in the management of the services and indeed, on the part of the health care professionals but it may lead to better care for people with dementia.

Setting Standards

The proposal for national standards of care across all sectors is an essential part of the Action Plan. It is important that all concerned in the provision of care to people with dementia have clear goals and common standards to adhere to. It is also important that these standards are carefully monitored.

Session 2: Good Practice in Dementia Care

Day Care with a Difference in a Hospital Setting

**Ms Anne Hutton
Day Centre, Leopardstown**

Introduction

The Carman Centre was founded just over five years ago, when an Eastern Health Board survey identified a need for a dementia day care service. The centre is located in the grounds of Leopardstown Park Hospital, in a small cottage-type building that has been modified to meet the needs of the patients. The Carman Centre was recognised at a European level as meeting the criteria for best practice in dementia day care. This paper outlines the principles of best practice on which the Carman Centre operates, considering the nature of the service provided, the patients, their carers, and the staff at the Centre.

The Day Care Service

The centre can provide care for nine to twelve patients per day. The catchment area covers approximately ten miles; ideally, the patients should take no longer than one hour to reach the centre, but traffic problems can cause longer journey times. The service is based on a social model rather than on a nursing model and the aim is to have no elements of institutional care. The cottage-type building was renovated into a non-institutional-type building with three rooms, a toilet and shower room, and an enclosed garden. Ambience and environment are very important features of the centre, so attention was given to the use of soft colour schemes and comfortable furniture. The garden is designed on a therapeutic plan with paved walks, a water feature, trelliswork, and raised flowerbeds.

The overall estimated cost of providing day care per patient is £22 per day, compared to £66 per day for residential care. Patients pay £1 for transport and £2 for lunch. Transport is provided to collect patients from their homes, with a staff member present, which provides a useful link with the home environment and the carer. The transport vehicle has a hoist and ramp access to the Centre is available, if needed.

The service can also intervene in a crisis, where appropriate, by offering extra day care, support by telephone or in person, by enlisting the support of other agencies involved or by providing either short-term or long-term respite care.

The Patient

The Carman Centre focuses on three important aspects of the patient:

- **The individuality of the patient**

The Centre uses Naomi Feil's criteria¹, emphasising that people are unique and must be treated as individuals. A patient profile is built up from the time of application to attend the day care, with particular care paid to previous personality traits and hobbies. Staff pay attention to body language and observe each patient closely, listening patiently to the patient and to any verbal feedback. This helps staff to understand the patient's needs and to intervene before problems arise. While patients are encouraged to read and do craft work, with reading materials provided in areas in which a patient would have had an interest, the patient's preferences regarding such activities are respected.

- **The needs of the patient**

The Centre strives to address the physical and social needs of the patient by focusing on the physical environment and ambience, through a continence programme, through the provision of a flexible programme of activities, and by focusing on keeping the daily living skills as intact as possible. Attention is also paid to the psychological and spiritual needs of the patient in a variety of ways, by the empowerment of the patient through conversations and activities, by respecting the personal space of patients, and through the provision of daily prayer service or reflective reading, where appropriate.

- **The autonomy of the patient**

Patient autonomy and independence in relation to activities of daily living are encouraged. For example, the staff eat with the patients but do not feed the patients, unless it is absolutely necessary. At times, patients rediscover life skills, like how to use cutlery, that they have lost through becoming over-dependent on a carer. The centre trains, informs, respects, and empowers people with dementia, focusing on the problems of ageing, either at a one-to-one level or in groups.

The Carer

Special emphasis is placed on developing a partnership between the carer and the staff. The main carer is encouraged to visit the centre prior to the patient attending or to accompany the patient on the first visit. Carers tend to be very protective and it is vital to establish a link of trust between staff and carer. Carers are encouraged to attend carer groups and to read appropriate literature, as the Centre believes it is important that carers receive appropriate information, physical support, and psychological care.

The Staff

There are three full-time staff, a staff nurse and two care assistants. There is also a community worker on a part-time basis, and if possible, this person is male, to help

¹ Feil, Naomi (1992). V/F Validation. The Feil Method. Edward Feil Productions, Cleveland.

balance the gender needs of patients. Staff do not wear uniform and do household tasks and eat meals with the patients. Staff meet each morning to review problems from the previous day and to prepare for the day ahead. To ensure continuous staff education and to promote a positive attitude to work, staff are encouraged to attend seminars and training days when possible. Staff working in the centre are selected on the basis of their versatility, of having a non-judgemental approach, and of being capable of paying considerable attention to detail, to be able to provide the best care to the patients.

Conclusion

It is difficult to assess the service, but the following factors suggest that it is meeting the needs of both the patient and the carer:

- Patients are happy and relaxed and there are minimal aggression problems – attention to body language and observation help in this regard.

The use of medication is minimal and patients who are on no medication maintain independence for a longer period of time.

- There is low to zero level of incontinence, due to the continence programme.
- Emphasis is placed on identifying and meeting a pattern of needs and on allowing autonomy.
- A flexible, failure-free activities programme is provided with in-built structure and routine.
- Carers feel supported and satisfied.
- The personal profile of each patient informs the staff on the patient's cultural and religious beliefs and the Centre strives to meet these needs.

The Carman Centre provides a service that is small, local, affordable and accessible to all dementia sufferers. Based on a social model, the centre is domestic rather than institutional in nature. The Centre focuses on training, informing, respecting, and empowering people with dementia and their carers and on developing staff that are educated, positive about their work, and always listening to the needs of the patients.

Identifying Carer Needs

**Ms Maureen Caffrey
North Eastern Health Board**

Introduction

In 1997, the North Eastern Health Board, working with the Alzheimer Society of Ireland, completed a project that identified the education and training needs of carers of people with dementia and then produced a training programme to meet these needs. This project was part of a European Union project, with partners in Sweden, Portugal, and Northern Ireland also involved.

Project Background

The project was titled HOME – **H**elping **O**lder people with dementia to be **M**aintained at home through **E**ducation and training. The title recognised the fact that the best of quality of life for people with dementia is achieved when the person can remain in his or her own home. The focus of the study was to identify the education and training needs and preferences of the carers. The project team in Ireland included representatives from the Alzheimer's Society of Ireland, the Department of Public Health Medicine in the North Eastern Health Board, the Department of Education/Training in the North Eastern Health Board and Care of the Elderly groups.

The project had two key objectives:

- To identify the educational, skills and support needs of carers.
- To develop an appropriate response to the needs identified.

The project team also hoped that the project would help develop closer contact between all the carers in the region. The project would also facilitate elderly people with dementia to remain safely in their home environment, by optimising informal and formal care.

Project Process

The project team took three steps to identify the needs of the carers:

Identifying the different carer groups that exist

Carers fell broadly into two categories: the informal carers, usually family members and usually unpaid, and the formal carers, usually in an organised setting and usually paid.

- **Gathering survey data**

Questionnaires were used to gather data from carers, both at a national level and in the North Eastern Health Board. Data was also gathered from focus

groups in the health board area.

- **Reviewing of the literature**

A detailed review of the literature, focusing on the needs of carers, was undertaken.

Survey Data

104 informal and 136 formal carers were included in the study. In both the formal and informal sectors, females give almost all care at 79% and 81% respectively. One interesting result was that a significant minority of carers (11%) are themselves elderly. The overall responses on the type of information the carers felt they most needed showed similar results for both the formal and informal sectors, as follows:

- General information on dementia.
- Information on behavioural difficulties.

Information on managing stress.

- Practical advice on managing a patient with dementia (informal carers).
- Information on alternative therapies (formal carers).

Surveys carried out by the European partners in the study identified very similar needs among carers.

The carers were also asked to contribute to defining the nature and content of an education and training programme that would meet their needs. The carers indicated that:

The course should be a mixture of lectures, discussions, and demonstrations.

- A mixed team should deliver the course, consisting of health care professionals, other carers, and experts with specialist knowledge.
- The education programme should be delivered in a phased manner, over a number of weeks, rather than having an intensive course delivered, for example, in one week. This reflected the fact that most carers do not like to leave the person with dementia for long periods of time.
- There was a need to provide cover care while the main carer was attending the course.

The Literature Review

The review of the dementia literature emphasised the need to provide a mixture of health and social care for people with dementia: the former usually provided by Medicine for the Elderly or Psychiatry of Old Age services in a hospital environment, the latter provided mainly by family members in the home of the person with dementia. Having completed a review of the literature, the project team concluded that the project should develop an education and training programme that would be of

use to all carers, whether the carer is a family member in the home or a health care professional.

Developing the Education and Training Programme

The final phase of the project involved the development of the course content and the delivery of the course. The course ran for ten weeks, one day per week. The course started with an introductory session, which proved very useful, particularly for the informal carers, to help them feel relaxed and comfortable in the training environment. A different topic was covered each week, covering all the issues identified by the carers. There was also a focus on personal development and care for the carers. In all, almost 90 carers attended the course, which was run in three centres, Cavan, Dundalk, and Trim.

Feedback on the course was gathered through questionnaires at the end of each day and through a comprehensive questionnaire at the end of the course. The overall feedback from this evaluation was very positive, indicating that the course content was generally well received and that the course was considered helpful. There was also much evidence of the intrinsic benefits of the course. Carers benefited in a socio-emotional way from the sharing of problems and from the support received from other carers.

Conclusion

Overall, this project provided the North Eastern Health Board an excellent opportunity to work in a real partnership with a voluntary organisation, the Alzheimer Society of Ireland, and to consult in a meaningful way with the carers. Although the project is now concluded, the benefits of the project continue: the North Eastern Health Board now has a training model on which to base further training programmes, a training manual is being produced based on the course content, and the health board is facilitating the development of support groups for carers.

Good Practice in Residential Care

**Ms Celine Phelan
St John of God Nursing Home, Shankill**

Introduction

This paper outlines a model for best practice in residential care for persons with dementia, based on the experience and the practices currently followed at the St. John of God Nursing Home, Shankill, Dublin.

Residential care occurs when it is no longer possible to care for the person with dementia in a non-residential environment. Deciding to place a person in residential care is a difficult decision for all involved. This decision is made more difficult when the person suffers from dementia, because of the additional stress caused by the nature of the disease on both the person themselves and on their partner or family. Once in residential care, nursing care plays a crucial role in determining the quality of life of a person with dementia. By delivering a high quality of nursing care, it is possible to help to maintain a lifestyle wherein the person feels a sense of self-esteem, of dignity, and of being valued by society.

Good practice in residential care covers a number of key areas, including:

- Individual assessment of each person prior to admission.
- Development and maintenance of a patient profile and care plan for each person.
- Provision of good, and where possible, consistent, medical cover.
- Good management of the residential home.
- Provision of training and personal development opportunities for all staff.
- Excellence in physical care.
- Excellence in pastoral care.

Excellence in psychological care.

The remainder of this paper outlines best practices in each of these areas.

Individual Pre-Admission Assessment

Most residential homes have admission criteria, but these criteria often exclude referrals where there is a cognitive impairment or a severe physical disability. Good practice in residential care should start with an individual evaluation of each person, to ensure appropriate placement.

Ideally, the pre-admission process should include:

- A visit to the residential home by the family and, if possible, by the potential resident. This visit serves as an information-sharing process, whereby the residential home gather details on the person and the family and the person are exposed to the ethos, the organisation and the operation of the residential home.

A visit by the nursing staff of the residential home, to either the home or hospital where the potential resident currently lives. The purpose of this visit is to build up detailed knowledge of the person's needs – this is the first part of the care plan. This visit also helps the partner/family to assess the care skills and technical competence of the nursing staff.

- A medical report from the person's General Practitioner (GP) or hospital, providing a medical history and an up-to-date medication regime for the person with dementia.

This process of pre-admission assessment means that the residential home has a detailed patient profile prior to admission and the admission itself is less stressful for the person and their family.

Patient Profile and Care Plan

A patient profile should be developed initially during the pre-admission process, detailing all relevant physical, emotional, social, physiological, and psychological capabilities and needs, as well as medical and family details. This patient profile is a particularly useful source of information on the person with dementia when agency nurses are employed. The patient profile should be constantly updated to reflect changes in the person with dementia.

A care plan should also be developed for each person. This care plan should be reviewed and evaluated regularly and modified to suit changing circumstances. Care goals should be set for each person, goals that are time-limited, specific, understandable, measurable, related to observed behaviour, and achievable. All staff should participate in defining and attaining these goals. It is also recommended that family members be allowed an opportunity to give input to the care plan.

Good and Consistent Medical Cover

Medical cover can be provided by the person's own GP or by a GP selected by the residential home. To ensure continuity of care and a quick response out-of-hours, it is recommended that a residential home set up a special relationship with a GP practice that ensures that out-of-hours calls are dealt with by a GP who is known to the patient and who is familiar with the residential home.

Good Operational Management of the Residential Home

Operational management of the residential home should cover a number of different areas:

- Regular (weekly) conferences involving all care staff, where the care and welfare of each person in the unit is discussed.

Regular (weekly) meeting of nurse management.

- Development of good processes for communication between staff and between the staff and the family. Nurses must be good listeners, to listen to the voice of the person with dementia and to listen to the family.
- Provision of good training for all staff.

Fostering of a good team spirit and motivation of staff to achieve high standards.

- Provision of an induction plan for all staff, including agency staff. This induction should communicate to the new employee the methodology and philosophy of care upheld by the residential home, a philosophy that advocates and guards the right of the older residents to excellence in care.

Training and Personal Development Opportunities for all Staff

Time must be allowed for the ongoing training of all staff, including auxiliary nursing staff, as training is a key contributor to the provision of quality care in residential homes. In addition to improving staff skills, regular and relevant training also helps sustain staff morale and encourages a willingness to pilot proven models of care and treatment, with the aim of enhancing the quality of the residents' lives. The provision of adequate information and training helps the staff to enable people in the residential home to achieve their full potential.

Training of auxiliary nursing staff is a particular priority and including some element of assessment and certification can enhance the value of this training from the recipients' point of view. Induction training for all agency nurses also helps ensure a high quality of care in a residential home.

Excellence in Physical Care

A residential home must provide excellence in physical care, emphasising the degree of self-help each person is capable of – staff should not increase dependency by inappropriate intervention in physical activities.

Excellence in Pastoral Care

Pastoral care is largely about listening and staff should be trained and encouraged to be active listeners at all times. Allowing a person to express feelings of fear, anxiety or despair and providing opportunities to acknowledge his/her sorrow and grief, his/her hope and desire, can have a healing effect on a person that cannot be provided in any other way. Emphasis should also be placed on appropriate use of language, avoiding patronising or dehumanising language when talking to or about a person with dementia.

Excellence in Psychological Care

The distorted and disturbed relationship between a person with dementia and the partner or family causes one of the biggest problems to staff caring for the person. Staff need to be trained and supported to be able to deal with challenging behaviours.

Residential homes must also strive to provide sensory stimulation for the person with dementia, including:

Daily physical exercises, gentle and passive but helping to prevent further pain and immobility.

- Social therapies, including stimulation for the thinking mechanisms which may not yet be impaired.
- Creation of a positive outlook in the residential home, eliminating any nihilistic attitudes that arise, and being creative in varying the routine of the residents.

Session 3: Keynote Address

Hearing the Voice of People With Dementia: Opportunities and Obstacles²

Mr Malcolm Goldsmith

Dementia Services Development Centre, University of Stirling, Scotland

Focusing on the Person with Dementia

The Action Plan for Dementia identifies six principles that should underpin the development and expansion of dementia services, starting with a commitment to person-centred models of care. The report is to be commended for this approach: when dealing with dementia, it is essential never to forget that we are dealing with people, not people in abstraction, but people in particular – someone's mother or father, someone's wife or husband, someone's sister or brother. This report places commitment to person-centred care as the first principle of care: a principle that should be self-evident to those involved in the care of dementia patients, but, unfortunately, a principle that often is not.

We can learn a lot from some books published recently, which are concerned with the problem of coming to terms with dementia within the family. *Remind Me Who I Am, Again* is written by journalist Linda Grant¹ about her reaction to and relations with her mother who, in 1993, was diagnosed as having Multi-Infarct Dementia.

Linda Grant came from a Jewish immigrant family. Her father had died several years ago and her mother lived alone. Linda and her sister were never quite sure of the exact history of the family, where fact and myth merged seamlessly: a fact that led to increased confusion for them as they tried to understand their mother and what she was referring to. The book describes how the two sisters coped with their mother's illness, reaching the conclusion that neither of them could cope with their mother within their own home. Some brief extracts from the book demonstrate the struggle of the two sisters:

“One of the Multi-Infarct Dementia's cruellest tricks is to preserve in its victim until quite a late stage, some insight into what is going on in their mind, so that they can observe themselves lose their own sanity. Depression and emotional instability is a marked characteristic of this disease and who wouldn't be miserable watching themselves go mad.” (Page 129).

“The dogma is this: Social Services comply with what the elderly client wants. What does my mother want? It depends on which sense of herself is in the ascendant at any given moment and with each of these there is no memory of there being another self that wanted something else.” (Page 179).

² This is an edited summary version of the paper presented by Mr Goldsmith at the Conference.

“She was wandering now in her own wilderness. How lonely it was in that desolate place with only death as the Promised Land.” (Page 246).

Iris: A Memoir of Iris Murdoch is a memoir of novelist Iris Murdoch who died of Alzheimer’s disease, written by her husband, John Bayley.² Bayley and Murdoch had experienced a long and deep relationship and Bayley focuses on the effect of Alzheimer’s disease on this relationship and how they learnt to cope with it. He writes of this relationship:

“Our mode of communication seems like underwater sonar, each bouncing pulsations off the other, and listening for an echo. The baffling moments at which I cannot understand what Iris is saying, or about whom or what – moments which can promote anxieties, though never, thank goodness, the raging frustration typical of many Alzheimer’s sufferers – can sometimes be dispelled by embarking on a joky parody of helplessness, and trying to make it mutual. Both of us at a loss for words.” (Page 44).

These two books describe two very different people, and are written from two very different perspectives, describing differing approaches, differing understandings and expectations, and different ways of coping with the devastating experience of dementia. These books highlight the need for us to focus on the person rather than on the illness and to remember that each person with dementia brings their own particular and unique history, personality and sets of relationships, as well as their own specific neurological impairment.

Communication is a Two-Way Process

How we can communicate with people with dementia is a real problem, but before we begin to address this problem, we must ensure that all those involved believe that people with dementia have a voice and that it is worth listening to. It must be accepted that many practitioners work on one of the following premises:

- That people with dementia do not have a voice, or
- If people with dementia do have a voice, that it is not worth the effort listening to it

We must recognise that communication is a two-way process, which means that we have to recognise our own involvement in that process. We must believe that it is possible to hear the voices of people with dementia, not just in the early stages but as the disease progresses. Many variables may affect this communication: the time of day, where and when communication takes place, our own levels of anxiety or stress – these variables can mean that a person with dementia can communicate one day, but not the next.

Research into the contribution people with dementia can make to discussions about their own care suggests that some contribution is possible.⁴ Individual descriptions of communication with people with dementia reinforce these studies.^{5, 6} Communication with people with dementia becomes more difficult as the illness progresses, but while it may be true to say that we do not have the time or the resources or the skills to hear the voice of the person with dementia, we should not assume that they have no voice.

John Killick, a teacher and a poet, has been actively involved in talking with people with dementia and recording these conversations in such a way that we realise that much of what they are saying is symbolic, metaphorical, even poetic.⁷ In a poem, 'The Monkey Puzzle', Killick captures some of the frustration of a person with dementia who feels that her whole existence has become managed without consultation, managed in an authoritarian fashion:

"I'm suffering from the Monkey Puzzle.
The Monkey Puzzle is this place.
The puzzle is how to cope with the Monkeys.

I can't remember anything of today
Except the peppering of my tongue. Yes,
My mouth was peppered again this morning.
I believe it is part of the Monkey Puzzle.
These little Monkeys have two legs,
You know, and wear suits.

....

I've come to the conclusion
that what we should do
is educate these Monkeys.
We should make it perfectly clear
That there are certain things
That are not done, even though
I know that they are laughing
Their heads off behind my back."

The Risk of Disempowerment

Many people with dementia experience a great sense of disempowerment and depersonalising tendencies among those giving care – these include infantilization, intimidation, labelling, outpacing, banishment, ignoring, withholding, accusing, mockery and disparagement.⁸ These experiences reinforce in people with dementia the tendency to withdraw and protect themselves, irrespective of the neurological impairments of their illness.

The first voices listened to tend to be those of medical specialists, then those of other specialists, then those of the carers, and then, at the bottom of the pyramid, the voices of the people with dementia.⁹

Hearing their Voice

Hearing the voice of people with dementia is a skilled and demanding task, with many obstacles as well as opportunities. The people with the most time and the greatest opportunities for hearing the voice tend to be the least trained and the least influential in making decisions about the services required.¹⁰ Barriers to communication are created in a few ways:

Through damage to the brain of the person with dementia.

- As the result of complex defence mechanisms built up by the person with dementia, to protect themselves.
- Built up by family, carers and practitioners, consciously or subconsciously.

These barriers need to be acknowledged and addressed. In general, all those involved are poorly trained and poorly prepared to hear and to understand the voice of the person with dementia. There is now a considerable amount of literature about the processes of communication and we can read about the breakdown in language processing, in motor speech production, and in other cognitive processes. But it is consistent with person-centred care that we concentrate on what a person with dementia is still able to do, rather than to focus on what they can no longer do.¹¹

There are many guidelines for us to explore and follow, which can help us in the challenging task of hearing and understanding what the person is trying to communicate with us.^{12, 13} For example, we can slow down and adapt to the pace of the person with dementia, and we need to become active listeners. The responsibility to maintain the communication process is ours. It can be likened to that of a tennis coach, retrieving whatever ball a student sends over the net and returning it in such a way that the less-skilled player is able to keep the ball in play.

Non-verbal communication may become even more important as the disease progresses. We also tend to spend a lot of energy trying to manage disruptive behaviour of a person with dementia, but, while that may benefit the carer, we must always remember the person with the devastating disease is the one who should benefit. Person-centred care always endeavours to provide care that focuses on the one who has the illness rather than the frustrations of those caring for them.

The Way Forward

We need to allocate more resources to studying the field of communication between people with dementia and their carers. Hearing the voice of people with dementia is a prophetic and liberating concept. Some work has been done on developing techniques to help this communication and some examples of good practice exist. Implementing

this Action Plan for Dementia offers the ideal opportunity to see things from a different perspective: to begin to hear the voice of the voiceless.

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Session 4: Parallel Sessions

Case Management and the Care of People with Dementia³

Professor David Challis

Personal Social Services Research Unit, University of Manchester

Introduction

In the UK there have been major developments in the social care of older people over the past ten years. The community care reforms were implemented in 1993, following the White Paper *Caring for People*¹ and focused the responsibility and funding for meeting the long-term care needs of elderly people and their carers on local social services departments. The reforms promote a needs-led service focusing on assessment, enhanced individual choice and the support of carers. A key vehicle for achieving these goals of co-ordinated, individualised care was the introduction of case (later care) management. The recent White Paper *Modernising Social Services*² provides continued support for the role of care management. This paper draws some lessons from the experience with care management in the United Kingdom, particularly the Lewisham scheme, which may assist in developing pilot care management projects in Ireland.

Care management can be provided in many different settings and for different target groups. Interventions have varied from the provision of social care to at risk individuals located within a social service department^{3, 4} to locations in a primary care setting, to locations within a geriatric multidisciplinary team setting.⁵ Care managers, working with relatively small targeted caseloads, control resources within an overall cost framework, so as to permit them to arrange more flexible and individualised packages of care.⁶ All of these projects have demonstrated improved morale and reduction in care needs for older people, improvements in the well-being of carers compared with non-recipients of the service, and a much improved chance of people remaining in their own homes without significant increase in costs.⁶

Over the past decade a variety of services have been developed to support people with dementia and their carers in the community, including specialist domiciliary care,^{7, 8} enhanced use of professional staff^{9, 10, 11} and integration into specialist service systems.^{12, 13, 14, 15} One conclusion from studies of both traditional and innovative interventions in long-term care, including those for people with dementia, is that the provision of the standard range of services, even if provided early, is not sufficient to have a marked impact on the probability of individuals remaining at home, nor significantly reducing carer ill-being. An 'intensive care management model' providing substantially different services both in quality and quantity, may also be required,¹⁶ particularly if specifically targeted upon those in need of extra support.¹⁷

The Dementia Care Case Management Model

³ This is an edited summary version of the paper delivered by Professor Challis at the conference.

The Lewisham Case Management Scheme¹⁸ was established to develop a similar model of care management in a community based service for mental health of older people. The model integrated specialist domiciliary care, specialist mental health care and intensive case management in the care of people with dementia living in their own homes. Although it was initiated before the Community Care Act, it was closely in accord with its principles. It was subsequently implemented district-wide.

The aim of the scheme was to provide effective community based long-term care which spanned the health and social service divide for older people with a diagnosis of dementia. The target population was individuals with a diagnosis of dementia, identified as having unmet needs and likely to be at risk of entry to institutional care, despite input from statutory services. Case managers with devolved budgets were responsible for providing long-term support based in the multidisciplinary team. The community based multidisciplinary teams, which included psychiatrists, nurses, occupational therapists, social worker and psychologists with administrative support, operated an open access policy where home based assessments were undertaken by one team member. This assessment would be taken to a case conference and a key worker approach adopted for subsequent management of the person with dementia, drawing on the specialist skills of team members. The implications of this approach to diagnosis and treatment and the operation of the team are described in a number of places in the literature.^{19, 20, 21}

Recipients of the Case Management Service

People selected to receive the special service were people at high risk of being admitted to institutional care because their needs could not be met by existing provision. Not surprisingly, therefore, 70% of those who received the service were categorised as severely cognitively impaired on the OBS scale²² and 70% scored either high or maximum disability on the CAPE scale.²³ Two thirds of the older people who were clients of the scheme were living alone and their mean age was 81 years. Slightly less than one third were male. Half of the carers of the elderly person were sons or daughters, one fifth were spouses and their average age was 59. Nearly one third lived in the same household or next door and they were in contact on average 5 days per week. Half of these carers were assessed as suffering marked stress on Rutter's malaise inventory.²⁴ Eleven per cent of clients had no identified carer.

Role of the Case Manager

A protected caseload of 20-25 clients and control over a budget gave case managers the opportunity to be flexible in developing their role in response to the complex practical, physical and emotional needs of clients and carers. They were responsible for the assessment, co-ordination, planning and review of their clients and placement in residential or nursing home if appropriate. They did not undertake case finding or screening, as they would have if they had been based in a front line social services

organisation. Hence intensive care management could be seen as a secondary care level of response to high levels of need.

Case managers supported carers through providing specialist skills to help them in their task and by generally sharing the long-term responsibility of caring. Despite the area in question having a relatively well developed home care service, case managers spent a considerable proportion of their budget on the purchase of home support provided through a range of helpers recruited by themselves and provided by external sources. An important part of their time was allocated to the selection, training and support of local helpers so that the scheme could respond with sufficient flexibility to the needs identified. Flexibility was essential both in terms of the kind of help and in the times that help was provided, for example, settling someone down for the night.

The goals of intervention in case management can be summarised under seven categories: supportive, therapeutic, practical, preventative, social, destitutional and organisational. The most frequently reported goals were supportive (68%), therapeutic (66%) and practical (56%). Under supportive goals the most frequently reported categories were the need for interventions to relieve carer burden, provide respite and assist carers. Therapeutic interventions were most often directed at devising strategies to reduce the problem behaviours associated with the clients deteriorating state. Practical goals were also geared towards the individual client mainly in the areas of personal care, health care and domestic care. Taken as a whole the prime objective of case managers was to support, sustain and enhance the quality of life of the client in their own home, and thereby to assist their carers. It is noteworthy that in only four cases was the goal of intervention related to the provision of long-term care away from the clients own home.

Costs and Outcomes

The research employed a quasi-experimental approach where individuals in one community team setting received care management and were compared to those in a similar community team setting without a care management service. The pattern of service provision varied between the group receiving case management and the control group. The level of home care support was higher, with an average of 13 hours per week for the case management cases compared with 5 hours for the control cases, as well as more diverse forms of provision. Respite care away from home was less frequent and was replaced for some cases in the scheme by respite care at home. More nursing input was provided but, predictably, less input from mental health team members.

The cost of care was estimated for the two groups, including costs to the various care agencies, costs to carers (which were calculated on the opportunity cost principle), the personal expenditure of the older person and the costs of housing. The weekly cost of people receiving the case management service was higher than for people in the control group. The difference in service receipt between the two groups constituted the main difference in costs. Additional home care provision accounted for 40 % of the cost differential. Dedicated case management provision accounted for 25% of the

differential while acute hospital care also accounted for 25%. Overall, 70 % of the excess cost was borne by the social services and 26% by health services. The higher level of service provision was to some extent offset by the lower cost incurred by carers. The balance of cost between carers and services is important as an indicator of the extent to which the scheme fulfilled one of the objectives of community care policy.

A range of outcome indicators were used covering aspects of needs, quality of care, quality of life and well-being for both people with dementia and their carers. The scheme was evaluated to discover whether it reduced admissions to residential care and the effect it had on clients and carers. By the end of a year around three quarters of each group of older people remained in their own homes, the remainder having been placed or died in similar proportions. The mortality rates of only 7% in the first year and 28% over the two years are very low compared with other studies of dementia. Differences between the two groups in the rate of placement only emerge in the second year. At the end of two years 51% of the case management group remained at home compared with only 33% of those in the comparison group. While the community tenure effect appeared more muted than in the other PSSRU care management studies,^{4, 5} it was clear that both experimental and comparison group patients were receiving support from a relatively resource rich community based old age psychiatry service, by no means typical of that to be found in most of the UK.

Quality of life measures were taken at six-month and twelve- month intervals on a range of indicators. Not surprisingly, for both groups, there was an overall deterioration in functioning over the year; scores decreased by between ten and twenty per cent. Clients' perceptions of their own situation were sought but the only positive finding was that after six months they felt more satisfied with their home environment, an indication perhaps that they felt more secure and less anxious. Inevitably assessment interviews with older people with cognitive impairment posed problems in about half the cases, although there were only serious difficulties in gaining intelligible views in one seventh of cases on initial interview. However, on ratings which were based on the carer's perceptions of the overall reduction in patient needs there were significant gains for the case management group at both six and twelve months. Reduction in needs specifically associated with activities of daily living showed a significant advantage to the case management group. No differences were found between the groups in levels of depression.

There was a significant reduction in the amount of total input by carers in the scheme by the end of the year, particularly for the main carers. Carers on the care management scheme also gained in terms of needs reduction and less overall strain. The indicator of stress, the malaise inventory²⁴ came close to an acceptable level of significance in favour of the experimental group at twelve months. At follow up, one fifth of the carers in the experimental group showed severe symptoms of stress compared with 40% in the comparison group.

Overall the scheme was evaluated in terms of five categories of aggregate risk defined as follows:

- Activities of daily living, including falling.
- The client's behaviour, including misery, wandering and aggression.
- The client's health.
- Environmental hazards, including hygiene and fire.
- Carer distress.

The case management clients were rated to be at a higher risk than the control cases on first assessment in all the above domains. After six months there had been a dramatic and significant decrease in the overall incidence of risk among the experimental group, while it fell only slightly in the control group. The average reduction in score between initial assessment and six months follow up was 0.88 for the experimental group but only 0.07 for the control group. This trend was maintained between the six and twelve month follow-ups. The reduction in risk was greatest in relation to the clients' activities of daily living and behavioural difficulties. The proportion of cases where the carer's level of distress constituted a serious risk was halved in the case management cases while there was no improvement in the control cases in this domain, suggesting that greater support to carers was provided by the scheme.

Policy and Practice Implications

This section outlines the policy and practice implications of care management.

Models of Care Management

Case Management has been identified in a US Congress Report as one of the four components, along with public education, information and referral and outreach, of an effective system to link people with dementia to needed services.²⁷ In the US context a debate has emerged about styles of case management, often framed as between the virtues of clinical or administrative models of case management. Translated to the UK this would mean the extent to which the role of the case manager is primarily that of a broker with a focus upon service arrangement to the exclusion of more clinical concerns. Administrative models are likely not to be seen as the province of professional workers in contrast to the clinical approach. As the US Congress report²⁷ concluded: "The kind of case management required...to link people with dementia to services is the clinical process in which the case manager is a helper, problem solver, and client advocate."

This latter point is relevant as to how the separation of assessment and provision, or purchaser and provider roles, is effected. The needs of effective practice do not always lead to organisationally neat solutions. On occasions, in work with people with dementia, part of the assessment function may be most effectively undertaken by a hands-on worker, because of their proximity to the elderly person over a considerable period of time, albeit closely supported by a case manager. Such

workers may also be crucial in undertaking other core tasks, such as monitoring well-being, routine, diet or medication intake, especially for people living alone. Thus, effective case management for these people would necessitate close links between those formally designated as providers and those formally designated as purchasers.

²⁵
The US Congress Report comments: “Agencies that provide services can provide comprehensive case management...case managers in agencies that provide services can be effectively insulated from financial pressures to refer clients to services of their own agencies rather than more appropriate service of other agencies”.

Targeting

The theoretical argument for alternatives to hospital care has usually taken the form that certain patients requiring lower levels of care than the norm of institutional care can be more appropriately supported in other settings. The targeting problem has been to effectively identify the characteristics of these individuals. The PSSRU care management projects were carefully targeted services, focused upon people with considerable needs and a high probability of entry to institutional care. Interestingly, while the results indicate that they achieved greater efficiency than existing services (greater improvements in welfare at similar cost), only the Darlington study shows significant cost savings, reflecting the high cost of long-stay hospital care. Hence, it is probable that if a similar case management approach were applied to cases where the opportunity for substitution of institutional by community care were less, then rising average costs could occur. This is because individuals whose needs fall just below that of present criteria of entry to institutional care currently receive relatively low levels of provision, and it is likely that the case management approach, with its more detailed assessments of need, could well lead to increased expenditure beyond that currently incurred.

While this might be justifiable in welfare terms it would not contribute to a policy of 'downward substitution'. Indeed, it is precisely the conflict between meeting broader welfare needs on the one hand and careful targeting on the other that would seem to account for the inability of some large scale case management schemes elsewhere to achieve the desired downward substitution despite demonstrating welfare gains amongst those receiving the service.²⁶

There is a real concern among policy-makers over the expansion of home care services. Additional resources for home care may lead to more needs being met rather than to the substitution of one form of care for another.^{27, 28} The development of mechanisms for achieving effective case finding and targeting is thus likely to be a continuing preoccupation of managers in providing alternatives to institutional care. In the UK, case management schemes target guidelines were specified and agreed with potential referral sources but, recognising the complexity of circumstances which lead to the need for institutional care, no rigid threshold of dependency was specified. In short, accountability for targeting was held by local managers after a person had been accepted rather than at pre-entry using rigid criteria. This is different to the United States where prospective use has been made of different types of scales in order to identify marginal cases.

Integration Issues

In order to fulfil the role accorded to care management following the community care reforms it is essential that arrangements are in place to facilitate the multi-disciplinary assessment of people with dementia into the care management process prior to decisions relating to arrangements for their long-term care, and particularly to ensure specialist clinicians contribute to this process. The development of appropriate links between health and social care can best be conceptualized by using the term vertical integration in the same way that it is used in economic theory. In this context it is defined as the integration of different processes or stages which are sequentially related to the same final product.²⁹ A number of studies in the UK suggest potential gains from this type of integration which would link secondary care with the decisions made in the context of care management.^{30, 31, 32} The experience of Australia, which has the community care reforms most analogous to those in the UK, gives credence to this type of arrangement.^{5, 29}

Initiatives in the UK arising from current government policy documents³³ such as the recent circular *Better Services for Vulnerable People* which emphasises the importance of assessment, rehabilitation and joint investment plans, provide a context where links similar to those discussed earlier, bringing together aspects of secondary healthcare, such as specialist assessment or rehabilitation skills, with front line community based activities, such as care management, offer fruitful areas for future exploration.²⁹ This circular also emphasises the point which was evident in the Darlington care management study: the importance of ensuring that integrative processes occur consistently at all levels between organisations, within organisations, within service models and within the activities conducted by particular professionals.⁵ Thus, the pursuit of opportunities for vertical integration may offer more appropriate responses for particular high need client groups.

Conclusion

The effective care of people with dementia is likely to require new service configurations which pay less attention to traditional boundaries, whether professional or organisational, than hitherto. In the UK there is now a requirement for health and social services to develop partnerships in the provision of care to vulnerable groups, including the pooling of budgets.³⁴ Within this framework, care management has a distinct role to play in relation to the provision of long-term community-based care for people with dementia.

Factors associated with effective care management appear to be an assessment and understanding of a person's daily routine, intervention at a pace and in ways which are acceptable to the elderly person, the involvement and support of family members in care plans and careful risk minimisation through anticipation and planning. Care management must also be focussed on at-risk groups and be responsive to the individual needs of people with dementia. It must also have the resources and the infrastructure necessary to meet the needs of clients. And it must be truly integrative, with particular emphasis on bridging the gap between primary and secondary provision. This involves a much greater degree of vertical integration in the provision of long-term care than exists at present. This is entirely consistent with the arguments for the development of old age psychiatry services and of care management in the recently published *Action Plan for Dementia* in Ireland.³⁵

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Discussion Points

The workshop discussion focused on the following points:

- There is a pressing need for pilot experimentation with care management in Ireland.
- Pilot projects should be introduced in both urban and rural areas.
- Care management needs to be properly resourced, if it is to be effective.
- Effective care management requires an expansion of existing community care services and facilities.
- Effective care management requires innovation on the supply side, through the promotion of local social entrepreneurship.
- Care management can be an important bridge between primary and secondary care provision for people with dementia.

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The Role of the General Practitioner in Dementia Care

Dr Murna Downs
University of Stirling, Scotland

Introduction

This paper considers the role of the General Practitioner (GP) in dementia care. The role of the GP is looked at from three points of view:

- What role might GPs play in the care of people with dementia and their families?
- How do GPs respond the needs of people with dementia and their families?
- What do GPs need to better serve people with dementia and their families?

The Potential Role of the General Practitioner

GPs are the first point of contact for families and often act as gatekeepers to services.¹ As such, they are uniquely situated to play a central role in the appropriate provision of support and care for people with dementia and their families.^{2, 3, 4, 5} Furthermore, the relatively few numbers of geriatricians and old age psychiatrists are insufficient to ensure that people with dementia and their families receive appropriate care and support.

Consensus exists as to the appropriate primary care of dementia.^{2, 3, 6, 7} Table 1 shows some evidence-based guidelines for primary care management of dementia, extracted from a publication in the British Medical Journal in September 1998.⁶ These guidelines reflect many recent publications on appropriate primary care for people with dementia.

Table 1: Evidence-Based Guidelines for Primary Care Management of Dementia

Guideline	Comment
Awareness of co-existence of dementia and psychiatric symptomology.	Patients may have co-existing problems, for example, depression.
Use of formal cognitive testing.	Very few memory clinics.
Awareness that there are some reversible causes of dementia.	For example, depression, urinary tract infection, thyroid problems.

Use of blood tests.	To identify if dementia is of reversible type.
Provision of information about the diagnosis and prognosis.	There is still a reluctance on the part of the GP to tell the patient.
Awareness of the carer's needs.	Respecting preferences for different type of supports.
Refer the patient and the carer to relevant support services.	For example, home help, meals on wheels.

Source⁶

Establishing a diagnosis early in the course of cognitive dysfunction provides clinicians with the opportunity to disclose the diagnosis to the person with dementia, a step that can be regarded as the first step in respecting and promoting autonomy for people with dementia.⁸ Recent research suggests that many GPs withhold diagnosis from the patient,⁹ a practice that has been likened to the situation whereby the diagnosis was withheld from people with cancer almost twenty years ago.^{9, 10} Now, with the advent of new dementia drugs and a growing culture that emphasises the rights and perspective of people with dementia^{11, 12} this reluctance on the part of GPs may ease. However, it is interesting to note the Best Practice Guidelines published in the BMJ make no mention of best practices in sharing the diagnosis.⁶

How Do General Practitioners respond to the needs of People with Dementia and their Families?

In addition to withholding diagnosis from the patient in many cases, studies^{5, 13, 14, 15, 16} have also shown that GPs often:

- Either fail to diagnose dementia or over diagnose it.
- Provide inadequate information about the diagnosis and prognosis.
- Provide inadequate ongoing management and support.

A study¹⁷ carried out recently in Stirling as part of a training initiative on dementia yielded some interesting results:

- Few GPs relied on cognitive screening to help with diagnosis, one of the best-practice guidelines.
- About half of all GPs surveyed assessed for depression but this percentage should be much higher.
- While 98% of GPs tell the carer about a dementia diagnosis, only 54% of GPs tell the patient.

- Referrals of the patient and family to family support groups and the Alzheimer Society are low whereas there is a much higher referral rate to medical experts.

When GPs were asked why they have difficulty both with the early diagnosis of dementia and with providing ongoing management of dementia, many indicated that they felt poorly trained, that dementia patients were a small percentage of their practice, and that the diagnosis itself can be difficult. GPs in this study requested help with establishing a diagnosis of dementia and with the task of offering support to people with dementia and their families.

What do General Practitioners Need?

The next step is to find better ways of helping GPs best support people with dementia and their families. These include:

- GPs should have access to sufficient resources in old age psychiatry, geriatric and neurology services, in the local area.
- Local support services should be available to people with dementia, for example, counselling and support groups.
- GPs need to know about the services that exist.

In addition, the following may help:

- The placement of a dementia-specific key worker in a GP practice.
- The provision of best practice booklets to GPs – the Alzheimer's Society published a booklet in 1995.³
- The communication of evidence-based best practice guidelines to GPs.⁶
- Training seminars.¹³

However, there is currently a lack of evidence as to which, if any, of the above are effective. That is why we need to develop an evidence base about effective interventions that will promote best practice in the primary care of dementia. A current study¹⁹ funded by the Alzheimer Society is developing three interventions: small group work, a computer decision support system, and a computer assisted learning package. The study will look at how effective each of these is in promoting appropriate dementia care.

It is important to acknowledge that people with dementia comprise a relatively small percentage of a GPs practice list.⁶ Nevertheless, given the excess disability which results from inappropriate care and the growing therapeutic optimism in dementia care,²⁰ there is a compelling need to improve the primary care response to dementia.

Discussion Points

The workshop discussion focused on the following points:

- The stigma attached to dementia in Ireland and the fact that a diagnosis of dementia has the potential to lead to major life changes for a person with dementia. For example, a GP cannot complete a renewal form for a driving licence for a person with dementia. The stigma and the awareness of the potential for major life changes may make a GP reluctant to confirm a diagnosis of dementia.
- The growing fear among GPs of litigation following an incorrect diagnosis of dementia.
- The general lack of awareness of dementia, both among the public and also among GPs.
- The availability of new drug treatment has led to an increase in the number of people requesting assessment for dementia – but this is not the complete solution to the problem.
- The lack of information for GPs on appropriate and accessible support services for people with dementia.

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Setting Up New Projects: The Western Alzheimer Foundation

Mr John Grant
CEO, The Western Alzheimer Foundation

Setting Up

The Western Alzheimer Foundation was formed four years ago to provide carers with practical help, information, and counselling in their caring role. The Foundation is a voluntary body with charitable status. The Foundation initially started with Carers Support Group meetings for carers of people with dementia in all parts of the Western Health Board area. From these meetings, it was clear that there were very few services available to carers. Carers identified information about Alzheimer's disease and the need for a break from caring as their two greatest needs.

In many cases, carers give up work to care for a family member and, at times, families find themselves in financial difficulties. Difficulties also arise with family members away from home, who do not understand the problems of caring for someone with dementia. The problems of caring for people with dementia also reaches beyond the family into the local community.

Fundraising and Publicity

Based on the information gathered from the carers meetings, the Western Alzheimer Foundation set up a committee to provide services in the Western Health Board area. Priority was given to fundraising, for two reasons:

- The development of services would require a sound financial basis.
- To approach Government agencies, the Foundation believed that it was important to be able to show that the Foundation itself was committed to raising funds to provide services.

The Foundation started a weekly lotto and then organised various other fund-raising activities: flag days, pub nights, sponsored walks, Tea Days etc. The Western Alzheimer Foundation has always used local newspapers and local and national radio and TV to create an awareness of Alzheimer's disease. The Foundation organises an information week every year, during which a mini-bus travels around the region giving information to the general public and identifying carers.

Developing a Home Support Service

The Foundation initially intended to build a respite home but information gathered from the carers indicated that they would like to look after the person with dementia at home, if they could get regular breaks from caring. The Foundation examined the option of day care centres but decided that the geographic spread of the population was too great to make day centres efficient. The Foundation then started an

Alzheimer home support service, the first in Ireland, placing trained personnel in strategic locations around the region.

The Foundation identified the FÁS Community Employment Programme as the ideal partner for the home support service. People from this programme, drawn from the unemployed, are trained to care for people with dementia. This programme provides excellent support for voluntary organisations, by paying the wages of the workers. However, some of the staff must be left go after one year, which is a negative factor, as staff have by then been fully trained and have built up a rapport with the families.

Feedback from carers on the Alzheimer home support service has been very positive, with carers enjoying the regular breaks and finding the service reliable and flexible and offering continuity. Doctors and geriatricians have been equally complimentary about the service. However, there is a growing demand for the service and the Foundation is finding it difficult to fund the required level of service. The Foundation had planned that, when a Respite Home was opened, the home support service would be discontinued, but instead, the plan is now to expand the service, due to the demand.

Establishing a Respite Home

The Western Alzheimer Foundation opened a respite home in Claremorris in 1996. On the advice of the Western Health Board, the home was opened for a six-month pilot, to gauge the need for respite care. But the initial demand was so great that the house remains open, and, in its first year, provided 250 carers with a weekly break from caring.

The experience gained from the Claremorris home was used to design a purpose-built respite home in Ballindine, which opened in May 1999. The Foundation emphasises the need for sufficient staff, so there are four staff to cater for the needs of the eleven people with dementia for whom the centre caters. Different activities are provided, including the Sonas programme, reminiscence, painting, prayers and singing, with a view to maximising the quality of life for the people in the respite home. The home caters for the needs of each individual person, valuing the importance of individual attention for persons with dementia.

Focus on the Voluntary Sector

The voluntary sector plays a critical role in providing services at a local level. The Western Alzheimer Foundation has developed strong ties with other voluntary bodies, including the Soroptomists, Social Services Groups, the I.C.A. and other carer groups. Voluntary organisations can often lead the way in introducing best practice and have a more flexible approach than some statutory agencies. Home respite care is the solution to the growing problem of Alzheimer Disease but, in addition to fundraising by voluntary bodies, more statutory funding is required to keep pace with the growing demands for services. Voluntary groups and statutory agencies have to work together

and have a more common-sense approach to the needs of their communities if the appropriate services are to be provided.

Focus on the Voluntary Sector and the Social Economy

Mr Maurice O'Connell
CEO, The Alzheimer Society of Ireland

The Alzheimer Society of Ireland

The Alzheimer Society of Ireland was founded in 1982 by a small group of carers who came together for support, information and advice. In 1984, the society was formally incorporated as a limited company with charitable status. There are now over 2,000 members in 28 branches and the Society is now the leading national voluntary organisation providing services to people with dementia and their carers. The Society's aim is to work for and on behalf of people with dementia and their carers to ensure that they have the necessary support and services to enable them to maximise quality of life, respecting the needs, the dignity and the rights of the individual.

The Alzheimer Society provides a number of core services:

- Day centres – there are 16 dementia-specific day centres.
- National Home Support and Respite at Home Service – there are currently 10 Home Support programmes, organised with FÁS. There are currently 250 trained care workers, drawn from the unemployed, catering for 2,000 people with dementia. FÁS provides most of the funding but there is a developing service provided by a combination of Health Board and private funding.
- Training – the training of care workers in dementia studies and physical care skills has been central to the Home Support programme. A certificate course in Disability Studies – Dementia Care will soon be accredited through the NUI. Support counselling training is also provided for volunteers and health care professionals.
- Information, resources and advice – 11 branch information offices throughout the country provide information to the public. Through its public relations programme, the Society strives to fight the stigma and promote a positive awareness of dementia.

Advocacy Model of Service

The Alzheimer Society of Ireland uses the advocacy model of service. This model recognises the rights and needs of the individual to maximise their independence, to take control of their own lives and to participate fully in the local community and in society in general. The Society also works towards a holistic response to the individual needs of people with Alzheimer's disease, keeping in balance the medical and the social, dependence and empowerment, the person and the patient. A holistic response helps ensure that people with dementia are not confined to the ward, excluded from the local community. The dignity of the individual with dementia is

paramount: the focus must be on the person as the key to the whole process of care and not as an object of care or a task to be attended to.

Both the person with dementia and their carer can become marginalised in a local community, because of inequitable finances, geographical factors, or the lack of specialist resources within the community care sector. Sometimes people with dementia have no diagnosis, no treatment, no prospect of cure and, therefore, no hope. When the disability becomes more progressive, a couple or a family can become very isolated, whether through pride, lack of knowledge, isolation, or lack of resources, in particular, lack of community care. Such people are the silent disadvantaged, living on the edge of the health services.

The Social Economy

The public services have limited resources. The private sector provides service based on profit. The voluntary sector is driven by need and focuses on the agreed task. The strong voluntary force of the Alzheimer Society enables some services to continue but more imaginative approaches are required to deliver all the required services. The FÁS Community Employment programme is a scheme to train unemployed people, usually long-term unemployed, in technical care skills to return to the work force after one year. A holistic approach to one disadvantaged group (the long-term unemployed) enables and enriches another disadvantaged group (people with dementia) in need of a service.

The social economy emerges when the voluntary, statutory, and private sector come together to meet the needs of a group or groups who otherwise would not get a service or a job. It has been described as that part of the economy that operates between the market economy and the public sector, consisting of differing mixes of income, government grants, contracts, and voluntary work.

The social economy has emerged from unmet needs of disadvantaged groups, like carers and people with dementia. For example, the Home Support and Respite at Home service has not been provided by the market economy or by the Health Boards to the level that meets demand. Neither the private economy or the public sector have been able to meet the needs of people who want to care for their relatives at home. Now, the potential of the social economy has opened up a new dialogue with the statutory bodies that can progress the cause of those in need of service as well as provide work opportunity for the unemployed, women returning to the work force and others.

In Partnership: Health Boards, Voluntary Sector, Carers, and FÁS

In the North Eastern Health Board area, the Alzheimer Society has been involved in a European Social Fund Programme for employment to train marginalised groups for employment. The final phase of the scheme is to set up a community business, using those people, from the Community Employment programme, who are already trained,

to meet the needs of people with dementia and their carers. This business will seek out contracts with the health board, voluntary groups, and the private nursing homes. The new business will be managed by volunteers, will have the backing of the Society's care service policy and procedures, and will have strong links with FÁS and the Health Board. The FÁS Community Employment programme will play a key role in moving the business towards market viability.

There is a new willingness on the part of Health Boards to work with the voluntary sector to ensure there is no duplication of services and to develop a greater partnership approach, thereby providing a more effective and efficient service to people with dementia and their carers. The expertise of the voluntary sector and especially the role of the carer as the expert have not been recognised to date. Recognition of the potential contribution of these two groups is an essential component for the future development of a service for people with dementia.

Challenges for the Future

Partnership of voluntary and statutory bodies is key to the future planning of services for people with dementia and their carers. In line with the recommendations of the Action Plan, there is a need for a commitment from government to provide dedicated services for people with dementia. Additional resources are necessary to meet the increasing burden on existing services and provision. There should be a focus on early diagnosis and the development of specialist services, as outlined in the Action Plan. The needs of people under 65 with dementia must also be recognised and the necessary services made available to them. There is also a need for an intensive awareness programme for health care professionals, for carers, and for the general public.

Discussion Points

The main points to emerge from discussion following the two presentations in this parallel session were as follows:

- There is a pressing need for liaison of services to ensure that all services are delivered in a co-ordinated way. There is a need for real partnership between statutory and voluntary sectors in future planning.
- The care requirements should determine the funding levels, not the other way round.
- There is a need to identify, train, and fund a specific person who will co-ordinate care for people with dementia. There was no agreement on whether this person should be from the voluntary sector or the statutory sector. The term 'Dementia Nurse' was proposed as a possible title for this position, but whether this was a psychiatric or general nurse was left open for discussion.
- There was acknowledgement that Public Health Nurses have heavy workloads. Therefore, funding is required for additional dementia-specific personnel in

this area. The current shortage of nurses was seen as creating a need for more care workers.

- There is a need to explore ways of training and extending the workforce available to care for people with dementia.
- The funding of families of people with dementia is vitally important. The existing funding systems available are both restricted and inadequate.
- There was general agreement that day centres are adequate in urban settings but are not suitable for rural areas given the dispersed population.

Session 5: Panel Discussion – Priority Setting

Priorities for the Future

Dr Eamon O'Shea

Introduction

The setting of priorities is an important part of planning for dementia. The final part of the conference was devoted to achieving some consensus on the priorities for the next three years. A number of speakers, drawn from different disciplines, with different experiences, were asked to set priorities for the future. The panel comprised the following people:

- Dr Eamon O' Shea, co-author of the Action Plan
- Dr Ruth Loane, Consultant in Old Age Psychiatry
- Dr Des O'Neill, Consultant Physician in Geriatric Medicine
- Ms Anna Buckely, a former carer of a person with dementia
- Dr Michael Loftus, Chairman of the National Council on Ageing and Older People
- Mr John Cooney, Chief Executive Officer, South Eastern Health Board

This paper sets out the priorities as discussed and agreed at the final session of the conference. It begins with a short summary of priorities as set out by each of the speakers named above. While each speaker highlighted different aspects of the plan, a surprising convergence of opinion emerges about what needs to be done to improve the quality of life of people with dementia and their carers. This convergence is captured in the discussion of overall priorities, which follows the individual contributions. The paper concludes with a short section outlining the need for more effective lobbying and advocacy on behalf of older people with dementia.

Dr Eamon O' Shea

This speaker identified the following priorities:

- Additional resources for the training and education of general practitioners and public health nurses given their front-line role in the process of early diagnosis and the care of people with dementia.
- The introduction of a pilot project in care management structures in an urban and rural setting without delay.
- The development of flexible, continuous and legislatively based home support services for people with dementia and their carers.
- The further development of Medicine for the Elderly and the accelerated development of Psychiatry of Old Age Services.
- Greater emphasis on the social, psychological, sensory and communication needs of people with dementia.

- The establishment of a committee to monitor the implementation of the Action Plan over the next few years.

Dr Ruth Loane

Dr Loane identified the following priorities:

- Additional resources for the early diagnosis of people with dementia, including the screening of all at risk elderly people. Any reversible or potentially reversible causes of dementia should be identified and treated. People with dementia and their families should also be informed about their diagnosis so that plans can be made with respect to care strategies and financial management.
- The provision of comprehensive, flexible and continuous home care services.
- The development of care management structures as a means of providing a co-ordinated and integrated pattern of provision.
- Investment in Psychiatry of Old Age services, including additional funding for day hospital facilities, acute psychiatric beds and long-stay psychiatric beds, to ensure an equitable provision of services across the country and continued development of geriatric medicine services.
- Investment in appropriate long-stay facilities for people with dementia who require long-term care.
- Greater emphasis on the social, psychological and sensory needs of people in residential care. For this to happen, staff in residential care will require more training to give them the skills to nurture and develop the diverse capabilities of people with dementia.
- Monitoring and evaluation of implementation of the Action Plan.
- Respect for the rights and preferences of the person with dementia.

Dr Des O' Neill

Dr O'Neill identified the following priorities:

- Greater recognition and representation of older people at the level of policy formulation and policy implementation. For example, older people should be represented on the Council for Disability to ensure that their needs receive the attention that they deserve.
- Experimentation with care management to ensure the delivery of services to people who need them and to facilitate more integration between primary and secondary care provision.
- Legislation to support the development and delivery of services for people with dementia. More generally, the law on older people in Ireland needs to be more fully developed.

Ms Anna Buckley

This speaker identified the following priorities:

- Flexibility in the provision of community care services, particularly outside normal day- time hours.
- The development of care management structures to co-ordinate and integrate existing services for people with dementia.
- Training and education for the carers of people with dementia.
- More support structures for carers, including the development of more extensive networking and counselling services.
- Additional resources for in-home respite care for people with dementia.

Dr Michael Loftus

Dr Loftus identified the following priorities:

- Additional resources for the training of general practitioners in dementia awareness. This will facilitate earlier diagnosis of dementia in the community.
- Continuing education for all health care professionals dealing with dementia.
- The introduction of a committee to oversee the implementation of the Action Plan.

Mr John Cooney

This speaker identified the following priorities:

- More effective lobbying to ensure that dementia receives the attention it deserves in the overall policy process.
- The need for health professionals working in the area of dementia in the Health Boards to ensure that the case for additional resources for people with dementia is effectively made in the context of the new resource planning mechanisms associated with the 1996 Health Act.

Overall Priorities

Four main priorities emerge from the various contributions outlined above. These priorities can be summarized as follows:

- **Additional resources for service provision**
There is a need for more resources to be allocated to dementia care. Without these resources it will be impossible to expand services in community care, secondary care and residential care. As part of this process, community care for people with dementia must be provided within an expanded legislative framework which would guarantee access to certain essential services for people with dementia and their carers.
- **Information and training**

There is a need for more information and training for people working in the area of dementia. This training should facilitate a person-centred approach to care and the delivery of services.

- **Care management**

Care management for people with dementia is critical to the success of the Action Plan. Care management is necessary to ensure that people with dementia receive appropriate services at the right time and in the right place. Care management can be the catalyst for the formal integration of primary and secondary care services for people with dementia.

- **Implementation committee**

The final priority is the need to establish a committee to oversee the implementation of the plan. The task of the committee will be to monitor progress with respect to the plan, review ongoing developments with regard to service provision and provide an overall evaluation of the process at the end of the three years of the plan.

Conclusion

The Action Plan sets out a model of good practice in dementia care. The essential element of the Plan is the importance of the person with dementia. The pathways to care model presented in the Action Plan leaves scope for flexible and innovative responses at a local level to the provision of services. 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 the Action Plan will require imaginative thinking on funding and ultimately, perhaps, some consideration of movement to a social insurance scheme for long-term care.

First and foremost, however, the Action Plan will require a commitment that action is required now 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 enduring message at the end of the Conference is that if the voice of the voiceless is to be heard, amidst the many competing demands for resources, those of us interested in the implementation of the Action Plan will have to raise our voices considerably and in unison.

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
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
Dr Nuala O’Donnell
Ms Catherine Mulvenna
Mr John Heuston
Vacant

*Ms Trish Whelan is currently on a career break.