



THE ALZHEIMER  
SOCIETY of IRELAND

# oASIs

ISSN: 0790-8792

Quarterly Newsletter of the Alzheimer Society of Ireland

Volume 28 Issue 1

Spring 2010



Pre budget submission CEO Maurice O'Connell, with Pat Doherty Head of Services and (left) Daragh Clery Minister for Labour.



## a day to Remember

Alzheimer's Tea Day

Palliative Care Research

National Positive Ageing Strategy



# Message from the CEO



Dear Friends,

As we begin what will no doubt be an extremely challenging year, we should not forget what has brought us to today. The mission, set out by the founding members of The Alzheimer Society of Ireland, is as relevant today as it was back in 1982. This early pledge, to maximise the quality of life of those living with dementia

and their families, is being continued with the help of 300 volunteers, 3,000 members and 700 staff, through the provision of services; carer support; vital fundraising; shaping government policy; raising awareness and challenging stigma. The commitment and dedication of staff and volunteers is evidenced every day in tiny details – like a warm greeting and embrace on arrival at a day care service – and in the more heroic forging of floods and snow drifts to ensure a client is warm and nourished. Mission in action!

Over the coming months there will be more talk of shrinking budgets, funding cuts and decreased fundraising income. It will try us all and times may get tough. But through it all, our mission to improve the living experience of people affected by dementia, and their carers and families, will ensure our steady focus and ease the pain of the challenges we face. And before too long stability will be re-established and pressures eased.

In the coming year, the passion that unites The Society in the fight against dementia, will enable us to continue growing and developing despite the challenges. Already, plans are in place for the expansion of services - in the Mid West Region a new short term respite service in Waterman's Lodge in Ballina/Killaloe. A new support group for younger people with dementia and their carers will commence in Abbeyleix and a new social club is being launched in Swords, Co. Dublin. Family Carer training is scheduled for the North West, North East and Southern Regions and a newly trained cycle of Volunteer Advocates will be expanding our capacity to enable people with dementia and their carers to speak out.

In the next issue of oASIs I will be highlighting the launch of an ambitious awareness and political lobbying initiative to establish a National Dementia Strategy. The initiative – which is being funded by a grant from The Atlantic Philanthropies - will be grassroots driven, and we look forward to the participation of families, volunteers, supporters and staff from around the country as agents of change. In the meantime, we rely on your continued support and effort to make our major fundraising initiative, Tea Day, a Real Day to Remember. So please help us raise vital funds for local services.

Warmest regards,

Maurice

## National Positive Ageing Strategy - Be Heard!

The government is in the process of devising a new National Positive Ageing Strategy (NPAS), which is a long-term plan to make Ireland a better place in which to grow older. The strategy will involve all levels of Government as well as city and county councils. It will cover policies, services and practices in areas such as health care, housing, transport, income, employment and independent living. It will also influence the activities of organisations in the private and voluntary sectors.

As part of the consultation process, The Minister for Older People and Health Promotion, Áine Brady TD, will hold a series of eight consultation meetings around the country during Spring 2010 (see list below). The aim of these meetings is to hear first hand, the views of older people on issues that affect them. That means you! The Alzheimer Society would like to encourage YOU to share YOUR voice and contribute to a better quality of life for older people and those people living with dementia in the years to come.

### 3 Key issues to be addressed in the NPAS are:

1. Access to timely diagnosis; comprehensive flexible person-centered services on the continuum care; case management systems; prevention and screening programmes and information that is accurate and timely.
2. Increased awareness and training for many stakeholders – general public, allied healthcare professionals, media, transport & emergency services etc.
3. There is a need for a National Dementia Strategy to address policy, planning and service provision in the future and the NPAS should support/endorse this proposal.

NPAS Meetings will take place in Limerick, Wexford, Kildare, Louth and Dublin during April. For further information contact Samantha at the Office for Older People on 01 635 3057.

For a copy of the Alzheimer Society's written submission to NPAS contact Helena O'Donnell at (01) 207 3800.

# Tea Day 2010

## Tea Party Tips

If you haven't hosted a tea day party before here are a few tips that our regular hosts find useful...



### Plan ahead

- Choose your venue – many people prefer to host their tea day parties at home or in the office. But you could also book your local community centre or sports club
- Draw up a guest list
- Use the posters you receive when you sign up to hold a tea day party to advertise your event
- Sell as many raffle tickets as you can.

### On the day

The key to a great tea day party...is good fun. Let the tea, chat and cake flow free. It's not a sombre occasion...it's a day to celebrate and of course to raise money for Alzheimer's care.

- Hold an auction of donated items – a cake from a local cake shop, a bottle of champagne from a well wisher... you'll be surprised how ready people are to offer if you ask!
- Hold competitions – You could fill a large vase or jar with marbles and hold a 'Guess how many marbles are in the jar' competition. The possibilities are endless!

It's nearly Tea Day Time! Everyone's favourite time of year is just around the corner. Alzheimer's Tea Day is taking place on 6th May 2010.

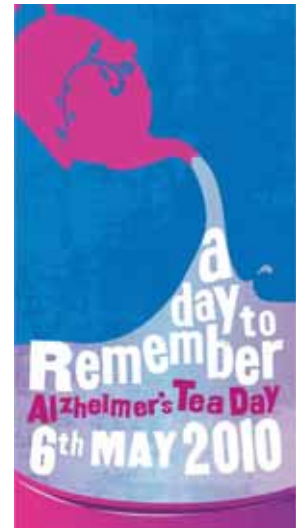
This year along with our Tea Day Patron, Pat Kenny, we are asking you to make it 'A Day to Remember' by hosting a tea day party and helping to raise vital funds for Alzheimer's services in the community.

Hosting a Tea Day party could not be easier, simply call our FREEFONE number 1800 719 820 or log onto [www.teaday.ie](http://www.teaday.ie) to receive our new tea day pack along with this year's tea day materials.

Pat's mother, Connie, lived with Alzheimer's disease for the last 14 years of her life, he knows first-hand the importance of helping to provide funding for vital support services for those affected by dementia. It was largely because of the services of the Alzheimer Society that Connie was able to stay at home and be cared for, by family, for longer. Pat's family story, like so many others, reminds us just how important Tea Day is, helping to bridge the gap between further funding cuts and service provision.

Tea Day is a wonderful way to show that we care about people living with dementia. Let's make this a **real Day to Remember**.

**To register for your Tea Day pack FREEFONE 1800 719 820 or log on to [www.teaday.ie](http://www.teaday.ie)**



## Social Inclusion

Social inclusion is about promoting the inclusion of the person with dementia and their carer in their local community, enabling their participation in the issues and decisions that affect their lives, securing their rights and ensuring that their interests are met, and services they need obtained. The Alzheimer Society believes that the promotion of self-advocacy groups for both people with dementia and their carers is central to achieving long term social inclusion for these two extremely vulnerable and isolated groups in society.

The Alzheimer Society's Social Inclusion Officer - Avril Dooley - is working on a number of different inclusion projects including a pilot community elder mediation service in partnership with Mediation Northside.

Mediation provides a way of making decisions and resolving conflicts which allows the views of all parties to be heard and

ideally produces results in mutually beneficial sustainable outcomes, improved communication between parties and which preserves relationships.

The principal aim of the elder mediation project is to offer older people, the person with dementia, families, caregivers and service providers a means of decision making and conflict resolution which minimises stress, promotes communication and understanding and takes in to account the best interests of all affected.

The pilot project will work with ten cases and an evaluation will be completed to examine the findings from the project and look at its future direction.

For more information on the plans for the elder mediation pilot project please contact: Avril Dooley, Social Inclusion Officer  
Tel: 01-2073802 E-mail: [adooley@alzheimer.ie](mailto:adooley@alzheimer.ie)

## Living with Dementia Family Carer Training

Last Autumn, the Alzheimer Society ran five pilot courses for ninety family carers in city and country venues around Ireland. The programme, which received dormant accounts funding, was called Living with Dementia Family Carer Training. It was designed to help family carers understand dementia, increase their confidence in their ability to care for relatives, and encourage them to identify, and look after, their own needs also.

The feedback to date has been very positive. The opportunity to learn and share experiences with others in similar situations was cited by carers as one of the most important aspects of the programme. Further courses are planned in sixteen venues nationally during the Spring and Autumn. Information on dates and venues will be available shortly from the Society's website [www.alzheimer.ie](http://www.alzheimer.ie) or by phoning (01) 207 3800.

## Profiling the Work of the Al

Many of us are reluctant to think or talk about death and dying. When we do, we often make light of it or tell people what we want or don't want done when we die. In many ways, we want to avoid the thinking and the talking. Notwithstanding this, there is an increasing awareness and debate in Irish society about the end of life and how people should and want to die. Some of the major disease groups have created awareness and responses to meet the needs of people when treatment or a cure is no longer possible for their condition. However, when we begin to think about the end of life care for people with dementia there is limited knowledge and expertise. The life expectancy of a person with dementia is unpredictable, and the disease can progress for up to ten years. Although dementia is a life-shortening illness, another

condition or illness may trigger death and be given as cause of death on the death certificate.

In 2008, The Irish Hospice Foundation (IHF) published Palliative Care for All calling for the extension of palliative care to a broader range of conditions including heart failure, respiratory disease and dementia. This report has contributed to greater understanding and increased debate, regarding how we can begin to approach integrating palliative care into the care pathway for the person with dementia. What is unique about dementia is the specific role the carer plays in supporting and caring for their loved one. Their knowledge and expertise is crucial

### Irish Hospice Foundation – Alzheimer Society of Ireland Joint Partnership Project: Integrating Palliative Care in Dementia Services

In response to one of the key recommendations in the IHF report, a two year action research project began in November 2009 to devise, implement and evaluate appropriate palliative care responses for people with dementia within an Irish health care context. The selected project site is based at St. Joseph's Residential Facility, Ennis, under the auspices of Clare Mental Health Services for Older People. The key research partners are the local primary care network and the specialist palliative care services from Milford Hospice, Limerick.

“Treat us as people and connect with us by eye contact and touch. Treasure us, we are precious human beings bereft of the ability to respond to our unexpressed yet deeply felt needs.”

(Christine Bryden, 57 year old person with fronto-temporal dementia talking about the end of life issues, 2005: 29 DASNI (2005))

### It is hoped that at the end of the project there will be:

- Clarity on nature, potential and timing of palliative interventions for people with dementia, their families and staff.
- A model of support and intervention developed for implementation in other services.
- Education material produced for key personnel in delivering palliative responses.
- Guidelines developed for the introduction of palliative interventions and referral to specialist palliative care
- Information materials available for service users, family members and health care professionals

More info: Contact Grainne McGettrick, Policy and Research Officer [gmcgettrick@alzheimer.ie](mailto:gmcgettrick@alzheimer.ie)

# Dementia at the End of Life

## Alzheimer Society of Ireland

to the care the person receives as they may be limited in their capacity to express themselves. Maintaining the personhood of the person with dementia, is crucial, and all those involved in the care must be committed to providing person-centred care to enable a good quality of life, at all the stages of the condition.

In order to address some of the deficits in the knowledge, understanding and practice the Alzheimer Society has taken a number of steps to support initiatives in this area. In addition, the organisation was and continues to be involved in influencing policy and informing the debate in Ireland in relation to the end of life needs of the person with dementia and the needs of those who care for them.



L-R Annie Dillon, Grainne McGettrick, Sarah White, Aileen Doran, Catherine Keogh, Majella O'Donnell and Dr. Una McConville

### **New Project seeks to identify and respond to the palliative care needs of people with dementia and their carers and families who access Alzheimer Society of Ireland services.**

When we think of palliative care we most often think of it being available for people with cancer. In Ireland palliative care is generally not available to older people and people with dementia. A palliative care philosophy includes care across the physical, emotional, social and spiritual dimensions of the person. In recent years it has become increasingly recognised that palliative care would be of benefit to most of us and particularly if we have a life limiting condition, including dementia.

Barbara Pointen, who cared for her husband Malcolm who had Alzheimer's Disease and died at home in 2007 said:

**'Effective palliative care begins not only with the right policies but also with people who have the right expertise. Quality of care, and of life, lies in nurturing the whole person: their physical, psychological, sensory, emotional & spiritual needs'**

The Alzheimer Society is working on this issue and at the beginning of the year was awarded a grant from the Irish Hospice Foundation's Small Research Project Fund for a

project called *'Opening Conversations – Developing a model of best practice for the Alzheimer Society of Ireland for best practice palliative care interventions for people with dementia and their families'*.

This project will run throughout 2010. Dr. Una McConville has been appointed the research coordinator. Majella O'Donnell, Aileen Doran and Sarah White, the three Alzheimer Society Staff with qualifications in dementia and end of life care, will participate in the research project at their local services in Sligo, Wicklow and Raheny. From the National Office Catherine Keogh, Care Practice Co-ordinator, Grainne McGettrick, Research and Policy Officer and Annie Dillon, Projects' Officer will also contribute.

**Work is already underway and the following are some of the areas that this project will address:**

- Examine research and practice already done on the issue of dementia palliative care
- Hold discussions with people who access our services and staff about what they see are the supports that would be of use in relation to palliative care for people with dementia, their carers and families.
- Develop relationships with local services including palliative care services.

At the end of the project we hope to develop dementia palliative care responses that are person centred and will help support people who come to Alzheimer Society services. Overall we hope this work will contribute to the well being of people with dementia, their families and carers.

A report will be compiled and will be available at the end of the year. Meanwhile for further information contact: Annie Dillon, Projects Officer, [adillon@alzheimier.ie](mailto:adillon@alzheimier.ie).

# Branch News



## NEWSFLASH - Blackrock

The Orchard Day and Respite Centre are running a pilot project in May where they will offer Respite 7 days a week to 11 clients. The cost of the service is €750 per client. For further details contact Renata or Jean on ph: 01 207 3836/7/8



### 1 Southern Regional Office

Soroptimists International, Cork, donated €2,500 to the Cork City Branch of the Alzheimer Society.

### 2 Midlands

A donation of €200 was made to the Monaghan Branch by the 4th Year Students at St Louis Convent.

### 3 Donegal

The Donegal Branch has a variety of fundraising activities happening in the next while;

- There's a fundraiser at The Europa Hotel, Belfast – 12 noon on Saturday 24th April.



- Gabrielle's Ball at the Mount Errigal Hotel, Letterkenny – 7:30 pm Saturday 24th April.
- The NorthWest 10K run is happening on Sunday 2nd May, the Donegal Branch is one of three beneficiaries.
- Golf Classic at Murvagh Golf Club, Donegal Town on Friday 9th July.
- Open day at Oakfield Park, Raphoe (the residence of Sir Gerry & Lady Heather Robinson) on Sunday 11th July. [www.oakfieldpark.com](http://www.oakfieldpark.com)

For further information on all the events contact the Donegal Branch Office on 074 972 2795.

## My Mini-Marathon

Last year, Eimear Byrne from Inchicore, was a member of the 'A Team' – the team of over 450 women of all ages who walked, ran and crawled the Flora Women's Mini Marathon in aid of the Alzheimer Society.

'I've done the Women's Mini Marathon for the past couple of years, and in 2009 decided to do it with some family and friends for the Alzheimer Society of Ireland. A relative of ours has Alzheimer's and avails of the services of the Alzheimer Society, and we thought this would be a great way to raise some much needed funds for people with Alzheimer's but also to raise awareness about the disease and The Society.

Our group was made up of all ages and all levels of fitness, and I would encourage as many people as possible to join me on this fantastic day. It's easy to do, just fill out the entry form in the Evening Herald or log onto [www.womensminimarathon.ie](http://www.womensminimarathon.ie) and then let Emily in the fundraising office know that you're joining the 'A Team' and she'll send you out a pack which includes sponsorship cards and the new mini marathon t-shirt!

If you're worried you might take too long to do it, don't be, with the big group of us it took us 3 hours to walk it, but it was worth every minute, knowing that each step you're taking is helping raise funds for Alzheimer's services in the community. And if that's not enough to keep you going, you have everyone around you supporting each other, it really is great craic.

The most important thing for us was raising awareness about Alzheimer's, lots of people saw the t-shirt and realised that they weren't alone and they could get help from the Alzheimer Society.

I'm really looking forward to this year and hope you will join me, making this year the biggest and best mini marathon for the Alzheimer Society of Ireland.'

**Thank you**



# Fundraising News

## Ways you can help...

### Wedding Favours

Getting married? Instead of giving your guests wedding favours why not consider supporting The Alzheimer Society of Ireland by making an in lieu donation. When you make a donation to The Alzheimer Society of Ireland in lieu of wedding favours, we can provide you with elegant forget-me-not cards for your reception tables, acknowledging your generous gift, appreciation of your guests and thanking them for being part of your special day.

We also have memory pins that you may wish to purchase as your wedding favours.

We are currently in the process of designing a new Wedding Favours card. We love it and we think you will too...watch this space!

### Giving back...

Are you a graphic designer? A copywriter? An artist? A business owner? You might possess a certain skill or work in a profession that could really help us.

You might be able to volunteer to design our next brochure, draft an advert or create a Christmas Card. If you are a business owner you might be able to help us in the most wonderful way possible by sponsoring our Tea Day, Cuba Cycle Challenge or some fundraising merchandise!

If you have any ideas of ways that you can help please contact us and let us know.

### Cuba Cycle Challenge

Hi Everyone,

It's Emma, the editor of oASIS here, and the latest participant to sign up to this year's Cuba Cycle Challenge - the Alzheimer Society's Annual overseas cycle challenge which takes place in May this year. It really will be a challenge for me, I haven't been on a bike in over 5 years, and as last week's training session proved, I might need stabilisers!

Signing up to the challenge couldn't have been easier, Emily from the fundraising team cleared up any concerns I had about fitness and fundraising. She assured me that even though our current economic climate makes fundraising even more challenging than before, that it is possible. She provided me and the rest of the group with a great sounding board for ideas and gave us many hints and tips on how we can reach our targets of €4,500. Not only that she pointed me in the direction of the fantastic cycle to work scheme which provided me with my bike, no excuse to get training now!

Our group training sessions have begun, gradually working up our fitness levels so we'll be prepared for the 325km cycle over 5 days. The next group session is a 50km cycle from Greystones to the Beehive, near Arklow, Co. Wicklow, and back again, about the same distance we will be cycling each day in Cuba, only the temperatures will be a little warmer!

Working off the excess from Christmas has been great fun, the team really help motivate each other, whether it's encouraging fitness tips, or helping you fundraise, we are all doing it for the same great cause, helping to raise funds for specific Alzheimer's support services in the community.

If you would like to find out more about the challenge contact Emily on 01 207 3816 - The Cuba Cycle Challenge takes place from 5th - 13th May 2010.

### Leaving a lasting gift

Have you recently bought your own house, started your own company, got married or started a family? You might be thinking about making a Will. Of course your loved ones come first, but just a small gift in your Will to The Alzheimer Society of Ireland could help provide much needed services for people in Ireland living with Alzheimer's.



The idea of making a Will is something, which may make some of us feel uncomfortable. Realistically however, it is something that all of us should do at an early age to ease the burden of the loved ones we leave behind.

A gift left in a Will is simply a means of giving something back. It provides you with the opportunity to ensure that your possessions and finances are divided up according to your wishes. It is about remembering the people and the causes you care about.

By leaving a donation in your Will you will be providing much-needed financial support which is vital in providing services for people in Ireland living with Dementia.

Leaving a lasting gift is easy and is something that everyone can do. Contact the fundraising department to find out how easy it is to leave a gift in your Will on 01 2073800.



✠  
**IN MEMORIAM**

Alice Byrne  
 Anne Behan  
 Bridie O'Regan  
 Capt Derek Furniss  
 Carmel O'Farrell  
 Christopher O'Toole  
 Christy McMahon  
 Christy Mitchell  
 Cissie Duff  
 Claire Prendergast  
 Dorothy Owen  
 Gerard Reynolds  
 Harriet Halliday  
 John Farrelly  
 John James Grannell  
 John Moore  
 John P Moan  
 Laurence Sweeney  
 Lily Bennett  
 Lily Cooney  
 Margaret (Peggy) Keating  
 Margaret (Rita) Lowen  
 Marianne Warren  
 Marie O'Carroll  
 Mark O'Malley  
 Mary Bradley  
 Mary Duffy  
 Mary Jo Doherty  
 Maura & Dinny McMahon  
 Maura Condron  
 Maurice Dore  
 May Booth  
 Michael Gleeson  
 Mrs Audrey Murphy  
 Mrs Mabel Ingram  
 Mrs Marie McGarry  
 Mrs Maureen Bagnall  
 Mrs Mollie Muldowney  
 Mrs Trea Nugent  
 Nora & Roger McNamee  
 Patricia (Patsy) Farnan  
 Peggy Foody  
 Rose Daly  
 Sarah Gallagher  
 Seamus Mulvey  
 Sheila Egan  
 Wesley & Georgie Graham  
 Ann Roe

**May they Rest  
in Peace**



We would like to thank everyone who participated in our Regional Christmas Memory Ribbon Campaign 2009.

We were delighted with the response and hundreds of Memory Ribbons were returned back to us in the weeks leading up to Christmas, which lead to our tree (pictured) begin completely covered with ribbons.

The total raised by the inaugural campaign was an astonishing €34,000. The proceeds of which will go directly to running our day care, respite and home care services.

**Thank You!**

**Dates for your diary**

| <u>Date</u>    | <u>Event</u>                  | <u>Venue</u>               |
|----------------|-------------------------------|----------------------------|
| 6th May        | Alzheimer's Tea Day           | Nationwide                 |
| 5th-13th May   | Cuba Cycle Challenge          | Cuba                       |
| 7th June       | Flora Women's Mini Marathon   | *27th April 2010<br>Dublin |
| 14th-20th June | Carer's Week                  | Nationwide                 |
| 17th-23rd Oct  | DLRCOCO Social Inclusion Week | Dun Laoghaire<br>Rathdown  |
| 21st Sept      | World Alzheimer's Day         | Worldwide                  |

*\*closing date*

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**Next Issue:** Summer/Autumn 2010 **Deadline for Copy:** 1st July 2010

The comments and views expressed in this issue are often personal and do not necessarily represent the position of the Alzheimer Society of Ireland.