



---

THE ALZHEIMER  
SOCIETY *of* IRELAND

---

# **How Can the Community and Voluntary Sector bring Added Value to Carer Related Research?**

Emer Begley, PhD  
Policy and Research Manager

**Care Alliance Research Conference**  
**21 November 2015**

## About the ASI



The Alzheimer Society of Ireland is a **national non-profit organisation**. Providing dementia specific services and supports and advocating for the rights and needs of all people living with dementia and their carers.





Our vision is an Ireland where **no one goes through dementia alone** and where policies and services respond appropriately to the person with dementia and their carers, at the times they need support.



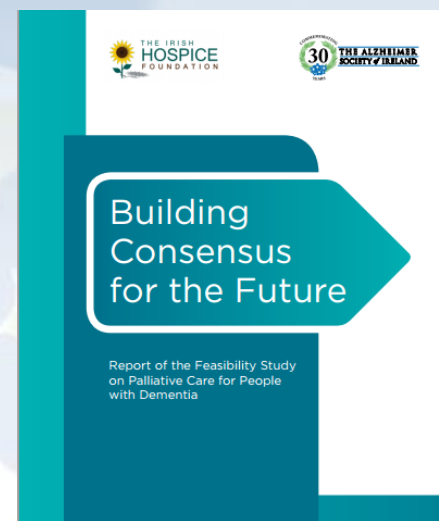
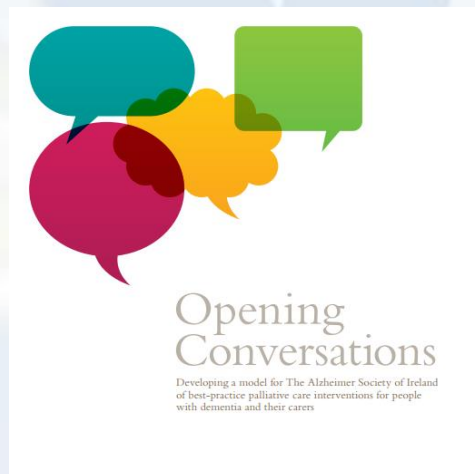
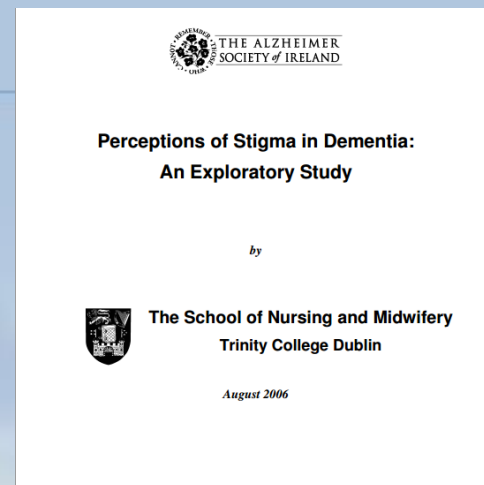
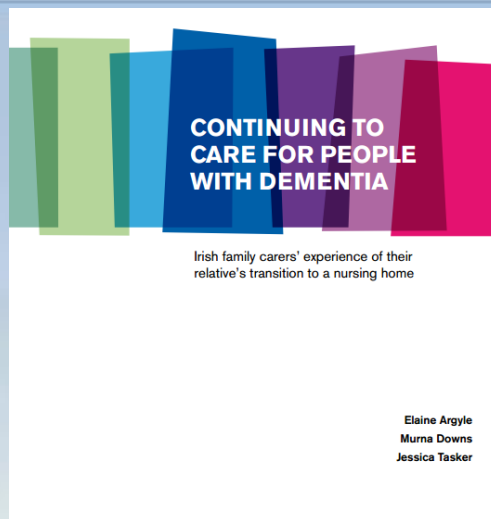


We are a **person centred, rights-based and grassroots led organisation** with the voice of the person with dementia and their carer at its core.



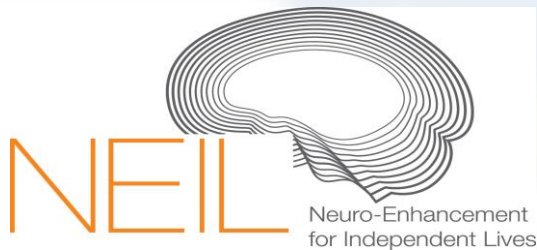
THE ALZHEIMER  
SOCIETY *of* IRELAND





## De-Stress

Three year **co-funded project** (2013-2016). Exploring caregiver stress, cognitive function (memory and attention), psychological and physical well-being. Looking also at genetic information and physiological data on stress at baseline and 12 months with spousal dementia caregivers. Being undertaken by the NEIL programme in TCD.



## *Our Research Strategy*

---

The Alzheimer Society of Ireland (ASI) is committed to supporting all forms of research that have relevance, meaning and impact on how people with dementia and their carers can live better quality lives and how, as an organisation, we can advocate for evidenced-based changes in policy and practice.



---

Participation ‘occurs when individuals meaningfully and actively collaborate in the governance, priority setting and conduct of research as well as in summarising, distributing, sharing and applying its resulting knowledge” (IHRF, 2014)



**FAMILY CARERS  
OF PEOPLE WITH DEMENTIA  
SAVE THE GOVERNMENT  
€807M  
EACH YEAR**

Cahill, S., O'Shea, E. and Pierce, M. (2012) Creating Excellence in Dementia Care, TCD/NUIG



**FOR EVERY ONE PERSON  
DIAGNOSED WITH DEMENTIA,  
THREE OTHER CLOSE  
FAMILY MEMBERS ARE  
DIRECTLY AFFECTED**



Cahill, S., Pierce, M. and O'Shea, E. (2012)  
Creating Excellence in Dementia Care, Dublin



**THE ALZHEIMER  
SOCIETY of IRELAND**

## *In conclusion*

---

- Identifying critical need and research questions prioritisation
- Where funding is available, commission and fund research
- Be the lynchpin between carers and research community
- Translate research and disseminate research information beyond the academic sphere
- Promote and facilitate the meaningful participation of carers in care related research
- Translate research findings into policy and practice



THE ALZHEIMER  
SOCIETY of IRELAND



---

# THANK YOU

[emer.begley@alzheimer.ie](mailto:emer.begley@alzheimer.ie)

01 207 3805



THE ALZHEIMER  
SOCIETY *of* IRELAND