

# 20 Years of Family Carer Research in Ireland



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# Pre-“Family Caring” Terminology

- Limited State Welfare – Struggling to feed family and get work
- Private Domain – Family
- High levels of Institutionalisation
- Considered to be Women’s Work

(Ref Care Alliance Ireland Discussion Doc 1 Oct 2015  
<http://bit.ly/1MVb8rc>)



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# Emergence of NGO's ? – (post Church led/founded orgs)

1960's – Beginnings of Disability Movement (KARE, NAMHI, Disability Federation of Ireland)

1970's - Independent Living Movement

1981 – National Council for the Aged (Semi-State)

1982 – The Alzheimer Society of Ireland

1987 – The Carers Association

1995 – Care Alliance Ireland

Early 2000's - Research Consortia –TILDA/NCPOP



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# Some Figures on Carer Research in Ireland

- c 35 on our database (2008-2015)
- 19 (mostly ongoing) here at conference
- [www.lenus.ie](http://www.lenus.ie) Open Access
- €322,000 – Significant primary research on Resilience of Family Carers of People with Dementia (HRB/UCD/Care Alliance Ireland)



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# Earliest Research Found (Internationally)

1982:

- *Family Care of the Handicapped Elderly: Who Pays?* M. Nissel and L. Bonnerjea. (Pp. 100; illustrated; £3.50.) Policy Studies Institute: London. 1982.
- *Caring for the Elderly and Handicapped: Community Care Policies and Women's Lives.* Equal Opportunities Commission. March 1982.



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# Earliest Irish Research

- *Who cares about the Carers.* Noonan, M. Council for the Status of Women. Dublin. 1983.
- *Caring for the Elderly at Home* (National Council for the Elderly O'Connor/Ruddle et al. (1988, 1994)
- O'Neill/Western Health Board (1999)
- Lane/South Eastern Health Board (2000)

(Focus on Caring for Older People – Mostly Descriptive – Some Surveys)



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**NATIONAL COUNCIL  
FOR THE AGED**

**CARING FOR  
THE ELDERLY  
PART II**

**THE CARING PROCESS:  
A STUDY OF CARERS IN  
THE HOME**



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*National Council for the Elderly*



FACT SHEET No. 1

## CARING FOR THE ELDERLY AT HOME

PREPARED FOR THE NATIONAL COUNCIL FOR THE ELDERLY BY  
PROFESSOR JOYCE O'CONNOR AND EILEEN MURPHY  
TO ASSIST THOSE WITH A RESPONSIBILITY FOR THE WELFARE OF THE  
ELDERLY AND THEIR CARERS  
REPRINTED AND UPDATED JANUARY 1994



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*Review of the*  
**Carer's Allowance**



Department of Social, Community and Family Affairs  
October 1998



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# Characteristics of Early Research

- Health Focussed (but reasonably wide collection of sub themes)
- Few published in journals
- Often once-off research (little follow up evident)
- Focus on Surveys and Scales

# More Recent Foci

- Carers Health and Wellbeing – CAI (2008, 2010); Carers Association (2009); Others
- Economic Cost of Caring -Visually Impaired, Dementia, MS. (Work ongoing re Cost of Disability)
- Condition Specific - Dementia, Parkinsons (2010)
- Some Other Significant/Novel Research - Caring/Elder Abuse, End of Life Care, Life After Care, Stress/Resilience, Telecare
- More recent focus on 'Lived Experiences'
- Looking at Trends - 3 Census's (2002, 2006,2011)



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**Health and Well-being of Family Carers in Ireland:**

**Results of a survey of recipients of the Carer's Allowance**

Liam O'Sullivan  
Care Alliance Ireland  
Coleraine House, Coleraine Street, Dublin 7  
[info@carealliance.ie](mailto:info@carealliance.ie)

RESEARCH WORKING PAPER 2008/11  
ISBN: 978-1-905485-72-7  
November 2008



## National Centre for the Protection of Older People

### Research Findings Family Carers of Older People: Results of a National Survey of Stress, Conflict and Coping

Dr. Attracta Lafferty, Prof. Gerard Fealy,  
Ms Carmel Downes & Prof. Jonathan Drennan

Fact File June 2014



#### Background

With the growing proportion of people aged 65 years and older worldwide and a desire by older people to remain living at home for as long as possible, there is an increasing reliance on families to provide care to older people living in the community.

For many carers, providing care to a family

#### Methods

The study design involved a cross-sectional national postal survey of family carers in receipt of a carer's allowance for care provided to a person aged 65 years and older. The survey was conducted using an anonymous self-completion questionnaire measuring stress, conflict and coping. A total of **2,311** carers completed and returned questionnaires, yielding



**Care Alliance Ireland**  
The National Network of Voluntary Organisations for Family Carers

[www.carealliance.ie](http://www.carealliance.ie)



**Parkinson's Association of Ireland**

[www.parkinsons.ie](http://www.parkinsons.ie)

Care Alliance Ireland and The Parkinson's Association of Ireland

## The Caring Reality of Family Carers:

*An exploration of the health status of Family Carers of people with Parkinson's disease*

June 2010

Author: Ann Stokes/Care Alliance Ireland



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# Several Overview Reports/Lit Reviews

Are they Research in the purest sense? Does that matter?

- Comhairle/ CIB (2002)
- Equality Authority (2005)
- Care Alliance (2010/2013/2015)

Literature Reviews -

- CAI (2014) - Relationship between Family Carers, Paid Care workers, and Caree.



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**Literature Review**  
on the Relationship between  
Family Carers and Home Care  
Support Workers

November 2014



**Family Caring  
in Ireland**

March 2015

# Current Drivers of the Research

- National Strategies? - (NB Dementia)
  - But absent from 2012 National Carers Strategy
  - National Disability strategy, no mention of “family” or “family carer” etc in the whole document.
- Need for more evidence based interventions? (Funders, The right thing to do)
- Lobbying Actions – need to be more evidenced/credible?
- EU/Eurocarers - Young Adult Carers, Working Carers
- Care Alliance Ireland/Family Carer Research Group



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# Sources of Funding

- State/Semi-State - National Council for the Aged/NCAOP (RIP), IRCHSS (RIP), HRB,
- Self Funded - Masters, Phd Students
- Philanthropy - (eg; Atlantic Philanthropies, Trusts, Genio)
- Other - Lottery Funds (via HSE/DOH)



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# Impact of Research - Cause and Effect?

- 1988 Report Made 4 Recommendations - Have they been implemented?
  1. Co-ordinator of Services for the Elderly
  2. District Liaison and Information Officers
  3. Respite and Intermittent Care Facilities
  4. Information, Training and Counselling Services



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# Family Carer Research Group

- Information Sharing
- Peer Support
- Builds Momentum
- Encourages Collaboration
- Meet Quarterly in Dublin
- Next Meeting – Jan 2016



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# Dissemination of Research

- Conferences
- Seminars
- eZines
- Media
- Journals
- Database
  
- Who is the audience?



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# Gaps?

- Disability and Caring (Discussion paper, Care Alliance Ireland- Forthcoming)
- Carer Assessments – Carer Experience, Impact
- Benefit Finding/Resilience/Stress/Self Management
- Inclusive research. Not just "including" carers in certain aspects but ground-up inclusive research for and with family carers
- Others???????



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# To the Future

- Bright
- Quality
- Collaborative



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# Some Questions to Pose

- Research or Rhetoric?
- Impact – Measuring

# Thank You !

## Contact Details

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<https://twitter.com/CareAllianceIrl>

<https://www.facebook.com/nationalcarersweek>



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