



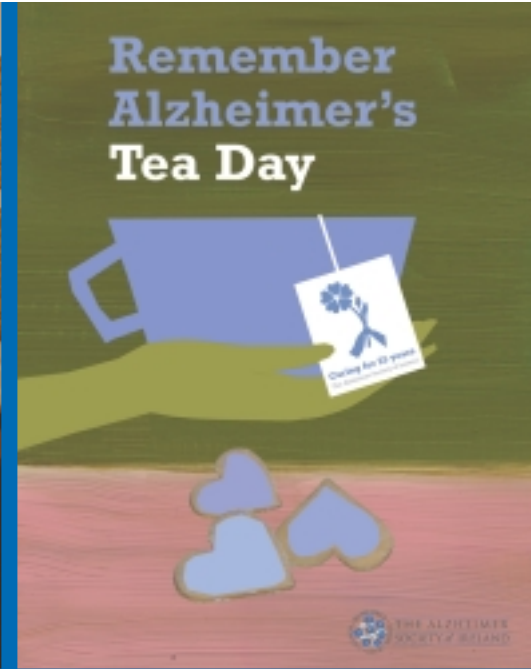
THE ALZHEIMER  
SOCIETY of IRELAND

# OASIs

Quarterly Newsletter of the Alzheimer Society of Ireland

Volume 25 Issue 1

Spring 2007



**Dementia Manifesto  
Launched**

**The Society's 25 Years of  
Caring**

**Vote for Dementia Rights**



**Caring for 25 years**  
The Alzheimer Society of Ireland



## Message from the Chief Executive



With the arrival of the Alzheimer Society of Ireland's 25th Anniversary, the work begun by Winifred Bligh and Imelda Gillespie in 1982 is to be celebrated. Their mission of maximising quality of life for those living with dementia and their families is being continued with the help of 300 volunteers, 3,000 members and 750 staff.

To mark this momentous year, many events will be taking place including our Tea Day on 3rd May, a Service of Remembrance and Life, an art exhibition, a carol concert in Christ Church Cathedral and an Anniversary Gala Ball. Please let us know if you are doing anything to mark the 25th Anniversary in your region so we can tell people about it. A funding appeal is also being undertaken this year for three important capital projects: the completion of the National Day and Respite Centre in Blackrock, Co. Dublin, Nolan House Day Centre in Rathdrum, Co Wicklow and Waterman's Lodge, Killaloe, Co. Tipperary which will be a Respite Centre for both clients and carers.

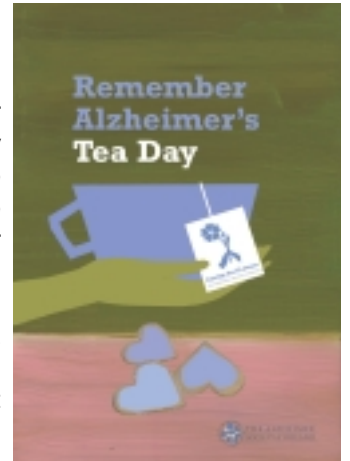
The Society looks forward to your continued support this year to bring about a world where dementia can be prevented and cured, where stigma is a thing of the past and where those who live with dementia have all they need to live happy and fulfilling lives.

*Maurice O'Connell*

## Tea Day

### Let us lift our cups to celebrate *Happy AnniveraTEA!*

You are once again invited to join with thousands of people across Ireland to host a Tea Party on Thursday 3rd May, on behalf of those affected by Alzheimer's disease and other dementias. This year marks the 25th Anniversary of the Society's founding and what better way to celebrate than by extending hospitality to friends, family or colleagues to raise funds for our services. Our goal this year is to have 2,500 registered hosts and to raise over €560,000. This money will go directly to running our services, 30% of which must be raised annually through voluntary contributions. Please remember that the funds you collect will be directed towards services in your local community and allocated to the branch office closest to you.



To register for a tea day party, just call 1800 719 820. Your very own tea day party pack will be sent out to you within 10 working days. It will include a poster, raffle tickets (books of 10), invitations, a collection box and a bank giro. Be sure to register by the 23rd April to guarantee the arrival of your tea day party pack in time for Tea Day on Thursday 3rd May.



*Ruth Matz, Maurice O'Connell and Tadhg Daly of the Irish Nursing Homes Organisation sharing a cup of tea – the INHO are supporting The Society's Tea Day Campaign this year and are asking all their members to hold a special tea party on 3rd May.*

### Charity in the Brain, not Heart

Charity begins... in the posterior superior temporal sulcus, according to scientists who have traced the origins of kindness in the brain. A study found that this part of the brain is more active in people who often engage in helping behaviour. The region, which lies in the tip and back of the brain, is linked to sorting out social relationships. US scientists scanned the brains of 45 volunteers using a technique that can watch the brain working. Participants either played a computer game or watched a computer play the game on its own. In either case, winning the game earned money for a chosen charity. Volunteers were also questioned about how often they put others before themselves. The brain scans revealed that the most charitable showed the most activity in the posterior superior temporal sulcus when the computer game was being played. The scientists think altruistic behaviour originates from the way people view the world, rather than how they act in it: perceiving others actions as meaningful is critical to altruism.

# Dementia Manifesto 2007 - 2009

In February The Alzheimer Society of Ireland launched its three year strategy outlining how the State should look after the 38,000 people who currently have a dementia in Ireland. The three year strategy addresses the service and policy issues raised by carers and people with dementia in the Dementia Manifesto 2007-2009.

Attending the launch in the Mansion House were numerous public representatives including the Labour Party health spokesperson, Liz McManus TD, Sinn Fein health spokesperson Caoimhghin O' Caolain TD, Fine Gael Health spokesperson Liam Twomey TD, Michael Woods TD, Joe Higgins TD, Barry Andrews TD, Sean Ardagh TD, Jan O'Sullivan TD, Beverley Flynn TD, Cecilia Keaveney TD, and Senators Michael Brennan, Geraldine Feeney and Tom Morrissey. Various representatives of the HSE and health professions were also there to listen to carer Mrs Elizabeth Moore, Board Member Jim Nugent and CEO Maurice O'Connell urge everyone to bring the Dementia Manifesto to the attention of our local general election candidates when they call to our doors.

Cautioning that 'the time for action is now' the Dementia Manifesto is the result of a year long process of grassroots led consultation supported by well developed evidence-based economic and social policy positions. The ultimate conclusion is that dementia must be recognised by government and policy makers as a national health priority.

Detailing the funding required, Maurice O'Connell, Chief Executive of The Society says: "We are looking for increased funding in three key areas over the next three years: €63 million for enhanced and flexible community based services; €12 million for early diagnosis, intervention, awareness and education; and €30 million for social and medical research. This correlates to the equivalent of a grant of €875 per year for each person with the condition in order to improve their quality of life and that of their carer and family."



Margaret Downes explores the 25 years of caring provided by the Alzheimer Society of Ireland and talks to one of its founding members, Winifred Bligh.

*"The provision of a properly funded, properly staffed and properly deployed dementia service is, in my view, one of the few measures of a truly civilised society."* These potent words were spoken by Dr. Anthony Clare in 1989, whilst addressing a packed public information evening about a less than glamorous medical condition, Alzheimer's disease.

Dr. Clare's view was shared by one important member of his audience that night, that of Winifred Bligh. A passionate and determined woman, Bligh had founded the Alzheimer Society of Ireland along with Imelda Gillespie in 1982 after they had a sister and a husband respectively diagnosed with early onset Alzheimer's disease.

Feelings of isolation and abandonment were common in families who found they were unable to access even the most basic of information about Alzheimer's disease. Doctors were unable to tell them what caused the disease and whilst they were told there was no cure, they were not told how best to look after their family members. These two extraordinary women found out the hard way that information, support and facilities for families with a diagnosis of dementia were non-existent and set about changing the dementia care landscape in Ireland for ever.

In a hall provided by the St. John of God's hospital in Stillorgan, Co Dublin, and with the vital support of the ever popular Gay Byrne radio show, Bligh and Gillespie established their "self help" Alzheimer Society at a packed meeting in December 1982. They had no money and no premises and Bligh already had a full time job in the publishing industry but over the next 25 years they would go on to garner significant political and media support for their cause and win over the medical profession in their efforts to encourage all forms of research into the causes and alleviation of the disease. Gillespie was later to retire from The Society in 1985 when she emigrated to Canada.

The early aim of the Society was to inform, educate and assist anyone who was interested in, or sympathetic to, the problems associated with Alzheimer's disease. Back in 1982, before the realisation that more rigorous medical research into Alzheimer Disease was needed, most people, including those in the medical profession, believed there was little that could actually be done for those with the condition.

So Bligh and Gillespie initially focused on the carers of those with Alzheimer's disease by offering information, understanding and a sense of solidarity to those who found themselves in a situation similar to themselves. The two women concentrated their efforts and resources into making life slightly less traumatic for the carers.

From the initial contacts made with The Society, from families as far as Donegal to Cork who wanted advice on how best to look after their mothers, fathers or spouses, Bligh quickly recognised the need for community back-up - the need to reach out to families where the impact of the disease was enormous.

In her efforts to provide

this much needed support and information, Bligh had contacted other countries in order to establish what sort of facilities, information, day care services, respite and longer-term care were available in their communities. She received significant information from the US where services for both families and those with the condition appeared to be the most advanced.

One particular issue Bligh tackled head on from the start was that of establishing the numbers of people in Ireland who had Alzheimer's disease. Official statistics about the condition were completely inadequate and unreliable. Bligh knew that without the backup of adequate statistics, any efforts to establish adequate services and support systems were doomed to failure.

In 1982, the only statistics available from the Medical Medico-Social Research Board indicated there were only 480 primary and secondary cases of Alzheimer's disease but they admitted that they really "weren't sure" and referred Bligh to an article in the British Medical Journal. In a parliamentary question tabled by Barry Desmond TD in 1983, these figures had been revised upwards to 850 cases. With constant lobbying, Bligh managed to convince those in charge of compiling the statistics that those with a dementia should be taken account of. Today, the statistics indicate there are 38,000 people with dementia in Ireland and this figure is expected to reach 103,998 by 2036.

Early on in the life of The Society, Bligh had realised the need to educate society in general with education programmes about Alzheimer's disease – not just those immediately affected by the condition. Central to achieving this objective were public information meetings which proved to be hugely popular and extremely useful. They were held all around the country and were the inspiration for the establishment of many of the branch networks that were subsequently formed. The meetings also facilitated The Society to attract supporters who would be in a position to financially contribute to its work. Early supporters and contributors included the Masonic Order who held their Festival of Charity for The Society with the support of Eric Waller who went on to become the Grand Master of the Order, the Knights of Columbanus, Kelloggs and Ladbrokes.

The Society's relationship with the medical profession was vital to the ongoing success of its work and a medical doctor attended every one of the public information meetings. While the doctors were there to inform the public about the condition, they also found the experience invaluable in learning first



Pictured at The Society's first Annual Conference were Michael Coote and Winifred Bligh



A 1988 public information evening attended by Jonathan Miller, Dr. Des O'Neill, Eithne Grealy, Fr. Damien, Dr. Donald Caird, Winifred Bligh.

# volutionize Dementia Care

hand about the problems experienced by families caring for those with a dementia. This was to prove an excellent resource for those educating the new generation of doctors about Alzheimer's.

Because one of the most important roles of The Society was to give families a break, Bligh quickly realised that in order to this The Society needed to find a place where those with the condition could be looked after during the day. The first Alzheimer Day Care Centre was opened in Sandymount in premises donated by the Red Cross Society and was managed by two retired nurses.

The huge demand for places in the Sandymount centre made it abundantly clear that there was a need for much bigger premises. Convinced by Bligh and her credentials in the caring profession, The Daughters of Charity in Blackrock decided to donate part of their facilities to the Society for the creation of new day care centre. The Superior of the Order then offered to help manage the centre with the help of volunteers from The Society.

A natural progression of the day care services run by The Society was the opening of their Respite services. The apparent need for carers to have a few full days respite became apparent and the Blackrock centre opened an eight bed respite unit in its premises. Bligh took up the post of National Co-Coordinator of Caring Services with the Society in 1992 to manage this and today The Society is developing new respite facilities in Waterman's Lodge in Killaloe and an assisted living project in Sligo.

By 1989 The Society had moved into permanent offices provided by the St. John of Gods Hospital and huge support for its work was given by Eithne Grealy, a nursing sister at the hospital who facilitated the support group there. It subsequently moved to Dun Laoghaire and today there are 31 Day Care Centres, 20 Home Care/Support Services, 28 Carer Support Groups, Social Clubs and the overnight Respite Centre. In 2005, the same Daughters of Charity in Blackrock donated some of their land to The Society for the building of a new National Centre of Excellence for Dementia Care in Ireland – it will be the new headquarters for The Society and will offer 24 hour/seven days a week respite care to those with a dementia. A whole new generation of dementia patients will continue to benefit from Bligh's determination and perseverance in the decades to come.

While The Society primarily addressed itself with providing information and support for families and help for those with the condition in the form of day care centres, Bligh always saw the issue of Alzheimer's disease and dementia as a being a "political problem". While the "consoling" function of The Society was the primary reason for its establishment, Bligh quickly realised it also had a political function.

She was determined to make the health authorities and policy makers aware of Alzheimer's disease and its prevalence in the country and she wanted to make them formulate a coherent plan for dealing with it. A programme manager with the then Eastern Health Board, Michael Walsh, was hugely supportive of her efforts while early political supporters included Vincent Brady, Michael Woods, Rory O'Hanlon, Niall Andrews and Barry Desmond. Local and

national political representatives were nearly always in attendance at The Society's public information evenings.

Bligh was urged on in this pursuit by Jonathan Miller, the then President of the UK Alzheimer Society, who urged Bligh and her fellow members of the Alzheimer Society of Ireland to become a political pressure group. Miller did not mince his words in his efforts to convince Bligh that the politicisation of the Society was the way to go and caring for those with a dementia was really a function of the State.

As far back as 1988, Miller envisaged that caring properly for those with Alzheimer's was "too complicated to be dealt with on a voluntary and private basis only. It is a scandal that the burden of looking after someone with Alzheimer's disease should be borne exclusively by the sufferers and the carers and (that) it was necessary for society to provide facilities to relieve the pain and turmoil of the carers and the sufferers. It is a duty of the State to provide care for those who need it," he stated.

But Miller was speaking to an audience all too aware of its need to convince the Government to take its

responsibilities for dementia care seriously. From its very first days, The Society always tried to exert pressure upon the community at large and their public representatives, especially the Government of the day, to take responsibility for those who have a diagnosis of dementia and their carers. While the vitally important work of organising fundraising activities and information meetings was necessary from the very beginnings of The Society and remains to this day a vital part of its work - not only for the money, but for the social cohesion it gives a group of people who are sharing similar

worries and difficulties in caring for someone with a dementia – The Society had always exercised the dual function of being a pressure group.

This remains the case today and Bligh's work over the past 25 years is evident in the publication of the Society's Dementia Manifesto, launched in February 2007. To formulate this Manifesto, The Society embarked on a comprehensive process of gathering information to identify the priority issues for people with dementia and their carers.

In the Manifesto, The Society is calling on the Government to recognise and designate dementia as a national health priority. The Society wants the Government to support enhanced and flexible community based services, support early diagnosis, intervention, awareness and education and advance medical and social research. The Manifesto will cost the Government €105 million to implement over the next three years but by working together with The Alzheimer Society of Ireland it can achieve the vision that Bligh and Gillespie had when they embarked on their important journey in 1982 - to achieve a world where stigma of the person with dementia and their carers is challenged and overcome and where those who live with dementia and their carers have all they need to live happy and fulfilling lives.

*Margaret Downes is the Press Officer of the Alzheimer Society of Ireland.*



*Launching the 1992 Alzheimer Awareness Week outside the Dail were Des O'Malley, John Bruton, Michael Coote, Albert Reynolds and Dick Spring*

# Branch News

## North Cork / South Tipperary Branch



From left to right: Mary McDonagh (home care worker Clonmel), Catherine and Billy Crotty (organisers), Eileen Graham (home care co-ordinator, Clonmel) May Moriarty (Treasurer Mitchelstown Branch), Mary Dunleavy (Chairperson Mitchelstown Branch), Mairead and Aidrian Roche (Organisers).

## Biking Across the Borders

A unique fundraising event took place recently on the border of two adjoining counties. A motorbike run and social night was held in Skeheenarinky, Tipperary. The proceeds of the event was divided between North Cork and South Tipperary. North Cork Mitchelstown's share of the funds will be used at the Day Care Centre and other services while South Tipperary Clonmel's share will be used to deliver even better home care services. Eileen Graham and Mary Dunleavy thanked the organisers, Adrian and Mairead Roche and Billy and Catherine Crotty, and assured them that the money was much needed and would help those living with a dementia and their families/carers.

## Waterford Branch

### *Remembering the Old Songs*

The Original Wren Boys of Ann Ryan, Sharon Boland and Breeda Dunne raised €1,900 for the West Waterford branch of the Alzheimer's Society during a wonderful travelling performance of their songs and music on St. Stephen's Day. The trio would like to thank their driver Patie Boland and we would like to thank all four for their creative fundraising efforts.



The Original Wren Boys Ann Ryan, Sharon Boland and Breeda Dunne with their driver Pattie Boland.

## South Dublin Branch

### *Brrr.....aving the Elements*

Sincere thanks to Emma Lester and Aimee Finn of Dun Laoghaire, Co Dublin, who gave up their Christmas Day morning in order to take part in a sponsored swim in the Forty Foot in aid of the Alzheimer Society of Ireland. In what is becoming an annual event, Emma and Aimee braved the elements to raise money and awareness for the society. Many thanks to both girls. It is great to know that our supporters are willing to give up even Christmas to help us.

## Clare Branch



John Sharry from Doolin and Kathleen Gibbons from Lisdoonvarna speaking to Bridget Hoey of the Clare Branch of the Society, while on the right the enthusiastic walkers put their best foot forward.

### *Fearless Walkers Beat the Burren*

Some 400 walking enthusiasts from all over Clare descended on Fanore in early January for the fifth annual Burren Walk in aid of the Alzheimer Society of Ireland. The weather proved inclement but this didn't put off the walkers who managed to complete the 10 km walk in record time. The walk is the main fundraising event of the Clare Branch and provides valuable funding towards improving and extending day care, home care and respite services in the county. O'Donoghue's in Fanore provided great food and entertainment for the walkers after the event and a big thank you to all the walkers and the organisers, especially Gerry Howard, Brendan Cusack, Liz White, Kay Flynn, and Marissa Butler McCarthy.



# Fundraising News

## Seascapes Colour a Great Exhibition



Dorset College in Dublin were the hosts to a wonderful Art Exhibition entitled, "Colours from Across the Sea". The work was provided by two very talented artists Raymond Moen from Australia and Alice Bennett from Zimbabwe.

Entry to the exhibition was by way of a donation to the Alzheimer's Society and over €500 was raised from the event. Sincere thanks to both Raymond and Alice and to the directors and staff of Dorset College for providing the venue. A huge thank you also goes to Christine O'Donnell whose hard work and passion for the event made sure that it was a fantastic success.

*Artists Alice Bennett and Raymond Moen at the exhibition*

## Flora Women's Mini Marathon 2007

This year the Mini Marathon is also celebrating its 25th Birthday. We are making a special appeal to all ladies to register to run (or walk) the Mini Marathon on behalf of the Society. Registration forms are available in the Evening Herald every Thursday and Saturday, from March 1st and online on [www.florawomensminimarathon.ie](http://www.florawomensminimarathon.ie) You need to register in order to take part on the day so make sure and get in early!!! Once registered, you can call the Dun Laoghaire Office on 01 2846616 and we will send you out your sponsorship pack.

## Whirly Buns go down a treat in Sligo

One of the Society's biggest supporters in Sligo, Sadie Davey, held a 12 hour marathon coffee day in her home to raise funds for the Sligo Branch. The early arrival of parish priest Monsignor Spellman got the day off to great start with jokes and reminiscences and treats such as rhubarb and apple tarts, homemade biscuits, scones, sandwiches and lashings of fresh tea and coffee meant there was a steady stream of visitors throughout the day. €2,000 was raised so well done Sadie, let us know the recipe for those whirly buns!

## You're a Winner

Elizabeth Blackmore, a first year student from De La Salle, Raheny, presents Ruth Matz with a cheque for the money raised by a Christmas raffle run by the 1st and 2nd Year pupils of De La Salle.



Many thanks to all the pupils and their teachers for their great initiative and for donating the proceeds to the Society.

## Happy 80th Birthday Tommy!



Tommy O'Brien celebrated his 80th Birthday recently and decided to mark the day by remembering the Alzheimer Society of Ireland. Instead of getting lots of presents for his birthday, he asked the guests at his party to make a donation to the Society. Tommy's wife, Molly, attended the Curlew Road Day Centre where she loved doing arts and crafts. Unfortunately Molly passed away in 2001 but Tommy never forgot the care and kindness shown to Molly by all the staff in Drimnagh so he came up with this fantastic fundraising idea. All his guests gave very generously and Tommy was able to present a cheque for €1,635 to Rita Buggy and Ann Curtis of the Curlew Road Day Centre in Drimnagh. Many thanks to Tommy and all his guests for their wonderful generosity – Many Happy Returns Tommy!

## King Crowned

Shane McKenna, organiser of the King of Greystones Triathlon was joined on Greystones beach recently by winner Liam Dunne, who is the current Irish University Triathlon Champion and model Jill Diffley to present a cheque for €70,000 to Margaret Downes of the Alzheimer Society of Ireland. Sponsored by Menupages.ie, the King of Greystones Triathlon is one of the most successful triathlon events in Ireland and attracted over 300 participants last year. This year's Greystones Triathlon Challenge will take place on Saturday 11 August and anyone interested in participating should log onto the website [www.kingofgreystones.com](http://www.kingofgreystones.com).



## Tribute to Mr Joe Rowe, RIP

Those members of the Alzheimer Society who knew Joe Rowe will be very sad to hear he passed away. Anyone who ever met Joe will never forget him. Joe, whose wife had Alzheimer's disease, worked with the Alzheimer Society in a voluntary and administrative capacity for 17 years. He was co-opted onto the Committee in 1985 and in 1986 he accepted the post of part-time administrator. Every afternoon Joe was found managing the office's administration, informal helpline and providing counselling and support to many carers and families dealing with dementia. Joe compiled The Society's first Nursing Home list which was an invaluable tool to those needing longer term care for their loved ones. Joe's advice was invaluable and he gave his support to many people in need of his kindness and understanding of the complex health and social welfare systems and he invited people to contact him at any time by giving his home telephone number. After time spent serving on the Board of the Society, Joe retired from the organisation in 2001 and was greatly missed. People will describe Joe as kind, understanding, modest, non-judgemental, approachable, and sometimes even mischievous. But above all Joe was always a "true gentleman". We would like to take this opportunity on behalf of all in the Society to extend our sincere sympathy to Joe's family.



Thanks to Dymphna Bonfield Blake who sent us a poem she wrote about her friend Alice who lived with Alzheimer's Disease for many years.

### Alice

*Oblivious of my presence, despairingly fidgeting  
Completely consumed by a meaningless task  
Folding, unfolding a piece of her clothing  
I try to envisage behind this blank mask*

*Confused flow of emotion, face constantly changing  
The light in those eyes, daily losing its spark  
A landscape of feelings, interchanging unceasingly  
Unaware of her brilliance being pushed in the dark*

*Fragment by fragment, she is robbed of life's clarity  
She panics, realising she is losing control.  
A painstaking search for a means of expression,  
She finds the right sentence, sending shock to the soul.*

*Her childlike cajoling and affectionate charming  
Reckless babble of multicoloured words flowing forth.  
Then sudden confusion bewildered and pleading  
I'm accused and refused: Is she testing my worth?*

*A once brilliant character, an artist and socialite  
Deprived late in years for slowing of mind  
Of family, friends, knowledge and dignity  
Abandoned for ignorance of ills of this kind.*

*Always a lady, she had high moral values,  
Real beauty, with family and many careers  
Intriguing, refreshing, rich traits interwoven  
This exquisite tapestry frays slowly with years.*



## IN MEMORIAM

Ms. Nan Kilbride  
Ms. Peggy Callan  
Ms. Mary McGauley  
Mr. Andy Leonard  
Mr. Noel Traynor  
Ms. Mary Hehir  
Mr. Martin Power  
Ms Elizabeth Lenihan  
Ms. Della Moroney  
Ms. Biddy Ryan  
Ms. Maisie Malone  
Ms. Mary Nevin  
Mr. Thomas O'Brien  
Mr. Patrick F. Collins  
Mr. Sean Cunningham  
Ms. Ann Devally

Mr. John (Jack) Eastoff  
Mr. Osmond Ghaleb  
Mr Josephine Lahiff  
Mrs. Betty Love  
Mrs. Patrica Malone  
Mr. Stephen McGrane  
Mr. Gerry Murphy  
Mr. Ben Naughton  
Mr. Liam O'Connor  
Mr and Mrs. Michael and  
Lo-Lo O'Donnell  
Mr. Jim O'Rourke  
Dr. Aengus and  
Mrs Esme O'Rourke  
Ms. Constance Phelan  
Ms. Margaret Smith

Mr. Michael Sullivan  
Ms. Elizabeth Faulkner  
Mr. O'Donovan  
Mr. Michael Hallinan  
Mrs. Joan White-Spunner  
Mr. John James Walsh  
Mr and Mrs. Roger and  
Nora McNamee  
Mrs. Doris Wojmar-Murdoch  
Ms. Florence Casey  
Mrs. Kathleen Coughlan  
Ms. Marion Mayne  
Mrs. Dunne  
Ms. Elsie Taylor  
Rev Dr. Hedley Plunkett  
Mr. Michael Murphy

Mr. Michael J Tierney  
Mr George Leahy  
Mr. Michael McCabe  
Mrs. Bridget Herbert  
Mrs. Maeve Clarke  
Mr. Noel (JN) Traynor  
Mrs. Frances Kelly  
Mrs. Ita Sloan  
Mrs. Mary Mara  
Mrs. Annie Clancy  
Mrs. Pat Kelly  
Mr. Peter Proudfoot  
Ms. Christina Ray

## May they Rest in Peace

oASIs was edited by Margaret Downes, 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.