



THE ALZHEIMER
SOCIETY *of* IRELAND

**Submission on Women's Rights to the Irish Human
Rights and Equality Commission**

August 2016



1. Introduction

The Alzheimer Society of Ireland (ASI) welcomes the opportunity to input into the Irish Human Rights and Equality Commission call for submissions on women's rights.

There is a significant and rising number of people currently living with dementia in Ireland; approximately 55,000 individuals¹. If current trends continue this will increase to 68,216 people by 2021 and to 132,000 people by 2041 (Cahill, S. & Pierce, M, 2013²). There is not a community in Ireland unaffected by dementia as the vast majority of people living at home (63%³). Although the main proportion of people who have dementia are over 65 years, as age is the main risk factor, there is a significant group aged under 65, an estimated 4,000 people, many of whom are in their 30's and 40's.

Irish women are much more likely to get dementia, including Alzheimer's disease, than men. With almost twice as many women living with the condition. There are currently more than 34,650 Irish women living with dementia compared with 19,800 men.

2. What is your experience of discrimination against women?

While evidence from Ireland on the gendered nature of dementia is limited there is a growing body of international research shedding light on this issue. Alzheimer Disease International Report (2015⁴) examines the effect of gender and dementia on three specific groups, namely women living with dementia; woman caring for people with dementia in a professional caring role; and women undertaking an informal caregiving role for someone with dementia.

In the UK dementia has not only become the leading cause of death among women but women are far more likely to end up as carers of those with dementia than men; suffering

¹ Department of Health (2014) *National Dementia Strategy*. Download from: <http://health.gov.ie/wp-content/uploads/2014/12/30115-National-Dementia-Strategy-Eng.pdf>

² Cahill, S. and Pierce, M (2013) *The Prevalence of Dementia in Ireland*. Genio Dementia Learning Event.

³ Ibid.

⁴ Erol et al (2015) *Women and Dementia; A Global Research Review*. Alzheimer Disease International. Download from: <https://www.alz.co.uk/sites/default/files/pdfs/Women-and-Dementia.pdf>

physical and emotional stress and job losses in the process. In addition, findings from Alzheimer's Research UK's 2015⁵ report shows that:

- Women are 2.3 times more likely to provide care for someone with dementia for over 5 years.
- Women carers report feeling less supported than their male counterparts.
- Women are 2.5 times more likely to provide intensive 24 hour care.
- 62% of women carers found caring for someone with dementia emotionally stressful.
- 19% of working women carers had to quit work to provide care.
- Women carers are more likely to feel isolated and depressed.
- 17% of working women carers felt penalised at work.

The World Health Organisation (2015⁶) in a paper on human rights and dementia state that women with dementia are often disabled from supporting themselves due to gender inequality as they often lack education and adequate pensions.

Bamford and Walker (2012⁷) shows that there continues to be a pressing need to raise awareness of the impact of discrimination, exclusion and stigma associated with dementia and the impact for women in particular. They maintain that while the 'feminisation of ageing' is a widely recognised trend, a comprehensive approach to the impact of dementia on women remains largely unexplored with regards to research and policy impact. Their research illustrates how women face a 'triple jeopardy' as a result of the associated stigma attached to their age, gender and decline in cognitive functions. The need for further research of the sex and gender specific risk factors for dementia, what results in more women developing dementia than men is highlighted in their research, alongside the need for greater evidence on diagnosis, treatment and responses.

⁵ Alzheimer Research UK (2015) *Women and Dementia; A marginalised majority*. Download from:

<http://www.alzheimersresearchuk.org/wp-content/uploads/2015/03/Women-and-Dementia-A-Marginalised-Majority1.pdf>

⁶ World Health Organisation (2015) *Ensuring a Human-Rights Based Approach for People Living with Dementia*. Download from:

<http://www.ohchr.org/Documents/Issues/OlderPersons/Dementia/ThematicBrief.pdf>

⁷ Bamford, S.M. and Walker, T. (2012) women and Dementia – Not forgotten. *Maturitas* 73(2): 121-126.

3. What can be done to end this type of discrimination?

The low status, financial rewards and inadequate training and support for paid care work impacts on women, their families and people living with dementia. There needs to be investment in care and support for carers in order to reduce the levels of discrimination associated with caring and being cared for.

Findings from recent research (Donnelly et al, 2016⁸) found that where family members were present in cases where older people required care, formal services were not prioritised. There is a need therefore to prioritise the roll-out of the carer needs assessment tool to identify the needs of family carers, the majority of whom are women.

Government can also support the development of Dementia Friendly Communities (DFC), which focuses on improving the inclusion and quality of life of people with dementia and their families. DFCs encourage and support dementia to be understood, recognised and accommodated in everyday life, giving people with dementia as much independence and dignity as possible whilst supporting them and their family carers.

4. What should the State do to make Ireland a better country for women and girls to grow up in?

There is a need for greater support for research regarding women with dementia, which focuses on the gender issues of living with dementia.

In the Alzheimer's Disease International Report referred to earlier in this submission, recommendations for action include:

- All countries need to understand the current and predicted prevalence and acknowledge that dementia disproportionately affects women. Accordingly, policy makers should review what support is currently available and what is required to meet future needs.

⁸ Donnelly et al (2016) Older People's Preferences for Care. UCD/ASI/IASW/AgeAction. Download from: [http://www.alzheimer.ie/getattachment/0ed58833-e646-41e4-ad7d-bdfec27b3d15/Final-Research-Report-A4-Report_LR-FOR-WEB-\(1\).pdf.aspx?ext=.pdf](http://www.alzheimer.ie/getattachment/0ed58833-e646-41e4-ad7d-bdfec27b3d15/Final-Research-Report-A4-Report_LR-FOR-WEB-(1).pdf.aspx?ext=.pdf)

- There is also a need for skilled care competencies for health and care staff and professionals working with people living with dementia with complex needs and co-morbidities.
- In all regions people should be able to access appropriate information and support in place, enabling women across the world to continue to provide care, and to feel cared for themselves.

The National Dementia Strategy includes six priority action areas to enable people to live well with dementia. Implementation of this Strategy and the development of a second strategy will be fundamental to supporting women in Irish society given the disproportionate impact of dementia and caring on women.

5. Is there anything else you would like us to know about women's rights?

People with dementia experience discrimination and treatment that contravenes their human rights. The Irish Dementia Working Group, in collaboration with The Alzheimer Society of Ireland, produced a *Charter of Rights for People Living with Dementia*⁹. One of the key principles in this charter is non-discrimination and it states that people with dementia have the right to be free from discrimination based on any grounds such as age, disability, gender, ethnicity, sexual orientation, religious beliefs, membership of the travelling community, civil and family status. In this regard, gender should not put people living with dementia at a further disadvantage.

6. Conclusion

The issues that present for women living with dementia and women as family and formal carers are interwoven with wider equality and rights issues that present for women more generally. For example, research shows that older women workers experience limited access to pensions because of low pay, poor conditions of work and their primary role in caring (Duvvury et al., 2012)¹⁰. This means that financial hardship is greater for women living with dementia. It is important for policy to be mindful of the specific equality and

⁹ The Alzheimer society of Ireland and The Irish Dementia Working Group (2016) *Charter of Rights for People with Dementia*. Download here: <https://www.alzheimer.ie/getattachment/About-Us/Policy/Human-Rights/A-Charter-of-Rights-for-People-with-Dementia/Charter-of-Rights-for-People-with-Dementia.pdf.aspx>

¹⁰ Duvvury et al (2012) *Older Women Worker's Access to Pensions*. NUI Galway and Queens university Belfast. Download from: http://www.icsg.ie/sites/www.icsg.ie/files/personfiles/oww_report_.pdf

rights issues related to women and dementia but equally important to acknowledge how this interconnects with the wider gender equality and rights context.

About the Alzheimer Society of Ireland

The ASI is the leading dementia specific service provider in Ireland. We work across the country in the heart of local communities providing dementia specific services and supports and advocating for the rights and needs of all people living with dementia and their family carers.

In 2014 the ASI provided over 1 million hours of care to approximately 9,500 people with dementia. In addition, our national helpline assisted 4,000 people in 2014. Our range of supports and services include a National Helpline, Dementia Adviser Service, Social Clubs, Alzheimer Cafes, Home Care, Day Centres, Respite Care, Family Support Groups, Family Education Programmes and Cognitive Stimulation Therapy Programmes. We are also the only national advocacy organisation for people 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. A national non-profit organisation, The ASI is person centred, rights-based and grassroots led with the voice of the person with dementia and their carer at its core.