Family Carers Report Poor Health and Quality of Life

We are pleased to announce the interim findings of our quantitative research on family carers’ health.

The research, presented at a seminar in October 2007, found that family carers are:

• 100% more likely to report fair / poor health compared to the population as a whole.
• 112% more likely to report having a poor or very poor quality of life.
• 36% more likely to report being dissatisfied with their health.
• Over 40% of family carers report having experienced stress or nervous tension.

In response to these findings, Liam O’Sullivan, National Development Officer for Care Alliance Ireland called for the introduction of a medical card for all of Ireland’s 161,000 family carers.

Enda Egan, CEO of The Carers’ Association, said: “This timely report provides further evidence to back up our call for the provision of more support to family carers, with a particular emphasis on improving the health of family carers in Ireland.”

Mary McMahon, CEO of Caring for Carers Ireland said; ‘Overload has a negative effect on the physical and mental wellbeing of family carers. Carers are an ‘at risk’ group with regard to their own health status.”

The final report is due to be launched in the next month, and will be available to view on our website: www.carealliance.ie.

Following discussion and reflection at the seminar, it was agreed to set up a research sub-group, to identify which aspects of it we can best use to progress issues for family carers, as well as feed into the upcoming development of a National Family Carers Strategy. The first meeting of this research sub-group took place on November 22nd and the group will continue to meet throughout the year. The news that we have been successful in securing three year funding from the Department of Community Rural and Gaeltacht Affairs has given a boost to this process, in particular as we plan to recruit a dedicated research officer later this year.
Dr. Geraldine Fennell (Board Member of Care Alliance Ireland) attends 20 Year Celebration of the Rosalynn Carter Caregiver Institute

Two days of intensive sessions – presentations and workshops – a welcoming reception and gala dinner, comprised the RCI celebration of 20 years’ existence. The programme was devoted to sessions presenting and discussing the ‘Re-aim’ approach to gaining acceptance and use among carer agencies and organisations for evidence-based findings from research. Geraldine felt the extensive travel was worthwhile to learn at first hand about RCI’s plan, with support from Johnson and Johnson, to bring cutting edge research findings to the fore to help family and professional caregivers.

For further information on the organisation see www.rosalynncarter.org

Care Alliance Board Meeting – July 2007

Some members of the board of Care Alliance Ireland at the July 2007 board meeting.

From left; Robin Webster (Age Action Ireland); Lydia O’Halloran (Irish Red Cross); Geraldine Fennell (Carers UK – Belfast Central); Rose O’Sullivan (West Cork Carers Support Group); Jean Day, Chair (Health Care Training); Kathleen Murphy (Newry and Mourne Carers); Catherine Keogh (Alzheimer Society of Ireland); Marie Lynch (Irish Hospice Foundation).
Department of Social and Family Affairs Announces Changes to Carer's Allowance

- Increase of €14 from €218 to €232 per week for recipients of Carer's Allowance aged 66 years and over.
- Increase of €14 from €200 to €214 per week for recipients of Carer's Allowance aged under 66 years.
- Increase of €14 from €200.70 to €214.70 per week for recipients of Carer's Benefit and Constant Attendance Allowance (from January 2008).
- Respite Care Grant to increase by €200 to €1,700 in respect of each care recipient (from June 2008).
- Weekly income disregard for Carer's Allowance will increase by €12.50/€25 to €332.50 (single) and €665 (couple) (from April 2008).
- Earnings threshold for entitlement to Carer's Benefit will increase by €12.50 to €332.50 per week (from April 2008).
- Any amount of Carer's Benefit, in excess of the basic SWA rate, will be disregarded for the purposes of Rent and Mortgage Interest Supplement, in line with existing arrangements for Carer's Allowance (from April 2008).

For further details you may contact the Department of Social and Family Affairs Information Line: 1890 66 22 44

International Brain Awareness Week 2008—March 10 -14th
Neurological Conditions: The Crisis of the Next Decade

A report carried out by the HSE has found that up to 800,000 people living in Ireland will be affected by neurological conditions by 2016. This will have significant implications for our health service, as the currently inadequate services for people with neurological conditions come under increased pressure. The Neurological Alliance of Ireland, the umbrella group for neurological charities, is organising a one-day conference to highlight this issue in Dublin on Tuesday 11th March.

The event ‘Neurological Conditions in the next decade’ will invite a number of high profile Irish speakers to present on these challenges. International Brain Awareness Week takes place in over 69 countries around the world. The NAI and its members are holding a series of events all around Ireland to mark the week.

Check out our website www.nai.ie for all details

Neurological Alliance of Ireland

Care Alliance Ireland Exchange
Design of an Assessment of Caregivers’ Impulsive Feelings to Commit Elder Abuse

Minhong Lee, Dong-Eui University, Pusan, South Korea, minhong@deu.ac.kr

Stacey Kolomer, University of Georgia, Athens

This study aims to identify the psychometric properties of the Impulsive Feelings to Commit Elder Abuse (IFCEA) scale. The sample included 387 South Korean family caregivers for their older family members with disabilities.

The internal consistency of the IFCEA was very good, and claims for the construct validity were demonstrated. Accordingly, the confirmatory factor analysis of the IFCEA confirmed that the scale had two factors: emotional abuse and physical abuse.

Conclusion: The IFCEA can be used by professionals to measure caregivers’ impulses to commit elder abuse as an early assessment in the caregiving relationship.

http://rsw.sagepub.com/cgi/content/abstract/17/6/729

Access to the full report requires a subscription via http://rsw.sagepub.com/cgi/reprint/17/6/729


Recent Studies on Informal and Formal Caregiving

"Job satisfaction rates are higher among formal caregivers who entered the profession after previously caring for a loved one informally.” American Journal of Alzheimer’s Disease and Other Dementias (September 2007)

The American Journal of Alzheimer’s Disease and Other Dementias published research reports touching on the job satisfaction of formal caregivers, caregiver sadness, and the impact of interventions on the caregiver. Notable findings included job satisfaction rates are higher among formal caregivers who have entered the profession after previously caring for a loved one informally; psycho-educational programmes may boost caregivers’ coping capacities and provide memory support for sufferers of dementia; and higher levels of a depressed mood were found in informal caregivers experiencing higher levels of disruption in their social relationships as a consequence of their caregiving.

For more information, click on the links at http://aja.sagepub.com
http://www.matherlifeways.com/aia10_07/

Counselling and Support’s Impact on Caregivers’ Health
American Journal of Geriatric Psychiatry (September 2007)

New York University researchers conducted a randomised, controlled trial where 406 families of people living with Alzheimer’s disease were enrolled in counselling and support programs. These families were compared to a control group over a period of 9.5 years. The results suggest that counselling and support provide both mental and physical health benefits to caregivers.

For more information, see the abstract at http://ajgponline.org/cgi/content/abstract/15/9/780
The Social Club Model of Dementia Care: A Research Report

“To be able to share experiences with people in similar situations is priceless; great friendships have been born and we as a group have shared some very happy and emotional days together”

This report highlights research carried out on the Social Club Model - a unique response to the needs of people with dementia and their spouse/carer in Ireland.

Social clubs are a gathering of people with dementia and their carers in a relaxed and supported environment, where social inclusion, the sharing of common experiences and enjoying each other’s company, are paramount. In their essence, they embrace the couple-hood of the person with dementia and their spouse.

This research report found the clubs to be beneficial to all involved. It highlights what is required to set up and sustain a social club, and the benefits as perceived by the members. It includes practical guidelines for developing and running a club as an appendix. The report also asks broader questions about the design of dementia services, the matrix of services that are offered, and the balance between more traditional models of dementia care and emerging models, like the social club model. The report aims to open up these questions for wider discussion in the dementia community, and influence policy-makers and service planners to think about couple-hood as a central concept of care.

For further information and a copy of the report, please contact Catherine Keogh, Care Practice Coordinator on (01) 284 6616 or email ckeogh@alzheimer.ie

A copy of the report will be available to download from the website in due course www.alzheimer.ie

Extra Care’s Family Carer Training and Support Programme

Extra Care’s Family Carer Training and Support Programme provides a resource for carers to enable them to carry out their caring role safely and effectively in their own particular situation. Each support programme is delivered on a one-to-one basis, usually in the carer’s own home covering areas such as Moving and Handling, and stress management. The content and pace of the training and support is tailored to each individual carer’s needs and circumstances.

In 2006 the Family Carer Programme was awarded a National Training Award, a major UK accolade. Funding has been secured to deliver this unique programme in Republic of Ireland.

For information contact:
Extra Care +44 (0) 28 9068 3273
Chronic Stress Can Steal Years from Caregivers' Lifetimes (Ref: Ohio State University, Sept 18, 2007)

The chronic stress that spouses and children develop while caring for Alzheimer's disease patients may shorten the caregivers' lives by as much as four to eight years, a new study suggests. The research also provides concrete evidence that the effects of chronic stress can be seen both at the genetic and molecular level in chronic caregivers' bodies.

The findings, reported this month by researchers from Ohio State University and the federal National Institute of Aging, were published in the Journal of Immunology.

These are the latest results from a nearly three decade-long programme at Ohio State University investigating the links between psychological stress and a weakened immune status. Previous studies have examined medical students, newlyweds, divorced spouses, widows, widowers and long-married couples, in each case looking for physiological effects caused by psychological stress.

In their recent study, Ronald Glaser, a professor of molecular virology, immunology and medical genetics, and Jan Kiecolt-Glaser, a professor of psychology and psychiatry, teamed with Nan-ping Weng and his research group from the National Institute of Aging. Earlier work by other researchers had shown that mothers caring for chronically ill children developed changes in their chromosomes that effectively amounted to several years of additional aging among those caregivers.

That work, remarkable as it was, looked only at a broad community of immune cells without identifying the specific immune components responsible for the changes. The Ohio State-NIA team wanted to identify the exact cells involved in the changes, as well as the mechanisms that caused them.

For the study, the researchers turned to a population of Alzheimer's disease caregivers they had worked with before, and compared them with an equal number of non-caregivers matched for age, gender and other aspects. They analysed blood samples from each group, looking for differences in both the telomeres and the enzyme, as well as populations of immune cells.

"Caregivers showed the same kind of patterns present in the study of mothers of chronically ill kids," Glaser said, adding that the changes the Ohio State/NIA team saw amounted to a shortened lifespan of four to eight years.

"We believe that the changes in these immune cells represent the whole cell population in the body, suggesting that all the body's cells have aged that same amount."

The caregivers also differed dramatically with the control group on psychological surveys intended to measure depression, a clear cause of stress.

"Those symptoms of depression in caregivers were twice as severe as those apparent among the control group," Kiecolt-Glaser said.

"Caregivers also had fewer lymphocytes," Glaser said, "a very important component of the immune system. They also showed a higher level of cytokines, molecules key to the inflammation response, than did the control group."

Other experiments showed that the actual telomeres in blood cells of caregivers were shorter than those of the controls, and that the level of the telomerase repair enzyme among caregivers was also lower. Kiecolt-Glaser said that there is ample epidemiological data showing that stressed caregivers die sooner than people not in that role.

"Now we have a good biological reason for why this is the case," she said. "We now have a mechanistic progression that shows why, in fact, stress is bad for you, how it gets into the body and how it gets translated into a bad biological outcome."

Much of the Ohio State work is now shifting to studies on how to intervene with that stress in hopes of slowing the weakening of the immune system in highly stressed people.
Offering simple training to people struggling to care for loved ones with Alzheimer's disease not only eases their burden – it even can keep patients out of nursing homes for an extra one and a half years. 406 elderly New Yorkers caring for spouses with Alzheimer's were tested. Half received training tailored to their family's unique needs. Half got today's standard: a list of Alzheimer's resources. Mittelman tracked these families for up to 17 years. Custom-trained caregivers kept their loved ones out of a nursing home for an average of one and a half years longer than their untrained counterparts. With annual nursing home costs now averaging US$60,000, that's a savings of US$90,000 per patient.

It didn't come at the spouse's expense, as trained caregivers experienced less depression and fewer physical health problems. Importantly, the training was simple: social workers met with caregivers once a week for six weeks, to assess each family's circumstances, discuss how Alzheimer's worsens and teach coping skills. Caregivers were given phone numbers to call counsellors for more advice whenever they wanted.

That ongoing tailored care is "a really crucial element," stresses Mittelman. Without it, when the patient "has a personality change and hits somebody for the first time in her life, you won't have anyone to turn to." Mittelman has begun new studies targeting training to early- and middle-stage Alzheimer's.

The US-based National Institutes of Health (NIH) is studying a similar programme that mixes in-home and telephone training, sessions that include role-playing to let caregivers practice the coping skills they're learning. The NIH study has tracked 640 dementia caregivers in five states for just six months so far. But initial results agree with Mittelman: trained caregivers report improved quality of life and feel they do a better job.

Together, the research represents a major shift in scientists' approach to Alzheimer's caregiving – from an emphasis on just giving families a break through respite care, to the idea of empowering them to better handle the stress of the job.


Jean Day, Chair, Care Alliance Ireland, speaking at the launch of Carers' Week 2007
Minister indulges in some retail therapy...

...and helps to make it stress-free for those with disability!

Christmas shopping at Headway, the national association for acquired brain injury, kicked off on 3rd December when Minister for Justice, Equality and Law Reform, and Fianna Fáil Dublin West TD, Brian Lenihan took part in our stress-free shopping evening for those with varying disability and their carers at Blanchardstown Centre.

"I was delighted to have been invited to the event, as Headway does so much work in the community to help those with acquired brain injury. 2007 was a really successful year and this was a great way to celebrate their successes," said the Minister.

"Headway clients developed this Retail Therapy event to overcome the difficulties they experience while Christmas shopping, such as accessibility, noise level, and communication difficulties. This was a fun and inclusive occasion for all, whether you were an individual with a disability, a carer or just somebody who could volunteer for a couple of hours" explained Deana Conaty, Day Rehabilitation Services Manager.

The centre was voted by Headway's clients as being the most disability-friendly shopping destination. Blanchardstown Centre has designated a car parking area for easy accessibility.

Lots of must-have Christmas items were donated by Sony and Gamestop as well as other retailers of the Blanchardstown Centre, such as the Body Shop, Budget Travel, McDonald's, Millie's, Newbridge Silver, Exit and O'Brien's Sandwich Bar. There was also a wrapping service for people with disability provided by Penney's.

"We were really pleased to be support this event," said Joe Gavin, General Manager of the Blanchardstown Centre, "and that our efforts to make the shopping centre accessible to all have been recognized by Headway's clients."

The event was a huge success and we are hoping that this will become an annual event. For more information on Headway, our services and upcoming events, please visit www.headway.ie.

Respite Break and Conference in Co. Clare

Caring for Carers Ireland’s forthcoming National Annual Respite Break and Conference will take place this year at the Clare Inn, Dromoland, Co. Clare from 7th-9th March. It is an integral part of the nurse-led programme of practical help and support to family carers and those for whom they care. The conference theme ‘the Future of Long-term Care in the Community: How to meet the needs of the Family Carer’ promises to spark insightful debate, with speakers to include:

President, National College of Ireland
Brigid Barron, Founder President, Eurocarers

Attendance will include over 450 family carers drawn from all regions throughout Ireland, together with group leaders, health and social care providers, policy-makers and decision-takers.

There are over 161,000 carers in Ireland. Family carers are dedicated people at all levels of society who care in the home for older people, people of all ages with disabilities and those with long-term illness. Their role may involve a 24 hour day and a seven day week, commitment without respite and often without sustainable financial help or emotional support.

Potentially, we may all be required to provide care for a family member at some stage in our lives. Ultimately, we will all need care.

This conference will provide a forum for discussion of key issues in health and community care provision.

For further information, contact: (065) 686 6515 or e-mail: mmcmahon@caringforcarers.org
Dergfinn Partnership Celebrates 10 Years

The Dergfinn Partnership’s 10th Anniversary Residential was held in Kee’s Hotel on Friday 16th November. Past and present committee members from Castlederg and Ballybofey and farther afield had an informative evening, a lovely meal, music and dance into the early hours. Jim O’Neil gave an excellent evaluation of the project’s work. Teresa Houston Laverty thanked everyone, including the committee and staff who were involved in the project that had made it such a tremendous success where it improved the quality of life of the disadvantaged, and especially their carers in the community. Paul Anderson, Dergfinn Project Manager since 1999, complimented the committee for their excellent support over the years which was unpaid, un-thanked, but had benefited so many. Paul gave a special thanks to Mary McNulty, Dergfinn Partnership administrator and to the funders’ support over the years, especially to Ciaran De Baroid of the Community Foundation of Northern Ireland who has been the main Project Officer representing the European Union Peace funders. The Dergfinn Partnership is part-financed by the European Union’s Programme for Peace and Reconciliation, managed for the Special EU Programmes Body by the Cross-border Consortium.

DergFinn Partnership Committee Past and Present

Back row from left to right: Dr. William Stewart (Derg Valley Care) Castlederg, Sylvia Burt (Sperrin Carers) Newtownstewart, Anka Warcholinska (Derg Admin Assistant) Letterkenny, Harriet McCafferty (Irish Wheelchair Association) Kilmecrennen, Charlie Bonner (Twin Towns Care of Aged) Ballybofey, Sean McMennamin (BorderArts) Castlederg, Gerald Sproule (Castlederg Enterprise Centre). Front row: Mary McNulty (DergFinn Administrator) Stranorlar, Elizabeth Given (Sperrin Carers) Artigavern, Teresa Houston Laverty (DergFinn Partnership Chairperson) Drumboe, Stranorlar, Theresa Browne (GROW), Crossroads, Muriel Perry (Donegal MS Branch) Convoy, Elma Harron (Childcare & Castlederg MS) Castlederg, Eileen McGlone (Formerly Sperrin NHS Lakeland now QE5) Omagh, at the DergFinn Partnership’s 10th Anniversary in Kee’s Hotel on Friday 16th November 2007. The DergFinn Carers Project is part-finance by the European Union’s Peace & Reconciliation Programme and the UK and Irish Governments through the Cross–border Consortium.
Two Presentation of Certificates Ceremonies for Carers in Galway, 14th September and 16th November 2007

Two carers ceremonies were held in September and November 2007 respectively, whereby carers in Galway graduated from care in the home training courses. Over 80 Carers were conferred with Certificates from the Irish Red Cross on Friday, 14th September for having undertaken a 13-week ‘Care in the Home’ Training Course, delivered by the Carers Department in Galway, HSE West, in partnership with Caring for Carers West, Údarás na Gaeltachta, and County Galway VEC. A total of four courses were delivered in Clifden, Dunmore, Claregalway and Gort. All 85 Carers were presented with Certificates by Éamon Ó Cuív T.D., Minister for Community, Rural and Gaeltacht Affairs in the Westwood House Hotel in Galway.

On Friday November 16th, 2007, 75 Carers were conferred with City & Guilds Institute (London) Certificates at a second ceremony in the Westwood House Hotel. Éamon Ó Cuív T.D., Minister for Community, Rural and Gaeltacht Affairs again presented the Carers with their Certificates. The Carers had all undertaken a similar ‘Care in the Home’ Training Course. Four courses were delivered in Inishmore and Lettermullen and two courses in Loughrea.

Other organisations involved in the delivery of these courses included: the Irish Red Cross, who were also involved in accrediting the courses, the Department of Social and Family Affairs, West of Ireland Alzheimer Foundation and FORUM.

The courses were provided for Informal Carers who are giving assistance on a voluntary basis to one or more family members, relatives, friends or neighbours, who have difficulties in looking after themselves, or in carrying out daily activities because of disability, age or long-standing illness.

The ‘Care in the Home’ Training Courses included First Aid and Emergencies, Practical Care Skills, Healthy Lifestyle & Nutrition, Moving and Lifting, Care of the Person with Dementia, Communication and Listening Skills, Fire Safety and Accident Prevention, Terminal Illness & Bereavement, Stress Management, Benefits and Entitlements, Support Services for Carers, Role of the Public Health Nursing Service, Home Help and Continence Promotion.

Michelle Harrison, Manager, Carers Department, HSE West, Galway said, “The demand for training courses for carers is likely to increase over coming years, which is related to a number of factors including an increasing population of older people and more and more people being cared for in the community. Previous evidence suggested that many carers have no training in care skills. This can lead to high levels of physical strain, isolation, and psychological distress. These training courses are a valuable way of assisting Carers, developing their personal skills and increasing their self-worth.

Evidence shows that training improves the quality of care provided and the quality of life of carers and care recipients. Research undertaken by the former Western Health Board, showed that training was identified as a major need by carers in Galway, Mayo and Roscommon. In response to these findings, Primary Community and Continuing Care Services, Galway, through the Carers Department, have co-funded and co-delivered a total of 20 ‘Care in the Home’ Training Courses over the past two and a half years in various locations in Galway City, County and the Islands, with further courses being planned for next year.”
‘Care in the Home’ Training Course certificates award ceremony, 14th September, 2007. Westwood House Hotel, Galway.

left to right
Michelle Harrison, Manager, Carers Department, Health Service Executive West; Carer from Dunmore Group Ann Daly; Alex MacLean, Acting General Manager, Primary Community and Continuing Care Services, Galway; Éamon Ó Cuív, T.D., Minister for Community, Rural and Gaeltacht Affairs; Bríd Lynch, Development Officer, Caring for Carers West; Carer from Claregalway Group, Frances Molloy.


left to right
Alex MacLean, A/ General Manager, HSE West, Primary Community and Continuing Care Services, Galway; Carer Maisie Frehill, Loughrea Course Graduate; Eamon Ó Cuív, T.D., Minister for Community, Rural and Gaeltacht Affairs; Carer Caroline O’ Loughlin, Lettermullen Course Graduate; Michelle Harrison, Manager, Carers Department, HSE West, Primary Community and Continuing Care Services, Galway.
Care Alliance Ireland is the National Network of Voluntary Organisations supporting family carers. Its main aim is to bring together voluntary groups supporting family carers to exchange information and to develop more effective policies and services for such carers.

Care Alliance Ireland was established in 1995 and currently represents a network of over 65 voluntary organisations concerned with the needs of family carers.

Care Alliance Ireland’s activities include providing Newsletters, Research, Annual Seminars and Interagency Networking.

To find about more about Care Alliance please visit our website or contact us by telephone or email.

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Carers’ Week Pictures 2007

Liam O’Sullivan (Care Alliance Ireland), Jean Day, Chair (Care Alliance Ireland), Anthony Carrick, (Disability Federation of Ireland) at the launch of Carers’ Week 2007

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