

De-Stress:

A study to assess the health & wellbeing of spousal carers of people with dementia in Ireland.



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Published by The Alzheimer Society of Ireland, 2017

Acknowledgements

The authors and research team would like to thank all of the people who contributed to this study. In particular, we wish to express our deepest gratitude to the caregivers who so generously gave up their time to take part in this research and to share their experiences with us.

Special thanks to The Alzheimer Society of Ireland and to Dr Emer Begley for her constant support throughout the course of the study. Thanks also to former ASI Policy & Research Manager Grainne McGettrick, and all of The Alzheimer Society of Ireland staff and volunteers around the country for their huge efforts in promoting this study, and facilitating recruitment and data collection.

This study would not have been possible without the support of many other groups and individuals who helped to raise awareness of this research; this included Family Carers Ireland, numerous local organisations representing older people with dementia, the GENIO dementia project coordinators, community partnerships, local parishes, hospitals and memory clinics, nursing homes, public health nurses, general practitioners and other health care providers. We would also like to thank Pat Dolan and his team in the Department of Social Protection, Longford, for supporting and promoting the study. Special thanks also to Liam O'Sullivan of Care Alliance Ireland and Dr Attracta Lafferty of University College Dublin for their advice and for sharing their contacts of caring organisations and researchers.

We are extremely grateful to Prof Derek Morris, Dr Joseph McPartlin, Dr Mary Cunneen, Dr Denise Harold, Laura Whitton and Mairead Flynn for their guidance and work on the laboratory aspects of this project.

Thanks also to co-Investigator, Prof. Ian Robertson, Research Assistants, Jennifer Rogers, Katie O'Donnell, Alan Galvin. Thanks also to Hannah Jellings, Melissa Maher and Sean O'Loughlin who worked as interns in the NEIL programme and provided vital assistance with the running of the study. We would also like to thank Catherine O'Donoghue and Anna Begley for their help with data entry.

Finally, the research team would like to thank The Alzheimer Society of Ireland and the Health Research Board who funded the study under the Medical Charities Research Group.

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Why we did this study

The world's population is getting older. The risk of developing dementia increases in older age, and in Ireland alone, it is predicted that 150,000 people will be living with dementia by 2046.

This trend means that the demand for carers of people with dementia will also increase, and at the moment, it is mostly family members who provide that care – in many cases a spouse or partner the same age as the person that they are caring for.



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In 2010, family and friends provided an estimated 81 million hours of care for people with dementia in Ireland, saving the State €807 million.

This caregiving by family members often means that people with dementia can stay living at home for longer, and such care is associated with better quality of life and positive health outcomes for the person with dementia.

If we are relying on family members to provide that care, we need to make sure these carers are protected too. They may be more at risk of stress-related health problems or of developing dementia themselves.

The De-Stress study set out to gather information about the health and wellbeing of family members who are carers of people with dementia. It was co-funded by the Health Research Board and The Alzheimer Society of Ireland through the Medical Charities Research Group grant scheme and carried out by researchers at Trinity College Dublin.

In the De-Stress study the research team worked with more than 200 carers who looked after a spouse with dementia (we refer to these individuals as 'spousal carers'). The aim was to find out more about their lives, their health, their caregiving and the impact this has on their lives. This study also explores the amount of stress they experience, as well as exploring the positive aspects of caring.

De-Stress is the largest study undertaken in Ireland to look at the wellbeing of people caring for their spouse with dementia.

What we set out to do

In this study we wanted to look at the cognitive function (including attention, memory, ability to plan) of spousal dementia carers and to see if there was any link with chronic stress.

We also wanted to see if we could find out mechanisms in the body that link stress and cognitive function in these family carers and to find ways to predict who would be at more risk of developing problems in the future.

As part of this process we collected data about the family carers, their health and wellbeing, their stress levels and the supports they access and receive.

How we collected the data

We spoke to people who were caring for their spouses with dementia. Many of the participants got involved in the study through contact with community and voluntary organisations, such as The Alzheimer Society of Ireland.

De-Stress is a longitudinal study, which means that after we started working with individual carers, we followed up with them over time to see how they were doing. From a scientific perspective, this is a valuable approach, because it captures changes in the same people over time.

Carers who took part in De-Stress filled out a questionnaire, answered a health screening survey over the phone and also took part in a face-to-face session to assess their cognitive function.

People who took part in the study did these baseline assessments and then repeated them around a year later. We also collected saliva (spit) samples.

The saliva samples also meant we could look at the body's natural stress chemicals (cortisol levels) and genetic factors that may influence how a person's cognitive functions change with age.

In total, we got a full set of data from 205 spousal carers, and from this we were able to measure their cognitive functioning, physical health, psychological wellbeing, level of social support and degree of loneliness, sleep disruption, and lifestyle factors as well as the use of caregiving support services and level of disability of the person with dementia that they were caring for.



What We Found

Who are the spousal carers in the De-Stress study?

Most of the spousal carers (65%) who took part in De-Stress were women, and half of all the people we interviewed were between 65 and 74 years of age. A quarter of the carers were over the age of 75.

Dementia is an umbrella term for a group of conditions with similar symptoms that affect memory, orientation, thinking, judgment and behavior and result in the loss of day-to-day function for the person. Alzheimer's Disease is the most common form of dementia. In this study the majority of carers were caring for a spouse with Alzheimer's disease (44.4%); 13.5% of the people receiving care had vascular dementia and 10.7% had fronto-temporal dementia.

More than half of the carers lived in cities or towns, and 43% lived in County Dublin.

The majority (65%) had their Leaving Certificate and some of those had gone on to higher education; few (16.3%) were still in part- or full-time employment.

15% of people we interviewed said they had given up their jobs in order to care for their spouse. Those who were still working reported missing an average of 1.34 days of work in the last month because of caregiving responsibilities.

How much recipient care do they provide?

Most carers (79%) reported that they themselves provided 81% – 100% of the care for their spouse. Women more commonly provided this level of care than men.

On average, carers had been caring for their spouse for approximately five years at the time of the initial assessment. The duration of caring ranged from one month to 19 years.

Half of the participants were sole carers, and almost half had been providing care for more than five years.

At the time of the initial assessment, nearly half of carers (48%) reported that they spent all of their waking time looking after their spouse.

What caregiving supports do they receive and access?

Nearly 42% of carers reported that they had not received any assistance with care from family and/or friends in the past 30 days. Women were less likely to receive caregiving help from family and friends compared to men.

Half of carers had received home help of some kind in the past 30 days; the average number of total home help hours was 34 hours in that 30 day period.

Most-accessed services included adult day care/non-overnight respite care (49.8%), home-help from a health aide (45%), home-visits by a registered nurse (33.6%) and overnight respite in a nursing home or respite centre (35.1%).

One in four De-Stress participants had availed of carer training, but 16% of carers reported that they had not accessed any formal support services to assist them with caregiving.

Of those carers whose spouse had gone into long-term care by the time of the follow-up assessment, nearly half visited their spouse every day. The vast majority of carers were very satisfied (65%) or fairly satisfied (27%) with the quality of care in the long-term care facility.

42% of carers had not received any assistance with care from family and/or friends in the past 30 days

What is the personal impact of caring?

The majority of carers agreed that there were positive aspects of caregiving, such as appreciating life more, plus caring made them feel needed and useful. Most felt they had not had a choice in taking on the role of spousal carer, but most took it on willingly.

Agitation/aggression, anxiety, irritability/lability, and night-time behavioural disturbances were rated as the most distressing care-recipient symptoms by carers.

Just 14% of carers reported little or no caregiving burden based on a scale that looks at areas such as health, finances, social life and interpersonal relations, and more indicated mild to moderate burden (40%). To assess the burden of caring we used a scale that looks at health, finances, social life and interpersonal relations. We found that 14% of carers reported little or no caregiving burden while 40% indicated mild to moderate burden, 36% experienced moderate to severe levels of burden while 9% had severe burden.

Nearly three-quarters of participants (73.4%) were still caring for their spouse at follow-up one year later; the spouses of 17% of carers had gone into long-term care and 9.5% of spouses had passed away within the follow-up period.



50% of carers had received home help of some kind in the past 30 days

What are the most challenging aspects of dementia caring?

We found that carer burden and quality of life were not related to the degree of loss of function of the person with dementia or the length of time providing care, or the time spent caregiving per day, or on support service use.

Carers were more likely to have high burden and lower quality of life if they had: a greater number of chronic health conditions themselves, if they reported difficulties in their own ability to function; where the person they cared for had more severe behavioural and psychological symptoms such as apathy, anxiety, irritability, agitation or aggression, night-time behavioural disturbances and appetite disturbances.



60% of carers had visited a health care professional at least once in the past **30** days on account of their own health



71% of carers have two or more health conditions or diseases at once, including arthritis, hypertension and diabetes.

How physically healthy are the carers?

Nearly 60% of carers had visited a health care professional at least once in the past 30 days on account of their own health.

Most carers were on medicines – in fact all but 17% of participants reported taking medication, most commonly blood pressure medication (57%) and medication for high cholesterol (30%).

It was very common (71%) for carers to have two or more health conditions or diseases at once, the most common being arthritis, hypertension (high blood pressure), and diabetes.

Three-quarters of carers were overweight (46.4%) or obese (30.6%). At the outset of taking part in the study one in five participants was on the road to frailty or was already frail. This figure rose to one in four after a year.

Almost a third of carers reported fairly bad sleep quality, and a further 9% reported very bad sleep quality.

Current rates of smoking were low and the majority of carers reported being non-drinkers (33.5%) or reported drinking a moderate amount of alcohol (63%); about 4.5% of carers drank hazardous or harmful amounts of alcohol.



Carer mental and emotional health: Depression and Anxiety

When we screened for psychological distress, about three-quarters of the carers were classed as having 'good mental health', while 13.4% of the carers had a moderate to a severe level of psychological distress.

One in three had seen a doctor about emotional problems or problems with their nerves, and 14% had done this after their spouse's diagnosis of dementia.

Depression and anxiety were common. About 37% of carers reported clinically significant depressive symptoms and a further 40% reported levels of depressive symptoms that were not clinically significant. About 35% reported anxiety symptoms indicating borderline (15%) or probable (20.6%) mood disorders.

Anxiety, stress, burden and quality of life generally improved among those whose spouse had gone into long-term care and those who had been bereaved at the follow-up assessment. However, the carers' depression and distress did not change significantly over the follow-up period.

Men reported significantly better mental health, quality of life and life satisfaction than women.

Older carers tended to report fewer symptoms of depression, anxiety, distress, burden, and stress and they rated a better quality of life and life satisfaction than younger carers.

Overall, carers reported having relatively high quality of life, but participants who reported greater carer burden had poorer quality of life.



37% of carers reported clinically significant depressive symptoms and a further 40% reported levels of depressive symptoms that were not clinically significant.

How do spousal carers rate their own mental health?

Although nearly 80% of carers rated their current emotional or mental health as 'good' or better, depression, anxiety and burden were common – one in three had significant symptoms of depression.

Compared to women, men reported significantly better mental health, quality of life and life satisfaction.

Men and older carers rated caregiving more positively than did women and younger carers.

Carers who were female, younger and caring for individuals with more severe behavioural and psychological symptoms reported poorer sleep quality.

How isolated or socially connected are the carers?

Most carers (82.9%) engaged in an active and relatively social activity at least once a month and more than 70% reported engaging in such an activity weekly.

Women had higher levels of social connectedness than men, but women also tended to report significantly higher levels of loneliness and having fewer close contacts whom they see regularly.

How confident were carers about their ability to provide care?

A little over a third of carers (35.9% at baseline; 35.3% at follow-up) reported difficulty completing at least one core activity of daily living important for providing care, such as managing finances, preparing food, shopping for food, and/or managing appointments.

Carers tended to feel most confident about managing prescription medications, and a little less confident about managing their spouse's behavioural and psychological symptoms related to dementia.

Confidence in accessing support services was rated the lowest. Men and older carers felt more confident in their abilities to manage caregiving than women and younger carers.

Self-confidence in managing symptoms decreased significantly over time among those who were still providing care at home at follow-up.

Self-confidence in managing symptoms decreased significantly over time among those who were still providing care at home.



A third of carers reported having difficulty completing at least one core activity related to caring such as managing finances, preparing food, shopping for food, and/or managing appointments.

Spousal carers experience cognitive decline, but we found no strong mechanistic links with stress

Carers' cognitive functioning

At baseline, 84% of carers rated their memory as good or better than good. This figure was 81% in the follow-up sample a year later.

We found that one in five carers possibly had problems with cognitive functioning, and a similar proportion forgot to carry out an action they had been earlier instructed to perform.

Psychological stress did not predict carer cognitive decline

In the initial survey, we found that poorer executive function and poorer self-rated memory were significantly associated with greater stress, but these patterns were not consistent at follow-up a year later.

We saw no significant associations between changes in carer stress and changes in cognitive functioning over the year of the study.

In addition, no consistent relationships were observed between levels of stress at the initial assessment and cognitive performance at follow-up, when other factors such as age, gender, demographic and other health-related predictors of cognitive functioning were taken into consideration.

Overall, we did not find that greater carer stress predicts poorer cognitive functioning and greater cognitive decline.

Physiological stress did not predict carer cognitive decline

We looked at levels of cortisol (a stress-related hormone) in the saliva of carers, but we could not see strong links between this physiological measure of stress and cognitive performance. Also, there was no evidence that higher levels of cortisol predicted faster decline.

Genetic marker APOE-4 did not predict carer cognitive decline

We analysed saliva samples from carers for the APOE-4 allele, a genetic marker that is linked with increased susceptibility of developing Alzheimer disease. We found no evidence that this APOE status was related to carer psychological and/or physiological stress or cognitive performance.

Geography is not a huge factor

We found no differences between urban/rural and Dublin/non-Dublin carers on: measures of psychological wellbeing and burden; quality of life; sleep quality; frailty; number of medical conditions; social connectedness and loneliness; self-efficacy; time spent caregiving per day; amount of help caregiving received from others; care-recipient symptom severity and support service use (other than home-care received).

Carers living outside Dublin and in rural areas tended to be the most physically active and they reported receiving a greater number of home care hours.



The Implications

What are the main scientific findings of the De-Stress study?

Overall the De-Stress study showed that higher levels of burden in family members providing care to spouses with dementia were associated with poorer quality of life and were linked to an increased number of chronic health conditions in the carer and more severe behavioural and psychological symptoms in the person with dementia.

Depression is a risk factor for medical conditions, including dementia. We found that one in three carers had clinically significant symptoms of depression, and the prevalence of these symptoms did not decrease among those who were no longer providing care at follow-up. This suggests that caregivers are at a high risk of mental health problems and need continued support after their caregiving role ceases.

De-Stress also identified high levels of anxiety among carers. Findings raise concerns about some carers' ability to carry out complex tasks key to looking after a person with dementia, such as taking safety precautions, managing health care appointments and medication regimens.

Based on the sample studied over a follow up period of a year, we did not find evidence of a link between the stress-hormone cortisol and cognitive decline among spousal carers.

The findings of the De-Stress study do not support the hypothesis that carers with a genetic susceptibility to Alzheimer's disease (have at least one APOE-4 allele) are more vulnerable to the effects of psychological and/or physiological stress on cognitive functioning or decline.

How can the findings of the De-Stress study inform policy development in Ireland to better support family carers?

The findings of the De-Stress study provide information about the level and extent of care being provided, and chronic physical and mental health conditions among carers. This information can now be used to inform and develop more suitable policies and interventions to support the health and wellbeing of carers in Ireland.

Of particular interest are the high levels of mental health issues among carers such as depression and anxiety, which can have an impact on confidence.

These findings highlight the need for adequate supports for carers to safe-guard their mental health. As anxiety and quality of life generally improved after carers were no longer providing care at home, our findings suggest that these aspects of psychological wellbeing are related to caregiving and that they can be changed. Providing carers with supports that mimic such transitions in care (for example, sufficient respite) may go some way to improve psychological wellbeing.

As we found no relationships between formal support service use and better carer psychological wellbeing, our findings suggest that formal services do not address the real needs experienced by family carers in Ireland. This may be because formal services are not allocated based on the factors that contribute most to carers' stress and burden. Our findings suggest that the biggest contributing factor to carer stress and burden was the severity of the behavioural and psychological symptoms of dementia. Of note, carer's confidence in managing these symptoms decreased over time. This highlights the unique challenges of dementia care and the importance of considering these in the provision formal supports.

What are the practical implications arising from the De-Stress report?

The Alzheimer Society of Ireland has identified several practical steps and resources highlighted by the evidence from the De-Stress study:

- Carer assessment needs to be standardised and rolled out as a matter of urgency, and the mental health of carers needs to be recognised as a potential issue and be addressed.
- Family carers need to be viewed and included as partners in the care of the person with dementia, working with formal care providers.
- Health promotion supports targeted at family carers are needed to promote healthy lifestyles, manage chronic disease and facilitate social connections. This will help to sustain the person in their caring role.
- Self-care programmes are needed to enable family carers to look after themselves more effectively.
- Family carers need to be supported in understanding and responding to behavioural and psychological symptoms of dementia – this includes learning practical approaches and the increased availability of formal services to provide support.
- Care workers need to be aware that they have a key role as not only supporting the person with dementia, but also the family carer.
- Family carer support needs to recognise and respond to experiences of different stages of the dementia journey.

The findings of the De-Stress report will inform and help to refine family carer training carried out by the Alzheimer Society of Ireland.

What are the limitations of the De-Stress study?

The De-Stress study gathered data from family carers who volunteered to take part. Many of those who declined to participate reported that they felt they were under too much stress or did not have the time or ability to take part. Thus carers with the highest levels of burden and stress and with the least access to resources to help with caregiving and the poorest physical and psychological health were most likely underrepresented in the study.

The year-long follow up may have been too short to measure cognitive decline, and it may be that a longer period of study is needed to capture changes.

Carer assessment needs to be standardised and rolled out as a matter of urgency, and the mental health of carers needs to be recognised as a potential issue and be addressed.

Outreach

One key objective of De-Stress was to inform the development of targeted interventions to optimise carer health and make care in the community a viable option.

Thanks to additional funding from the Health Research Board under their Knowledge Exchange and Dissemination Scheme (KEDS) in collaboration with Trinity Healthy Brain, we have translated scientific content into useful, digestible and engaging short films and web content about health and wellbeing. These articles and films are available online and can be delivered to the public through facilitated workshops.

Based on the data collected in the De-Stress study and through consultation with carers and other experts the web and film content provides information on caring for the carer and managing the sometimes challenging behavioural and psychological symptoms of dementia.

The web resource – ‘Take the Stress out of Caring’ can be accessed at www.hellobrain.eu/carers.

The films we produced were ‘How can we support carers?’ and ‘How can I manage challenging behaviour?’, and our goal is to make more films if we can secure further funding to do so.

What’s Next?

De-Stress is an important baseline study that captures information about the health and wellbeing of spousal and family carers in Ireland of people with dementia in Ireland.

Further research is needed to explore the best ways to help caregivers become more confident and effective in dealing with the behavioral and psychological complications experienced by the person with dementia.

Future research should also consider the unique needs of dementia caregivers and how formal care services and supports can best be allocated and delivered to meet these needs and safeguard carers’ own mental and physical health.

Further research is needed to explore the best ways to help caregivers become more confident and effective in dealing with the behavioural and psychological complications experienced by the person with dementia.





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