



THE ALZHEIMER
SOCIETY *of* IRELAND

National Conference

1982 – 2017

A Brief Overview of the Founding and 35-Year History of The Alzheimer Society of Ireland (ASI)

Winifred Bligh and Imelda Gillespie met in January 1982, as they had a sister and husband respectively diagnosed with forms of dementia. As carers they found that not only were they unable to access even the most basic information about Alzheimer's disease or dementia but that information, support, and facilities for families were non-existent. From this first meeting they founded The Alzheimer Society of Ireland (ASI) and set about changing the landscape of dementia care in Ireland forever.

1982 – 1986 Founding the organisation – Responding to gaps and needs

- **1982:** July: First public meeting held in Blooms Hotel, Dublin where the Alzheimer's Disease & Related Disorders Society was formed (shortened to Alzheimer Society of Ireland in June 1983)
- December: A packed first public meeting was held in St. John of God's and ASI was formally launched and a committee set up. In response to gaps the early aim of the Society was to inform, educate and assist those living with Alzheimer's disease and other dementias.
- **1983:** The ASI was publicly launched at a press reception held in the Burlington Hotel; the meeting was addressed by Professor Gordon Wilcock, Radcliffe Infirmary Oxford, who was a renowned researcher into Alzheimer's disease. Dr. Michael Woods TD attended. Following the meeting the committee was expanded to include Mary Higgins and Michael Coote, Vincent Brady, Helen Smith, and Michael Duffy.
- **August 1984:** The ASI was incorporated as a limited company and committee members appointed as directors on the executive committee.
- **January 1985:** The first public meeting outside Dublin was held in the Imperial Hotel in Cork and a committee set up by Mary Dunleavy and others.
- **By October 1985:** The ASI committee established sub-committees including: Support Groups, Publicity, Fundraising, Membership, Social Services, Library and New Branches sub-committees to undertake the increasing tasks.
- **By 1986** support groups continued and further public meetings were held. In September 1986 Winifred Bligh addressed the Alzheimer's disease International (ADI) conference in Paris. Winifred and Michael Coote were appointed to represent Ireland on the ADI Executive Council. This proved to be key to the decision by ADI to hold its 5th international conference in Ireland in Trinity College Dublin in 1989, an event this is credited by the founding committee with putting The ASI firmly on the map.

1987 – 1991 Putting the fledgling organisation on the map

- **1987:** The first Day Care service opened in Sandymount. A second Day Care was opened when the Daughters of Charity provided St. Teresa's Blackrock; this later expanded to a four-bed unit for overnight respite. The first bus was obtained with a grant from the Kellogg's foundation.
- Nuala Dunphy was appointed as the first employee of ASI in the role of part time Office Secretary.
- Support groups and local committees expanded, the first newsletter was published and the first Carer's Handbook, produced by Chris Ryan, Nurse Tutor at St. John of God's was launched.
- **1988:** In February the fifth annual meeting in St. John of God's was addressed by Dr Jonathan Miller (President of Alzheimer Society UK). He also appeared on the Late Late Show, helping to further raise awareness of dementia and the ASI.

- Ronan Smith (Now Chair of the Irish Dementia Working Group) joined the committee and Joe Rowe became voluntary counsellor, providing information and support through the phone and by post from the office in St. John of God's.
- **1989:** The ASI hosted the high-profile ADI International conference in Trinity College Dublin. Attended by 250 delegates from 22 countries, the conference was opened by the president of ADI Princess Yasmin Aga Khan and the Minister for Health, Dr Rory O' Hanlon. Receptions for delegates were hosted by the Lord Mayor of Dublin and the Minister for Health and the edited proceedings, compiled by Dr. Des O Neill, were published in 1991. This year also saw the inaugural meeting of the Limerick Branch organised by Lillian Sullivan and Gildas Gordon.
- **1990:** The idea for Alzheimer Europe was generated at a meeting of ASI's Michael Coote, Franz Baro (Belgium) and Henkter Haar (Netherlands). Alzheimer Europe was formally founded in 1991 with nine members including Ireland, represented by the ASI.
- 1990 also saw the first CEO, Norman Stuart appointed and Nuala Dunphy made fulltime secretary based in an office in St. John of God Hospital, Stillorgan, Co Dublin.
- By the beginning of the 1990s, the strong Branch network that exists today was well on its way. Following public meetings Branches were formed in Limerick, Cavan and Drogheda. The Limerick Branch formally opened an ASI office in Limerick. New services opened including Waterford Day Care service and Sybil Hill Day Care in Raheny. An information pack for GPs was launched by Dr. Rory O'Hanlon, Minister for Health. In 1991 Winifred Bligh was appointed ASI National Coordinator of Respite Care.

1992 – 2000 Development and Expansion

1990s: The organisation developed further with the Branch network expanding to include Donegal and others. The ASI Branches worked unstintingly to raise funds, lobby local politicians and the health boards, providing support groups as well as developing services in their areas.

The Limerick Branch opened Garryowen Day Care Centre and the Monaghan Branch opened Drumkill Day Care Service. Between 1996 and 2000 more Branches were set up including in Kildare and Waterford. Services opened included Mallow, Carlow, and the Dundalk Project launched. Dunally Day Care, Sligo was opened by President Mary Robinson, Merlin Park Galway opened by the Mayor of Galway and Tralee Day Care was opened by the Tánaiste Dick Spring. President Mary McAleese opened Curlew Road Day Care Centre. Both President Robinson and President McAleese were patrons of ASI. Fundraising continued including through the by now annual ASI Tea Day.

In 1999 Maurice O'Connell was appointed CEO following the retirement of Norman Stuart. A grant of £1 million was obtained from the Department of Health to assist the funding of ASI services in 2000. Information products included a new video produced to replace 'Caring without Limits' and political engagement began. By the end of the 1999 ASI had launched a website.

2000 – 2010 Development and Information

- **2000:** The National Freephone Helpline service was launched.
- **2000 -2005:** The organisation continued to develop through the Branch network and at national level. Services developed included Cavan Day Care (2003) and Bessboro Day Care Centre was opened by the Cork Branch in 2006 and officially opened in May 2008 by President Mary McAleese.
- **2005:** The ASI hosted the Alzheimer Europe annual conference in Killarney in June. Campaigns included an awareness campaign, using TV and radio advertising and information products; the campaign highlighted the early signs of Alzheimer's disease. In September the ASI report 'Early Onset Dementia – A Needs Analysis of Younger People with Dementia in Ireland' was launched by Tánaiste and Minister for Health, Mary Harney T.D.
- The Daughters of Charity donated land in Blackrock for building of The Orchard and National Office. A national advocacy manager was appointed to develop a new type of approach that supported the voice of the person living with dementia and their carer.
- **2006:** ASI held the First National Dementia Summit, which brought people with dementia and family carers together to agree priority issues. The ASI commissioned a policy paper on the economic perspective of dementia.

- **2007:** ASI launched the 'Dementia Manifesto: The Time for Action Is Now'. Calling on the Government to support enhanced and flexible community based dementia services, support early diagnosis, intervention, awareness and education, to advance medical and social research and to designate Dementia a National health priority.
- **2007:** The process of applying for funding from Atlantic Philanthropies began.
- **2008:** Developing its policy and research function, the ASI contributed to the Irish Hospice Foundation's 'Palliative Care for All' report, which included an appendix specifically on the issue of dementia and palliative care.

2011 – 2017 Development and Advocacy

- **2011:** ASI held the Second National Summit at the Dáil. Participants included Sean Donal O'Shea, then caring for his mother, Debby – who passed away in 2016 - and Joe English who had been diagnosed with dementia in 2004. Joe and his wife April participated in the ASI Dáil Summit in Spring 2011 and in association with ASI made the video 'Living with Alzheimer's' to highlight the disease. Joe passed away on November 4th, 2014, RIP.
- **2012:** Supported by the ASI, Dermod Slevin, a person with dementia, represented Ireland at the first meeting of the European Working Group of People with Dementia, which met in Glasgow in April 2012. In 2012 at the ASI 30 year conference Dermod was the first Irish person with dementia to address an ASI conference.
- **2013:** The development of 'voice' via the Irish Dementia Working Group and the Dementia Carers Campaign Network (DCCN) took place. Both groups became involved in key ASI advocacy activities including conference presentations, political and awareness campaigns, research participation and many high profile TV and radio appearances including on The Late Late Show.
- **2014:** The ASI's pioneering national awareness campaign 'Forget the Stigma' took place featuring people with dementia and carers in an outdoor advertising and radio campaign. In December, Ireland's first National Dementia Strategy was launched.
- **2015:** ASI started a corporate sponsorship programme for the first time and secured partnerships with Allianz, BMW, Certus and PWC.
- **2016:** The All Party Oireachtas Group on Dementia was launched with ASI as secretariat. Helen Rochford Brennan, former Chair of the Irish Dementia Working Group was elected Chair of the European Working Group of People with Dementia run by Alzheimer Europe. The new Mobile Information Service bus hit the road and the HSE's 'Understand Together' dementia campaign launched with ASI as partner. ASI's first AlzTalks event, celebrating diversity and capacity, took place.
- By **2017:** The De-Stress report on carer stress was launched with TCD as the ASI continued to inform policy change through new research and submissions; traditional and digital media had increased threefold in a few years and one of the ASI's campaign videos went viral. Over 50 TDs, Senators and Oireachtas staff attended ASI dementia awareness sessions.
- Throughout all this time the ASI Branches and services continued to work to support and develop local services. Waterman's Lodge Respite centre was developed by the Limerick Branch using dementia design principles. Officially opened by President Michael D Higgins in 2012 it won a Specialist Centre of the Year Award at the prestigious Irish Health Care Awards in 2015. Dementia friendly initiatives were developed and supported at national and local level from 2013 through to 2016.

Increase in ASI Services and Service Delivery: From the beginning in 1982 ASI endeavoured to provide much needed dementia specific services. By the end of 2016 the range of Dementia Specific services provided by ASI nationally included 50 Day Care and 30 Home Care Services and Respite Services, 8 Dementia Advisers, the National Helpline and Information Service and Information Bus, 36 Support Groups, 22 Social Clubs and 28 Family Carer Training Programmes. By the end of 2016 ASI had delivered 877,320 hours through Day Care, Home Care and Respite services. The Dementia Advisers had taken on 1,710 new clients and the National Helpline was contacted by 5,000 people.

2017– Celebrating 35 Years of the Alzheimer Society of Ireland

Over the past 35 years there has been an enormous amount of work done by a vast number of committed volunteers and staff, too numerous to mention in this brief overview. ASI have led the way to raise awareness of dementia, challenge stigma, lobby for political change, including recognition of dementia and the service needs of those living with the condition and their carer's. Since 1982 the Society developed and expanded and now includes the Voluntary Board and 19 Voluntary Branches located all around Ireland. There are over 400 volunteers and almost 900 Staff.

ASI is the leading specialist provider of dementia specific services and resources and supports the Irish Dementia Working Group and the Dementia Carers Campaign Network. 2017 sees the launch of the latest ASI strategic plan to guide the organisation in its work over the next three years.

The voice of those with dementia and their carers informs the heart and development of the ASI's work.



ASI Fundraisers Women's Mini Marathon



2007 Dementia Manifesto Launch



ASI's Nuala Dunphy, Michael Coote with ASI Founder Winifred Bligh



Waterman's Lodge opening with President Michael D. Higgins.

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