

# Care Alliance Ireland

## Exchange

Spring 2014 Issue 43

### Care Alliance Ireland Fully Compliant with the Governance Code

At the November 2013 Board Meeting of Care Alliance Ireland, the Board of Directors declared our full compliance with the Code of Practice for Good Governance of Community, Voluntary and Charitable Organisations in Ireland.

Speaking on the occasion, Liam O'Sullivan, Executive Director, said: "I would like to pay tribute to our Board, the Carmichael Centre and others for their support on this journey. It goes to show that high standards in governance can be achieved by any NGO willing to put time and reflection into the process. As an alliance of organisations who support Family Carers, we felt it was important to demonstrate high levels of governance in our work. We also feel that it is the right thing to do and may spur on others to embark on this journey."

Gerry McCaffrey, Chairperson, added:

"After considerable work and reflection, the board is delighted to be able to declare full compliance with the code. It will be a legacy for the organisation into the future and we encourage our member organisations to declare their intention to sign up to the code and thus begin the journey towards full compliance. We commit to supporting our member organisations with this and invite them to contact us in this regard."

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## National News

### National Carers Week

National Carers Week will take place from 9 to 15 June 2014



Plans are underway for the eighth National Carers Week, which will be held from 9 to 15 June 2014. Last year there were over 130 events in every county in Ireland. This year we are hoping to beat that record. We encourage groups to consider organising an event for the Family Carers they work with. National Carers Week can also be a great opportunity to reach out to Family Carers who may not have used their services before.

We have 10 National Organisations who are partners this year and who will be organising events around the country. These are: the Alzheimer Society of Ireland, Brí Ireland, Care Alliance Ireland, the Carers Association of Ireland, Caring for Carers Ireland, the Disability Federation of Ireland, the Irish Hospice Foundation, MS Ireland and Parkinson's Association of Ireland. We are especially delighted to announce the Irish Cancer Society as a new partner (see page 12).

Nuala Carey has agreed to support National Carers Week again this year by taking part in our photo shoot and speaking at the national launch, which will take place on Monday 9 June.

The whole National Carers Week team is very excited to be working on preparations. If you would like to hold an event for Family Carers during the week please see our website [www.carersweek.ie](http://www.carersweek.ie) for tips, ideas and more information.

### European Adult Carers Project Progresses Work Plan

At the January meeting of TOYAC (Together for Young Adult Carers) progress was reported on the development of a handbook for those with an interest in supporting such carers. Care Alliance Ireland together with Carers Trust (Scotland) are leading on this aspect of the project. It is intended that the handbook will be available in May of this year. For more details see [www.youngadultcarers.eu](http://www.youngadultcarers.eu).



Right: TOYAC Partners Meeting, Dalmellington, Scotland, January 2014

## National News

### Nationwide Survey of Neurological Carers Highlights Impact of Budget Cuts



Cuts to the Respite Care Grant, changes to Medical Card provision and other cutbacks, are having a significant impact on Family Carers of people with neurological conditions according to a nationwide survey published as part of Brain Awareness Week 2014 by the Neurological Alliance of Ireland in association with Care Alliance Ireland.

In a survey of over 170 Family Carers, 82% reported being impacted by cuts to home care packages over the past three years, 77% by cuts to respite services and 70% by cuts to home help. Over one-fifth of carers could not access respite at all.

42% of Family Carers had given up work to look after the person with a neurological condition while 64% reported a significant fall in family income since the onset of the condition.

Speaking about the findings, Executive Director of Care Alliance Ireland, Liam O'Sullivan noted: "It is clear from this survey that successive cuts to supports for Family Carers are creating a climate of worry, uncertainty and distress. This is very disappointing in light of the publication of the National Carers Strategy in 2012 which commits to valuing the role of Family Carers in Ireland".

Mags Rogers, Development Manager with the Neurological Alliance of Ireland said: "We are calling on the Government to use the improving economic situation to reverse the cuts to these vital supports for Family Carers".

Neurological conditions of the brain and spinal cord affect over 700,000 people in Ireland. National Brain Awareness Week took place 10 - 15 March this year to promote awareness of neurological conditions. For a full list of events that took place nationwide go to <http://tinyurl.com/nz2d3q7> or [www.nai.ie](http://www.nai.ie).

## National News

### OPRAH, Older People Remaining At Home

Within the Age Friendly Cities and Counties Programme structure, the Ageing Well Network implementing an action research project called OPRAH. It is aimed at identifying and implementing changes in six pilot sites across the country, to support significantly older adults remain living in their own homes and communities, and reduce multiple hospital attendances or premature admission to long-term nursing home care.

The initiative will test the feasibility of creating integrated and innovative person-centred home care systems in which supports and services are tailored to meet the individual health and wellbeing needs of older adults to stay living in their own home.

A National Working Group comprised of senior personnel from key service organisations and academia will provide governance. This offers an opportunity to influence change at national level regarding components of support structures and the possibility of amalgamating budgets to allow 'money to follow the person' to provide individual choice and reduce escalation towards nursing home care.

For more information go to <http://tinyurl.com/nzr4wlv>.

The National Working Group will discuss opportunities to allow money to follow the person to provide individual choice and reduce their escalation towards nursing home care.



## National News

### New Auditors Appointed for Care Alliance Ireland

After a comprehensive selection process, guided by the Audit and Risk Committee of the Board, Duignan Carthy and O'Neill have been appointed as our new auditors.

Liam McQuaid, Managing Partner said: "We are delighted with the appointment as auditors to Care Alliance Ireland and look forward to working with the board and staff to ensure the highest standards of corporate governance during the audit process. Duignan Carthy O'Neill is a firm of Chartered Accountants established for over 40 years and has offices in Dublin."

Services include:

- Audit & Accounting
- Taxation
- Corporate Finance, Due Diligence and Dispute Resolution
- International Business
- Corporate Recovery and Insolvency.

Duignan Carthy O'Neill clients include substantial not-for-profit entities as well as subsidiaries of multinational companies, Irish-owned businesses and pension funds. For more information see [www.dcon.ie](http://www.dcon.ie) or contact Liam McQuaid, Managing Partner, Duignan Carthy O'Neill, 84 Northumberland Road, Dublin 4, telephone 01 668 2404.

DUIGNAN CARTHY O'NEILL  
CHARTERED ACCOUNTANTS



### News in Numbers

**99**

Member organisations of Care Alliance Ireland

**€2.52**

Social value created for every €1 invested according to research demonstrating the Social Return On Investment offered by Carmichael Centre's resident member service

**4,510**

Current Likes on National Carers Week Facebook Page

**76**

Number of organisations fully compliant with the Governance Code

**359**

Number of organisations 'on the journey' towards being compliant with the Governance Code

**7,291**

Unique users on Care Alliance Ireland website in 2013 – 18% increase on 2012 figure

**€23m**

Extra resources to be allocated in 2014 from Fair Deal Scheme to Home Care and Community Supports

## Member News

### Alice Taylor launches the Carer's Guide and Emergency Card

26 March 2014 marked the Bantry launch of two innovative aids that have been developed to assist Carers in West Cork.

"These initiatives will be a valuable support to Carers" said Alice Taylor, renowned author, who launched the tools. "Knowing that someone will be able to step in at short notice will give Carers great peace of mind". The Carer's Guide and Emergency Card have been developed by the West Cork Carers Support Group in response to recommendations from a research project aimed at improving supports and service provision for Carers.

Many Carers who took part in the research expressed concern about what would happen if they were involved in an accident, or at short notice, were unable to care.



*"I am always nervous to go out shopping, leaving Dad on his own at home. I mean suppose something happens to me while I'm out; Dad would be left alone helpless. It's my worst nightmare. A card I can keep on me to let people know that I look after Dad would be a Godsend."*

The Carer's Emergency Card identifies the card holder as a Carer and includes a place to write emergency contact numbers. The Carer's Guide is a folder where Carers can record all of their caring activities plus vital information such as the medical details of the person they care for. In the event of an accident or emergency, the card would alert emergency response staff to the fact that there is also someone else at home in need of help. The guide would then be used to ensure continuity of care if the Carer is away from home. The guide can also be used to ease communications between the Carer, the caree and care professionals when Carers need to take a well-deserved respite break.

The card and guides will be distributed free of charge to Carers and any statutory, community and voluntary service providers who come into contact with Carers.

West Cork Carers Support Group would like to express thanks to HSE South, who have sponsored and supported the project.

For more information about the West Cork Carers Support Group Carer's Emergency Card, Carer's Guide and other supports available for Carers in West Cork contact:  
tel: 027 53848,  
e-mail: [westcorkcarers@eircom.net](mailto:westcorkcarers@eircom.net),  
or visit [www.westcorkcarers.ie](http://www.westcorkcarers.ie).



Alice Taylor with members of West Cork Carers Support Group



## Member News

### The Palliative Care Needs of People with Dementia – Voice of the Carer



The Irish Hospice Foundation hosted a seminar in the University of Limerick on 26 March for staff caring for people living with dementia, to raise awareness of the palliative and end-of-life care needs of these people and their families, and to highlight some Irish initiatives that are being rolled out to meet those needs. During the day, people heard about the importance of palliative care for people with dementia, progress on the Health Service Executive's National Dementia Education Programme and the National Dementia Strategy. There was also a range of presentations on dementia palliative care projects from healthcare settings in Cork, Kildare and Sligo.

Stephanie Booth launched the Irish Hospice Foundation's "Changing Minds" Programme that is aimed at promoting excellence in end-of-life care for people with dementia and had the audience on their feet, and some in tears, after she gave an account of her journey to date caring for her husband, well-known actor Tony Booth, who has dementia.

*Stephanie Booth expressed the real and often unaddressed challenges of caring for a loved one with the condition.*

Stephanie described the insidious nature of dementia and expressed the real and often unaddressed challenges of caring for a loved one with the condition. She described Tony's decreased appetite and subsequent weight loss (a common problem associated with dementia) and her efforts to address this, one being to limit the number of cigarettes he smokes, as these suppress appetite, and the often unwelcome response she gets in relation to this. In an RTÉ radio interview Stephanie commented "I love him with all my heart but I don't always like him any more". Stephanie put words on what many Family Carers face on a day-to-day basis.

The need to make dementia the "new normal" was raised by Stephanie and she described the social shame and embarrassment that is too often linked to the illness. She appealed to healthcare workers in the audience to discuss and listen to Family Carers and spoke about the right that we all have to die well with dignity and respect. Stephanie noted the importance of discussing death and care preferences early in the dementia illness rather than later when the person with dementia is unable to make choices about their care in an effort to give people the exit from life that they deserve.

This seminar was the first of three to be arranged by the Irish Hospice Foundation this year. The locations for the other seminars are the North East and South East. For more information see <http://tinyurl.com/p3f56nf> or contact [Deirdre.shanagher@hospicefoundation.ie](mailto:Deirdre.shanagher@hospicefoundation.ie).

## Member News

### Bloomfield Health Services Reaches Out to Family Carers



Bloomfield Health Services is an independent not-for-profit healthcare provider located at the foot of the Dublin Mountains at Stocking Lane in Rathfarnham, Dublin 16. It commenced service provision in 1812 and was originally located in Donnybrook Dublin 4 until 2005 when it moved to its current location where it provides a state of the art environment for the care and treatment of its patients and residents. Bloomfield Health Services is owned by the Religious Society of Friends and the service is delivered based on Quaker ethos and principles. The Centre at Rathfarnham consists of two services – Bloomfield Hospital and New Lodge Nursing Home.

Bloomfield Hospital is a 114 bed Mental Health Hospital, registered as an approved centre with the Mental Health Commission. It specialises in the provision of mental health treatment and care to Older Persons (Psychiatry of Old Age) and Adults providing services for persons with Serious and Enduring Mental Health disorders, complex Mental Health issues associated with Neuropsychiatric Disorders and Dementia.

New Lodge is a 36 bed Nursing Home, registered with the Health Information and Quality Authority. It provides for excellence in delivery of care and treatment to frail Older Persons and Adults in comfortable and well-designed environment.

Through the course of our daily work, we support Family Carers in their visits, by including them in all aspects of their loved one's care and through the provision of information and support. We host a family day once a year, and throughout the year there are many other events that Family Carers can enjoy with their relatives – concerts, café evenings and our annual Olympic programme to name but a few.

Bloomfield has also begun to reach out to our local community to support Family Carers there in the management of their own mental health needs and also providing information and support to facilitate their caring role. This takes the form of Carer Workshops, for family members of those with Dementia and those with Severe and Enduring Mental Illness.

We have a number of specialist services, including services for patients with Huntington's Disease and patients with Dementia; in this context we have ongoing partnerships with a number of support organisations. For example, we have hosted coffee and information mornings for Family Carers with the Huntington's Disease Association of Ireland and we will also be supporting and speaking at their respite weekend in June.

We have both clinical and research links with TCD and UCD and continue to develop services for carers through research and development.

The South Dublin Alzheimer Café is held here in Bloomfield once a month and this supports Family Carers in an informal relaxed setting. This is a partnership that involves a number of organisations including Age Action Ireland, the Alzheimer Society of Ireland, the HSE and Trinity College Dublin. This year we have begun to work closely with the Carers Association and are providing psycho-educational talks about the nature of the caring role and self-care in that context.

(Continued on page 9)



## Member News

### Bloomfield Health Services Reaches Out to Family Carers (con't)

Through our public lecture series and library talks series we have reached out to the local community on minding their own mental health, with special consideration given to times of transition and when extra roles are required, for example, whilst parenting, caring for another and during retirement. For more information see [www.bloomfield.ie](http://www.bloomfield.ie).

#### Our events for Carers Week include:

Alzheimer Cafe with special focus on caring  
Vintage Café – for our own Family Carers with concert  
Lecture evenings – caring for oneself whilst caring for others – for the local community to access as well as Family Carers  
Carer Workshops: caring for a family member with Dementia.

### Milford Care Centre - The Compassionate Communities Project

The Compassionate Communities Project was initiated by Milford Care Centre in 2011 and piloted in an area of Northwest Limerick City. It has now been extended to the whole of Limerick City and to the town of Newcastlewest in County Limerick.



Milford Care Centre is committed to providing specialist palliative care services of the highest standard and recognises that death, dying, loss and care affect us all and are not just the responsibility of health and social care professionals. Most people who are living with advanced life limiting illnesses spend their time at home and in their communities and neighbourhoods, with families, relatives, friends and work colleagues. The majority of people affected by advanced illness want to be cared for, and to die, at home.

Many people feel unprepared when such illnesses befall them or others and are uncertain as how to offer support and assistance, or even how to talk together about what is happening. In many local communities and health and social care organisations there is a need to renew, rediscover or find new ways of caring for and supporting one another – those who are dying, their families, the bereaved and those who work with them.

The Compassionate Communities Project seeks to work in partnership with individuals, groups and communities, to enhance the social, emotional and practical support available to those living with a serious life-threatening illness, those facing loss and those experiencing bereavement. The Project aims to provide information about death, dying, loss and care (in whatever circumstances they occur), and explore and develop a range of personal and community support.

For more details visit <http://tinyurl.com/q8mtfyn>.

## Member News

### MS Ireland to Host European Conference 8 – 9 May 2014



This year MS Ireland is delighted to host the 25th European Multiple Sclerosis Platform, a two-day conference in the Gibson Hotel, Dublin.

The conference offers a dynamic mix of presentations, interactive sessions and debates, as well as a special gala dinner and entertainment. Highlights will include:

- *Progress on rehabilitation*: Peter Feys, President of RIMS
- *Rehabilitation and the role of carers*: Dr Jacinta Morgan
- *Carers' concerns*: Elizabeth Golding & Ruth Herbert
- *Rehabilitation in action*: Peter Flachenecker
- *Reducing social isolation of people with MS*: Haley Sanner, George Pepper & Žilvinas Gavėnas
- *Launch of the Code of Good Practice*: Professor Gavin Giovannoni.

Register at [www.emsp.org](http://www.emsp.org).



### World MS Day

Join MS Ireland on the 28 May 2014 to shout about MS, raise the issues affecting everyone living with MS and raise funds to continue our nationwide community-based services.

This year we will be asking people (with MS and without) to think about barriers to access in their life and make a one-day wish for a world without those barriers. For example: one day there will be a cure for Progressive MS, one day I won't have to choose between paying for DMDs and taking my children on holiday, one day companies won't discriminate against people with disabilities.

See [www.ms-society.ie](http://www.ms-society.ie) to see how you can get involved.

## Member News

### Galway Head Injury Support Group

Chairperson Martin Moran reports on the group's recent respite break:

"On the weekend of the 31 January to 2 February, 28 of us headed for the Sligo Park Hotel for a respite weekend break. We were greeted with tea/coffee and freshly baked fruit scones on our arrival and this was the beginning of a fantastic weekend. The staff were so friendly, couldn't do enough for us and the accommodation left nothing to be desired. The meals were delicious and the service excellent. To top everything it actually snowed on the Friday night which added to the incredible ambience of our after dinner drinks, ceol/glór agus craic in the lounge bar. Needless to say the hotel was full to capacity for the weekend and justifiably so for the quality of service they offer. We will return sometime soon."



Pictured above, left to right:  
Ann Kelly & May Cashin; Regina Murphy & Tom Lane; Kathryn & Seán Cummins

Our forthcoming events, both to be held in the Quest Building:

7 May: How to Use a Defibrillator, 8.00pm

11 June: Pampering Evening for Carers, 7.00pm

GHISG provides counselling, therapy and support to individuals, couples, families and children who have been affected by a family member with an acquired brain injury. Fully qualified counsellors will answer your telephone call (Mondays and Wednesdays, 6:00pm to 7:30pm) and if one-to-one counselling is required it will be arranged for you.

LoCall Telephone Counselling provided by GHISG 1890-32-31-30

## Member News

### **Irish Cancer Society latest National Partner in National Carers Week**



We are delighted to announce that the Irish Cancer Society has become a partner in the 8th National Carers Week, taking place this year from 9 - 15 June.

Speaking on the decision, Donal Buggy, Head of Services at the Irish Cancer Society said: "The Irish Cancer Society is delighted to be a supporter of National Carers Week 2014. Each year, approximately 30,000 people are diagnosed with cancer in Ireland. We know that a cancer diagnosis brings with it many challenges for a cancer patient and their family, who often become the primary carers while their loved one is going through treatment. Long periods of illness challenge the physical, financial and psychological resources of the Carer and the Society recognises the vital role of those who provide care and support to cancer patients across the country. National Carers Week offers an opportunity to pay tribute to the thousands of Carers in Ireland who make countless personal sacrifices and dedicate themselves to looking after others."



Jennifer Graham, Projects Executive with Care Alliance Ireland said: "The National Carers Week Team is very excited to welcome the Irish Cancer Society as a partner for Carers Week 2014. We greatly appreciate the Irish Cancer Society's recognition of the dedication and selflessness of Family Carers and we hope with their support, those caring for loved ones with cancer may have an opportunity to attend events and enjoy a well-deserved break this Carers Week."

For more information see [www.carersweek.ie](http://www.carersweek.ie).

## Practical Resources

### The National Careline

The Carers Association offers a confidential, friendly and supportive Care Line. Just Freefone 1800 24 07 24 to talk to our experienced and trained staff. They will listen to your concerns and offer practical advice on a range of topics. Eight volunteers were recruited this year and due to their contribution, we have extended our opening hours to Monday to Thursday, 9.00am – 5.30pm and Friday 9.00am – 5.00pm. A recent monitoring and evaluation session with our volunteers highlighted their desire to offer more hours, which we hope will result in even more extended opening hours in 2014.



### Blog on Life After Caring



**The New Old Age**  
Caring and Coping

#### After Caregiving, Comfort in Having Helped

By Judith Graham, 8 March 2013

Caregiving is so all-consuming, it can seem impossible to imagine life after, when all of those responsibilities are suddenly gone.

It is then that many people become aware that they were on autopilot, with their deepest emotions and needs kept at bay. Some are washed with relief. Others feel adrift. Some go back to life as usual. Others are permanently changed. Read more at <http://tinyurl.com/knjgghd>. Read another article about after the caregiving ends <http://tinyurl.com/kz8wktt>.

### When Caring Ends

Life After Care Booklet – produced by Care Alliance Ireland in collaboration with five European Carer organisations.

To download go to <http://tinyurl.com/njlxctk>.





## Practical Resources

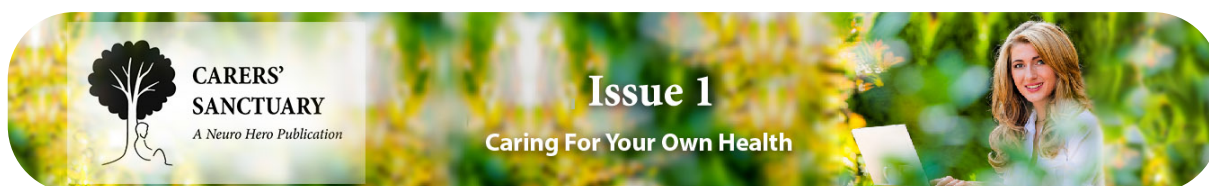
### The Rise of the “e-Caregiver”: How Technologies Can Support Family Caregiving



The National Alliance for Caregiving (US) recently hosted its 8th Annual National Conference of Caregiving Coalitions in conjunction with the Aging in America: 2014 Annual Conference of the American Society on Aging. The annual meeting brought together caregiving coalitions and advocates from across the United States to discuss the latest in caregiving legislation, advocacy, and innovation. To view the presentation on Caregiving and E-Technology go to <http://tinyurl.com/nven72o>.

### Carers' Sanctuary Magazine

Carers' Sanctuary is a free, quarterly, online magazine for family caregivers. It blends useful information and support with entertaining features and stories. Edition 1 has just been launched and is available to view online at <http://magazine.neurohero.com/>.



## Dates for Your Diary

### Alzheimer Society Tea Day

1 May 2014

Nationwide

<http://tinyurl.com/nmsjyfg>



### The Wheel's National Conference

15 May 2014

Dublin

<http://tinyurl.com/lghdt5n>



### World MS Day

28 May 2014

Nationwide

[www.ms-society.ie/pages/what-we-do/world-ms-day](http://www.ms-society.ie/pages/what-we-do/world-ms-day)



### National Carers Week

9 - 15 June 2014

Nationwide

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

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



## European News

### Eurocarers to Receive Financial Support from The EU Commission

Under the EU PROGRESS funding scheme for European Umbrella NGOs, Eurocarers has been selected as a successful recipient of EU Commission funding for the period 2014 – 2017. This is great news for Carers across Europe and will enable Eurocarers to build on its work and increase its reach and impact across the EU institutions.



### Call for European Carers Manifesto

Eurocarers has recently called for a European-wide Carers Manifesto. It has proposed to Members of the European Parliament the following actions to support this initiative:



- Including Carers' issues in social policy development, that is, to actively target Carers in initiatives like the European Innovation Partnership on Active and Healthy Ageing, the Employment Package and the Social Investment Package, the PROGRESS programme, the European Social Fund, the Health programme, gender equality initiatives, the social OMC etc.
- Formulating a specific EU action programme to ensure and coordinate an effective exchange of information, experience and good practice between relevant stakeholders.
- Activating EU funding to contribute to capacity building of Carers in relation to provision of support and advocacy as well as support exchange of information, research and networking.
- Promoting data collection and monitoring to support sound policy development (for example Horizon2020).
- Adopting legislative measures to explore the possibility of binding measures, while respecting national competence and the principle of solidarity (for example a Directive on carers leave).

For further details go to <http://tinyurl.com/o877lxp>.

### Eurocarers Newsletter

The latest edition of the Eurocarers Newsletter is available at [http://www.eurocarers.org/News\\_Newsletters.php](http://www.eurocarers.org/News_Newsletters.php).



## Member Profile

### **Cork Mental Health Housing Association**



Cork Mental Health Foundation & Housing Association was established in 1962 to promote positive mental health and to provide those who have experienced mental health difficulties with adequate housing within the community.

Cork Mental Health Foundation focuses on mental health promotion and does this through a number of different projects within primary schools, secondary schools, workplaces and community groups. It offers free mental health awareness presentations to groups and would be happy to assist any carer groups in Cork City or County who would require assistance in this area. This would focus on areas such as stress management, work-life balance and any other areas the group would like to be covered.

Cork Mental Health Housing Association provides housing to those who have experienced a mental health difficulty and also provides information and assistance to those looking for housing. We currently have 28 properties in Cork City and County and support over 100 residents in these properties. These properties vary from 24-hour staffed premises to independent living properties within the community. These properties are accessible to anyone who has used the mental health services and are eligible for social housing. We work in partnership with Cork City Council, Cork County Council and the HSE in the provision of these housing units and supports.

For more information go to [www.corkmentalhealth.com](http://www.corkmentalhealth.com) or call 021 4511100.



## Irish Research

### **An Evaluation of Met and Unmet Needs, Carer Burden and Barriers to Accessing Services amongst Family Carers of People with Dementia - A Qualitative Study**

*O'Brien, C., Buckley, C., Ní Chorcoráin, A.*

Department of Epidemiology and Public Health, UCC, Department of General Practice, UCC, Department of Psychiatry, UCC

National Institute of Health Sciences, Research Bulletin, January 2014.

Go to <http://tinyurl.com/k8wssrj>

#### **Introduction**

The increasing prevalence of dementia means that many people are taking on a caring role for someone with dementia, often on a full-time basis. Few studies have explored the needs of carers in Ireland, and in particular there is little literature on the barriers to accessing services.

#### **Methodology**

In-depth semi-structured interviews were conducted with six Family Care givers of people with moderate and advanced dementia who were identified through snowball sampling. A framework analysis, with stages of familiarisation, identification of thematic framework, indexing, mapping and interpretation, was undertaken.

#### **Results**

The primary reported barrier to service use was the lack of information received at time of initial diagnosis. Once diagnosed, adequate support is not seen as available. Carers reported isolation and uncertainty about what was available to support them. Financial burden resulted from the family member's dementia, and resulted in carer stress and in most cases limited access to services.

#### **Conclusions**

Information emerged as the key theme. Carers want information and it is necessary to have information, such as a diagnosis, in order to access services.

#### **Presented**

As a poster presentation at the Association of University Departments of General Practice (AUDGPI), University of Limerick on 8 March 2013.

#### **Results**

Five major themes emerged from the textual data:

- information
- money
- limited service availability
- support
- transport.

#### **Conclusions**

Consideration needs to be given to approaches to the diagnosis and disclosure of the diagnosis and the signposting of services.



# International Policy and Practice Publications



## New Report on Young Carers in Education

Young Adult Carers at School: Experiences and Perceptions of Caring and Education

Dr Joe Sempik and Professor Saul Becker

Young Carers International, The University of Nottingham

To read the report go to <http://tinyurl.com/lyljb6>.

### Young Adult Carers at School: Experiences and Perceptions of Caring and Education

Dr Joe Sempik and Professor Saul Becker  
Young Carers International  
The University of Nottingham



## New US Report Calls for Inclusion of Family Caregiver Assessment in InterRAI Assessment Tool

### *Listening to Family Caregivers: The Need to Include Family Caregiver Assessment in Medicaid Home-and Community-Based Service Waiver Programs*

This 50-state study, conducted by the National Center on Caregiving, Family Caregiver Alliance and commissioned by the AARP Public Policy Institute, was released in December 2013.

The study is the first detailed analysis of family caregiver assessment tools and processes in use by the states in Medicaid HCBS 1915 (c) and 1115 Waiver programs. Forty-six states and the District of Columbia responded to the study survey, a 92% response rate.

Key findings include:

1. The concept of assessing a family caregiver's own needs is not well understood in Medicaid HCBS programs. A minority of states view the assessment process as directed to the family caregiver, asking questions about their own health and well-being and identification of services and supports for the caregivers.
2. Only about 30 percent of states include any family caregiver assessment in their Medical HCBS waiver programs. Only 15 states met minimum defined criteria for family caregiver assessment.
3. Most states that do assess family caregiver needs use the information to develop a service plan for the care recipient and to help connect family members and friends to needed services and supports.

The eight policy recommendations include calls for family caregiver assessment to be part of all assessment tools for Medicaid HCBS Waivers programs; expansion of family caregiver assessment questions in the interRAI HDS-HC (the most widely used assessment tool across state Medicaid Waiver programs), and increased funding for community-based supportive services under the National Family Caregiver Support Program.

The research was funded by the John A. Hartford Foundation and the US Administration for Community Living, Administration on Aging.

**Full Report:** <http://tinyurl.com/owzkpbq>

**Three-Page Brief:** <http://tinyurl.com/olcufh5>

# International Policy and Practice Publications

## Report on Transitional Care highlights need to Engage with Family Members

*Family Caregiving and Transitional Care: A Critical Review, Mary Jo Gibson, Kathleen A. Kelly, and Alan K. Kaplan, October 2012*

### What is at Stake?

Transitions between settings are recognised as the most vulnerable points in the delivery of health care and long-term services and supports (LTSS). The risks to older adults during transitions are well established, and can be associated with poor outcomes, as well as avoidable hospital readmissions and emergency room use. Breakdowns in care during transitions from hospital to home resulting in negative outcomes have been documented for more than a decade. Such risks include duplicative tests, medication errors, lack of coordination, poor communication among professionals across settings, problems in the timeliness of care, and lack of access to vital home and community-based services.

Family caregivers play critical roles in transitions from hospital to home or other post-acute settings. They not only provide the vast majority of personal assistance received by older adults with disabilities in the United States, but also health-related care, including coordination and continuity during such transitions. In fact, family caregivers are usually the persons who will actually implement care plans following release from the hospital. Transition decisions that are made hurriedly at the point of discharge can change the course of patients' lives for years, as well as the lives of their family caregivers.

### Major Findings

#### *Family Caregivers Receive Inadequate Support*

Relatively little research has been conducted on how family caregivers perceive their own roles and needs during transitions across settings. However, the evidence that is available indicates they do not receive adequate recognition or support during the discharge process from health care professionals.

#### *Family Caregiver Involvement Can Improve Patient Outcomes and Continuity of Care*

The evidence base on how family caregiver involvement affects the quality of health care remains sparse but is expanding. It shows that their involvement has improved outcomes for persons with physical, mental, and cognitive disorders, contributes to greater patient satisfaction, and improves continuity of care. However, evidence suggests that family caregivers should not be expected to provide complex medical care in the home, especially without training or in-home support from professionals.

#### *Health Professionals Are Increasingly Recognizing the Need to Work with Family Caregivers*

Very little research has been conducted on health care professionals' perceptions of family caregivers roles and needs or on their communication with them. However, leading physician, nursing, social work organizations have affirmed family caregivers' contributions and the need to work in partnership with them.

# International Policy and Practice Publications

## Report on Transitional Care highlights need to Engage with Family Members (cont'd)

### *Many Transitional Care Programs Do Not Actively Engage Family Caregivers*

While four of the seven transitional care programs reviewed do offer specific steps to actively engage family caregivers as partners, in the other three programs they are viewed more passively. In the latter, mention of family caregivers focuses on how they can help patients adhere to discharge instructions or medication regimens, not on how their expertise can be tapped to improve transitional care or how their needs as individuals should be assessed and addressed (both during discharge and for their caregiving role afterward) as part of effective discharge planning. Outcomes for family caregivers, such as reductions in stress, have been reported for only two of the programs.

### *A Greater Focus on Long Term Services and Supports is Needed*

Only a few of these programs place substantial emphasis on coordinating care with LTSS after release from the hospital. This part of the care continuum is essential for most of the "high risk" older adults on which the programs focus, and it is the part in which family caregivers play starring roles.

### *New Teaching Guides and Programs Are Available but Often Not Accessible*

While there are good methods of and tools for engaging family caregivers in transitional care, they are not yet being used widely. For example, a growing body of teaching programs, guides and checklists is becoming available to assist both patients and family caregivers during transitions. The challenge now is to make these materials easily usable and available when needed, especially at the point of care. New technologies, especially digital personal technologies, hold promise in this regard.

### *Barriers to Greater Engagement with Family Caregivers Need to be Recognized*

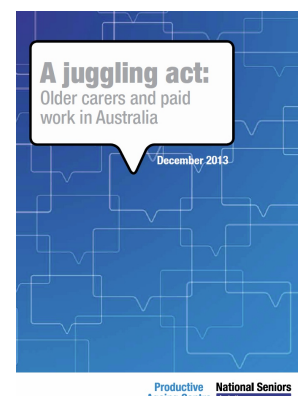
Barriers to greater engagement of family caregivers as partners during care transitions include financial pressures on hospitals to reduce length of stay (although increasingly patients are older and sicker) and insufficient attention to arranging and integrating LTSS in health care delivery. Patient education materials continue to be written at a level that most patients and caregivers cannot understand. Further, many patients and families are reluctant to ask questions for fear of being labelled "difficult," and they remain largely unaware of their discharge-related rights during transitions.

To read the full report go to <http://tinyurl.com/lgcd54l>.

## Older Carers and Work – New Report from Australia

Caring responsibilities limit the ability of many older people to work and older carers can face challenges both in the workplace and in finding work, according to new research from the National Seniors Productive Ageing Centre (Australia).

For more see: <http://tinyurl.com/lukfj5u>.



# International Policy and Practice Publications

## No proven benefit from home visits for older people, finds research review

**No consistent evidence that older people live longer or lead more independent lives as a result of preventative home visits, finds study.**

*by Mithran Samuel, 12 March 2014 in Community Care*

There is no consistent or robust evidence for the benefits of preventative home visits to help improve the independence of older people, a review of research conducted over the past 20 years has concluded. There is no evidence to demonstrate older people who receive such visits live longer or lead more independent lives than those who do not receive the visits, found an Oxford University and University College London analysis of 64 randomised controlled trials, mainly in the UK, United States and Canada.

The trials studied involved over 29,000 people aged over 65 who were living independently, and researchers analysed their findings about the impact of home visits on mortality rates, falls, the risks of injury and illness, rates of hospitalisation or institutionalisation, and the overall quality of life.

The research defined home visits as interventions by health or social care professionals to boost the independence of older people, including through the provision of information, assessment, referral to other services or efforts to increase medication compliance. It stressed that the study did not cover home care services to “treat or rehabilitate people with medical problems”.

"We are not saying that those people currently getting home care visits should have this service withdrawn," said Sean Grant, from Oxford University's Centre for Evidence-Based Intervention. "This review is pointing out that despite home care visits being available to [older people] in many countries, there is no robust, consistent evidence to show they provide any benefit to [older people] that we can measure. It is possible that some programmes may provide some benefit. In the light of this review, however, policy-makers, professionals and families should carefully consider the alternatives when making decisions about effective means of support for [older people] in the community.'

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The review examined trials that focused solely on home visits and those where home visits were part of a wider programme of services.

Researchers found that the quality of evidence from the trials was “variable” and many provided limited information on what might have worked and what did not work within services.

(Continued on page 23)

# International Policy and Practice Publications

## No proven benefit from home visits for older people, finds research review (cont'd)

The review recommended that any future trials needed to provide more detailed information, such as why older people needed home visits, how many home visits they actually received, and the characteristics of older recipients of home visits and the professionals delivering the service.

### About the research

The research team identified 64 relevant studies, carried out from 1981 to 2012 in 13 countries, and involving 28,642 older people. Eleven of the studies were in the UK.

The average number of home visits per study was 4.9. In 27 studies, visits were made by nurses alone, and in 20 cases, they were made by other professionals, such as occupational therapists or social workers. In 17 of the studies the objective of the visits was falls prevention, while in 25 it was a comprehensive assessment of the person.

In 50 of the 64, the control group who did not receive home visits received their “usual care” services, and there was low risk of bias in most (41) of the studies.

Twenty-six of the studies reported outcomes about the number of participants admitted to institutional care, and researchers found “moderate quality evidence of no clinically important difference” between people who received the visits and those who did not.

Fifteen reported the numbers of people admitted to hospital for which there was “moderate quality evidence of a small relative effect that may not be clinically important” from receiving home visits.

Twenty-three studies recorded the number of people who fell for which there was “moderate quality evidence of a small effect...but it was not statistically significant”.

For more information, see <http://tinyurl.com/nn8ptgx#>.

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## 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 go to <http://tinyurl.com/o7ppmgrp>.

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## 10 Reasons To Join Us

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