



THE ALZHEIMER  
SOCIETY of IRELAND

# oASIs

Quarterly Newsletter of the Alzheimer Society of Ireland

Volume 24 Issue 3

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# Vote

The time for action is NOW



Dementia Rights  
For All



Better Funding  
for Quality Service



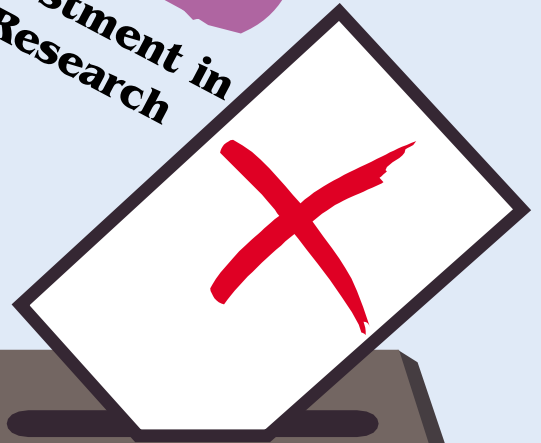
Equal Access  
to Services



Investment in  
Research



Diagnosis, Education  
and Awareness



# A Message from the CEO



Dear Friends,

With World Alzheimer's Day only days away, I am reflecting on the impact of people power and collective bargaining. On Thursday 21 September tens of thousands of people, in more than sixty countries worldwide, will come together to campaign for a single goal - to make politicians and policy makers realise that

dementia needs to be recognised as a health priority in their nations and across the globe.

The impact of dementia on individuals and on families is devastating, reaching far beyond its physical and psychological symptoms, into the social fabric and financial affairs of the family affected. Social unacceptability, discrimination, and social isolation are still part and parcel of day to day living for people with dementia and their carers/families and this must change.

Though current thinking about healthcare policy supports the wishes of people with dementia and their carers/families to live independently, within their own communities for as long as possible, the reality is that as

a civil society, we are not providing adequate levels of supports and services appropriate to the needs of families at the time and in the way that they need them. This must change.

In partnership with you - our clients, carers, families, members, volunteers, staff and allied healthcare providers - we have developed a Dementia Manifesto which identifies positive, achievable solutions to facilitate a more dementia focused approach to healthcare policy. It also offers clear strategies on how these solutions can be implemented. We believe it will catalyse change and lead to improvements in the quality of life of people living with dementia.

And so, friends, in the run up to the next election, I ask for your support in achieving our goal to have dementia recognised as a national health priority in Ireland. Lobby your local politicians; question them about their policies for providing dementia-specific services when they knock on your door; and please, make your vote count when the election comes about.

Good luck to us all and many thanks to everyone who participated in the development of the manifesto.

*Maurice O'Connell*

## World Alzheimer's Day



Around the globe people with dementia, carers and Alzheimer's associations will rally together on World Alzheimer's Day - Thursday 21st September - to meet the challenge of dementia. Thousands of people in more than sixty countries will come together in different ways to raise awareness of the impact of Alzheimer's and dementia, one hundred years after the disease was first diagnosed by Dr. Alois Alzheimer in 1906.

This year's theme, "No Time To Lose", highlights the fact that dementia presents one of the greatest health and social challenges of our time but it often goes unrecognised as such. This needs to change. There is no time to lose in getting dementia recognised as a national health priority in Ireland so that those affected by the condition can access timely diagnosis and appropriate services/supports and so that we begin to address the issues of discrimination, isolation and social exclusion experienced by people with dementia and their carers/families.

Building on the success of last years anti-stigma campaign, the findings of the Society's new report

'Perceptions of Stigma in Dementia: An Exploratory Study' will be launched by the Minister for Health & Children, Mary Harney T.D., at a half-day seminar on the issue which is taking place in The School of Nursing & Midwifery, Trinity College Dublin, D'Olier Street from 9.30 am to 1.30 pm. Guest speakers include; Dr Mary McCarron and Louise Nolan (TCD), Dr Mary Cosgrave (Beaumont Hospital), and keynote speaker Mr Jim Jackson (Alzheimer Scotland: Action on Dementia). Further information / bookings by contacting Joanna Harney on (01) 284 6616 or e-mail [info@alzheimer.ie](mailto:info@alzheimer.ie).

### Watch out on World Alzheimer's Day, the Alzheimer Society will be:-

1. Holding a half-day seminar on Perceptions of Stigma and Dementia
2. Launching 'Perceptions of Stigma and Dementia: An Exploratory Study' - , which highlights a number of key issues and identifies the way that people with dementia experience different elements involved in stigma.
3. Writing to all the local and national public representatives to brief them about World Alzheimer's Day, the impact of dementia in their constituency. Politicians will be invited to write a letter of support to the Society and all responses will be put on our website.

# Dementia Manifesto — The Time for Action is Now

The Alzheimer Society of Ireland's *Dementia Manifesto* focuses on the issues and policies that impact on people living with dementia and highlights the changes that are necessary to better plan for and support people affected by this condition.

## Why should Dementia be a National Health Priority?

- There are 38,000 people with dementia in Ireland; by 2026 there will be 70,115; by 2036 there will be 103,998
- There are 50,000 carers of people with dementia in Ireland
- Right now, there are 100,000 people in Ireland whose lives are directly affected by dementia; this figure increases three or four-fold when you consider the effect on the wider family
- The 2006 baseline cost of dementia in Ireland is estimated at €400m
- Demographic trends, health and social care cost and disease burden all point to the fact that dementia must become a national health priority issue.

## The Solutions

In order to make dementia a national health priority, The Alzheimer Society of Ireland is calling on the present and future government to invest in three main areas over the next three years:

1. **Early diagnosis, intervention, awareness and education**
2. **Enhanced and flexible community based services**
3. **Medical and Social Research**

The total financial investment required to achieve implementation of this manifesto is €105m over 3 years – with €4m going towards awareness raising, €21m for service provision and €10 for medical and social research annually.

### 1. Early Diagnosis, Intervention, Awareness and Education

- ✓ The delivery of education and awareness training for GPs and the primary care teams
- ✓ The delivery of a general public awareness campaign on risk reduction/preventative strategies
- ✓ Addressing the stigma associated with dementia by running innovative and creative campaigns targeting various stakeholders

- ✓ Build capacity among people with dementia themselves to act as their own advocates.

### 2. Enhanced and Flexible Care Services

- ✓ In order to consolidate and grow its services, The Alzheimer Society of Ireland, as the national dementia service provider, needs core HSE funding of the service provision element of its work
- ✓ Diagnostic services need to become community based, with increased links between the consultant and the primary care team with the primary care team playing a central role in the diagnostic and assessment process. Part of this process is to support the development of a much greater number of memory clinics throughout the country, providing a range of diagnostic, assessment and support services
- ✓ A movement towards a community based model of assessment for the person (as is the current practice with the Psychiatry of Old Age teams)
- ✓ Acute patient care needs to be dementia proofed i.e. the facilities and staff need to be able to respond to the particular needs of people with dementia in a holistic way; the transition from acute care back to the community needs to be managed through creative responses to enable the fast tracking of the person with dementia back into the community, freeing up essential in-patient beds
- ✓ Information and psychological support services for the person with dementia and the carer/family
- ✓ The mainstreaming of the pilot Dementia Rights Advocacy project (currently funded by Comhairle)
- ✓ Increase the provision of home, day and respite care services, social clubs, support groups, holiday and transport services
- ✓ Set standards of care for people with dementia in residential care settings including dementia-specific design, dementia specific activity programmes and training for staff. There is an urgent need to modernise the current public residential care services and to work with the private sector to ensure quality driven dementia specific programmes are a feature
- ✓ The exploration and development of palliative care and end of life services both in the residential and community setting is needed
- ✓ Support the development of a range of specialist services for people with younger onset dementia.

*Continued on page 6*

By Professor Eamon O'Shea



Niall Tierney, Chairman ASI and Prof. Eamon O'Shea

Few countries have specific health and social care policies for dementia and where a policy exists it is mostly encompassed in wider generic policies and statements on ageing. Similarly, the health economics of dementia is in its infancy which is surprising given that dementia is one of the most devastating and costly group of diseases and its impact on the care systems of all countries will increase in the future due to population ageing.

In Ireland, the stated objective of public policy for people with dementia is to encourage and facilitate their continued living in their own homes for as long as is possible and practicable. The *Action Plan for Dementia* (APD) reinforced the need for a social model of dementia that is focused on care in the community and on maintaining and developing the 'personhood' of the person with dementia. Unfortunately, progress has been slow in embracing this person-centred, holistic model of care for people with dementia. The medical model is still dominant.

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

The Government's 2001 Health Strategy: *Quality and Fairness: A Health System for You* accepted the general thrust of the APD and committed to its implementation over a seven year period. However, despite some improvements in recent years in enhanced training and education for staff, increased at-home respite care, additional specialised dementia units and more old age psychiatry consultants, progress has been slow in implementing the Action Plan. ***A reluctance to commit significant additional resources to dementia care is at the heart of the problem.***

The original APD required less than €20 million per year over a three year period for its full implementation which equates to €25m per year at today's prices. This is equivalent to an annual grant of just over €650 per person with dementia. When presented in this way, the cost is minimal relative to the potential gains to be had. There should be a significant public investment in dementia care as part of a new strategy of making dementia a national health priority.

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

## Prevalence of Dementia in Ireland

Prevalence of dementia increases almost exponentially with age, nearly doubling every five years, but the increase is much more rapid for females for whom prevalence is much greater in the oldest age categories. There were just over 34,000 people with dementia in the country in 2002, made up of 20,000 females and 14,000 males.

In line with the ageing of the population the major increase in the number of people with dementia is likely to occur after the year 2021, with the numbers increasing to over 100,000 by the year 2036. There are currently 38,000 people with dementia in Ireland. Approximately 4,000 new cases arise in the general Irish population every year.

## Family Care

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

## The Economic Impact of Dementia

The estimated baseline cost of dementia for Ireland at the beginning of this decade was €344 million. Adjusted for

# or Dementia Care in Ireland

inflation, the 2006 baseline estimate is just under €400 million. Family care accounts for 57 per cent of the overall cost of care, rising to 76 per cent if family care is valued using substitution labour costs (applying the national minimum wage) rather than on an opportunity cost basis.

The contribution of family care is in contrast to the relatively low provision of community care for people with dementia. Community support services for people with dementia and their carers are under-developed and fragmented in Ireland. Generally, people with dementia do not come into contact with the health and social services until a crisis occurs, involving the person with dementia, their carer, or both parties. It is not surprising, therefore, that only 6 per cent of the cost of dementia in Ireland is attributable to community care services. In contrast, nearly, one third of the burden of care is attributable to residential care.

## Current Policy

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

The Government's 2001 Health Strategy: *Quality and Fairness: A Health System for You* accepted the general thrust of the APD and committed to its implementation, but over a seven year period. The additional resources necessary to fully implement the APD have not been forthcoming. It is clearly time for a restatement of our commitment to provide for people with dementia in the country.

## Future Strategies and Priorities

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

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

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

Dementia care is provided by a variety of sources making co-ordination and integration critical for efficient and effective delivery of services. The provision of new information and advice centres would go some way to addressing concerns and frustrations with the current fragmented system. Something more is needed however to ensure that people with dementia receive timely and appropriate services that are embedded in their own local communities.

Although the emphasis in this paper has been on developing primary and community care services for people with dementia, the needs of people with dementia in residential care are also important. Connectedness to family and friends remains important for people with dementia at all stages of the disease, so people should be able to access good quality care in local generic long-stay units. In general, more attention should be paid to the design and scale of any type of residential facility accommodating people with dementia. The care process within long-stay facilities is also important. Psychosocial approaches are needed to complement medical and neurological models of service delivery. There should be more emphasis on developing meaningful communication with patients, using all of the senses, through reminiscence, music and various therapeutic and time-intensive activities. Quality of life for people with dementia is a complex issue, but it is influenced by many things other than conventional nursing and medical care.

## Conclusion

The message of this paper is the importance of making dementia a national health priority, beginning with the full and accelerated implementation of the APD. The emphasis in the paper has been on primary and community care solutions to the problems that exist in this area. Families continue to provide the bulk of care for people with dementia, but they need more support if the current high level of provision is to be maintained. Support structures must be collective and public if the full potential of older people with dementia and their carers is to be realised. Inter-generational solidarity at all levels of society is the key to achieving full citizenship rights for all older people.

*Eamon O'Shea is Professor of Economics at the Centre for Social Gerontology, National University of Ireland, Galway. (This article only features highlights of the report. A full copy can be read on our website [www.alzheimer.ie](http://www.alzheimer.ie) or call 01-2846616).*

# Alzheimer Hero Day

20th October 2006

## Write-to-Remember Campaign *encourages children to write about their Hero's*

The Alzheimer Society of Ireland is launching a Write-To-Remember Campaign as part of their school awareness and educational programme, Hero Day, which is taking place this year on October 20, 2006. The Society is hoping to proactively build awareness of dementia and break down stigma through its programme for children as well as support their development as writers. So far 84 primary schools around Ireland have signed up to participate in the programme.

This year, the Kidare born writer, Mary Arrigan, has agreed to become the inspirational figurehead for the Alzheimer's Hero Day and Write-to-Remember Campaign. Mary has captured the imagination of children of all ages and is an award winning (the Hennessy Short Story Award, the Sunday Times/CWA Short Story Award and the International White Raven's Award) author of over 30 books for children and teenagers. Mary's father, who was diagnosed with Alzheimer's in the later part of his life, was the inspirational hero in her life.

Mary's books have been translated into Dutch, German, Polish, Danish and Swedish and before she became a full time writer, Mary was an art teacher who loved listening to her students conversations! She has given readings to children as part of the writers in schools scheme in Ireland, Wales, London and Australia. The

characters in her books are mostly ordinary people who get caught up in events that test their courage and spirit. Mary's latest book, *Chocolate Moon*, is about the relationship between a boy called Chris and his grandmother who has Alzheimer's disease.



Children's author  
Mary Arrigan



The Write to Remember campaign is aimed at children from first to sixth classes and allows them to write at their own distinct level of competence. We are hoping the Write-to-Remember campaign will help children to find their own voice and develop their ideas about who are the hero's in their lives. Children are being challenged to write daily for a period of 10 straight days during the month of October and are supported in their efforts through sponsorship by family and friends.

Schools wishing to participate in the Write-To-Remember should contact Ruth Metz at 01-2846616. Alternatively, your children or grandchildren can participate on an individual basis by calling Anne Harrington at the Society on 01-2846616 and she will send on a brochure and sponsorship card.

*Continued from page 3*

### 3. Social and Medical Research

- ✓ Prevention and delaying the onset of dementia reduces the number of people affected, the duration of the condition and the human and economic cost of caring. The Government must ascribe much greater importance to dementia research when making decisions about allocating funding for medical research. It also needs to advocate this position at EU level
- ✓ The state's social research agenda and research agencies/policy advisors/think tanks (CPA, NCAOP, ESRI, NESF, NDA, HRB) need to address dementia-related issues as part of their work

- ✓ A social research agenda promoting investigation into best care practices needs to be resourced as well as researching new and innovative service models, palliative care, the use of technology and dementia.

**A full copy of this manifesto is available on our website [www.alzheimer.ie](http://www.alzheimer.ie) or call 01-2846616. With a general election due, we are asking all our members, supporters, carers and families to bring our manifesto to the attention of your local general election candidates when they call to your door. You can also write or email to your T.D. highlighting the issues relevant to your area. For more information on this campaign contact Sarah O'Callaghan on 01-2846616.**

# Fundraising News

Congratulations to the following winners of the Tea Day Raffle which took place on July 7th in Dun Laoghaire.

**First Prize:** 2 nights B&B with one evening meal in the Hotel Drogheda, Co. Louth.

**Winner:** Ms Una Markey, Knocknagee, Co. Carlow.

**Second Prize:** A weekend stay in on the Select Hotels of Ireland

**Winner:** Ms Marian Meacle, Upper Merrion Street, Dublin 2

**Third Prize:** An overnight stay in the Beacon Hotel, Sandyford

**Winner:** Mr. Liam Smith, Parkgate Street, Dublin 8

**Fourth Prize:** An overnight stay and dinner in the Ferrycarraig Hotel, Wexford

**Winner:** Mr John Waters, Raheen, Co. Limerick

*Thanks to everyone who participated in the Raffle and thanks to all our sponsors.*

## Looking Nifty on a Honda Fifty



Are you the owner of a proud Honda 50? Or are you the proud owner of a Honda 50? What ever state the "50" is in, take it out clean it up, relive your youth, and the joy of the open road. Organisers of the Culchie

Festival are looking for people to participate in the great Honda 50 run during the Bank Holiday weekend in October, the proceeds of which will go towards raising money for the Meath Branch of the Alzheimer Society and Irish Autism Action. They are looking for over 200 Honda 50's to come to Summerhill Co Meath on Sunday 30th of October at 12 noon to take part in the 20k fun run to help set a new Guinness Book of Records for the longest line of Hondas ever in the world. So go look in the shed or the garage or in your neighbours shed but find that Honda and be part of history in the making'.

Official entry forms and information packs from Mary Egan, Killbride, Clonbur, Co Galway. Phone: 09495-48106.

## Family Walk to Remember

Big thanks to Phil Fitzgerald, who along with the members of her extended family, raised €1,900 for the Alzheimer Society following a charity walk on June 4th, 2006. A wonderful



*Phil Fitzgerald and family tired but happy at the end of their charity walk*

day was had in the sunshine and the family would like to thank everyone who sponsored them. Pictured are some of the family group, including little Rungtawan Tuohy, who at five years of age, is one of our youngest supporters. Well done Rungtawan, hope we'll be seeing lots of you in the future.

## Dundalk to Cork For a Few Dollars More

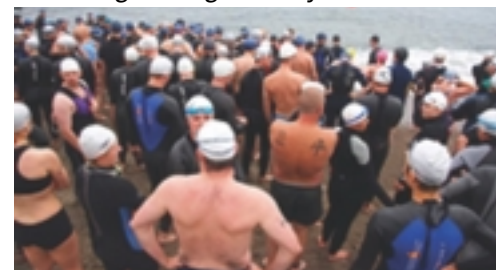
Big thanks to Sarah Lait who set out on a 387km trek from Dundalk to Millstreet, Co. Cork on her trusty horse on August 14th to raise money for the Alzheimer's Society, the National Council for the Blind and Our Lady's Hospital for Sick Children. An accomplished horse woman, Sarah set out with a group of volunteers and 10 horses for this unique fundraising event. Her journey took five days and she entered Millstreet's Annual International Horse Show in a blaze of glory on Saturday 19th August on her chestnut mare nicknamed Lilly. Mr Noel C Duggan led Sarah into the main Arena to a barrage of camera flashes. Many thanks to Sarah and her volunteers.

## King of Greystones Triathlon Challenge



*The organisers of the Triathlon Challenge*

The 4th King of Greystones Triathlon Challenge in aid of the Alzheimer Society of Ireland took place on August 12th at Greystones, Co. Wicklow. The challenge, which consisted of a 750m swim, a 20k cycle and a 5k run, attracted over 200 participants, the biggest ever number and while the weather wasn't perfect, the atmosphere was great with a huge number of supporters on hand to cheer on family and friends. The event raised €65,000 for the Society and an enormous thank you must go to the wonderful organisers Fergal and Shane McKenna and Alison Heasley and the event Sponsors Menupages.ie. A huge thanks also goes to the superb volunteers and safety marshals who generously gave up their Saturday to ensure that all competitors got home safely. And finally a huge word of thanks must go to all the competitors who gave so generously with their time, and talents, to ensure that the 4th King Of Greystones was crowned in a blaze of glory.



*Participants in the Triathlon Challenge get ready to take the plunge*

# † IN MEMORIAM

Mr William Carson	Mr Sean Leamy
Mrs Mary Carroll	Mr Ben Naughton
Mr Bernard Naughton	Mr Seamus Breathnach
Mr James Shiels	Mr Sean Byrne
Mr Alec Darlington	Mr Michael Cleary
Mr Michael Dowling	Mrs Inez Greenlee
Mr Brian Kelly	Mr Danny Moynihan
Ms Bernadette Madden	Dr May Sullivan
Mr John Byrne	Mrs Maura Reynolds
Mr Ivor John Basil Underwood	Mrs Claire Mason
Mrs Sadie McElnea	Mr John Noonan
Mr Daniel Moynihan	Mr & Mrs Joe & Clare Kennedy
Mr Christopher Reid	Mrs Moira Whelan
Ms Catherine Quinn	Mr Patrick Bond
Ms Maura Brennan	Dr Patrick Morrissey
Ms Della Walsh	Mrs Pauline Rowntree
Mr Herbie Ogrin	Mrs Henrietta Bryant
Ms Mary McMahan	Mr George Molloy
Ms Kathleen Cunningham	Mrs Clare French
Ms Mary Fealy	Mrs Estella Thompson
Ms Bridget McCarthy	Mrs Margaret Landy
	Ms Tina Lynch

**May they Rest in Peace**

## NATIONAL CONFERENCE 2006

This year the annual national Conference is taking place in the Sligo Park Hotel on 17/18 November. The Right to be Heard is the theme of the Conference and there will be sessions for participants on Media Awareness/Political Lobbying, Advocacy and Rights and Stigma and Discrimination. The conference will also feature a number of workshops on capital developments, the how to of advocacy, innovative services and unravelling the legal and financial issues of dementia.

The sessions on media training/awareness/political lobbying will take place on the Friday evening. The workshops will take place immediately after lunch on the Saturday. Participants will select which workshop they wish to attend.

### IMPORTANT DATES

Date	Conference Details	Venue
21 Sept	World Alzheimer's Day <i>No Time to Lose</i>	
21 Sept	Perceptions of Stigma and Dementia	TCD
October	Write-To-Remember Campaign	Schools everywhere
12/14 Oct	22nd International Conference of ADI <i>Dementia – A Challenge for the 21st Century</i>	Berlin, Germany
20 Oct	Alzheimer Hero Day	
17/18 Oct	ASI National Conference <i>The Right to be Heard</i>	Sligo