



All-Party **Oireachtas Group**  
on **Dementia**

## Report One

# **Learning about Dementia: The Scottish Experience**

Visit on 26 & 27 January, 2017

Deputy Mary Butler & Senator Colette Kelleher

24.02.17



Houses of the  
**Oireachtas**  
Tithe an Oireachtais

## Background

The All-Party Oireachtas Group on Dementia was formed in 2016 to enhance cross party collaboration on dementia issues, to act as a forum for learning and knowledge sharing and ultimately to help improve the lives of people with dementia through better policies and practices. The group is run in partnership with The Alzheimer Society of Ireland, which acts as secretariat for the group.

In its first year the group hosted the inaugural dementia awareness training for Oireachtas members and heard first hand from people with dementia about what they would like to see achieved.

For 2017 the group has set an ambitious priority list (see appendix 2), key among them is learning about international best practice and bringing that knowledge home to enhance the policy process in Ireland.

The first action to achieve this goal was a study visit to Scotland. This report sets out in detail who we met (see appendix 1), what we learnt and how best these lessons can be applied.



*Visit to the Alzheimer Scotland Dementia Resource Centre at Bridgeton Cross*



*Visit to the Scottish Parliament to meet the Minister for Mental Health, Maureen Watt MSP*

## Lessons for Ireland

- Statutory access to adequate post-diagnosis support is crucial. Scotland has dedicated staff (Link Workers) who provide that support.
- Adequate data is key to planning services and supports for people with dementia. A Dementia Registry would help us plan for the future.
- Dementia care in acute settings could be improved by appointing a senior person with responsibility for dementia within the hospital.
- Ongoing and successive dementia strategies are required to progress incremental change for people with dementia and those who care for them.
- Creating a dedicated Ombudsman for Older people would enhance protections for older people.
- The Dementia Friendly Communities model could be rolled out nationwide with a key role for Dementia Advisers in dementia community development.
- Small, low cost interventions can have a big impact for people with dementia.



*Meeting with Mark Hanniffy, Irish Counsel General and Sandra White MSP Chair of the Cross Party Group on Age, Aging and Older People*

## Overview

- Scotland with 5 million people has a similar sized population to Ireland (4.5 million). However, Scotland estimates that they have 93,000 people with dementia compared to the 55,000 estimated for Ireland.
- Scottish policy, approach and delivery of services and supports for people with dementia is considered advanced and progressive in a European context.
- Scottish Government policy and action on dementia is expressed in published National Dementia Strategies (2010 -2013), the second Strategy (2013 - 2016) and a forthcoming Strategy (2017 - 2020) to be published shortly.
- The view expressed from different perspectives was that the argument for national action on dementia has been won, with the focus now on delivery.
- Whilst Scotland has many positive initiatives in place they struggle with embryonic integration across health and social care, post code lotteries, people under 65 and people with Down syndrome also fitting poorly within a system focusing primarily on older people.
- A key focus of the first two National Dementia Strategies in Scotland has been on early diagnosis, building the strengths and of capabilities of people with dementia and their families to support them to live ordinary lives, in their communities without stigma for as long as possible.



*Meeting with Alzheimer Scotland Dementia Advisors*

## Post-Diagnosis Support for People with Dementia

- The Scottish Government guarantees an entitlement of one year of post-diagnosis support from a named Worker. This guarantee has been delivered by a national network of Link Workers. There are an estimated 70 Link Workers in place.
- The network of 70 Link Workers was based on a 2014 estimate of 5,000 people with dementia being diagnosed per year. This has transpired to be an underestimate – there are currently 17,000 people requiring access to a Link Worker. As a result there are waiting lists for Link Workers in different parts of Scotland, with people with dementia experiencing a post code lottery. The Minister responsible Maureen Watt emphasised the importance of data for planning.
- Link Workers are from a variety of backgrounds with a full cost of approximately £35k with some employed by NHS, others by local authorities and 39 commissioned and funded by IHSCPs and employed by Alzheimer Scotland.
- The role of Link Worker is to work intensively with the person with dementia and their families for one year after they have received the diagnosis. The Link Worker does home visits, provides information, training, signposts and linking the person in with a range of primary care and community supports, preparing the person for the future with advanced health care directives, power of attorney etc.

See job description:

[http://www.alzscot.org/assets/0002/1100/Edinburgh\\_Link\\_Worker\\_-\\_Approved\\_by\\_Ed\\_Council\\_-\\_job\\_description.pdf](http://www.alzscot.org/assets/0002/1100/Edinburgh_Link_Worker_-_Approved_by_Ed_Council_-_job_description.pdf)

- Feedback from the person with dementia from the Scottish Dementia Working Group whom we met was very positive about the Link Worker support, though she emphasised that the Link Worker needed to be knowledgeable about dementia and its different forms to be effective. The importance of being able to reconnect with the Link Worker after the year's entitlement expired was also mentioned as the needs of the person with dementia changes.
- Another person with dementia with more complex needs was not able to access the Link Worker network. Access to counselling was key for this person.
- The members of the Scottish Dementia Working Group meet regularly with Minister responsible.

## Dementia Advisers

- The National Network of Link Workers is complemented by a smaller network of Dementia Advisers employed and funded by Alzheimer Scotland. This role focuses more on community development role e.g. setting up and supporting Alzheimer Cafes and other supports, providing carers education. Some Dementia Advisers work out of new, model, state of the art, high street Dementia Resource Centres, one of which we visited in Glasgow.
- There is a big focus on Dementia Awareness Training in the National Dementia Strategy to create Dementia Friendly Communities so that all services and supports including training for first responders, the police, and the prison services, as well as equipping those working in care homes, hospitals, and home care settings to provide dementia appropriate care. This training is often provided by Dementia Advisers.
- Dementia Advisers often work alongside networks of volunteers (*Knowing Me Knowing You* programme) and provide creative solutions for challenging situations e.g. adapting the environment for people with dementia and with Down syndrome.
- Dementia Advisers also work to create a network of 'Dementia Friends' in the community including working with and through schools.

## Dementia in Acute Hospitals

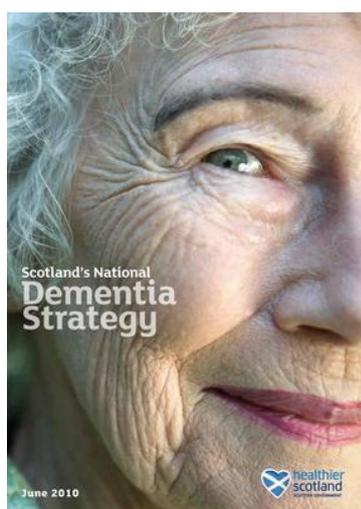
- The first two Scottish National Dementia Strategies also focused on improving the care of people with dementia in acute hospitals. A national programme called *Fixing Dementia Together* is in place with Dementia Nurse Specialists in place in each acute hospital in Scotland.
- There is a call for the families of people with dementia to have an entitlement to stay in hospital with their relative as of right, as with parents and children.

## Dementia Data

- The Minister responsible for dementia emphasised the importance of accurate and robust data for planning purposes; "numbers are important". She supported the establishment of a Dementia Registry. The importance of sound data was also emphasised by Geoff Huggins, the most senior Government official working on dementia strategies since 2009.

## National Dementia Strategy

- The Minister said that she would share the soon to be published 2017-2020 National Dementia Strategy for Scotland. The focus will be on building on achievements to date, embedding post-diagnosis support and eliminating the post code lottery. Her aim was to deepen rather than broaden the focus of the Strategy, focusing on initiatives with greatest impact.
- The new Strategy will provide for continual and ongoing Dementia Awareness Training and workforce training for all including people working in supermarkets; having 50 Dementia Champions in the NHS, in acute hospitals at ward levels and in the community; Dementia Ambassadors in Care Homes and Dementia Friends in every community. Funding for Dementia Awareness Training is to be provided through the National Dementia Strategy. There will also be a focus on developing excellence in end of life and palliative care and 'realistic medicine'.
- There will be a continued emphasis on Care Co-ordination and on systems change and leadership on dementia across Health and Social Care.
- The Minister also mentioned looking after the carers with good access to respite care, homecare and GP support. Voluntary Sector has a key role with Government and Alzheimer Scotland working well nationally and locally. She spoke positively about the new 'dementia shops'.



### Scotland's National Dementia Strategy 2013-2016

- One years post-diagnostic support
- Rights based
- Embrace the process of redesign and transformation of services
- All applies to people with learning disabilities too



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## **Learning from Others about Dementia**

- The Minister emphasised the importance of international co-operation and learning from others. Scotland is a member of the European Joint Action on Dementia, which is focusing on four different dementia related strands:
  - 1) Diagnosis and post-diagnosis, with France in the lead;
  - 2) Care Co-ordination, with Italy in the lead;
  - 3) Quality of care in residential settings, with Norway in the lead;
  - 4) Dementia Friendly Communities with UK in the lead.
- The Chair of the Cross Party Group on Older People mentioned the importance of the national network of post-diagnosis Link Worker support and the unfortunate post code lottery and the lack of integration between health and social care. She also mentioned the value of Dementia Awareness Training for all including banks, shops, police, fire service and care homes.
- The Cross Party Group on Older People is the longest established such group in the Scottish Parliament and acts as a watchdog and calls officials, Ministers and agencies to account. It meets 4 times a year as well as having an annual national event. Civil Society organisations are also members of the Cross Party Group. The establishment of a Commissioner (Ombudsman) for Older People is a campaigning priority.

## **Small Things Make a Big Difference for People with Dementia**

- Small things make a big difference for people with dementia. Adaptations to flooring meant that a person with dementia and Down syndrome became happier and also regained continence. A simple business card explaining a person's dementia symptoms can transform how a person with dementia is responded to, as is having a key to disabled toilets. A programme to introduce rickshaw day trips from care homes was also mentioned as beneficial.

## Appendix 1

### Outline of the trip

#### *Wednesday 25th January*

6:40pm: Depart Dublin for Edinburgh

#### *Thursday 26th January*

8am: Train from Edinburgh to Glasgow

8:55am: Meeting with Jim Pearson, Director of Policy and Research for Alzheimer Scotland

9:30am: Visit the Alzheimer Scotland Dementia Resource Centre at Bridgeton Cross

9:45am: Meeting with Lorna Hart, Alzheimer Scotland Dementia Adviser

10:15am: Meeting with Anne Macdonald and Carol Hargreaves, Vice-chairs of the Scottish Dementia Working Group

11am: Visit the Dementia Café

11:15am: Train back to Edinburgh

12:50pm: Meeting with Mark Hanniffy, Irish Counsel General

1pm - 2pm: Meeting with Sandra White Member of the Scottish Parliament (Chair of the Cross Party Group on Age, Aging and Older People)

2pm - 2:30pm: Meeting with Maureen Watt, Minister for Mental Health

3pm: Follow up meeting with Mark Hanniffy

#### *Friday 27th January*

9am: Meeting with Geoff Huggins, Director of Health and Social Care of the Scottish Government

## Appendix 2



All-Party **Oireachtas Group**  
on **Dementia**

**All-Party Oireachtas Group on Dementia**

2017 Priorities

31.01.17

1. Close the Dementia data and planning gaps

- Secure funding to establish a publicly funded Dementia Registry
- Disseminate the findings of the dementia mapping project and advocate for the creation of a dementia plan for each of the nine Community Healthcare Organisations (CHO)
- Establish statutory Dementia Forums in each CHO where people with dementia are directly involved

2. Make timely diagnosis of Dementia and follow up part of the 90 Primary Care Networks

- Mainstream the 'GP Prepared' project (part of the National Dementia Strategy)
- Grow the Dementia Adviser Network from the current 8 to 33 (one for each of the 26 counties, plus four extra in Dublin and one extra in Cork, Galway and Limerick) with the goal of having 90 (one in each Primary Care Network)

3. Make homecare accessible, affordable and a high quality experience for people with Dementia

- Create a statutory entitlement to homecare as part of the Fair Deal scheme (Willie O Dea's Bill)
- Develop a funding model and invest in developing the infrastructure of homecare on a par with residential care. Increase spending on homecare from €373m in 2016 to €1b by 2021
- Establish targets to meet the needs of a proportion of people with dementia and monitor progress
- Introduce statutory regulation of homecare (Colm Burke's Bill)

4. Highlight the needs of key groups of people with, and affected by Dementia, including

- People under 65
- People with Down Syndrome
- People living in rural areas
- People with dementia living alone
- Carers of people with dementia

5. Aspire for Ireland to be a world leader for Dementia care and support

- Renew, resource and reform the National Dementia Strategy with targets to monitor progress
- Roll out Dementia Friendly Communities nationwide
- Learn from other countries, in particular similarly sized countries like Scotland and Denmark
- Highlight the need for Integrated Care Pathways for people with dementia
- Fund research on dementia: prevention, care and cure

Appendix 3

**All-Party Oireachtas Group on Dementia  
2017 Calendar of Events**

Date	Event
Thursday 26 <sup>th</sup> and Friday 27 <sup>th</sup> January	Visit by Deputy Mary Butler and Senator Colette Kelleher to Scotland
Thursday 2 <sup>nd</sup> February	Meeting of the All-Party Oireachtas Group on Dementia <i>Focus: Report from Scottish Trip, 2017 Priorities and Calendar of Events</i>
Thursday 2 <sup>nd</sup> March	Quarterly Dementia Awareness Session for Oireachtas Members
Thursday 23 <sup>rd</sup> March	Roundtable Event Hosted by the All-Party Oireachtas Group on Dementia <i>Focus: Home Care</i> <i>Invite key stakeholders, incl. Minister Helen McEntee, Deputy Willie O’Dea, Senator Colm Burke, Professor Eamon O’Shea</i>
Thursday 6 <sup>th</sup> April	Meeting of the All-Party Oireachtas Group on Dementia <i>Focus: Dementia Mapping Project</i> <i>Invite Mary Manning, HSE National Dementia Office, and Pat McLoughlin, ASI CEO</i>
Wednesday 12 <sup>th</sup> / Thursday 13 <sup>th</sup> April	Quarterly Dementia Awareness Session for Oireachtas Members <i>Focus: highlight results of mapping project by constituency</i>
Thursday 11 <sup>th</sup> May	Meeting of the All-Party Oireachtas Group on Dementia <i>Focus: Primary Care, including Dementia Adviser Network and GP Prepared Project</i> <i>Invite Dr Tony Foley</i>
Week beginning 22 <sup>nd</sup> May	Group visit to Memory Clinic in Mercer’s Institute for Research on Ageing, St. James’s Hospital
June	Preparation of All-Party Group Statement on Dementia for Budget 2018
Thursday 15 <sup>th</sup> June	Meeting of the All-Party Oireachtas Group on Dementia <i>Focus: Dementia and Down Syndrome</i>