

Care Alliance Ireland

Exchange

Summer 2013 Issue 41

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7th National Carers Week Exceeds Expectations

Now a significant event in the calendar of many organisations supporting Family Carers, National Carers Week, which took place between June 10 – 16 exceeded our expectations. Events took place in every county across Ireland, and thanks to support from EBS, a radio campaign with Nuala Carey reached in excess of two million listeners. In the run up to the week, our Facebook page became the second most 'talked about' page within the NGO sector in Ireland and in excess of 4,300 people now 'Like' our page.

The objectives for the week were:

- To raise awareness of Family Carers in our community.
- To deliver events for Family Carers throughout the country.
- To engage with Family Carers not yet availing of carer support services.

Based on the feedback from various stakeholders we have succeeded in meeting these objectives. A full report on the week has been prepared and the nine national partner organisations will come together in September to plan for 2014. A full National Carers Week Newsletter will be published in the Autumn.

Current and former Family Carers at the launch with Nuala Carey.



National Carers Week 2013

In Pictures

'Guiding Support for Family Carers'



The Lord Mayor of Dublin Cllr. Naoise Ó Muirí speaking at the launch in the Oak Room of the Mansion House.



Kerry Family Carers enjoying National Carers Week.



Duhallow Carers Group Coffee Morning in Cork.

National Carers Week 2013

In Pictures

RTE's Nuala Carey presents certificates to the winners of the schools' competition *"How We Care"*

1st Place: Noel O'Gorman,
4th Class Cahermurphy NS,
Kilmihill, Co Clare.



2nd Place: John Enright,
6th Class Carnane NS,
Fedamore, Co Limerick.



3rd Place: Geraldine
Corcoran,
5th Class Eglish NS,
Ahascragh, Ballinasloe,
Co Galway.



Care Alliance Ireland News

Care Alliance Ireland Embarks on a Membership Review and Development Initiative

We are currently undertaking a membership review and development initiative which we are confident will increase our reach and impact in the Family Carer sector.



Speaking on the initiative, Liam O'Sullivan, Executive Director, Care Alliance Ireland said: "There are hundreds of not-for-profit organisations in Ireland who are supporting Family Carers in their own unique way. We want to engage with as many of these organisations as possible to support them in this valuable work".

Applications for membership are open to any not-for-profit organisation with an interest in supporting Ireland's Family Carers. Click here to see our most recent [updated membership flier](#).

Alongside this initiative, our 88 current members are being invited to provide feedback on our activities, priorities and impact. To our current members, we assure you of our commitment to continue to offer you a responsive service and niche support in your work with Family Carers.

New Chairperson for Care Alliance Ireland

Gerry McCaffrey was elected Chairperson on 23 May.

Gerry has been a senior manager in several blue-chip healthcare manufacturing companies (both pharmaceutical and medical devices) since 1988. He has managed virtually all functions at different times – quality, regulatory, operations, supply chain, research and development and site management.

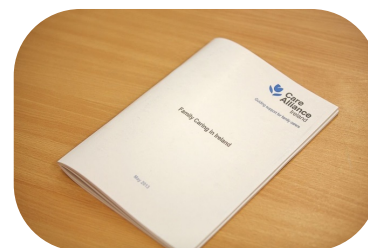
He established and operated his own business between 1999 and 2002, providing quality systems and business process improvement training to Industry. Speaking on his appointment, Gerry said: "I am looking forward to this role in supporting the board and the executive in implementing our organisation's vision and mission and in guiding the organisation over the coming years".



Care Alliance Ireland News

Publication of Major Report on Caring in Ireland

23 May marked the launch of a significant new publication for the Family Carer sector in Ireland. Entitled *Family Caring in Ireland – An Overview*, the report produced by Care Alliance Ireland brought together the key reports on Family Caring in Ireland and abroad in one succinct publication.



With 219 references, this report will be a useful tool for all with an interest in the topic. Sections include:

- Defining Caring
- Quantifying Caring
- Health, Financial and Employment Impacts of Caring
- Caring and Disability
- Young Carers
- Male Carers
- Life After Care
- Supports available for Family Carers
- NGOs providing Carer Supports
- International Carer Bodies



We believe that this publication will be a great resource for those working with and supporting Family Carers into the future. Since its publication in May, there have been in excess of 600 downloads of the report. To download it [click here](#).



Above: Liam O'Sullivan and Gerry McCaffrey (newly elected Chairperson) at the launch of the report, in the grounds of the Carmichael Centre.

Left: Liam O'Sullivan, speaking at the launch of the report.

Care Alliance Ireland News

AGM – A Busy Affair

This year's AGM took place on 23 May in the Carmichael Centre. The annual report for 2012 was circulated to all members present ([now available to view here](#)) as were the financial statements ([now available to view here](#)).

On the day, we also launched our new report, *Family Caring in Ireland – An Overview*, and we also heard from Christine Marking, a senior lobbyist and advisor, about influencing the institutions of the European Union. To view Christine's presentations, [please click here](#).

Photos from the AGM



Above left: Dermot Maguire and Marie Lynch, Board Members

Above right: Christine Marking

Middle left: Claire Leonard, President, Down's Syndrome Ireland

Bottom left: Áine Uí Ghiollagáin, Secretary General, Cúram

National News

New HSE Structures Announced

26 July 2013 – Board Disbanded – Operational control moved closer to Services – More Integration Promised – Better Performance Management – Head of New Directorates and other changes announced. For more information see www.hse.ie or <http://tinyurl.com/lsuqvq6>.



Update on NDA Resource Allocation Study

The Value for Money and Policy Review of disability services recommended moving towards a needs-related model of resource allocation, and the introduction of individualised budgeting.

The National Disability Authority is engaged in a programme of research which is designed to advise the Department of Health and the HSE on the best way to allocate resources so that they match people's support needs.



"InterRAI has been selected by the HSE to be the single assessment tool for older people. If the disability version of this system were to work well, there could be obvious benefits in having a common language and assessment framework over the life course."

This work consists of three stages:

1. A literature review of some of the leading resource allocation systems internationally that use individual support need as a basis for determining individual budgets.
2. The trialling of four models over two phases in 2012 and 2013 to determine their suitability in an Irish context, to test their strengths and weaknesses, user satisfaction, resources required, time taken to use the models. This exercise will show up some information around links between assessment and cost, and is expected to conclude in the Autumn.
3. Examining issues around implementation of the different systems.

A full update on progress is available to view at <http://tinyurl.com/kcfd2f>

National News

Carmichael Centre's Upcoming Free Seminars

Carmichael Centre for Voluntary Groups is delighted to announce the following FREE seminars for staff, boards and volunteers in the community and voluntary sector:

5 September: Risk Management

Speaker: Pat Reidy, Xyea

What are the risks and how does your organisation manage them?

19 September: Social Finance

Speaker: Donal Traynor, UCIT

Find out how to access social finance for your organisation.

24 October: Social Media & Fundraising

Speaker: Caroline Egan, CramdenTECH

How to harness social media for your funding campaigns.

14 November: What is SROI? (Social Return on Investment)

Speaker: Sandra Velthuis, Whitebarn Consulting

How the SROI framework can help your organisation to measure, account for and manage its social, economic and environmental value.

Book NOW to avoid disappointment.

Full details and online booking on:

<http://bit.ly/19XeDf2>

or contact Carmichael Centre, North Brunswick Street, Dublin 7

Tel: 01 873 5702. Email: tssinfo@carmichaelcentre.ie



Numbers at a Glance

4,317

Number of followers of National Carers Week Facebook Page - *nationalcarersweek*

33.6

The average number of hours of care provided per week by Ireland's Family Carers

46 – 54 years

The highest concentration of Family Carers by age

98.3%

Those in receipt of the Carers Allowance who care for a family member

16.8%

The increase in the number of male carers aged 15 years and older, between Census 2006 and 2011

38%

Carers who look after someone in the same household reporting feeling completely overwhelmed by their caring responsibilities

277,064

28-day reach of National Carers Week Facebook Page over the period 30 May - 29 June, 2013

National News

Update on European Young Carers Project



The six project partners from around across Europe met in Dublin in May to progress our work plan. We heard about the current situation of Young Adult Carers in a number of EU States and the challenges in progressing supports and awareness. The following day, Care Alliance Ireland hosted a seminar that brought together some key Irish organisations active in the development of Young Carer support services. Presentations were made on current initiatives and possible development opportunities. Promising initiatives aimed at young adult carers in third level are being developed within DIT (Student Carers Support Group) and we look forward to hearing more about this over the coming months. For more details on the DIT initiative contact Jill Barrett, DIT Careers Service, jill.jf@gmail.com.

The TOYAC website is now live with some considerable resources to view:
www.youngadultcarers.eu

The next study visit takes place in The Netherlands in October.

A Selection of Member Organisations' and Other Stakeholders' Pre-Budget Submissions



The Disability Federation of Ireland
<http://tinyurl.com/o9dsaza>



The Alzheimer Society of Ireland
<http://tinyurl.com/msol6r8>



Age Action Ireland
<http://tinyurl.com/k59b9g2>



The Carers Association
<http://tinyurl.com/mu3plr8>

Opportunities to Influence Policy

Delay to Public Consultation on Standards for Disability Services



The National Disability Unit within the HSE has advised that the information meetings on public consultation for draft interim standards for adult day services due to take place in early September, are now being postponed until mid-October. This is at the request of the Chair of the Standards Sub-Group, as additional work has been identified and needs to take place prior to the consultation process.

Review of the Nursing Homes Support Scheme

Department of Health Invites External Consultants to Review of the [Nursing Homes Support Scheme](#). In recent weeks, the Department of Health has advertised an invitation to tender for the following:

The overall objective of the Review is to examine the future sustainability of the Nursing Homes Support Scheme, taking account of Government policy, relevant demographic growth trends and the current and projected fiscal situation and to make costed recommendations as to how the Scheme should operate in the short (to 2016) to medium (2023) term, to ensure that it best supports government policy, and how residential and community provision will be balanced as part of an overall approach. Government policy is to support older people to live in dignity and independence in their own homes and communities for as long as possible and where it is not possible to maintain a person at home, the policy is to support access to quality long-term residential care.

Terms of Reference:

- 1. To examine the on-going sustainability of the Nursing Homes Support Scheme,*
- 2. To examine the overall cost of long-term residential care in public and private nursing homes and the effectiveness of the current methods of negotiating/setting prices,*
- 3. Having regard to 1. and 2. above, to consider the balance of funding between long-term residential care and community based services,*
- 4. To consider the extension of the scheme to community based services and to other sectors (Disability and Mental Health), and*
- 5. To make recommendations for the future operation and management of the scheme.*

The deadline for expressions of interest passed on 16 August 2013.

We in Care Alliance Ireland look forward to the speedy progression of this review and once again call for the more flexible allocation of nursing home resources to enable people to remain cared for at home if that is their and their family's wish.

Dates for Your Diary

CEO2CEO Forum

Building Effective Relationships with Your Board

10 September 2013

Dublin

<http://tinyurl.com/pv29q74>



Stroke Awards 2013

Closing date for nominations

20 September 2013

National

www.stroke.ie



Carer of the Year Awards

Closing date for nominations

27 September 2013

National

<http://carersireland.com/carersoftheyear2013.php>



Budget Day

15 October 2013

National

www.finance.gov.ie



Forum on End of Life in Ireland

24 October 2013

Dublin Castle

www.hospicefoundation.ie



Members' News

Carers Awards Announced by Two Member Organisations

The Carers Association's annual Carers of the Year Awards 2013 have been launched and nominations are being sought for Ireland's Carer of the Year and Young Carer of the Year. Throughout Ireland, Family Carers dedicate themselves to providing remarkable levels of care in the home for children and adults with special needs, disabilities, mental illnesses, frail older people and loved ones who are terminally ill. Once a year we give them the acknowledgment they deserve through our awards.



If you know a Family Carer or Young Carer (under 18) who you would like to recognise for all the care they provide please nominate by filling the Online Form at <http://carersireland.com/carersoftheyear2013.php> or call the Careline to request a form on 1800 240724.

The closing date is Friday 27 September 2013. Each person nominated will receive a Commemorative Certificate. The Overall Carer of the Year and Young Carer will be celebrated at a ceremony in November. For further questions please call the Careline.



Amanda Norris (Young Carer of the Year 2012) with her siblings Demi and Adam for whom she helps care, along with mum Antoinette and brother Sam.



Amanda Norris (Young Carer of the Year 2012), Mary Kennedy, Peter Riordan (Family Carer of the Year 2012) and Catherine Cox.

Stroke Awards 2013

This year marks the Irish Heart Foundation's 4th Annual Life After Stroke Awards to celebrate the incredible courage and determination of those affected by stroke and their carers. Sponsored by Boehringer Ingelheim, winners will be honoured at a glittering lunch event hosted by RTE broadcaster, Marty Whelan.



You can nominate at www.stroke.ie or contact Emma-Jane on tel: 01 634 6925 or email: emorrissey@irishheart.ie.

Members' News

Online Resource Launched for MS Care Givers



MS Ireland is delighted to announce the launch of a new online care giver resource. This 60 page resource looks at various elements of care for someone providing support to a family member or friend living with MS. It aims to provide practical information, signposting to services and support care givers in their important role.

The care giver resource is available at www.ms-society.ie

Care givers to people with MS are usually spouses, children and/or ageing parents. Caring for someone with MS can be difficult as the condition is unpredictable and so care giving needs are continually changing. Each person with MS has a different set of symptoms and disease course.

As we know, the needs of those with MS vary greatly and can change drastically over time, but often not in a progressive pattern. This can make care giving very complicated, as it may be difficult to know when the person with MS will need care and how much he or she will need. We hope this resource will be of help to people if caring becomes an issue for them and their family.

Aidan Larkin, Services Development Manager with MS Ireland, authored the resource and says of its launch: "We are thrilled to offer this service to care givers of people with MS. They provide invaluable and irreplaceable care and support to their loved ones, often with little recognition and support for themselves or the person they care for. The resource offers reliable information and signposting for issues that crop up for care givers from time to time. We hope it will be an organic resource and will change and adapt as people use it."

If you or your family are experiencing issues with care giving and you wish to speak to someone, our Regional Community Workers would be happy to assist. Working in every county in Ireland, our professional and experienced team complement the care givers resource with local knowledge and information. Log on to our website for local contacts.



www.ms-society.ie | 01 678 1600 | info@ms-society.ie | MS Information Line: 1850 233 233
Find us on Facebook, Twitter, YouTube and LinkedIn

Members' News

Forum on End of Life in Ireland

Dublin Castle, 24 October, 2013

Forum 2013 will explore the theme *Length of Days - Quality of Life*. This one-day conference will look at the different perspectives of longevity: ethical issues at end of life, community responses to dying, death and bereavement, and how to secure quality of life as people age.



Forum 2013 is organised by the National Council of the Forum on End of Life in Ireland, which is an initiative of the Irish Hospice Foundation. It is chaired by Mrs Justice Catherine McGuinness and was formed in July 2010 following an extensive year-long public consultation which identified what end-of-life issues mattered most to Irish people. A work plan, developed to address the issues raised, is being carried out by the National Council.

Prof Goran Hermerén will be the international guest speaker at the conference. He has been professor of philosophy at several universities, and since 1993 professor of medical ethics at Lund University, Sweden. He served as President of the European Group on Ethics in Science and New Technologies in Brussels from 2002 until 2011. He is currently involved in several EU-funded research projects and is the chair of the permanent working group on science and ethics of All European Academies (ALLEA). He has written a number of publications, mainly on ethical problems in medicine. He is also an artist, and has exhibited his abstract paintings and graphical works in Sweden and abroad.

Mrs Justice McGuinness stated: "Forum 2013 will be open to interested members of the public as well as healthcare professionals. This is our third Forum event and it always presents a valuable opportunity for us to get feedback on progress we are making and some guidance for our future work. The theme for this year will look at the many challenges that we face as a society to ensure that we live well as we live longer. The Forum will allow us to explore the different perspectives on longevity. We are delighted to have speakers of the calibre of Prof Hermerén addressing our conference."

Details of Forum 2013 are available on www.hospicefoundation.ie. The closing date for bookings is Friday, 27 September. It is open to the public and professionals interested in end-of-life issues.

Some Figures on Dying

About 29,000 people die in Ireland each year.

IHF research in 2004 revealed that most people wish to die in their own homes surrounded by their loved ones, pain-free, conscious and able to communicate.

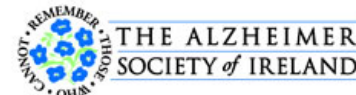
However, more than seven out of 10 people die outside their own homes and 43% die in busy acute hospitals.

Some three-quarters of all deaths occur at or over the age of 65 years. For each person who dies, about 10 people are likely to be bereaved.

Members' News

The Alzheimer Society Launches its 2014 pre-Budget Submission

The Alzheimer Society of Ireland launched its pre-budget submission for 2014 at the Royal Irish Academy on 19 June 2013. Speakers at the launch included Gerry Martin, CEO and Professor Ian Robertson, Director of NEIL, Trinity College, who highlighted the importance of dementia prevention. Former businesswoman, Helen Rochford-Brennan also spoke about her personal experience of being diagnosed with early-onset dementia. The pre-budget submission for 2014 is calling on Government to make dementia a political priority, to ensure a National Dementia Strategy is published, with a focus on timely diagnosis and cost-effective post-diagnostic interventions, and to commit to enhancing provision of education and support services for carers. Over 25 cross-party political representatives attended the event.



For more information see: www.alzheimer.ie

Parkinson's Association of Ireland – Social Gathering, 7 September 2013

This year we are having a social gathering in the Hodson Bay Hotel, Athlone. In the heart of Ireland's Lake District Hodson Bay Hotel & Spa is stunningly situated on the tranquil shores of Lough Ree.



On Saturday 7 September, we will hold an information update in the morning and will be scheduling interactive activities after lunch. For further details see <http://www.parkinsons.ie/SocialGathering2013>

Members' News

Galway Head Injury Support Group Promote Four Events this Autumn

25 September 2013

Information Evening on
Safety In The Home
Venue: Quest building

30 October 2013

Citizens Information Evening
Venue: Quest Building

November 2013

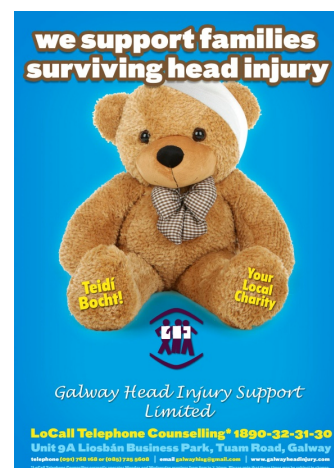
Annual Social
(venue & date to be confirmed)

11 December 2013

Pampering Evening
Venue: Quest building

For more details, contact:

T: 091 768 168 E: galwayhisg@gmail.com W: www.galwayheadinjury.com



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Practical Resources

The Essential Carer's Guide

By Mary Jordan

Publisher: Hammersmith Press

Second edition

The second edition of this helpful handbook builds on the strengths of the first version. A lot has changed since 2006, when Mary Jordan's original guide for carers was published, and the new edition has, of course, been updated to reflect changes in benefits and entitlements, as well as shifts in provision of health and social care. (Note that, inevitably, these are UK-centric.)

From first steps in arranging for an occupational therapy needs assessment for both the cared for and the carer, through to dealing with wills and probate, the Essential Carer's Guide takes the new carer through the hazards likely to be encountered along the way, and provides a wealth of useful resources to follow up specific needs in more detail.

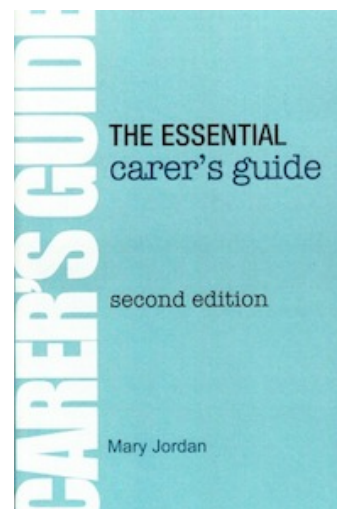
There are particularly strong chapters on managing change successfully (this is something that is bound to be an issue, where anybody is becoming less able to manage their life as they used to) and on financial issues; dealing with professional carers (including how to choose domiciliary support or residential care); and balancing the needs of both parties in the caring relationship. The chapter on nutrition helps you steer a course between the dictates of healthy eating and tempting the appetite of someone who perhaps no longer enjoys their food as they did, with lots of commonsense suggestions to help. There is a similar down-to-earth approach to social life, getting out and about, and keeping boredom at bay.

At the back of the book is a list of further resources for each chapter - a useful quick reference guide to where you can find more information on specific topics - many of them now, of course, on the internet.

The author has extensive experience of caring for elderly relatives combined with an insider's understanding of the health services, having spent almost ten years as an NHS manager, and recent experience working for a major dementia charity. Her style is straightforward and free from jargon, and there are numerous real-life case histories illustrating solutions that others have applied to many common problems.

Reviewed by: Frances Leckie www.independentliving.co.uk/index.shtml

Published in paperback at £12.99, you can purchase it at the special price of £9.99, [here](#).



Practical Resources

Caitlin's Wish – A Book for Children with Sick or Disabled Family Members

Caitlin's Wish is an enchanting, moving story of one little girl's journey as she comes to terms with her father's life-changing disability.

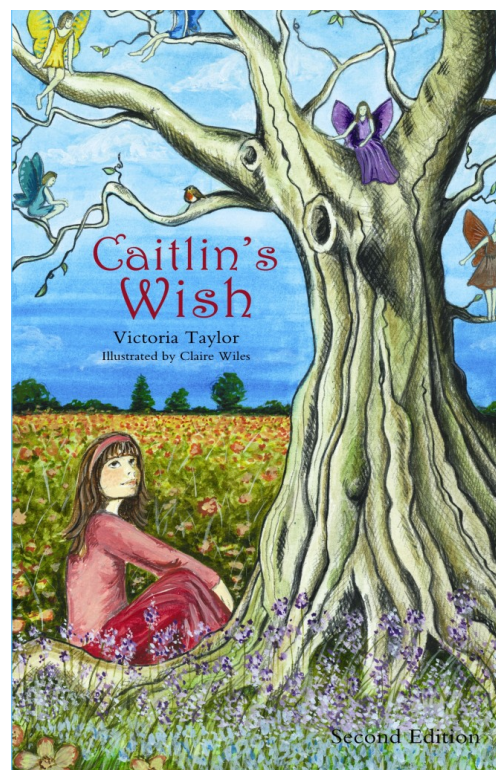
Completely unique in its ability to raise awareness of what it's like to be a young carer, yet within the context of a magical fairytale, it weaves real life events into a mystical, magical world of angels, fairies, pixies and a very special healing tree.

The underlying messages within Caitlin's Wish are those of hope, love, inspiration and an idea that anything is possible if you just believe in yourself! It empowers young carers and children of all ages to focus on the positives in life in order to triumph over adversity!

"Just the right combination of fact and magic!"
Ewan Main, Carers Trust.

"Caitlin's Wish gives a unique insight into what it is like for a child to be faced with the unexpected illness of a parent and the challenges of being a young carer. Caitlin's Wish is a source of inspiration and enjoyment to children in Wales and around the world."
Gwenda Thomas, Deputy Minister for Children & Social Services, Welsh Assembly Government.

Caitlin's Wish is available from [Troubador Publishers](#).



Research and Practice Reports

A Good Life in Old Age? Monitoring and improving quality in long-term care



As ageing societies are pushing a growing number of frail old people into needing care, delivering quality long-term care services – care that is safe, effective, and responsive to needs – has become a priority for governments. Yet much still remains to be done to enhance evidence-based measurement and improvement of quality of long-term care services across EU and OECD countries. This book offers evidence and examples of useful experiences to help policy makers, providers and experts measure and improve the quality of long-term care services.



The full report is available to read at www.oecd.org/els/health-systems/good-life-in-old-age.htm

The fastest-growing age group are people over 80 whose numbers will almost triple by 2060, rising from 4.6% of the population to 12% in 2050 in the European Union. It is estimated that up to half of them will need help to cope with their daily activities.

New Independent Report from the US Provides a More Robust Value on Informal Care

How do we measure and quantify care? In particular care provided by Family? A recent (June 2013) US report, produced by the objective Congressional Budget Office, identified a figure of US\$234b for caring for older persons.



CONGRESSIONAL BUDGET OFFICE

www.cbo.gov/sites/default/files/cbofiles/attachments/44363-LTC.pdf

For, AARP, the leading US Ageing NGO's take on the report see <http://blog.aarp.org/2013/07/19/just-how-valuable-is-family-caregiving/>

Reasonable estimates can vary, but the main finding from the CBO and AARP estimates is clear. The magnitude of family caregiving dwarfs other public and private costs associated with providing long-term services and supports to people with disabilities of all ages.

Research and Practice Reports

Engaging Family Caregivers as Partners in Transitions Report on A Quality Improvement Collaborative

Engaging Family Caregivers as Partners in Transition is an American report which highlights a three-year initiative, [Transitions in Care – Quality Improvement Collaborative](#), involving 45 health care provider teams engaging and supporting family caregivers as a core strategy for improving patient transitions from one care setting to another. More than 200 team members from the participating providers – hospitals, home care agencies, nursing home rehab programs, and hospices – worked together to develop and test changes that went beyond a sole focus on the patient to look at family caregiver strengths, needs, and limitations in the transition process. The report details what participants did, what they learned in the process, and the impact of their efforts.



The overarching goal of this project was to improve transition processes and outcomes by including family caregivers in decision making, and providing them with relevant information, preparation, and training. The foundation of that broad goal – and an essential basis for all further work – was early identification of family caregivers, allowing timely self-assessment of their needs for training and support. Specific strategies to achieve that goal were:

- Inclusion of the family caregiver in medication reconciliation;
- Identification of post-discharge patient needs and discussion of patient discharge options with the family caregiver;
- Discharge preparedness (training, expectations of the day of discharge);
- A well-orchestrated day of discharge;
- Closing the loop, including post-discharge communication with the family caregiver and the receiving agency.

As part of the initiative, participants were asked to complete the following question: "If I were a family caregiver, I would want health care professionals to..."

The responses summarised were as follows:

- Keep me informed
- Tell me the truth about diagnosis and treatment options
- Be more patient and compassionate
- Listen to what I need, feel, want
- Respond to phone calls in a timely fashion
- Give me information in language I can understand
- Treat me with respect
- Understand my culture and family background

The full report and a six page summary are available to download [here](#).

Research and Practice Reports

Towards better support for family carers: A richer understanding

Authors: Sheila Payne, Gunn Grande.

This special edition of Palliative Medicine aims to address the important topic of how best to support lay people (family, friends and significant others; hereafter called 'family carers') who provide care to patients during advanced illness and through the process of dying. It is widely recognised that these people have an essential role in providing physical care, emotional and social support; financial resources; advocacy and anticipatory care and in negotiating and coordinating care during the final phases of life. The presence of family carers who are able and willing to provide care is essential to facilitate important patient choices, such as place of care and place of death. It is a challenging and demanding role, which few people aspire to, but which many will have thrust upon them, in often difficult circumstances and following a 'crisis'. Undertaking this role may have physical, psychological, social and financial consequences for carers, which outlast their period of care and may influence their bereavement. Yet remarkably until relatively recently, there has been little academic interest in how family carers adapt to and manage their role in caring for those who are facing death.

For the full text of the article, [click here](#).

For more information, contact: Sheila Payne, International Observatory on End of Life Care
Email: s.a.payne@lancaster.ac.uk

Member Profiles

National Council for the Blind



NCBI, the largest national sight loss agency in Ireland, offers a range of services to over 17,000 individuals (and their families) who are experiencing some loss of vision, caused by a range of medical conditions and circumstances. All of our work is based on the belief that people who have impaired vision and people who are blind should have the same choices, opportunities and rights as others to fully participate in the society in which they live. To this end we work directly with people experiencing sight loss and their significant others and we work on their behalf, by striving to make Ireland a country where public services and local authorities aim for accessibility of the environment itself, the information related to it and the opportunities within our society for all.

Our front line services are individualised and are offered in a way that the areas of a person's life which they identify as being most impacted upon by sight loss, are addressed first. For many people, the inability to read ordinary sized print presents a particular difficulty that leaves them feeling dependent on others for some of the day to day tasks they used to carry out so easily. For others, difficulty recognising people's faces, going down steps or moving from one place to another can present problems and for the vast majority of people with whom we work, driving a car is not an option.

When a person makes contact with NCBI we discuss with them the impact of vision loss on their daily functioning, including: communication, home and personal care, getting around, leisure, social activities, training, employment, and the psychological impact of sight loss as well as their general health, living situation and supports available to them.

Information is shared regarding the particular eye condition that has been diagnosed and its meaning. Very often the conversation focuses on the anxieties and fears that a person has around managing their day to day life and the future. Often people find that their preconceptions about sight loss and how people function with reduced vision come from "way back" and the current possibilities, although not the cure they really want, are much broader and more hopeful than they ever imagined.

Many people attend with (or include in the conversation) their partners or primary carers and this is important because in our experience sight loss (particularly that which is acquired during adulthood) impacts not only on the individual experiencing it, but also on those around them who are usually trying to do what's best.

For many people, being given a diagnosis can be quite a lonely experience – one that they find difficult to share with those around them and one that loved ones often find hard to understand. Many people find that roles within the family change, family members try to be helpful and often seem to get it wrong, communication becomes difficult and people try as best they can to protect each other from the upset and the pain that they are all feeling in the first stages of sight loss and often thereafter.

Member Profiles

NCBI continued

This has significant implications for the individuals themselves and for those who care for them as well as for services such as those offered by NCBI and others who care for and support older people, which remain hugely under resourced.

NCBI was founded in 1931 when its work was both carried out and funded by volunteers. The organisation has moved to a model of service where professional front line staff and volunteers work side by side and service provision is at all times lead by the specific requirements of the people who choose to engage with us. Front line services are now co-funded by the HSE and income obtained through donations, charity shops, legacies and specific fundraising events.

The number of people with sight loss is set to rise by 21% by the year 2020 when it is estimated that 5% of the population (271,996 people) will have a vision impairment.

Approximately 95% of people on NCBI's database have varying levels of usable vision while about 5% of people using NCBI services are completely blind. Both low vision and blindness are likely to impact upon the quality of life of an individual and in many instances their families too. Just as there are many different causes of sight loss which may present a person with static or fluctuating levels of vision, and may impact on central, peripheral or overall visual acuity, there are as many different responses to sight loss as there are people living with it. For this reason NCBI's services are individualised so that people's interaction with this organisation relates directly to their particular situation and how sight loss is impacting on their life.

Through communication about anxieties, worries and fears in a safe environment, offered by NCBI, people can discover possibilities for getting on with their lives in ways that they never would have imagined. Introduction to appropriate magnification in the early stages of diagnosis can make a world of difference to a person's quality of life. Access to information through computers that have large print on screen and speech, telephones with enlarged font and books that can be listened to, are just some of the things that enable people to continue to live independently and to do what they enjoyed prior to being visited by sight loss, albeit in a slightly different way. Group based activities and one to one conversations with others experiencing sight loss offer opportunities for people to share experiences and this is something that many have found helpful.

As well as working directly with individuals and their families, another aspect of NCBI's work relates to campaigning for prevention of sight loss, awareness programmes, advocacy and influencing those factors in society which impact upon the quality of life, safety and opportunities for people who experience sight loss or are blind. Influencing the public policy agenda to include and address issues of vital importance to those who live with sight loss forms a significant part of our work both at local and national levels. NCBI works with public and private sector bodies to influence positive change in addition to its ongoing direct work with people who are blind or vision impaired and their wider family systems.

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Caring in the News

Media coverage of caring-related issues since April 2013

Carers issue new appeal on cuts - The Cork News, 19 April 2013

<http://thecorknews.ie/articles/carers-issue-new-appeal-cuts-10354>

Dinny celebrates 90, happy at home with family - The Nationalist, 20 April 2013

www.nationalist.ie/news/south-tipp-today/dinny-celebrates-90-happy-at-home-with-family-1-5013701

Short film brings home reality of cuts facing family carers - The Tuam Herald, 2 May 2013

www.tuamherald.ie/2013/05/02/short-film-brings-home-reality-of-cuts-facing-family-carers/

So who cares for the loving carers? - The Evening Herald, 7 May 2013

www.herald.ie/lifestyle/so-who-cares-for-the-loving-carers-29248864.html

Why Sam keeps smiling - The Irish Independent, 7 May 2013

www.independent.ie/lifestyle/why-sam-keeps-smiling-29246540.html

Full-time carers working 110 hours a week - The Irish Time, 10 June 2013

www.irishtimes.com/news/full-time-carers-working-110-hours-a-week-1.1422486

Carers' survey reveals financial worries and lack of State support - The Irish Examiner, 11 June 2013

www.irishexaminer.com/archives/2013/0611/world/carersapos-survey-reveals-financial-worries-and-lack-of-state-support-233798.html

Catherine's story highlights plight of 187,000 family carers - The Irish Independent, 11 June 2013

www.independent.ie/irish-news/catherines-story-highlights-plight-of-187000-family-carers-29334534.html

Respite care grant cuts leave carers 'angry and bitterly disappointed' - The Irish Times, 11 June 2013

www.irishtimes.com/news/respice-care-grant-cuts-leave-carers-angry-and-bitterly-disappointed-1.1424752

Family 'thrilled' about HSE U-turn on disability transport cuts - The Journal.ie, 20 June 2013

www.thejournal.ie/family-thrilled-about-hse-u-turn-on-disability-transport-cuts-959097-Jun2013

Alzheimer's carries stigma and little hope of cure - The Irish Times, 9 July 2013

www.irishtimes.com/life-and-style/health-family/alzheimer-s-carries-stigma-and-little-hope-of-cure-1.1456801?page=2

Waterford urged to nominate Carers of the Year and Young Carer of the Year 2013 - Waterford Today, 24 July 2013

www.waterford-today.ie/waterford-today-news/20252-waterford-urged-to-nominate-carers-of-the-year-and-young-carer-of-the-year-2013-20252.html

International News

Eurocarers AGM/Conference

Late May in Dublin was a busy period for carer related events.

The Eurocarers AGM and Conference took place, at which a new president was elected. The overarching goals for 2013-2014 of EUROCARERS are:

- to increase awareness of the need to support carers in policy and practice;
- to contribute to the 2014 European Year, topic not yet finalised;
- to find ways to secure sustained funding;
- to ensure carers issues as a theme in the 2014 EU Parliament Elections.

Robert Anderson (outgoing President) informed the AGM that during the last few years, the visibility of carers and particularly informal carers has increased in the European policy debate on health, ageing, employment and social policy. For instance, one of the main policy initiatives in the area of employment, the Employment Package, specifically refers to the need of promoting formal employment in household services in part to support informal carers. Furthermore, last February the Commission published a series of policy documents, for example the Social Investment Package, which explicitly refer to carers (specifically in a special document addressing long-term care). A number of new EU research projects also address informal carers. He reported that Eurocarers has worked hard to ensure that carers are represented either in research and dissemination activities, for example in projects such as SmartCare, INNOVAGE and AIDA.

The latest of the Eurocarers newsletter is available to [download here](#).

Irishman Appointed President of European Carers Organisation

We are delighted to report that Frank Goodwin, founder of The Carers Association (Ireland) and up until recently on the Board of Care Alliance Ireland, has been appointed as President of Eurocarers, the European Association Working for Carers (www.eurocarers.eu). We wish Frank all the best in his new role.



International News

World Carer NGOs Meet in Dublin

The inaugural meeting of the International Alliance of Carer Organisations (IACO) took place on 22 May in Dublin. The meeting was a great success with presentations on Family Carers in attendee countries as well as discussion on future projects for IACO. Member countries from the United States, Canada, Sweden, the United Kingdom, Ireland, Australia and New Zealand took part in the discussion. IACO will seek to influence the UN and the WHO and to progress the position of Family Carers Worldwide. Care Alliance Ireland, as a founding member of IACO, hosted the group on the evening of 22 May, and were delighted to hear the retired Ambassador to the UN, Mr Richard Ryan, speak about his experience on the UN Security Council and more broadly about NGOs influencing the UN. Two sub-committees have been set up and Care Alliance Ireland sits on the Communications Committee which had its first teleconference on 25 July.

Members of IACO with retired ambassador Mr Richard Ryan at the inaugural meeting in Dublin.



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 88 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.

Become a member of Care Alliance Ireland:
www.carealliance.ie/membership

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10 Reasons To Join Us

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