



THE ALZHEIMER
SOCIETY of IRELAND

OASIS

Quarterly Newsletter of the Alzheimer Society of Ireland

Volume 25 Issue 4

Winter 2007



Annual Conference 2007

Social Space: Equal Place

6th Annual Burren Walk



Caring for 25 years
The Alzheimer Society of Ireland

Christmas Message from the CEO



Dear Friends,

2007 has been a significant year for the Alzheimer Society, marking 25 years since founders Winifred Bligh and Imelda Gillespie set out as pioneers in the field of dementia care in Ireland. Over the intervening years, much has changed in Ireland's

political, economic, health and social landscape. However, not enough has happened to reduce the physical, emotional and financial impact on individuals and families living with dementia. Social isolation, financial strain and inadequate support services were highlighted as major issues for carers in our recent carer survey*.

Growth, innovation and challenge have featured strongly again this year. Our services now employ 730 staff and provide more hours of care to more clients and families than ever before. In total there are 94 services spread across the country; comprising day care, home care, overnight respite and support group services; plus innovative pilot programmes such as social clubs, advocacy service, and telecare programme. And of course our national and online helpline services offer information and a listening ear to those impacted upon by Alzheimer's / dementia.

Operational funding continues to be a major challenge – particularly in relation to traditional day care services. Although there has been some improvements, on average 30% of our service costs – or ?3.5 million annually – comes from voluntary contributions through the efforts of our branches, volunteers, staff and supporters. This is neither practical nor sustainable and it interferes with our capital development campaigns.

We are standing on the cusp of a new era in dementia care and the Alzheimer Society is leading the way forward. The Dementia Manifesto 2007-2009 sets out a three-year

strategy for government and policy makers. Our Seanad Nominee, Sen Tony Kett, will play an integral part in our campaign to role out the manifesto and to have dementia recognised as a National Health Priority.

Negotiating a 'fair deal' for people with dementia needing nursing home care is a key concern going forward and we will continue to lobby the Minister for Health & Children, the Minister for Older People and all political representatives to ensure that the distinct needs of our constituency are represented. Efforts will continue to address funding difficulties at local and national level. Our capital projects in Blackrock (Co. Dublin) and Killaloe/Ballina should be completed in the coming year expanding our services in Dublin and the Mid West.

Active volunteerism was and will continue to be core to the Alzheimer Society. I would like to particularly thank all those who, during 2007 and throughout our 25 year history, given generously of their time, energy and expertise in a myriad of ways – on branch committees, in centres/support groups, on our helpline, for project/ administrative work and of course raising funds to keep us going.

Thanks also to our corporate sponsors and private donors and all our supporters who collectively shaved heads, run marathons or pushed their personal boundaries to raise funds in our name. I would particularly like to thank Celebrity You're a Star Nuala Carey, actress Doireann Ni Chorraigan, Maeve Binchy, Pat Kenny and all the high profile people who helped us to raise awareness and money through the year. Thank you to our Board, volunteers, staff and members; and of course a big thank you to Winifred Bligh and Imelda Gillespie for initiating this wonderful organisation.

I wish you all every peace and happiness this Christmas and for the year ahead.

A handwritten signature in black ink that reads "Maurice O'Connell". The signature is written in a cursive, flowing style.

Maurice O'Connell
Chief Executive

European institutions commit to making dementia a European priority in 2008

During a lunch debate organised by Alzheimer Europe on the 6th November, hosted by François Grossetête MEP (France) representative of different European institutions gave their clearest signal to date that the fight against Alzheimer's disease and other forms of dementia would feature prominently in the plans of the European Institutions in 2008.

Jean Georges, Executive Director of Alzheimer Europe stressed: "At this meeting, we heard the clearest signal

yet that our campaign to make dementia a European public health priority is bearing fruit. It is encouraging to hear that Alzheimer's disease will figure prominently in the plans of the European Commission, the European Parliament and the French Presidency in 2008. Alzheimer Europe and its national member organisations are looking forward to collaborating with all three European institutions to make a difference for the 6.1 million Europeans living with a form of dementia".

*"Living with Dementia – The Experience of Carers in Ireland" was carried out by the Alzheimer Society of Ireland in conjunction with Lundbeck Ltd and launched in October 2007.

Annual Conference 2007

Towards A Voice: 25 years of Dementia Care and Advocacy 1982-07

“This has by far been the most interesting conference – keep it up!”

This year's annual conference took place over two days and has been deemed a great success by those who attended. The Minister of State with Responsibility for Older People, Marie Hctor TD opened the Conference and warmly thanked and congratulated The Society for our contribution over the past 25 years and the work we do. She also recognised the need and importance of dementia specific services for people with dementia and their families and carers.

The conference also saw very informative and practical presentations and workshops on a range of topics including Creative Communications, Understanding and Responding to Behaviours, Legal and Capacity Issues and Elder Abuse. The feedback on the content of the conference was overwhelming; we hope everyone will benefit from viewing the presentations, all of which are available on our site www.alzheimer.ie



“Inspirational speakers”



“Thought provoking day, I am leaving with renewed enthusiasm to continue the challenge of making the lives of those with dementia interesting and productive”



By Grainne McGettrick and Catherine Keogh

The Alzheimer Society of Ireland's (ASI) first social club opened its doors in Bray, Co. Wicklow in 2005. Since then two other clubs have been developed and all three clubs are running successfully.

Social Space: Equal Place, The Social Model of Dementia Care is a small scale study on the social club model which was carried out by ASI through a mixed methodology of questionnaires to members and staff, qualitative interviews with key stakeholders and a member-checking session of the initial themes with one of the clubs. The data was analysed and key themes are presented in the findings.

The Social Club is unique in the context of dementia service provision in Ireland. Social clubs are a gathering of people with dementia and their carers (usually but not exclusively the spouse) who come together in a social context to support each other, share experiences and enjoy each other's company. The social clubs offer a range of benefits to their members and provide additionality of service provision.

“it gives support which helps to alleviate the feeling of being the only one in that position”

Personhood

Maintaining personhood in the advance of cognitive impairment is considered best practice in dementia care. 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. It implies recognition, respect and trust” (Kitwood, 1997, p8). The maintenance of personhood constitutes a key role in the caregiver's lives as the dementia progresses.

Studies on the concepts of caregiving report that the caregiving role is associated with increased stress. In relation to dementia, studies have repeatedly shown that caregivers of those with dementia show an increased rate of stress, depression and loneliness than those caring for non-dementia patients.

Sustaining the caregiver in their role can influence the experience of dementia; therefore any consideration of the support of the person with dementia must automatically include their caregiver. Many caregivers of people with dementia feel socially isolated. Not only have elements of their significant relationship changed, but they may also have lost access to their social support networks; a natural stress-buffering tool.

Becoming socially isolated within an already stressful situation can increase the perceived stress and strain and reduce caregiver coping ability. Studies have found a pervasive and profound effect of social support on health of the elderly, therefore interventions targeting social support enhancement may prove to be both economical and effective. However one would surmise that interventions which involve both the caregiver and person with dementia would serve to be equally if not more effective, as they address the concept of social support plus a concept widely written in the literature - Couple Identity.

Beeson reports that “the longing for interpersonal intimacy stays with every human being from infancy throughout life; and there is not a human being who is not threatened by its loss” (Beeson, 2003, p141). The loss of companionship, loss of reciprocal exchange of affection, loss of a confidant, especially in the marital dyad – can affect quality of life for spouses of people diagnosed with dementia (Beeson, 2003). Loss of identity was also reported, particularly when that identity was strongly linked to the identity of the couple.

This highlights the concept of couple identity. The ‘I’ becomes the ‘We’ and much of one's identity can become linked to the identity as a couple. Losing this identity is a real threat to the caregiver's well-being. Not only are they dealing with increased stress in managing a chronic illness, but they are losing the one confidant they would have talked to about it. Loneliness in itself is “not caused by being alone, but a response to the absence or loss of a definite needed relationship of a close attachment figure” (Weiss, 1973, p 54).

“as a couple it allows us to meet others with similar interests”

Embracing the couple's identity does much to maintain the personhood of the person with dementia, as it is inextricably linked to their spouse. In fact, much of what has been written about dementia centres on the concept of personhood and it's relation to social being. Therefore, doing things together for the couple is an essential component of who they are, both individually and together. In doing so the benefits are potentially two-fold: to embrace the identity of the couple, thereby recognising personhood within the context of couplehood; and to provide social support and its benefits to the caregiver.

Other models exist that involve the carer and person with dementia, e.g. The Alzheimer Café Model (Miesen, 1997). As is often the case, models are adapted and

merged with others, when culturally adapting them to a specific context. The social club model was to focus almost exclusively on the person with dementia and the carer, and in particular the “couple”. It would have an entirely ‘social’ agenda with the support being provided in an informal way. The model would differ in relation to other ASI services in that the ‘service users’ would run the service. The staff would play a facilitator’s role in the group. It was to be flexible, informal and fun. The philosophy was to reflect the building of relationships and maintaining the ‘couple’. The social club would be fully voluntary in nature and provide peer support in a purely social environment.

Findings

The research findings highlight the significant benefits for the members who attend. The feedback from all the research participants indicates that the club benefits the members in a number of ways by meeting a series of needs. The list is substantial:

- Addressing social isolation
- Providing the space for worry-free socialising and outings
- Maintaining a social network and social skills
- Sharing of carer strategies
- Providing support to one another in an informal social setting.
- Recognition of the ‘couple’

Reflections and implications for practice and policy development

Central to the success of the clubs appears to be the staff resource and the informality of the clubs. In fact, the very naming of the meetings as ‘clubs’ as opposed to ‘care’ or ‘service’ reveals much about their underlying philosophy. Being a member of a club, has an entirely different connotation to being a user or client of a service. This itself places the social clubs in a unique position as part of the overall service matrix of an organisation.

The other element that is central to the unique philosophy of the clubs is the integral involvement of the spouse/carers as an equal member of the club, in addition to the person with dementia. Embracing the couple and their identity as central to the structure is unique to the philosophy of the social club. On further reflection, it also becomes apparent that it is the involvement of the carer that allows the club to function as an informal club, thus differing from formal service

models. The clubs and involvement of the carers means the feeling of responsibility for the person with dementia on the staff is shifted, allowing for the informality that is so welcomed by all who responded.

Current dementia practice models of home, day care, respite and long-term care, all serve to separate the couple for periods of time and shift the responsibility for caring in favour of the service provider for the periods of time the person with dementia is under their care. It is important for policy makers to consider if social clubs enable carers to care longer by supporting their responsibilities, as opposed to traditional models that encourage them to abdicate their responsibilities for short periods of time?

“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”

Questions need to be raised about which response works best from a policy and practice point of view, or do they have mutually exclusive benefits?

More questions need to be asked about whether the social clubs can address the need for the carer to have a ‘break’ but still be in the company of their loved one, just with shared responsibility for a period of time. Or as pointed out earlier, do all these models work in tandem, and benefit the person with dementia and the carer at different times and in different ways?

There are broader social policy implications too. The policy approach of providing services ‘to’ as opposed to in ‘conjunction with’ the person needs to be debated, particularly in the field of dementia care. Giving people affected by dementia a genuine voice in relation to what services they need and want should be reflected in the policy approach to service provision. In addition, social policy needs to re-examine the current models of provision as well as research and identify new models of care that can support the concept of couplehood.

Social Space: Equal Place The Social Model of Dementia Care, by Catherine Keogh and Grainne McGettrick, is a small scale study of ASI which will be published in January 2008. For further details on the social clubs or a copy of this report contact ASI on (01) 284 6616 or info@alzheimer.ie.

Branch News

New Office in North Tipperary

The Minister for Older People, Marie Hctor TD officially opened the Society's North Tipperary Branch's new office in O'Connor's Shopping Centre, Nenagh. At the opening the Minister commended all those who had worked hard to develop the new office, which will provide a drop-in and information service. Congratulations to everyone involved in expanding dementia supports in North Tipperary.

Cork Branch

Cork City Branch was delighted to accept a presentation from the Soroptimist International Cork of €28,000. A number of the members from both groups attended the presentation function.

Cork City Mini-Marathon Campaign goes from strength to strength with over 120 runners this year. Making this the biggest 'A' team yet, many thanks...

Waterford Branch



Waterford launched its "Life Story Book" and this substantial piece of work won a gold medal at the Irish Design Effectiveness Awards (IDEF). Congratulations to everyone involved with this book. The book is a practical and meaningful tool in providing formal and informal care to people with dementia and it can be purchased from Andrea Lloyd at 051 856 831. The cost of the book is €15.

Waterford Branch hosted a summer barbeque for clients and carers which was a great success.

Carol Service

Help us celebrate the festive season and join us in Christ Church Cathedral on Tuesday 11th December at 11.15pm for a Christmas Carol Recital. The Cathedral's Children's Choir will be getting us in the Christmas Spirit. The recital will be followed by a mulled wine and mince pie reception. All are welcome.

Opening of the Cairdeas Day Care Centre, Raheny

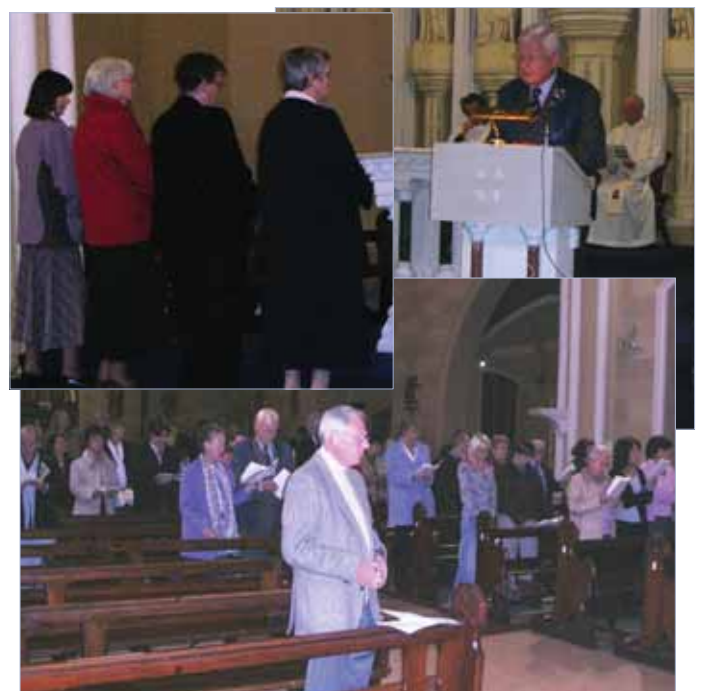
On November 7th, the North Dublin Branch were joined by Senator Ivor Callely, Chairman, Dr. Niall Tierney and founding member Winifred Bligh for the official opening of the Cairdeas Day Care Centre in St Joseph's Hospital, Raheny, Dublin 5.

The Society has been providing Day Care Services in Raheny for 16 years and recently moved from its premises in Sybil Hill. Approx 100 clients use the centre weekly and enjoy an extensive programme of activities. Best Wishes to all involved in Cairdeas.



Celebration of Life - in South Dublin

The Celebration of Life Service took place on Wednesday 24th October, in St John Baptist Church, Blackrock, Co. Dublin to remember those who are living with dementia and those who have passed away. After the service there was a reception in St Theresa's, Temple Road, Blackrock. Many thanks to everyone who participated in and organised the service, particularly co-celebrants Fr. Edward O'Callaghan and Rev. O'Dowd.



Fundraising News

25th Anniversary Gala Ball

The cream of Dublin's Business Community turned out to show their support for the Alzheimer Society of Ireland (ASI) at its inaugural Gala Ball on Friday 16th November. The beautiful surroundings of the recently renovated Shelbourne Hotel provided a fitting backdrop for the glitzy event. The night got underway with a drinks reception, followed by a sumptuous four-course meal, a lively auction and wrapped up to the tunes of 70's themed 'Boogie Nights' band. Almost €100k was raised at the ball and the proceeds will be used for our first 24 hour/ 7 day a week overnight respite centre currently under construction in Blackrock, Co. Dublin. Thank you to corporate sponsors, donors, volunteers, MC Nuala Carey, and Auctioneer Simon Ensor. Big thank you to Honorary Chairman, Liam Fitzgerald.



The 10K Burren Walk – Sunday January 6th 2008



Starting to think about New Year's Resolutions? Well why not kick start them by taking part in the Alzheimer Society of Ireland's 10K Burren Walk. The Clare Branch of the ASI will be hosting their sixth annual sponsored Burren Walk in Fanore next January. The walk will start and finish at O'Donoghues Pub where entertainment and refreshments will be provided. All are welcome and proceeds will go to local service. For more information on the event or to obtain a sponsorship card call Brendan Cusack on (065) 707 4164

Montage of Fundraising Pictures



Students of North Presentation Secondary School

Brendan Dowling who ran the Dublin City Marathon and raised €16K for the Carlow Branch



Mini Marathon (Ladies of Cork & North Cork Mini Marathon) (Nicola Keating & Andrea Graham)



Memory Walk



Nenagh Fundraising Evening

Snapshots from around the country

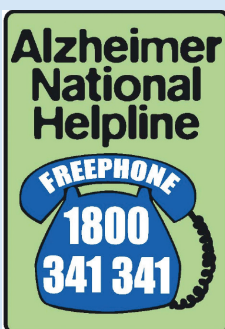
- **St Joseph's Secondary School**, Spanish Point, Co Clare, held a fashion show on the 12th September raising funds for the Clare Branch
- On Friday October 26th **Hunters Rest Fenagh**, hosted a Table Quiz in aid of our branch in Tullow
- The **Birches Day Care Centre** received a cheque from the Dundalk Raft Race Competition for €5,500
- In **Wexford** the **Active Retirement Group** held a coffee morning and raised an impressive €1,000
- On the 10th October, **City Square and the Munster Express** held a Fashion show in the Tower Hotel, Waterford in aid of the Waterford Branch.
- The **Gaultier Guild of the ICA** donated €2,000, the

proceeds of a Sale in the Fisherman's Hall to the Waterford Branch

- The **Alzheimer Society of Ireland** would like to thank all those who took part in the Dublin City Marathon and all those who supported them in this challenging event. We are sincerely grateful for all your support
- On Friday 31st Aug a fantastic fundraising night was held in the **Roundhill Bar, Carrigatoher, Nenagh**. The evening's entertainment was provided by an array of talented dancers, musicians and singers. All proceeds from the night went towards the conversion of Waterman's Lodge, Ballina, Killaloe.

Dates for your diary

| DATE | EVENT | VENUE |
|-------------|-------------------------|-------------------------|
| 11th Dec | Childrens Carol Recital | Christ Church Cathedral |
| 6th Jan | Burren Walk | Clare |
| 11th Feb | World Day Sick | Nationwide |
| 10-14th Mar | Brain Awareness Week | Nationwide |
| 1st May | Alzheimer Tea Day | Nationwide |
| 2nd June | Womens Mini Marathon | Dublin |



The Alzheimer National Helpline will close on Christmas Eve, Christmas Day and St Stephen's Day and re-open on Thursday, 27th December 2007.



IN MEMORIAM

| | |
|----------------------|---------------------|
| Ms Agnes Furlong | Mrs Frances Nardone |
| Mr John Bergin | Gerard Finn |
| Mrs Kathleen Philips | Margaret Flanagan |
| Mrs Pauline Kerr | Susan O'Neill |
| Mr William Hopper | Margaret Moroney |
| Mrs Patricia Austin | Kathleen Cullinan |
| Mr Fintan Purcell | Marie Dwyer |
| Ms Joan Greig | Mrs Mona Cusack |
| Ms Bea Feeney | |
| Ms Catherine Smyth | <i>Volunteer</i> |
| Mr Paddy Craughwell | Isabelle D'Ellenne |
| Mr Patrick Byrne | |
| Eva Kenny | <i>Care Worker</i> |
| Mrs Kitty Kavanagh | Bridie Brophy |
| Mr Tony Garbutt | |
| Maura Quinn | |
| Mr Joseph Doyle | |
| Mr Patrick Griffin | |
| Mrs Teresa Kilty | |

May they Rest in Peace

Media Appeal – Would you tell your story?

Raising the profile of Alzheimer's Disease and the work of the Society, eliminating stigmas, representing the views, needs and concerns of all affected by dementia, and campaigning for better statutory services (including specialist services for younger people with dementia) are key objectives of the Alzheimer Society, and therefore they are always at the core of our PR activities. The media and the general public are generous in terms of their interest in and support of the real impacts of Alzheimer's disease and dementia they need an insight into the lives of people who have been touched by these conditions either personally or through a loved one. We are regularly asked to source people with dementia or carers/family members, to participate in radio/print interviews or to make comment on a topical issue, and we are keen to enlarge the group of contacts we currently have on our files.

Would you be prepared to tell your story to the media?

If you are interested or if you have any queries/questions on what would be involved please phone Sarah O'Callaghan at (01) 284 6616/086 809 1772 or email socallaghan@alzheimer.ie

Charity You're A Star Update

“And the results from the judges that really matter are in.”

The final figure for the amount of money raised for the Society is.... **€41,178.57**

This is a fantastic achievement and would not have been possible without the hard work of so many people. Many Thanks to everyone involved, from banner makers and supporters in the helix to the people who voted, and of course, the wonderful Nuala Carey, whose courage and vocals did us proud.



oASIs was edited by Sarah O'Callaghan, Alzheimer Society of Ireland

Address: Alzheimer House, 43 Northumberland Avenue, Dun Laoghaire, Co. Dublin. **Phone:** 01-284 6616 **Fax:** 01-284 6030
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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.