

Care Alliance Ireland

Exchange

Winter 2014 Issue 45

Major Report Launched on the Relationship between Family Carers and Home Care Workers

Launched on 18 November, this is the first report of its kind to pull together all the major research in the topic. A key aspect of care for those with care needs is often overlooked. This report has successfully brought together the major research on this topic and has distilled down the key points. Commissioned by Care Alliance Ireland and authored by Ann Stokes, this peer reviewed report is adding to our understanding of the key relational issues that occur in home care settings.

Speaking on the launch of the report, Gerry McCaffrey, Chairperson, Care Alliance Ireland, said "This piece of work, nearly two years in the making, is a major contribution to Family Carer research and in particular an aspect over overlooked – that is the triadic and often interdependent relationship between a paid home care worker, a client in need of support and the wider family. We look forward to building on this work into the future".

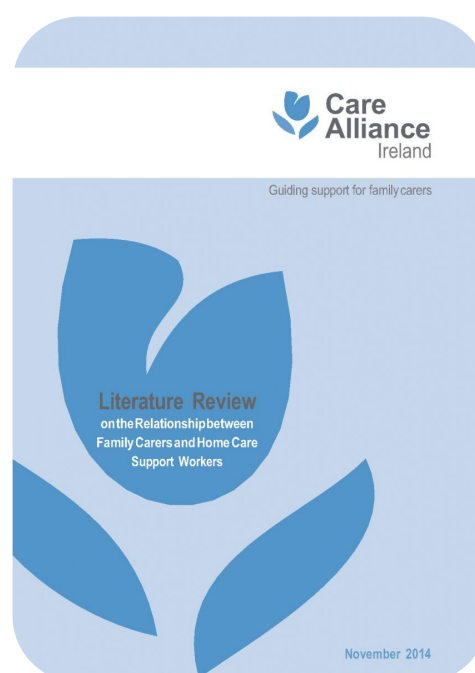
The full report is available to view at <http://bit.ly/1xJvKMF>.

A summary document is also available to view at <http://bit.ly/1HuD1Tm>.

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News

Report on the Relationship between Family Carers and Home Care Workers

Findings:

- Home-based care involves a number of different parties: the person in receipt of care; often at least one family carer; one or more home care support workers; and a range of professional staff.
- Although caring as a whole has been well-researched, far less attention has been paid to the dynamic of the relationship between the person being cared for, the family carer and home care support workers, with an almost complete absence of Irish research.
- There is increasing recognition that models of care provision need to adopt a relationship-based approach, in preference to one that focuses solely on the individual in need of care and/or that only notes the division of labour between different roles.
- Unfortunately, the literature rarely defines what is meant by 'relationship' and if/how this differentiates from 'interactions'.
- Various enablers to quality relationships between home care support workers and family members have been identified, including, but not limited to: common goals; spending time together; continuity; honest communication; mutual respect; compassion; friendliness; reciprocity; and shared values.
- Conversely, numerous barriers to positive relationships between home care support workers and family members have also been identified, including, but not limited to: lack of contact; disregard for expertise; unrealistic expectations; and the structure and approaches of associated professional services.
- Researching the specific experiences of family carers in terms of their relationship with home care support workers, it has been found that they value services that are appropriate and competent, but that they consider positive relations to be equally important.
- Researching the specific experiences of home care support workers in terms of their relationship with family carers, it has been found that the challenges posed by poor working conditions can negatively affect their ability to provide high quality care (this includes: lack of training; dirty work; workload pressures; unpredictable scheduling; unsocial hours; lack of supervision; feeling trapped; being taken for granted; low pay).
- Home based care in a palliative context adds another layer of complexity to the dynamic between the person at the end of their life and their carers.
- The roles of family carers and home care support workers are undeniably interlinked and the two systems of care need to be planned and implemented not alongside each other but together.

News

Annual General Meeting Report

Our 19th AGM took place on 16 September and was well attended by a large number of our member organisations. Chairperson Gerry McCaffrey brought the members through our 2013 Directors Annual Report and Financial Statements, which are fully SORP compliant. He summarised our activities and achievements in 2013 and spoke of the exciting times ahead for Care Alliance Ireland, in particular as we begin the process of recruiting a Policy and Research Officer.

We in Care Alliance Ireland endeavour to demonstrate the highest levels of corporate governance as evidenced by our full compliance with the Governance Code.

Immediately before the AGM separate presentations were given by two of our Directors. Avril Eason, who was heavily involved in drafting our Strategic Plan, presented it to the audience and outlined the actions we would be delivering over the coming years to make the plan a reality (available to view at <http://bit.ly/1wqV58I>). With the enhanced funding we have received over the period 2014 to 2016 under the Scheme to Support National Voluntary Organisations, we have set some ambitious targets. Clare Duffy then spoke about the work of the National Carers' Strategy Monitoring group. The group, which is led by the Carers Association, where Clare works, is working intensively to ensure that the commitments made in the 2012 National Carers' Strategy are delivered on. Both presentations are available to view on our website www.carealliance.ie.



Outgoing Directors with other directors Avril Easton, Ann Kavanagh (outgoing), Geraldine Clarke (outgoing), Dr. Gerry McCaffrey, Marie Lynch (outgoing), Dermot Maguire, Clare Duffy, Fergus O'Rourke, Robin Webster (outgoing)



Avril Easton (left) and Clare Duffy speaking at the Care Alliance Ireland AGM on 16 September, 2014



News

New Members Strengthen the Board

We are delighted to have five new directors in Care Alliance Ireland. Four were nominated by member organisations in advance of the AGM, whilst one had been co-opted onto the board earlier in the year and was subsequently elected at the AGM. Meet them here:

Fergus O'Rourke

Fergus has worked as an IT analyst and business analyst in various financial services organisations. He has carried out voluntary work for several Irish and British charities. Fergus is an Associate of the Chartered Institute of Management Accountants.



Rosemary Daynes

Rosemary is a Regional Coordinator of Crosscare Community and Food Services. She has been working with Family Carers for the last six years through the Crosscare Carers Support Programme. She has a BA in Psychology and a MA in Development Studies. Rosemary has experience of being a Family Carer in her personal life.



Deirdre Shanagher

Deirdre is currently working with the Irish Hospice Foundation as a Development Officer. She is a registered general nurse who has worked as a nurse and nurse manager for even years, primarily in a nursing home setting. Deirdre obtained a MSc in Gerontological Nursing in 2011 and is a member of the All Ireland Gerontological Nurses Association and the Irish Association of Palliative Care.



Speaking on Deirdre's election, Sharon Foley, CEO of the Irish Hospice Foundation said: "The Irish Hospice Foundation are delighted to continue working with Care Alliance Ireland in highlighting and advancing the needs of Family Carers across the country as they care for people with a life threatening illness right to the end of life and into bereavement after their caring role ends. The recent election of Deirdre Shanagher to the board of Care Alliance Ireland signals our continued commitment to Family Carers who provide end-of-life care right across the country and we look forward to this ongoing engagement with the alliance during Deirdre's tenure on the board".

News

Jimmy Duggan

Jimmy worked for 39 years in the Department of Health in a variety of roles including the Office of the Minister, human resources, finance and service areas including hospital care, drug misuse, older people and palliative care. Prior to his retirement in 2009, he headed up the Primary Care Division of the Department with specific responsibility for a number of services including general practitioner services and the Primary Care Strategy. He has been a Director of Caring for Carers Ireland for a number of years and is currently Vice-Chairman.



Speaking on Jimmy's election, Caring For Carers Ireland said: "We are looking forward to working with the organisation on issues of concern which relate to Family Carers"

Ann Walsh

Ann was first introduced to the role of a Family Carer at age 14 when she looked after her elderly grandaunt in her summer holidays. She returned to this role later in life when her husband became seriously ill and in addition looked after her late mother when she needed full-time care. She is passionate about home carers getting the recognition they deserve and chose this as the topic of her thesis when she studied and gained a First Class Honours degree in Community Development. She became involved with the Donegal Carers Association and later was Secretary for a number of years of a local carers support group. She volunteers in the community and voluntary sector and serves on a number of voluntary boards.



Speaking on Ann's election, Ann Kavanagh, Chairperson, Donegal Carers, said "We know Ann Walsh will represent all Carers not just Donegal Carers as our representative in Care Alliance and her contribution will be to all our benefit."



Some new Directors at a board induction session, 20 October 2014

News

Strategic Plan Launched at Annual General Meeting

Following extensive consultation with our member organisations, potential member organisations and a wide array of other stakeholders, our new strategic plan was formally launched at our AGM on 16 September.

Speaking on the occasion of the launch, Chairperson Gerry McCaffrey said: “This new plan positions Care Alliance at the heart of the Family Caring sector. In supporting our members in their direct work with Family Carers we can be confident that into the future the services they provide for Ireland’s Family Carers will continue to improve and deliver tangible positive outcomes for the people they serve. We are delighted to be recruiting for a new Policy and Research position have no doubt that this new appointment will bring real added value to the sector”.

This plan builds on the achievements of the previous strategic plan and is based on those guiding principles which are fundamental to the work we do: raising awareness of Family Carers and enhancing their quality of life through effective collaboration, networking and partnership with our member organisations and other stakeholders. The plan identifies our strategic priorities for the next three years, whilst recognising the challenges that face our member organisations and the caring sector as a whole.



Liam O'Sullivan, Executive Director, and Dr Gerry McCaffrey, Chairperson, at the launch of our Strategic Plan

Strategic Priorities for 2014 to 2017

1. Providing a united voice for, and strengthening the impact and relevance of, Family Caring organisations in Ireland.
2. Providing up-to-date, relevant information to our members in a timely and accessible manner.
3. Supporting primary and applied research on Family Caring and the role of Family Carers.
4. Building the profile and raising awareness of Care Alliance Ireland.
5. Ensuring we have the capacity and resources to progress strategic priorities.
6. Supporting member organisations and international alliances

Full details of the plan can be found on our website www.carealliance.ie.

News

Care Alliance Ireland Recruiting - Policy and Research Officer

Thanks to receipt of enhanced funding under the Scheme to Support National Voluntary Organisations, we are recruiting a Policy and Research Officer to complement our current staff. Interviews for the position took place on 18 November and we look forward to introducing our new team member to you over the coming weeks and months. The new role will enable us to focus on increasing the depth and breadth of our work in the policy and research domains and we look forward to actively engaging with member organisations and other stakeholders in maximising the impact of this new resource.

News In Numbers

€51

The value of the partial restoration of the Christmas Bonus to Family Carers in receipt of the Carers Allowance

5.2%

GNP growth predicted by the ESRI in 2015

57 years

The mean age of respondents to study on carer stress (see page 18)

8,651

Number of followers on National Carers Week Facebook page
www.facebook.com/nationalcarersweek

€35m

Additional ring-fenced amount for mental health services in Budget 2015

6,833

Number of unique visitors to www.carealliance.ie year to date, up 14% on 2013 levels

1,309

Number of downloads of young adult carers booklet (to download go to <http://bit.ly/1yU0xns>)

National News

The Palliative Hub

The Children and Young People Palliative Care website has been developed by The All Ireland Institute of Hospice and Palliative Care (AIHPC) with a number of collaborators to act as a gateway to information about children and young people's palliative care on the island of Ireland.



It is aimed primarily at assisting parents, guardians, carers and the wider public in understanding what children's palliative care is and seeks to help filter the wide range of information available on the internet.

There was a recognised need from within the palliative care community, both in the Republic of Ireland and in Northern Ireland, for a dedicated children's palliative care website, to provide general information about children's palliative care and a central point that parents, carers and the general public can use to access specific information, such as services offered by organisations. This access is provided via links and downloadable documents.

Throughout the website you will see a number of photos, stories and quotes. All of these are of real children and parents who have availed of palliative care services in Northern Ireland or the Republic of Ireland. We would like to especially thank them for allowing us to share their photos and experiences with the wider public.

This website is part funded by the International Charity Bazaar, the Diplomatic Corps in Dublin's voluntary fundraising organisation, and the AIHPC. The AIHPC is funded by a consortium of funders led by the Atlantic Philanthropies, with additional funding from the Health Research Board, Irish Cancer Society, Irish Hospice Foundation and the Public Health Agency. For further information see the Institute website - <http://bit.ly/1y6gOWz>.

Carers' Strategy Monitoring Group – Update

The group continues to meet regularly and representatives have now met with officials in seven different government departments, seeking their full engagement in implementing the commitments made in the 2012 National Carers' Strategy.

The group looks forward to the second report on the progress towards implementing the Strategy, that we understand will be published over the coming weeks.

National News

Budget 2015

Budget 2015 has been described by many as a turning point. There was nonetheless major disappointment that the Respite Care Grant was not restored to its previous levels. Some changes to income supports for eligible Family Carers are detailed below.



Water Conservation Grant

There will be a water conservation grant of €100 per year that will be available for all primary residences of customers who apply to Irish Water, payable through the Department of Social Protection.

Christmas Bonus

A Christmas Bonus of 25% of the rate of the weekly payment will be paid to all long-term welfare recipients in early December, at a cost of over €63 million. The Tánaiste said: "The Christmas Bonus was abolished by the previous Government in 2009. I am pleased to say that I am in a position to partially restore the Bonus this year – it is in recognition of the position of vulnerable households".

Source: www.welfare.ie <http://bit.ly/1upuFJ7>

Some member organisations responses to the Budget

The Carers Association

"angry that cut to family carers' Respite Care Grant was not reversed in Budget 2015". See <http://bit.ly/1t7V07I>



The Irish Heart Foundation

"Cigarette hike will save lives, but failure to impose sugary drinks tax a missed opportunity." See <http://bit.ly/1wtETqF>



IRISH HEART
FOUNDATION

The Irish Hospice Foundation

"Chief Executive Sharon Foley called for some of the €25 million allocated in the health budget to deal with delayed discharges in hospitals to be used to support and augment specialist palliative care services in the community including hospice homecare teams, nurses for nightcare and children's outreach nurses." See <http://bit.ly/1uoBOst>



National News

Charities Regulator Established

1. The Charities Regulatory Authority (CRA) was formally established on 16 October 2014.
2. There will be no immediate effect on your organisation's work or fundraising, and there is no immediate action that your organisation needs to take.
3. The website is now live and contains a register of all charities in Ireland that have a CHY number, as issued by the Revenue Commissioners.
4. All CHY charities are now automatically be deemed registered charities under the 2009 Charities Act and each of these charities will be issued with an Irish Registered Charity number.
5. Over the coming months (anticipated to be between 16 October and February/March 2015), the CRA will write to each organisation on the register, inviting them to visit the online registration page in order to provide additional required information. The CRA will supply these organisations with a PIN number for these purposes and it is expected that the first such invitation will be issued in late October.
6. The act also requires that all organisations that DO NOT have a CHY number and:
 - have a charitable purpose
 - are formally constituted as not-for-profit (or public benefit) organisations
 - raise or apply funds for a charitable purposeseek inclusion in the register of charities within 6 months of establishment day.
7. Organisations that are in doubt as to their charitable status should seek inclusion the register.



Charities Regulator,
Úna Ní Dhubhghaill

Source: The Wheel, 16 October 2014

See www.charitiesregulatoryauthority.ie

Governance Corner

KnowledgeNET



carmichaelcentre
KnowledgeNET

Does your organisation demonstrate good governance?
How would you know? Have you read Carmichael Centre's resources on this topic? See the KnowledgeNet resources on governance at <http://bit.ly/1phv2nc>. Care Alliance Ireland is keen to support member organisations in their quest for good governance. Contact info@carealliance.ie.

Update on Care Alliance Governance – November 2014

Many of you will recall that in November 2013 the board of Care Alliance Ireland declared our full compliance with the Governance Code for Community and Voluntary Organisations.

A thorough review of our current compliance status was undertaken in October of this year, using the Governance Code's self assessment checklist and a report on this was presented at the 18 November board meeting. The review found that a number of current policies need to be reviewed, a continuity plan needs to be documented and a Health and Safety Statement needs to be drafted. One other item requiring addressing is that the terms of reference for the Audit and Risk Committee will be put to our member organisations for their approval at the next annual general meeting. For more information on the code, see www.governancecode.ie.

Governance Code Compliance Numbers

97

Organisations fully compliant with Governance Code,
up 28% since May 2014

517

Organisations 'on the journey' towards compliance,
up 44% since May 2014

Member News

The Alzheimer Society of Ireland's #LivingWithDementia Campaign



On 17 September the Alzheimer Society of Ireland (ASI) launched its #LivingWithDementia campaign. The campaign centres on the theme of living well with dementia and talking about dementia with friends and family. The campaign launched in Dublin city centre with an exclusive screening of two new short films to an audience of over 100 guests.

The films present the lives of two people living with dementia in different ways. The first film featured Kathy Ryan, who has early onset dementia and lives with her two sons. In the film Kathy talks about learning about her diagnosis and her hopes and fears for the future. The second film features Sean Donal O'Shea who cares for his mother, Debbie, who has advanced early onset dementia. Sean Donal talks about how his mother's diagnosis changed his life and that of his family. Both films capture the realities of living with dementia and how dementia affects each person differently. There has been an overwhelming response to the videos online, having been shared on national media platforms, ASI's YouTube channel, as well as www.alzheimer.ie along with receiving 50,000 views on the ASI's Facebook page (and this number continues to grow).

The ASI has also developed a range of new information resources to support people with dementia who are recently diagnosed. Developed in partnership with the Irish Dementia Working Group, the new resources reflect the lived experience of people with dementia, their words and their experiences. They cover areas such as what to do after a diagnosis, how to live well day-to-day and driving. They also include a new help-card to support people when they are out and about in their communities.

Copies are available on www.alzheimer.ie or by calling the helpline number 1800 341 341. For more information on #LivingWithDementia visit www.alzheimer.ie.



Member News

Information Pack for Carers launched in West Cork



WEST CORK CARERS SUPPORT GROUP
Supporting Carers in West Cork since 1998

Citizens Information

Public Service Information
Provided by the Citizens Information Board

The launch of a new information pack, which gives an overview of the supports and services available to Family Carers in West Cork was welcomed in Cork any beyond this October. The pack which, is a joint initiative by West Cork Citizens Information Service and West Cork Carers Support Group, is a valuable resource for the many people who provide care for family members, neighbours or friends who are sick or infirm. It is also a good example of local agencies working together to pool resources and expertise for the benefit of the local community.

The reality is that at some point most of us will either give or receive care. It is a role that we may inherit along with other family responsibilities or one that can be thrust upon us as a result of unexpected illness or an accident. Whichever the case, it is important that we have knowledge about the supports and services available.

Information about income supports, HSE supports, housing grants and tax credits as well as important information about the different stages of caring, managing medications and ways that carers can look after their own health and well-being are all included in this pack.

The pack, which is free, is available from West Cork Citizens Information Service, Wolfe Tone Square, Bantry, Tel: 0761 07 8390 and West Cork Carers Support Group, Bridge Street, Bantry, Tel: 027 53848.

West Cork Citizens Information Service provides an independent information, advice and advocacy service to the community on rights and entitlements. It is a free and confidential service, which is funded by the Citizens Information Board.

West Cork Carers Support Group provides a wide range of services and supports aimed at improving the quality of life of Carers. The group is open to all Carers, whether they care for a family member, friend or neighbour. Supports are provided to Carers of older persons, to Carers of children or adults with a long-term illness or physical or intellectual disability and to Carers of persons experiencing mental distress. It is funded and supported by the HSE.

"I wish that this pack had been available five years ago when my mother became ill and we had to provide full-time care for her. It would have helped me access the supports and services I needed. It should be made available to every new Carer from the beginning."



Staff of West Cork Carers launching the carers information pack

Member News

Palliative care needs of Family Carers



Family Carers play a vital role in the care of people with progressive life-limiting disease. While Family Carers are generally happy to support their loved ones on their final journey, they often undertake this work without any formal acknowledgment or support. The Irish Hospice Foundation is cognisant of the journey that Family Carers take with their loved one as together they face death, and after death, the Family Carer faces bereavement. In the absence of an end-of-life care strategy and pending full implementation of the National Carers' Strategy, the Irish Hospice Foundation is committed to supporting family carers providing end-of-life care. To inform this work in supporting Family Carers, a literature review was carried out.

The literature illustrated that the role of being a Family Carer providing end-of-life care is complex, often undervalued and underrepresented. Family carers were identified as being of value to Irish society and to the Irish economy. However, Family Carers were also found to require support in the form of timely and appropriate information, respite care and financial assistance. The impact of being a Family Carer was apparent in the literature with carer burden being raised consistently with experiences of anxiety and depression. In addition, the literature review identified that Family Carers experience higher amounts of isolation when being in the caring role and were found to experience significant losses upon the death of their loved one or on transition to a continuing care setting. The importance of including Family Carers in care decisions was highlighted. However, patient autonomy and sense of self were also found to be important, and the need for striking a balance between the two was highlighted. Due to the round-the-clock nature of care, Family Carers require ongoing support, respite, information and encouragement to manage and maintain social networks. They also require that their bereavement needs be met and acknowledgement that bereavement needs may become prominent before their loved one has died.

The Irish Hospice Foundation currently hosts the CARE website www.carers.ie that provides practical information and guidance for people who are caring for someone who has been diagnosed with a life-threatening illness and where there is a reasonable possibility that this person will die within six months. We are interested in receiving feedback in relation to this and connecting with anyone who has an interest in this area. Please contact: deirdre.shanagher@hospicefoundation.ie.

Caring in the News

Selection of media coverage of caring related issues since September 2014

Talking found to help dementia patients – The Irish Times – 3 September 2014

<http://bit.ly/1B4FMKk>

New app aims to help people caring for relatives with dementia – Irish Independent – 9 September 2014

<http://bit.ly/1olsfmd>

Family Carers to benefit from new merger – Nationalist – 17 September 2014

<http://bit.ly/14aJgfK>

New advice information pack for carers launched – Southern Star – 10 October 2014

<http://bit.ly/1B4G8AT>

Carers save the State €77m every week: why are we not rewarded? – Irish Independent – 15 October 2014

<http://bit.ly/10T8cWT>

Pressure of caring role highlighted by College of Psychiatry of Ireland – Irish Medical Times – 16 October 2014

<http://bit.ly/1whT12q>

Thousands sign petition for restoration of respite grant for carers – Irish Times – 27 October 2014

<http://bit.ly/10T8j51>

Reading for Life: MS sufferer makes most of every day – Irish Independent – 27 October 2014

<http://bit.ly/1xg4epE>

Married to Alzheimers: how we faced reality in Tony's twilight zone – Irish Times – 28 October 2014

<http://bit.ly/1wzI9iY>

21 family carers receive special awards – RTÉ News – 12 November 2014

<http://bit.ly/1xMg0ov>

Irish Research and Practice Reports

Care Alliance Ireland and Trinity College Research on Post-Caring accepted for Journal Publication

The 2011 research report, *Between worlds: the experiences and needs of former Family Carers*, has been accepted for publication in the prestigious journal *Health & Social Care in the Community*.

Abstract

While the financial, physical and psycho-social burden for caregivers is recorded, less is known about the post-caring experience. The purpose of this qualitative descriptive study was to explore the experiences and needs of Irish former Family Carers in the post-caring and care transitions period. Former Family Carers were defined as family members who provided physical and/or social care to a family member with an illness or disability in the home for at least 6 months prior to nursing home/hospice placement or death. A total of 40 Family Carers were recruited from members of, or known to, voluntary care groups/associations in Ireland. Fourteen participants took part in a focus group discussion and 26 participated in one-to-one, semi-structured interviews, all of which were undertaken in 2010. The focus group discussion focused on gaining a broad understanding of the participants' post-caring experiences and the emergent themes formed the basis for the development of a semi-structured interview guide. Data from the focus group were analysed inductively using Creswell's qualitative analysis framework, while template analysis was the method of analysis for the 26 individual interviews. For the participants in this study, post-caring was a transition that comprised three, interrelated, non-linear, iterative themes that were represented as 'loss of the caring world', 'living in loss' and 'moving on' and symbolised as being 'between worlds'. Transition was a complex interplay of emotions overlaid with economic and social concerns that had implications for their sense of health and well-being. This exploratory study begins to address the dearth of data on post-caring/care experiences, but further research is needed to inform support interventions to enable former family carers to 'move on'.

Authors: Patricia Cronin, Geralyn Hynes, Marianne Breen, Mary McCarron, Philip McCallion and Liam O'Sullivan.

Speaking on the news, Liam O'Sullivan, one of the authors of the report, said "It's wonderful for this research to be given a platform for further dissemination. Its inclusion in this widely read journal will make a big impact on its reach. Caring does eventually end and the wider health and social care community must be cognisant of the needs of this significant cohort of people".

Irish Research and Practice Reports

University of Limerick Researchers Identify the Value of Benefit Finding in Caring

Social support mediates the association between benefit finding and quality of life



Published in the September 2014 edition of the *Journal of Health Psychology*, three University of Limerick researchers report on how benefit finding can help Family Carers.

Abstract

The psychosocial pathways underlying associations between benefit finding and quality of life are poorly understood. Here, we examined associations between benefit finding, social support, optimism and quality of life in a sample of 84 caregivers. Results revealed that quality of life was predicted by benefit finding, optimism and social support. Moreover, the association between benefit finding and quality of life was explained by social support, but not optimism; caregivers who reported greater benefit finding perceived their social support be higher and this, in turn, had a positive effect on their overall quality of life. These results underscore the importance of harnessing benefit finding to enhance caregiver quality of life.

Authors: Charles Brand, Lorna Barry and Stephen Gallagher

Journal of Health Psychology published online 9 September 2014, <http://bit.ly/1tleEXC>.

Speaking on the findings, Dr. Stephen Gallagher, a Health Psychologist from the Centre for Social Issues Research at the University of Limerick, said that their research found that caregivers report a higher quality of life if they look at their caring role in a positive light.

Dr. Gallagher and his colleagues Charles Brand and Lorna Barry wanted to examine the positive aspects of caregiving and to see if these would be associated with better quality of life. He said: "We found that carers who were caring mostly for people with mental health problems, were more likely to report a better quality of life if they viewed their role as bringing benefit to their lives. These benefits, such as being more grateful, having a new sense of purpose, having more patience and new responsibility, led to a feeling of being more supported which in turn contributed to improvements in caregiver's quality of life".

This study is in direct contrast to others that have found caring to be hazardous for health and demonstrates for the first time that when viewed from a more positive standpoint, caring may be less detrimental for health.

Dr. Gallagher also said: "Although our results help to raise awareness of possible benefits of looking at caregiving roles differently, the challenges faced by many caregivers, especially in the current economic climate where there is often uncertainty about service availability and funding supports may impact on shifting from the negative to the positive."

Irish Research and Practice Reports

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



Overall Aim

The overall aim of the study was to examine family carers' experiences of caring for an older person and explore the impact of caregiving on the carer and the conflict that may arise within the caregiving relationship.

Authors: Dr. Attracta Lafferty, Prof. Gerard Fealy, Ms. Carmel Downes & Prof. Jonathan Drennan, National Centre for the Protection of Older People, University College Dublin

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 a 58% response rate.

Summary Findings

Carer Profile

- 43.7% of carers were found to be at risk of clinical depression, and such depressive symptoms are associated with potentially harmful carer behaviour.
- 48.3% of carers looked after an older family member for more than 80 hours a week.
- Approximately one-third of carers reported that they experienced moderate to severe or severe burden.
- 85% of carers reported feeling that they 'often or always' coped well as a caregiver and over three quarters indicated that they 'often or always' found caregiving worthwhile (79%).
- 43% of carers reported that they never or only sometimes felt supported in their caregiving roles.

Routine screening of both the carer and care recipient is necessary to identify carers at risk of engaging in abusive behaviours

Mistreatment Experienced by Carers

- 56% of carers reported experiencing some form of mistreatment by the care recipient in the previous three months.
- 13% reported being physically mistreated by the care recipient in the previous three months

Continued on page 19

Irish Research and Practice Reports

Family Carers of Older People: Results of a National Survey of Stress, Conflict and Coping (con't)

Potentially Harmful Behaviours (PHBs) Engaged in by Carers

- Overall, a third (37%) of carers reported engaging in PHBs in the previous three months, with 17% reporting that they did so at least sometimes.
- 8% of carers reported that they engaged in any potentially harmful physical behaviour, and 2.7% reported that they engaged in such behaviours towards the care recipient at least sometimes in the previous three months
- Verbal abuse was the most commonly reported form of abuse engaged in by carers

Caregiving Factors Associated with PHBs

- Perceived quality of caregiving relationship (poor/fair)
- Relationship to the care recipient (spousal carer)
- Duration of care (providing care for longer)
- Hours of care provided a week (greater number of hours)
- Levels of help provided (higher levels of care provided)
- Appraisal of the caregiving experience (less positively valued)
- Perceived adequacy of social and professional support (perceived less adequate)

Care Recipient Factors Associated with PHBs

- Dementia diagnosis
- Age of the care recipient (64 to 74 years)
- Higher dependency levels

The full report and two page fact sheet are available to view at <http://bit.ly/1x2Xrx6>.

Carer burden, being a male carer and having a poor perception of the quality of the carer-care recipient relationship were the strongest predictors of PHBs

Irish Research and Practice Reports

Irish research published in British Journal of Mental Health Nursing



Family Carers: lived experience of caring for relatives with an SMI (Serious Mental Illness)

This study explored Family Carers' lived experience of caring for a relative with an ongoing mental illness. An interpretative phenomenological approach was adopted. Participants (n = 8) were self-selecting and members of SHINE, an Irish voluntary organisation supporting people with mental illness and their families. Three super-ordinate themes were interpreted from the interview data. The first theme, 'nobody told me this was the way it is' represents participants' experiences of not understanding what was happening to their relative and what they should do when their relative was first diagnosed. The second theme, 'feeling excluded', represents the participants' sense of exclusion. For some, the reason for this exclusion was because of the confidentiality embedded in the Mental Health Act. The final theme, 'you don't feel judged' represents the importance of the support group to participants, especially at the beginning when their relative was first diagnosed. The study findings illustrate the importance of education for relatives, and the role support groups play in support and education.

Authors: Anne Cleary, Francis Walsh, Maura Dowling

British Journal of Mental Health Nursing | Vol. 3 | No. 4 | pp 151–156

<http://dx.doi.org/10.12968/bjmh.2014.3.4.151>

<http://www.magonlinelibrary.com/toc/bjmh/3/4>

The Irish National Dementia Educational Needs Analysis 2014 Report Published

"In this study the general practitioners we spoke with had a good working knowledge of the dementia care pathway in principle, but very little confidence in its existence in their local area in most cases."

Excerpt of conclusion section of the Irish National Dementia Educational Needs Analysis 2014 Report (p. 76). For more see www.dementiaelevator.ie.

International Research

Technology and Caregiving: US Report Finds Three Key Supports Required

Research Catalyzing Technology to Support Family Caregiving

Authors: Richard Adler & Rajiv Mehta, National Alliance for Caregiving

The roundtable discussion of key actors in the US Caregiving field reported that successful caregiving technologies require three supports:

Framing the Issues

- Mapping the landscape
- Creating shared language
- Collecting relevant data

Creating a Fertile Environment

- Spurring a national conversation
- Developing business cases

Maximizing the Value

- Coaching complements technology
- Inspiring social conversations.

The full report can be read at <http://bit.ly/caretech14>.

Fifth Global Forum on Incontinence

Better care, better health – towards a framework for better continence solutions

Conference summary report is available at <http://bit.ly/1v4or1l>.

Spousal Caregivers: Who's the Frailest of Them All?

Does Dementia Caregiving Accelerate Frailty? Findings From the Health and Retirement Study

Kara B. Dassel, PhD and Dawn C. Carr, PhD

Key Findings include:

For caregivers of spouses without dementia, only 31.6 percent had increased frailty. Two years following the spouses' deaths, the risk of dementia caregivers being more frail was even greater, with 94.3% higher odds of increasing frailty. The authors of this study suggest that chronic stress plays a role in these negative health outcomes associated with caregiving, and that the specific chronic stress factors that differ between dementia and non-dementia caregivers should be examined.

For more see <http://bit.ly/1F6Ck0v>.

International Research

Quality end-of-life care for dementia: What have Family Carers told us so far?

A narrative synthesis

Authors: Nathan Davies, Laura Maio, Greta Rait and Steve Iliffe

What is already known about the topic?

- Carers of people with dementia experience high levels of stress, strain and burden.
- People with dementia at the end of life do not always receive high-quality end-of-life care.
- Research of carers of people with dementia has focussed on the diagnosis and transition stages of dementia.

What this paper adds?

- Strengthens the call for further exploration of carers' views about end-of-life care for dementia.
- Carers' views are mixed and lie on a spectrum of acceptance of their relative as actively dying with dementia.
- Combines the small amount of data available about quality end-of-life care for dementia from the views of carers.

Implications for practice, theory or policy

- Greater investment is needed in bereavement research and practice for those who are less accepting of their relative as actively dying both before and after death.
- Carers need to be included in the development of individualised care plans which may replace the fallen Liverpool Care Pathway.
- Professionals should be aware of the differences between carers who have different relationships with the person with dementia such as spouse or adult child, with different priorities and commitments.

For more see: <http://bit.ly/1xWCliZ>.

Practical Resources

The Palliative Hub, Learning Platform

AIHPC is delighted to announce that the Palliative Hub Learning Platform is now live and provides on line palliative care education programmes targeted at health and social care professionals and the wider community. These have been developed by AIHPC partners and others.

The site is at <http://learningplatform.thepalliativehub.com/>.

The Learning Platform currently has awareness-raising resources on palliative care for health and social care professionals.

This includes an AIHPC presentation aims to raise awareness of palliative care and encourage health and social care professionals to consider the role of palliative care when caring for an individual and their family with a chronic or long term health condition. The presentation is freely available (you will need to set up a login account) and takes approximately 30 minutes to view.



THE PALLIATIVE HUB

An All Ireland Gateway to
Palliative Care Information

International News

Eurocarers Opens an office in Brussels

Stecy Yghemonos, the newly appointed Executive Director of Eurocarers, deliver this message:



"It is my pleasure to inform you that, a couple of weeks ago, Eurocarers opened its very first liaison office in Brussels. This new development in the history of our network has received support from the European Commission and we are confident that this will help us position Eurocarers as a strong and credible partner for EU, national and regional decision-makers and stakeholders. Our primary objective will obviously be to act at the interface of your activities and the decision-making process in order to make sure your interests, good work and the contribution of carers to health and social care systems – and the economy as a whole – are taken into account in EU and national policies.

In the next few weeks and months, you can therefore expect to hear from us as we intend to develop a number of tools and services aiming to:

- Provide you with first-hand information and briefings on relevant opportunities (and challenges) for policy influencing.
- Put a number of communication tools at your disposal to support the promotion and dissemination of your work.
- Develop capacity-building activities and tools to assist your direct involvement in the policy agendas that are relevant to our work.
- Build an information hub as well as technical assistance services to facilitate our participation in EU projects.
- Speak with one voice on behalf of carers.

My colleague Francesca Centola (Administrator) and I very much look forward to collaborating with you and making your work more visible!"

For more information on Eurocarers see www.eurocarers.org.

International Alliance of Carer Organizations



The work of the International Alliance of Carer Organizations continues, with Care Alliance Ireland being an active member of the Communications Committee. The committee met by teleconference on 15 September. Agenda items included a review of the draft strategic plan, the collection of carer statistics from member countries and a discussion on website development.

International News

EU Interest Group on Carers

The Interest Group on Carers was launched by Eurocarers seven years ago and has been one of the most active since. The aims of the Interest Group are to bring together interested Members of the European Parliament and relevant stakeholders in order to:



1. Serve as a forum for debate: to discuss and debate European policy development for their impact on carers and their interests
2. Initiate policy action: to take initiatives that can lead to/influence EU policy initiatives, i.e. Parliamentary Questions, amending policy proposals, discussions with the relevant policy makers, host events/hearings on carers and their interests.

Over the years, many topics, themes and policy proposals with a bearing on carers have been discussed and debated, and the Group has made an important contribution to putting carers and their issues firmly on the EU agenda. One of the main activities will be to actively advocate the development and implementation of an EU Carers' Strategy.

The first meeting was held on 15 October, addressing the recent report on long-term care, published by the Social Protection Committee.

National Network of Caregiving Coalitions

Update from the National Alliance for Caregiving (US) on the cost of family caregiving

A new study from RAND Corp. estimates the value of family caregiving at \$522 billion dollars annually, which is about 15% larger than Virginia's entire economy.

Researchers arrived at the estimate by tallying the hours friends and family devote to elder care and calculating the cost if that work were performed by unskilled workers earning the minimum wage. The cost would be higher - an estimated \$642 billion a year - if skilled nursing care was used instead. By comparison, Virginia's total GDP in 2013 was about \$453 billion, according to the U.S. Commerce Department's Bureau of Economic Analysis."

Source: "Cost of family caregiving in U.S. estimated to be \$522 billion a year, study says" Washington Post, October 28, 2014 <http://wapo.st/1tFpgN2>.

About Us

Care Alliance Ireland is the National Network of Voluntary Organisations supporting Family Carers. Our vision is that the role of Family Carers is fully recognised and valued by society in Ireland.

We exist to enhance the quality of life for Family Carers. We achieve this by supporting our member organisations in their direct work with Family Carers through the provision of information, developing research and policy in the field, sharing resources, and instigating opportunities for collaboration.

There are approximately 274,000 Family Carers in the Republic of Ireland. Family Carer support is provided by a number of organisations, including those dedicated solely to carer support and others who support carers as part of their response to individuals with specific conditions.

We work with our 99 member organisations and other agencies to support them in their work with Family Carers. Our membership includes all the carers organisations and virtually all the condition specific organisations currently providing services to many of Ireland's Family Carers.

To apply for membership of Care Alliance Ireland, please [click here](#).

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10 Reasons To Join Us

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