



THE ALZHEIMER  
SOCIETY of IRELAND

# OASIs

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Quarterly Newsletter of the Alzheimer Society of Ireland

Volume 26 Issue 3

Autumn 2008



Message from  
the Chairman  
Couplehood  
World Alzheimer's Day

**KING of  
GREYSTONES 2008**





# Christmas Cards 2008

The Alzheimer Society of Ireland  
Christmas Cards



This year The Society has increased its range of quality personal Christmas cards again, ensuring there is something for everyone! As always, all proceeds from the sale of these cards will go directly to The Society. All packs cost €5 and come with envelopes.

### Manger with Star



### Santa with Toy Pack



### Christmas Door



Each of these packs contains 10 cards (16cm x 12.5cm) with the Society's logo and verse 'With Every Good Wish for Christmas and the New Year' in English and Irish.

### Choir of Angels



### Manger with Animals



Each of these packs contains 6 square format cards (14cm x 14cm) with the Society's logo and verse 'With Every Good Wish for Christmas and the New Year' in English and Irish.

## Exclusive Designs for the Alzheimer Society of Ireland

### The Three Kings



### Annie Tempest Exclusive



Exclusive by local Irish Artist Richard Whyte

6 cards per pack (12.5cm x 1.12cm)

10 cards per pack (16 cm x 12.5cm)

Both read 'With Every Good Wish for Christmas and the New Year' in English and Irish.

If you have any questions or would like further information, please contact fundraising on 01 284 6616 or email fundraising@alzheimer.ie.

## Please complete Order form below

Name: _____							
Address: _____							
Contact Telephone No: _____							
Email: _____							

Item	Price	Qty	Total	Item	Price	Qty	Total
Manger with Star	€5			The Three Kings	€5		
Santa with Toy Pack	€5			Annie Tempest Exclusive	€5		
Christmas Door	€5			Donation			
Choir of Angels	€5			Sub Total			
Manger with Animals	€5			Postage & Packing			
<b>Postage &amp; Packing</b>				<b>TOTAL</b>			
1 - 4 packs €2.50    5-8 packs €3.50    9-12 packs €7.50							
<i>All rates are according to An Post Rater</i>							

Please return to: Emil Brew, The Alzheimer Society of Ireland, Temple Hill, Blackrock, Co. Dublin.

**Method of Payment:**

I enclose a cheque (made payable to The Alzheimer Society of Ireland)

I wish to pay by credit card. **Card Type:**  VISA     Mastercard     American Express     Other

Valid from                      Expiry Date                      Security Code

Signature: ..... Date: .....

REGISTERED CHARITY NO CHY 7868

# A Message from the National Chairman

In my new role as National Chairman I am delighted to welcome you to the Autumn oASIs newsletter, which will give you a flavour of the breadth of work and activities that have been happening in recent weeks and months.

September is a time of reflection for all those involved in dementia care. World Alzheimer's Day, on 21 September, focuses our minds on the 40,000 Irish people, 5.4 million Europeans and 24 million citizens of the world that are currently affected by dementia, their carers, families and friends. We know that our ageing population means that more people will enter the high at risk category every year. More people will develop the condition. More carers and families will journey with their loved one's as they strive to live as normally as possible post diagnosis.

Dementia is being recognised as a health priority by governments throughout Europe and around the world. President Sarkozy has made a commitment to produce a European Plan for dementia during France's EU Presidency. But Ireland is lagging behind.

Families receiving our services tell us that they wish to continue caring for their loved one at home. However, two thirds of carers are caring for more than 14 hours a day. Most are without adequate services to support them; many without sufficient information or training; some without financial security, living in poverty and isolation. More needs to be done, by government, the HSE and by the Alzheimer Society.

More services; more hours of care; more training; and more support for the carers and families in need. These themes dominated our recent organisational review. They also reflect the cries of the 3,200 families we currently provide assistance to and the desperation of the 750 families on our waiting lists for months. And these themes form the backbone of our recent Budget 2009 submission to the Minister for Finance, Brian Lenihan.

Our o calls for increased funding for current services – to ease the financial burden of a 30% shortfall in HSE

funding. It calls for increased funding to ensure that the 750 families on our waiting lists get a basic package of Society services. Capital investment is called for to ensure the completion of our two major development programmes and monies for specialist services to meet the needs of the younger people living with dementia are essential. Despite the current economic difficulties substantial investment in dementia care must be a priority.

We have now reached the mid-point of our three-year Dementia Manifesto strategy but little or no progress has been made. Dementia is not being prioritised in health & social service delivery. A dedicated budget line for dementia has yet to be established. Amid inadequate funding and increased cutbacks, families continue to bear the lion share of the baseline cost of dementia care. All the while, 11 more people develop a dementia every day, and the proverbial 'pie' is getting smaller.

The global theme for World Alzheimer's Day is 'No Time To Lose' and there is no time for government – and the HSE to lose in recognising the looming crisis of insufficient funding and inadequate service provision. It's time to follow our European partners in recognising this devastating condition as a National Health Priority. The catch-up must start now!

In closing, I'd like to acknowledge the significant contribution and commitment of my predecessor, Dr Niall Tierney, who remains an active member of the Board. With the help of all the Board, volunteers and staff of the Alzheimer Society we will face the challenges ahead in striving to ensure a better quality of life for all those affected by dementia. I hope that over the term of my office I will have the opportunity to meet as many of our members and supporters as possible.

*Best wishes*  
*Kevin Norton*

## World Alzheimer's Day - 21st September

World Alzheimer's Day (WAD) is the day when people who are affected by Alzheimer's disease and related dementias unite in solidarity raise awareness about Alzheimer's / dementia globally. On this day each year, - 21 September - people with dementia, carers and Alzheimer organisations from more than 77 countries join forces to speak out about the challenge of dementia on individuals, families and societies.

This year the focus of WAD is to highlight the role and value of dementia carers. In Ireland more than 50,000 carers are caring for someone with symptoms of dementia. Our carer survey last year revealed that many carers are caring for more than 14 hours per day without adequate support services, financial supports, training or general understanding of their tremendous contribution. Social isolation and stress have a significant impact on health and wellbeing of carers.

These challenges are faced by carers in other countries too and they will become the global focus of WAD as we once again remind ourselves and others, that in dementia care there is 'No Time to Lose'.

The Alzheimer Society is holding a programme of events, meetings and celebrations throughout the country to commemorate World Alzheimer's Day 2008. The events will be take place from 15<sup>th</sup> to 29<sup>th</sup> September including the launch of 'Social Space: Equal Place, *The social model of dementia care*' report on 18<sup>th</sup> September in The Mansion House, Dublin 2 and a concert for carers in Cork City as the showcase event on WAD itself.

For details on World Alzheimer's Day events contact Fiona on (01) 284 6616, e-mail [info@alzheimer.ie](mailto:info@alzheimer.ie) or visit [www.alzheimer.ie](http://www.alzheimer.ie).

**Personhood is a term many of us are familiar with and thanks to the work of Tom Kitwood and many others since, it has become synonymous with dementia care.** We understand that embracing the person with dementia's personhood encourages them to maintain their sense of self and well-being. Personhood is defined as "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being" (Kitwood, 1997, p8).



In fact the terms relationship and social being are the crucial words in that definition, and therefore are inextricably linked to personhood. One does not exist without the other. For all of us, whether we care for, work with or are friends with people who live with dementia, we know that the relationship we have with them is the most important thing. We also know that people with dementia have fundamental social needs as human social beings. This does not change with the onset of the condition, but what can change is access to social relationships due to stigma, embarrassment, protectiveness, lack of choice and control over their lives and a society that does not always support those they don't understand.

However there is another concept beginning to be discussed in the literature and recognisable to many as 'couplehood' or 'couple identity'. It looks at how people, who are in relationships for a considered period of time, develop a 'couple identity' that is often separate but integral to their personal identity.

Simply put it is when the 'I' becomes the 'We'. It's the first clear evidence that someone you know is in a significant relationship when the answer to the question 'How are you' becomes, 'We're grand'. The 'we' here might mean the person and their partner, or indeed as life changes the person, their partner and their children.

Couple identity refers to the identity that a couple take on in their relationship and is what helps sustain that relationship. If that identity has been crafted over many years, as is the case with many people with dementia and their spouses/partners, then embracing couplehood as well as personhood would seem beneficial, not just to

the person with dementia but also their spouse/partner.

We are aware through research and through contacts with family caregivers that they can become socially isolated due to a number of factors, including the often overwhelming nature of their caring role. Finding a way in which we can not only embrace the social needs of the caregiver, but to do so in a way that supports the couples' identity would seem to address some of these needs. The social club model was developed as a direct response to some of these issues.

Dementia services in the main centre on the 'couple' being separated for a period of time be that through day, home or respite care. The social club model was innovative in not only bringing together the couple, but doing so in a way that met both their needs in a pro-active way. 'Being in the same boat' as others who attended lessened the sense of stigma, and reduced any concerns over the 'wrong word being used in the wrong place'. Social norms and rules did not apply within the embrace of the social club. It is a place, where everyone could be equal.

It is also a place, where the couple get to have fun and be supported to do things together. In this way it supports that very fundamental identity of how couples are together, which has been crafted over many years of a relationship.

It indeed also supports the caregiver in their journey, which sometimes can bring them back to the 'I'. This is a difficult and painful journey, and having someone walk beside you matters. Couple identity inevitably changes as the person living with dementia progresses, and the relationship in itself can take on a less reciprocal arrangement, as the person's skills and abilities change. Sallstrom (1994) described the carer of a person with dementia as 'lending a hand', then 'giving a hand', before eventually 'taking a hand' in their care for their loved ones with dementia. As friends, volunteers, service providers and family of these caregivers and their loved ones, it is important for us to hold their other hand as they journey with the person with dementia.

**To be able to share experiences with people in similar situations is priceless, great friendships have been born and we as a group have shared some very happy and emotional days together.**

Staff member



## Key Recommendations

- The adoption of the Social Club Model should be considered across all regions in the Alzheimer Society of Ireland to augment existing services and meet social needs of client and carer
- Additional resources must be identified and allocated in service planning to ensure that the Social Club Model's long term viability and sustainability are secured
- Key staff in the regions must be supported and appropriately trained in the philosophy of the Social Club Model – which should include an educative process in group, counselling and facilitation skills
- Consideration of the couple and their 'couplehood' in all aspects of service and support delivery needs to occur to meet the need of being socially supported together
- The findings of this research should be shared with key health and social care professionals in dementia care through dissemination of this report, presentations at conferences etc.
- The report should be disseminated to policy makers in order to influence and augment new models in dementia care.

## Key findings that emerged from the research were:

- The club provided a space for worry-free socialising of people with dementia, their spouse/partner and others
- The club provided a forum for sharing caring strategies and receiving support
- The club promoted the social network and skills of the person with dementia
- The club addressed some of the social isolation felt by carers and their partners.



## Key factors that were crucial to the success of the club were

- Their relaxed, informal nature
- The members' active involvement in the running of their own club
- Staff that are skilled in dementia care, are empathic and embrace the philosophy of the club
- Going on outings and social occasions.

Report By Catherine Keogh

# Branch News

## Social Club Holiday

The Social Clubs from Bray, Kildare and Rathfarnham went on their first group holiday to Kilkenny. A wonderful time was had by all and we hope to have many more trips like this in the future.



## Westmeath Branch

A massive thank you to the Lakeland Vintage Club, Abbeyshrule, Co Longford who fundraised €3000 for the Society in Longford and Westmeath



The 6th Annual King of Greystones Charity Triathlon Challenge took place on August 9th in Greystones, Co. Wicklow. The challenge, which consisted of a 750m swim, a 20k cycle and a 5k run, attracted a huge number of participants. This year we were really lucky with both the weather, it stopped raining just before the race began, and the supporters, who were all on hand to cheer on family and friends. 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. An enormous thank you must go to the wonderful organizers headed up by Shane McKenna and Andrew Dungan. A huge thanks also goes to the superb volunteers and safety marshals who joined us in giving up their Saturday to ensure that all competitors got home safely. Not forgetting a massive thank you and well done to all the competitors who took part.

## Social Club Report Launch – Social Space, Equal Place

On Thursday 18th September the Society launched its Social Club Report, Social Space, Equal Place. The report released findings of 'The Social club model of dementia care' which indicate that our new social club services could hold the key to breaking down social barriers, addressing isolation and challenging the stigma of Alzheimer's for couples living with the condition. The Society currently runs three pilot social clubs in



Rathfarnham (Dublin), Bray (Wicklow) and Athy (Kildare). All clubs meet weekly for three hours, providing a worry free environment for both people living with dementia and their carers to socialise and relax in. For further information on these Social Clubs please contact the Helpline 1800 341 341



## Annual Conference Nurturing Ourselves, Caring for Each Other

This year's Annual Conference takes place in the Tullamore Court Hotel on the 10th and 11th October. The theme for this year is 'Nurturing Ourselves, Caring for Each Other'. This year the focus is on caring for ourselves and on how to support each other in our various caring roles, with an emphasis on health and well-being. Many people who are caring do not get an opportunity to prioritise their own needs and we hope through this conference we will learn more about how best to approach the issues of caring for those who care.

We want to conference to provide an opportunity to gain a greater understanding and experience of how to care for each other as well as nurture ourselves. Through workshops, talks and group discussions we aim to equip participants with some of the skills and knowledge necessary for their caring role by providing the best quality of care to people living with dementia. The conference will a great opportunity to network and exchange ideas and expertise among participants.

Further details on the programme and registration are available from the Society, contact Fiona by phone (01) 284 6616 or by email [fodonnell@alzheimer.ie](mailto:fodonnell@alzheimer.ie)



# Fundraising News

## Failte Towers

After an eventful week of long nights and even longer days, Patricia McKenna packed her bags and checked out of Failte Towers. A huge thank you goes to Patricia for nominating us her charity and for letting us be a part of the experience, which enabled us to raise the profile of the Society nationally and help raise much needed funds. Many thanks to everyone who joined us in Bellingham Castle, and to those supported us by voting at home. Without you this would not have been possible.



## The Alzheimer Society of Ireland – Annual Gala



This year, the Society's Annual Gala Ball will take place on 21st November in the Shelbourne Hotel. Last year was a great success, with the cream of Dublin's Business Community turning out to show their support for the Society. We hope to make this year's event an even bigger success.

For further information on tickets or event sponsorship contact Emily (01) 284 6616/ [fundraising@alzheimer.ie](mailto:fundraising@alzheimer.ie)

## Mycharity.ie

Eoin Bryan, Donal Behan, Karen Kirran, Kevin English, Laura Casey, Paul Coyne, Paul Handley, Emmett Sheridan and Russell Morling are running the Addidas Dublin Marathon on 27th October 2008.

Darren Flynn is running the Great North Run on 5th October.

Jean Jones, Michelle O'Dwyer and Stephanie Jones are doing the Cork Women's Mini Marathon on 28th September.

*To sponsor any of the fundraisers we have mentioned or to set up your own fundraising page log onto [mycharity.ie](http://mycharity.ie)*

## Move to Blackrock

We are currently in the process of moving both National Offices and Blackrock Day Care and Respite Centre into our new state of the art purpose built facility in Blackrock. Our new address is The Alzheimer Society of Ireland, Temple Hill, Blackrock, Co. Dublin. Ph (01) 284 6616 Helpline 1 800 341 341

## Dates for your diary

DATE	EVENT	VENUE
9th August	King of Greystones Triathlon	Greystones
21st September	World Alzheimer's Day	Worldwide
10th & 11th October	Annual National Conference	Tullamore Court Hotel
21st November	Annual Gala Ball	Shelbourne Hotel

## World Alzheimer's Day - Events happening in your area

DATE	EVENT	VENUE
Tues 16 <sup>th</sup> September	Launch of the Cuba Challenge	Dublin
Thurs 18 <sup>th</sup> September	Launch of Social Club Research –Social Space; Equal Place	The Mansion House
Mon 22 <sup>nd</sup> September	Support Group Meeting – Tullamore Open Morning Open Morning Open Morning Open Morning	Bridge House Hotel Longford Office Laois Office Carlow Office
Wed 24 <sup>th</sup> September	Public Information Evening -Mullingar	Annebrook House Hotel



### IN MEMORIAM

Ms Elizabeth Behan	Mr Tom Fogarty	Mrs Ann Aldritt	Ms Meave Doyle
Mr Ted Cotter	Mr John C Warde	Ms Mary Hughes	Ms Mary King
Ms Jane Hughes	Mrs Mary Burns	Ms Pauline Synnott	Ms Catherine Parkinson
Ms Sheila O'Connor	Mr Paddy Joe Horan	Mr Myles Healy	Ms Elizabeth Acker
Ms Grace Cooke	Mr Thomas Mahon	Mr Paddy Hughes	Ms Mary Hughes
Mr William Swan	Mrs Peg McEntee	Mrs Christina Byrne	Mr William O'Donnell
Mr Jack Flood	Mrs Annie Sheehan	Mrs Teresa MacMahon	Mr PJ O'Loughlin
Mr Alfie Keegan	Mr Jimmy Toner	Mr Joe Breaden	Ms Delia McCarthy
Mrs Mary Grealey	Mr Tommy Lynam	Dr Maureen Kelly	Ms Kay Meade
Mrs Monica Mitchell	Mrs Margaret Evans	Mrs Geraldine McGovern	Ms Peggy O'Donnell
Mrs Elizabeth Ryan	Mrs Peig Fitzpatrick	Ms Margaret Fitzpatrick	Ms Mary Reynolds
Mrs Elizabeth Acton	Mrs Tess Devlin	Mr Patrick O'Reilly	Ms Mary Linehan
Mrs Noreen Duncan	Mr Danny Horgan	Mr Robert O'Neill	Ms Esther Norton
Mrs Mary Haynes	Mrs Ellen Tutty	Ms Mona Cullinan	

**May they Rest in Peace**

oASIs was edited by Emma Hamilton, Alzheimer Society of Ireland.

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