



Care Alliance Ireland Exchange

Autumn 2017 Issue 56

Care Alliance Ireland – UCD Family Carer Research Conference



Pictured at the Care Alliance Ireland/UCD Family Carer Research Conference are Donal McKenna (Chair CAI) with Deirdre Murphy (DCU) and Janet Diffin (QUB)

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Consultation on Home Care Services – Deadline for Submissions Extended

Following representations made by a number of not-for-profit organisations, the deadline for making submissions on the review of home care supports has been extended to 2 October. See notification [here](#). You can find a full copy of the consultation form [here](#). Zoe Hughes, Policy and Research Officer, has been consulting with many of our member organisations in advance of making our own submission.



Improving Home Care Services in Ireland:
Have Your Say!

News

Report on Family Carer Research Conference – 31 August

Attended by in excess of 50 researchers, practitioners and Family Carers from across the island of Ireland, this second biennial Care Alliance Ireland Research Conference was this year co-hosted by the UCD School of Nursing Midwifery and Health Systems.

Head of School Professor Thilo Kroll opened the conference. Chairs for the various sections of the conference included Mr Donal McKenna, Care Alliance Chair and Mr Robert Cullen, Family Carer.

The conference began with a presentation by Ms Áine Tehan, outlining the work of the UCD EnCareDementia Project, a project that Care Alliance Ireland's Sandra McCarthy is currently heavily involved with; Sandra is the lead on the dissemination and outreach aspects of this HRB-funded project.

This was followed by the first of three oral paper sessions, with presentations on the topics of male carers, online Family Carer training and home care packages. In excess of a dozen poster presentations were displayed throughout lunch and included topics on young carers, transitioning out of caring roles, COPD and caring, and Family Carer training.



After lunch, the second two panels took place, with presentations tackling the topics of the experiences of Family Carers of children with cystic fibrosis, Family Carers/supporters of those with mental health conditions, engaging dementia carers in research, and Family Carer assessments (both in a palliative care context and in an acquired brain injury context), amongst others.

Several of the papers and presentations were video recorded and will be available on our website over the coming weeks.

Joanna Joyce, Advocacy Officer,
The Alzheimer Society of Ireland

News

Pictures from the Family Carer Research Conference – 31 August



News

Members at EGM Approve New Constitution

Following a review by the Board of Directors, and approval by members at an EGM on 19 September, Care Alliance Ireland adopted a new Constitution.

In light of the Companies Act 2014, it was considered good practice to review and update our governing documents. We spoke with other organisations in the not-for-profit sector that have successfully managed this process. Particular thanks to Diarmaid O'Corrbui in the Carmichael Centre and Patricia Towey of the Huntington's Association for their support. This new governing document is based on the model proposed by the Charities Regulator and the one currently used by the Carmichael Centre. The thinking is that some of the rules/procedural aspects that were previously in the Memorandum and Articles of Association would be better placed in a new Company Governance Handbook. This makes future changes to election rules/procedures, etc. easier to progress, without the necessity to call EGMs each time.



Implementing SVR in Ireland

Implementing SRV in Ireland



Speakers Include:

- **SUSAN THOMAS, SYRACUSE, NEW YORK**
Training Inst for Human Service Planning, Leadership, and Change Agency.
- **RAYMOND LEMAY, OTTAWA, CANADA**
Exec Director of Family & Children's Services of Lanark, Leeds & Grenville.
- **AOIFE O'TOOLE, KILDARE, IRELAND**
CEO of Dara Community Living in Co. Kildare.
- **MOLLY O'KEEFFE, KILDARE, IRELAND**
Development Manager with Possibilitiesplus.
- **SELINA DOYLE, KILKENNY, IRELAND**
People/Culture/Development, St Patrick's Centre.
- **MICHAEL J. KENDRICK, MASSACHUSETTS, U.S.A., Director – Kendrick Consulting.**

"Reshaping human service Approaches so that people with disabilities can obtain Personally Appealing and Life giving Social Roles within Community."

You're invited to this exciting opportunity where experienced practitioners and teachers share insights on *SRV* (Social Role Valorization); on the challenges of moving from congregated settings to more normative settings, impacting the daily lives of people so they can access the good things of life.

Fees: Organisations €80, Family Member €50, Lunch included
[click here for more information and registration](#)

News

Policy and Research Officer Reporting

Zoe Hughes, Policy and Research Officer



Zoe continues to work with member organisations to increase collaboration across the policy and research brief of Care Alliance Ireland. Whilst the summer months are often quiet, it is a chance to catch up on reading missed during the busy spring – you can see some of these key policy and research documents via our Research & Policy Roundup [here](#). The Roundup is constantly updated with new documents and stories.

If you would like to raise any issues with Zoe, please don't hesitate to get in contact.

Work undertaken on research and policy issues recently includes:

- Representation of Family Carer issues, along with colleagues from other local and national organisations, at the HSE National Patient Forum.
- Attendance at and representation of member organisations and Family Carers at the Annual Pre-Budget Forum, hosted by the Department of Social Protection in July. We anticipate some positive changes for Family Carers in Budget 2018. You can see the full text of our Pre-Budget Submission [here](#).
- Organisation of the 2nd biennial Care Alliance Ireland Research Conference, along with our partners in the event, the UCD School of Nursing, Midwifery and Health Systems. More than 50 practitioners, students and Family Carers attended the day-long conference on 31 August – see the full event review on page 2.
- Preparation of the Care Alliance Ireland submission to the consultation on home care services (Dept of Health).
- Work continues on the Discussion Paper series, with papers currently in progress on the topics of romance and its effect on Family Caring, and caring when relationships are strained. As always, Zoe welcomes any feedback on the papers in this series, and suggestions for topics to be addressed.
- Continued availability to member organisations to consult and support on key policy & research issues.

For more information on these, or any other policy & research matters, please contact Zoe (zoe@carealliance.ie).

News

Towards Resilience in Family Caregiving for People with Dementia – Update



With the help of Sandra and the research team at UCD, the EnCaRe Network Group of Family Carers are currently preparing for their sixth research session. Over the last five sessions the group has explored what it is to be resilient as a Family Carer of a person with dementia and have identified numerous areas that they feel can enhance Family Carer resilience. Sandra has been working closely with the group and has been supporting them as they start to focus on the type of support(s) they would like to target with the EnCaRe programme. Over the summer, the group was delighted to welcome two new members and Sandra has been working with them and the original members to help them settle in and ensure they are up to speed on the progress has made to date.

Sandra also contributed to the recent Care Alliance Ireland Family Carer Conference and provided an overview of the EnCaRe project at the event.



If you would like more information about Sandra's work on the EnCaRe project you can contact her at sandra@carealliance.ie.

Empowering Professionals to support Young Carers (EPYC) Project update



The EPYC project is continuing apace and the transnational partners met in Vienna in mid September. The database of resources identified from intellectual outputs one and two is available on the [EPYC website](#) and represents a wide range of supports from across Europe which can be accessed online or by request from the authors.

The meeting in Vienna was very productive with the group discussing the creation of their own, new national resources, and the development of the third output, which is intended to lay the groundwork for increased awareness and understanding of young carers and the specific challenges they face.

To find out more about EPYC's work, please contact Denise at denise@carealliance.ie.



Left: the EPYC partner meeting in Vienna



News

Journal of Care and Caring Accepts Care Alliance Ireland Paper

The second edition of the International Journal of Care and Caring (IJCC) has been published and includes a wide range of articles.

Our own Zoe Hughes' paper on defining carers, entitled "Defining and profiling family carers: reflections from Ireland" has been accepted for publication in the Debates and Issues section of the journal and will be published in the third edition in October 2017.

The journal defines this section as follows: "The journal encourages critical engagement with policy and practice developments and aims to include contributions from different areas of the world in each edition. Its regular Debates and Issues section features dialogue with carers' organisations, policymakers, trade unions, employers and academics, to encourage global dialogue and international sharing of ideas, expertise and experience."

This second edition includes an editorial by Professor Sue Yeandle, University of Sheffield, UK, which summarises the entire collection of papers. The Debates and Issues articles are and will remain Open Access. Access to the other papers requires a subscription.

The IJCC welcomes contributions of research/scholarly articles for peer review, shorter Debates and Issues pieces, book reviews, and conference reports. For details of how to submit, and guidance on the IJCC's remit and focus, please visit their webpages at: <https://policypress.co.uk/journals/international-journal-of-care-and-caring>.



"I warmly welcome this timely and important new journal, which is extremely relevant for our network, offering an exciting new forum for debate and international exchange of knowledge about care, carers and caring."

Stecy Yghemonos, Executive Director, Eurocarers – European Association Working for Carers

Sláintecare Report Published

The all-party Oireachtas Committee on the Future of Healthcare recently published its findings. The Sláintecare report makes recommendations on expanding health and wellbeing, primary care, social care, dental and mental healthcare. The full report is available [here](#).



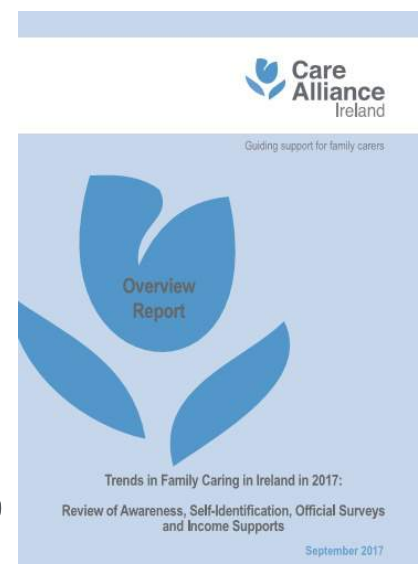
We in Care Alliance Ireland welcome the focus that the report places on primary care and integrated care, and the specific recommendations to increase resourcing in the areas of home care, palliative care and disability services.

News

Latest Overview Report Published

The latest paper to be published by Care Alliance Ireland looks at some of the trends and statistics in Family Caring in Ireland. The paper, entitled, *Family Caring in Ireland in 2017 – Trends in Awareness, Self-Identification, Income Supports and Official Surveys*, seeks to explore the interrelationships between Family Carer identification, Family Carer prevalence statistics and supports for Family Carers.

To provide a context for the analysis, the paper provides a brief summary of the Family Carers movement, both in Ireland and internationally. We explore the meaning of the terms “awareness” and “identification” used by some leading not-for-profit Family Carer organisations. The combination of reliable statistics combined with personal carer stories in securing media and political interest and support is considered. Irish published statistics and international data are reviewed, and some plausible causes of the large discrepancy in Family Carer numbers reported in different studies are suggested. We review trends in state income supports, both absolute and relative, and the possible drivers of these changes. We also examine how different policy changes in Ireland since 2000 may have impacted reported carer numbers. We conclude by discussing how Family Carer identification, Family Carer prevalence statistics and supports for Family Carers are closely interlinked. We ask if specific awareness campaigns can have population-level impacts and raise some questions in relation to public preferences for income supports, prioritisation, the use of evidence-informed services and interventions and finally what we call ‘apparent demand’ for care.



Speaking on its launch, its author Liam O'Sullivan, Executive Director said:

“We hope that this paper helps explain some of the reasons for the difference in prevalence rates of Family Caregiving from various surveys in Ireland. We have also looked at some international data to help understand the importance of the language used in the surveys. The report also takes a look at the changes in income supports for Family Carers since 2000. We hope this paper will be a useful addition to the Family Carer sector and wider health and social care sector.”

News

Care Alliance Ireland Presenting at 7th International Carers Conference

Care Alliance Ireland is delighted to have a strong line up of six papers, both oral and poster, that we will present at the 7th International Carers Conference in Adelaide, Australia in October 2017. Whilst some papers reflect primary research and projects that are being led and undertaken by Care Alliance Ireland, others represent collaborative initiatives, for example, the paper we will present on behalf of Dr Carol Kelleher (UCC) on "Family Carers' Experiences of Role and Identity Transition on Cessation of the Caring Role – Implications for Policy and Practice".

Care Alliance Ireland will be represented by our Executive Director, Liam O'Sullivan. We are also glad to be able to report that, thanks to funding secured by Carers Australia and by the International Alliance of Caregiver Organisations (IACO), much of the cost of travel and accommodation and indeed the entire conference fee is being covered by sponsorship from Novartis.

We are also delighted that Dr Attracta Lafferty (UCD) will be presenting a number of papers at the conference on the topics of carers of people with intellectual disability, dementia and carer resilience.

Full abstracts of the presentations are in the following pages.



News

Care Alliance Ireland Presenting at 7th International Carers Conference

Oral Presentations

Post-Caregiving: Family Carers' Experiences of Role and Identity Transition on Cessation of the Caring Role – Implications for Policy and Practice

Presenter: Liam O' Sullivan, Executive Director, Care Alliance Ireland

Authors: Dr Carol Kelleher (University College Cork), Liam O'Sullivan, Sally-Ann Back (West Cork Carers Support Group, Ireland) and Paul O'Mahoney (Family Carers Ireland)

This presentation on the POSTCARE project highlights how successful partnerships between carers, care recipients, researchers, carer associations and policy makers can improve the lives of carers and their care recipients at a regional and national level in Ireland.

The central aim of the Irish National Carers' Strategy (2012) is to recognise the value and contribution of carers to civic society, and to support and empower them to participate as fully as possible in economic and social life. Post-caregiving involves significant challenges for former carers including: return to work or education; economic and financial challenges; rebuilding social networks; changed family relationships; dealing with complicated grief; and identity rebuilding. However, the far-reaching and complex economic, social and psychological needs of former carers remain misunderstood and unmet.

POSTCARE is a collaboration between University College Cork, West Cork Carers Support Group, Family Carers Ireland and Care Alliance Ireland funded under the Irish Research Council New Foundations programme. Its aim was to develop evidence-based supports and policy to support former carers post-caregiving by providing a nuanced knowledge of Family Carers' post caregiving experiences of loss, role and identity transition on cessation of the caring role, and thus specifically respond to the aim of the National Carers' Strategy, i.e 'to review existing transition arrangements for carers at the end of their caring role'.

Using a participatory action research approach, POSTCARE prioritised responsive information exchange with those most impacted by the research, namely former carers, and responded to the issues, challenges and concerns facing former carers via a series of participant-led workshops and supports. Through dialogue with 23 former carers (13 women and 10 men) and three regional and national Carer Associations, the project outputs incorporated guidelines, an action plan and the co-development of peer supports to change and influence policy and practice.

Overall, POSTCARE has informed national policy and the delivery of carer supports in Ireland and internationally, thus empirically and practically addressing carer needs as prioritised by the National Carers' Strategy, and fostered continued engagement with partner NGOs on a longer-term basis.

News

Care Alliance Ireland Presenting at 7th International Carers Conference

Supporting Professionals to Support Young Carers — an EU Experience

Presenter: Liam O'Sullivan, Executive Director, Care Alliance Ireland

Authors: Liam O'Sullivan, Denise Dunne (Care Alliance Ireland) and Ben Salzmann (Diakonisches Werk Berlin Stadtmitte e.V, Germany)

Research has provided clear evidence that heavy caring responsibilities among young people can result in emotional difficulties, health problems, social exclusion, and limited opportunities for social and leisure activities. In spite of this, professional support services are lacking in many EU countries. Since mid 2016, six separate carer, youth and educational organisations from across Europe have been collaborating on a project entitled Empowering Professionals to support Young Carers (EPYC).

The project targets youth workers primarily but also education, health and social care professionals in Austria, Germany, Ireland, Italy and Scotland who work with, or intend to work with, young carers directly or indirectly. Awareness-raising tools such as posters, flyers, web resources and videos have been shared, and tools and interventions are being collated, including questionnaires, motivational interviews, checklists and services navigators. This material is available to anyone on a dedicated website. The eventual desired outcome of the project is increased knowledge and competence amongst practitioners in identifying young carers and initiating and developing support services for them.

This presentation will describe both the process of collating examples of young carer interventions and the content itself. We will reflect on the challenges we anticipate in maximizing the use of the tools. We will also reflect on the type of relationships and impact of the relationships that have developed during the course of the project. As part of the presentation, the live website and its contents will be displayed.

The presentation will illustrate the importance of collaboration when working in this area. As most European countries still lack awareness of and support for young carers, learning from existing good practices in other countries can prove to be very helpful in nudging forward young carer support interventions at national level.

News

Care Alliance Ireland Presenting at 7th International Carers Conference

Carer Needs Assessment Development – The Experience in Ireland

Presenter: Liam O'Sullivan, Executive Director, Care Alliance Ireland

Authors: Liam O'Sullivan, Clare Duffy (Family Carers Ireland), Linda McDermott Scales (Health Services Executive, Ireland), Natalie Vereker (Health Services Executive), Kris Dhondt (Rehab Care, Ireland)

Identifying the needs of Family Carers is increasingly being viewed as a key intervention in the development of fully integrated health and social care and in reducing Family Carer burden, stress and depressive symptoms. Carer Needs Assessments (CNAs) have been enshrined in law in the UK for over 20 years and are significantly embedded in assessment processes, while in the US there have been some legislative initiatives to bring Family Carers closer to the centre of care.

In 2010, an international collaborative Working Group was established to develop a CNA for national and international use. This group was comprised of statutory health providers, not-for-profit national carer/advocacy organisations (NGOs) and the international not-for-profit organisation 'interRAI™', which specialises in evidence-based assessment systems development. The Working Group are developing a CNA, initially paper based, which is currently being piloted with adult Family Carers in a longitudinal study across 11 countries, including Ireland, in order to finalise the tool. Once the pilot is complete, the CNA will be available as part of the 'interRAI' integrated suite of assessment tools which is in use Ireland and internationally across health care settings.

The target population for the pilot study is adult Family Carers who are providing an ongoing and significant level of care to an older person who is in need due to illness, disability, or frailty. Approximately 600 Family Carers will be recruited internationally. The final potential target population is all Family Carers who provide significant levels of care.

This initiative is innovative as it represents a first collaboration between a state health agency, a number of not-for-profit agencies and a leading academic health care assessment systems design collaboration (interRAI), in developing, testing and (potentially) implementing a comprehensive standardised assessment tool. Current models of CNA have not been exposed to sufficiently comprehensive evaluation.

This presentation charts the progression and challenges of this initiative, using an Implementation Science Framework. There will be a discussion on the learning from the process together with a wider assessment of the future potential for Carer Needs Assessments in general, with a view to their use in supporting the wellbeing of Family Carers.

News

Care Alliance Ireland Presenting at 7th International Carers Conference

Poster Presentations

Stigma Experienced by Family Carers

Presenter: Liam O'Sullivan, Executive Director, Care Alliance Ireland

Author: Zoe Hughes, Policy and Research Officer, Care Alliance Ireland

Many Family Carers are happy for others in their circle of friends and family to be aware of their caring responsibilities. This is often easier when the 'reason' the person being cared for requires care is a condition which is likely to elicit a particularly empathetic response – such as dementia, or a significant medical condition. However, not all conditions that necessitate family members becoming Family Carers necessarily fall under this category, for example, mental health, HIV, addiction or COPD. For many carers, stigma can be a significant factor, which can have an impact on their wellbeing. It can also impact on their willingness or ability to access supports needed throughout their caring journey.

Whilst the notion of 'stigma' has developed and changed – and is still under debate – since it was first developed in the 1960s, in general it can be seen as set of misguided opinions about a group of people, built upon assumptions which have developed over time. The notion of stigma, as it relates to mental health and disability is usually discussed in the context of the person receiving care, yet it is clear that those who provide significant levels of care also experience stigma related to a myriad of other factors.

The objective of this poster presentation is to outline the key types of stigma experienced by Family Carers (via literature review) including data from a general survey undertaken by Care Alliance Ireland in 2015 of 800 family carers. It is clear there are issues of stigma which have not yet been addressed by research or indeed by support organisations, yet are experienced by many Family Carers. This is an internationally relevant topic which speaks to a lesser-discussed challenge for support organisations, who may have little to no experience in discussing these sensitive topics with Family Carers.

News

Care Alliance Ireland Presenting at 7th International Carers Conference

Do Leaflet Drops and Targeted Social Media Ads Increase Carer Identification

Presenter and author: Liam O'Sullivan, Executive Director, Care Alliance Ireland

In April 2016, Ireland's Census of Population took place. Since 2002, a specific question in the Census has attempted to capture the prevalence and (more recently) the intensity of Family Caregiving.

Within the advocacy/civil society area in representative democracies, there is a long history of placing value on raising awareness of causes as a means of improving the situation of those such organisations seek to represent. The carers movement is no different in this regard and has for a long time placed emphasis on carer identification. Not-for-profit organisations regularly seek to justify their role, funding and existence by claiming that awareness raising is a key aspect of their work. In doing so they argue that this supports carer wellbeing and that in addition it supports the resourcing and accessing of specific carer support services.

Data from previous population censuses in Ireland have over time demonstrated an increasing level of carer identification, over and above that which would have been expected due to demographics/medical advances alone. This suggests that carer identification interventions can be effective, notwithstanding the impact of other cultural influences over time. No research however has been conducted to date to test this hypothesis.

This poster tells the story of a small-scale study/specific intervention that took place in the days running up to Census night; namely a suburban house-to-house leaflet drop (n = 269) and use of geographically targeted paid social media posts (Facebook: reach 1,763) together with a similar social media intervention targeted to two other geographical areas in Ireland (one rural, one mixed: Facebook: reach 1,989 and 1,076 respectively).

Following the release of national as well as local area population Census statistics in July 2017, we reviewed the impact, if any, such small-scale and local interventions had on carer identification, as measured by changes to self-reported caregiving through completion of the Census form in those particular geographical areas.

We will discuss the possibilities for future interventions that impact on carer identification.

News

Care Alliance Ireland Presenting at 7th International Carers Conference

Having an Impact: Supporting High-Quality Family Carer Training

Presenter: Liam O'Sullivan, Executive Director, Care Alliance Ireland

Author: Zoe Hughes, Policy & Research Officer, Care Alliance Ireland

For most Family Carers, the onset of caring responsibilities is an unexpected development, and many Family Carers will have little to no experience of the various tasks and skills that are needed in that role. Many support organisations offer training and educational opportunities for Family Carers. However, many also struggle with how to maximise the effectiveness of such training, how to measure impact and outcomes, and how to address specific implementation challenges.

Throughout 2016, Care Alliance Ireland delivered a project that aimed to address these gaps, involving a range of health and social care practitioners in Ireland. A three-strand project was delivered, which included:



- a series of seminars in locations across the country
- a booklet that included feedback from participants as well as other practice resources
- a website that builds on the booklet material for practitioners and hosts an interactive database of training (both online and face-to-face) available for Family Carers in Ireland (face-to-face) and beyond Ireland (online).

This poster presentation focuses on the measurement of core skills and information gained by participants at the three seminars that took place in 2016. Baseline measurements were taken of participants' knowledge and awareness of current training available for Family Carers, their use of outcome-focussed interventions, and their ability to provide high-quality training and support interventions for Family Carers.

Over the course of the seminars, average measurements increased significantly, indicating an increased level of knowledge and confidence on the part of individuals. We posit that for practitioners in the field, this enables them to focus more on outcomes, rather than outputs. An additional outcome of this seminar series was an increased level of observable and self-reported cooperation and peer learning between a wide range of support organisations. By working with support organisations to increase their capacity to create and deliver these focussed training interventions, our objective to be of benefit to Family Carers accessing these supports has been achieved.

Member News

Bodywhys Seminar in Athlone for Parents



Athlone - October 2017

Are you supporting a family member with an eating disorder?

If so, this free course is for you

Bodywhys and Athlone Community Services Council Ltd
invite you to attend

PiLaR : Peer Led Resilience 4-week programme :

Evening programme for families and friends.

When: 4 Thursdays in October (starting October 5th)
Time: 7 - 9pm
Venue: Shamrock Lodge Hotel, Clonown Road,
Athlone, Co. Westmeath

Places are limited. Attendance is FREE but booking is essential.

Contact Athlone Community Services Council: 090 642174 / 086 1721564
or Harriet Parsons, Bodywhys: 01 283 4963 / helpline@bodywhys.ie

Member Profile

Enable Ireland

In 2016, Enable Ireland provided services to 5,080 children and their families in centre- and community-based settings in 14 counties throughout Ireland. The organisation uses its expertise in assessment and intervention to achieve the best possible outcomes for children and their families. Enable Ireland understands that every child and family are unique and have diverse needs and their approach to providing services puts the child and family at the centre of all decision-making that affects them.

Enable Ireland provides a range of services and supports to children and adults with disabilities and their families and carers. These include clinical assessment, occupational therapy, speech and language therapy and physiotherapy, education and training for children, adults, parents and carers. Family Support Services offered include in-home respite, community and residential respite, and centre-based respite. A diverse range of training and workshops are offered to parents and carers based on individual needs and include training on Lámh, positive parenting, Assistive Technology, postural management, baby massage, sleep training and Feeding Eating Drinking Swallowing (FEDS). Enable Ireland's social worker service provides counselling and advice to families and carers to help with practical, emotional, and social needs. Support to parents and carers is provided both in a one-to-one setting and in groups.

Respite breaks allow a family caring for a child with a disability a much-needed break. Breaks can be for a few hours, overnight, weekends or for longer periods depending on need and availability. Children play an active part in planning their respite break and enjoy a range of activities which are appropriate for their age, interest and ability. For children, Enable Ireland has overnight respite services in Clare, Wicklow and Tipperary. For adults, Enable Ireland has respite houses in Clare, Wicklow and Cork.



The range of services that Enable Ireland provides depends on the specific contracts in place between Enable Ireland and the HSE, and will vary depending on the part of the country you are in. You can find full details of Enable Ireland services available in your county by visiting www.enableireland.ie/services/service-centres.

Enable Ireland's mission is to work in partnership with individuals, families and carers using their services to achieve maximum independence, choice and inclusion in their communities.

Contact details:

Enable Ireland, 32F Rosemount Park Drive, Rosemount Business Park, Ballycoolin Road, Dublin 11

Tel: 01 872 7155

E-mail: communications@enableireland.ie

Member Profile

DEBRA Ireland

What is EB?

- A distressing & painful genetic condition that causes the layers of the skin and internal linings to blister & tear at the slightest touch.
- There are currently no effective treatments for EB. The management of EB requires 3-hour bandage changes, 3 times per week.
- EB is rare – an estimated 1 in 18,000 babies born are affected by it.
- It is a genetic condition, caused by a fault in one of a number of genes that are responsible for holding the layers of skin together.
- There are different forms, which vary from debilitating to devastating. Some forms are so severe that babies do not survive & others result in dramatically reduced life span.
- In severe cases, almost no part of the body remains untouched & the care of EB requires a large multidisciplinary team of medical specialists.



For people whose skin doesn't work, we do.



DEBRA Ireland is the patient-led organisation, established over 20 years ago, to support families living with EB. The major focuses of the organisation are patient care and research.

Pictured are Claudia, aged 13, and her dad, Gary.

DEBRA Ireland:

- Provides a 32-county Family Support Service for patients and their families. This is a needs-led service, which offers emotional, financial and practical support.
- Funds specialised nursing care, including bandage change and palliative care nurses, as required.
- Liaises closely with hospital MDTs, providing funding and support when required.
- Funds and supports research, working with EB research groups around the world. To date, €2.5 million has been invested in EB research.
- Raises awareness of EB and advocates for improved care for people living with EB.
- Works with the Irish Skin Foundation to establish an EB patient registry.
- Leads several projects on behalf of DEBRA International, including the development of clinical practice guidelines.

For the coming year DEBRA Ireland's advocacy team will work towards:

1. Ensuring the current HSE-funded EB outreach nurse is made permanent.
2. Highlighting the need for two additional HSE-funded EB outreach nurses.

To access any of our support services or get in touch with a member of the DEBRA team please visit our website www.debraireland.org.

Member News

Members' Annual Reports and other Recent Publications

A number of our member organisations have recently published their 2016 Annual Reports. You can download these by clicking on the respective organisation's logo below.



St. Michael's House
Services for people with intellectual disabilities



**THE ALZHEIMER
SOCIETY of IRELAND**



**The Irish
Hospice
Foundation**

Striving for the best care
at end of life for all



Ability West

cross  care

The Irish Wheelchair Association has recently published its latest [Strategic Plan](#).

**Irish
Wheelchair
Association**

**Strategic Plan
2017 - 2020**



Dementia Care Management Trial in Germany Offers Promising Results

Effectiveness and Safety of Dementia Care Management in Primary Care. A Randomized Clinical Trial

Jochen René Thyrian et al JAMA Psychiatry. Published online July 26, 2017.
doi:10.1001/jamapsychiatry.2017.2124

Key Points

Question What is the effect of dementia care management, a model of collaborative care, on the treatment and care of people with dementia and their caregivers in primary care?

Findings In this randomized clinical trial of 634 people with dementia, dementia care management significantly reduced neuropsychiatric symptoms and caregiver burden and increased use of antidementia drugs compared with care as usual. Dementia care management was found to be a safe intervention.

Meaning Dementia care management may significantly improve the outcomes of treatment and care among people with dementia and caregiver burden and should be incorporated into routine care.

Abstract

Importance Dementia care management (DCM) can increase the quality of care for people with dementia. Methodologically rigorous clinical trials on DCM are lacking.

Objective To test the effectiveness and safety of DCM in the treatment and care of people with dementia living at home and caregiver burden (when available).

Design, Setting, and Participants This pragmatic, general practitioner-based, cluster-randomized intervention trial compared the intervention with care as usual at baseline and at 12-month follow-up. Simple 1:1 randomization of general practices in Germany was used. Analyses were intent to treat and per protocol. In total, 6838 patients were screened for dementia (eligibility: 70 years and older and living at home) from January 1, 2012, to March 31, 2016. Overall, 1167 (17.1%) were diagnosed as having dementia, and 634 (9.3%) provided written informed consent to participate.

Interventions Dementia care management was provided for 6 months at the homes of patients with dementia. Dementia care management is a model of collaborative care, defined as a complex intervention aiming to provide optimal treatment and care for patients with dementia and support caregivers using a computer-assisted assessment determining a personalized array of intervention modules and subsequent success monitoring. Dementia care management was targeted at the individual patient level and was conducted by 6 study nurses with dementia care-specific qualifications.

Main Outcomes and Measures Quality of life, caregiver burden, behavioral and psychological symptoms of dementia, pharmacotherapy with antidementia drugs, and use of potentially inappropriate medication.

Results The mean age of 634 patients was 80 years. A total of 407 patients received the intended treatment and were available for primary outcome measurement. Of these patients, 248 (60.9%) were women, and 204 (50.1%) lived alone. Dementia care management significantly decreased behavioral and psychological symptoms of dementia ($b = -7.45$; 95% CI, -11.08 to -3.81 ; $P < .001$) and caregiver burden ($b = -0.50$; 95% CI, -1.09 to 0.08 ; $P = .045$) compared with care as usual. Patients with dementia receiving DCM had an increased chance of receiving antidementia drug treatment (DCM, 114 of 291 [39.2%] vs care as usual, 31 of 116 [26.7%]) after 12 months (odds ratio, 1.97; 95% CI, 0.99 to 3.94; $P = .03$). Dementia care management significantly increased quality of life ($b = 0.08$; 95% CI, 0 to 0.17; $P = .03$) for patients not living alone but did not increase quality of life overall. There was no effect on potentially inappropriate medication (odds ratio, 1.86; 95% CI, 0.62 to 3.62; $P = .97$).

Conclusions and Relevance Dementia care management provided by specifically trained nurses is an effective collaborative care model that improves relevant patient- and caregiver-related outcomes in dementia. Implementing DCM in different health care systems should become an active area of research.

Research

Caregiving Needs Increase as Older Adults Approach End of Life

Dying adults in the United States have 2.5 people assisting them, on average, according to a new study. Yet those caring for adults at the end-of-life, especially spouses, are likely to report that they have no one assisting them and no time for themselves. Researchers at Icahn School of Medicine at Mount Sinai have found that dying adults received almost twice as many hours of help per week compared to those not at the end-of-life, and that end-of-life caregivers were significantly more likely to report physical difficulty related to giving care. Their analysis was published in the July issue of *Health Affairs*.

Katherine Ornstein, PhD, Assistant Professor of Geriatrics and Palliative Medicine at the Icahn School of Medicine at Mount Sinai and coauthors used the National Health and Aging Trends study and its linked National Study of Caregivers to profile end-of-life caregiving in the United States. They found that older adults at the end of life had an average of 2.5 caregivers assisting them and received 61.3 hours of help per week versus 35.5 hours for older adults not at the end of life. 35 percent of end-of-life caregivers reported physical difficulty related to giving care versus 21 percent in other caregivers, and 51 percent reported having no time for themselves versus 40 percent in other caregivers. For end-of-life caregivers who were spouses, nearly two-thirds reported that they receive no support from family or friends. This is the first study to prospectively examine all the paid and unpaid caregiver support individuals receive at the end of life using a nationally representative sample.

"This study reveals the huge reliance our society places on family and other unpaid caregivers throughout the course of serious illness and especially at the end of life," said Dr Ornstein. "Although receipt of paid caregiving increases toward the end of life, the vast majority of older adults do not receive any paid help. They are relying on families for their care, which is often quite complex and challenging. We must recognize and support the vital role of family in end of life care."

Previous studies are often limited to the experience of one primary caregiver or to individuals with one specific disease. Furthermore, prior studies of end-of-life caregiving often asked about these experiences after a loved one died and are subject to recall bias.

Compared to other caregivers, end-of-life caregivers reported higher rates of financial difficulty caring for those with cancer. End-of-life caregivers who were spouses reported the most care-related challenges, including increased depression and physical difficulty.

"The challenging job of a caregiver is not usually restricted to a few months before an individual dies and we must do more to support them throughout the often long course of serious illness. Palliative care, which provides an added layer of support for patients and families in the setting of serious illness, is one critical tool to support caregiving families. State and federal legislation, as well as workplace policies, are also essential to providing the needed support to seriously ill people and their families," added Dr. Ornstein.

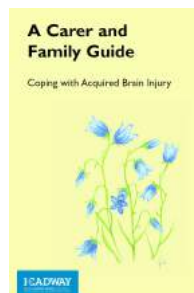
Journal Reference:

1. Katherine A. Ornstein, Amy S. Kelley, Evan Bollens-Lund, Jennifer L. Wolff. A National Profile Of End-Of-Life Caregiving In The United States. *Health Affairs*, 2017; 36 (7): 1184 DOI: 10.1377/hlthaff.2017.0134
2. Website reference: <https://www.sciencedaily.com/releases/2017/07/170711092832.htm>

Resources

Resources and Booklets Available for Family Carers and Professionals

Family Carers Ireland: a free booklet detailing entitlements and supports for Family Carers is available by calling 1800 24 07 24 or emailing careline@familycarers.ie.



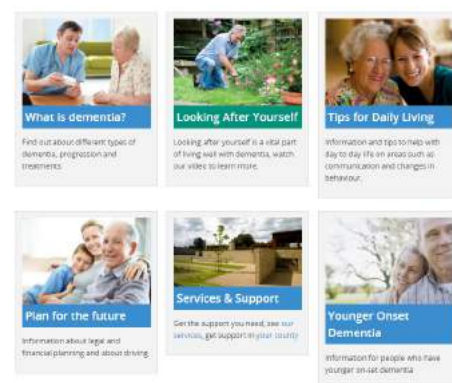
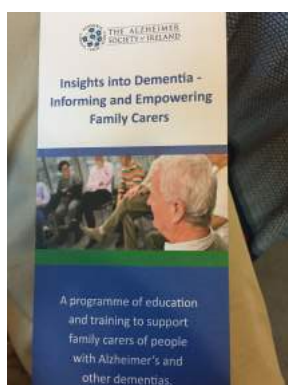
Headway (Brain Injury): Family and Carer Guide is available [here](#).

Enable Ireland: Guide to Accessible Apps, Games and Toys. Available to download [here](#).



Down Syndrome Ireland have produced a new booklet, Supporting Children with Down Syndrome in Primary School. A limited number of printed copies are available from their national office info@downsyndrome.ie or call them on 01 4266500.

The Alzheimer Society of Ireland: variety of on-line and hard-copy resources and publications for Family Carers of people with dementia available [here](#).



Governance Corner

Good Governance Awards – Key Note Speaker Announced



The closing date for the Awards was 15th September and having been winners within our category last year, we look forward to hearing which entrants have been shortlisted. We are delighted to hear that a leading advocate for Family Carers in the UK, and former CEO of Carers UK, Baroness Jill Pitkeathley, currently Chair of the House of Lords Select Committee on Charities in the UK, will give the key note address. For further details see www.goodgovernanceawards.ie. Davy's most recent publication, Charity Insight, features an article by Diarmiad O'Corrbui, CEO of the Carmichael Centre, describing the rationale for establishing the Good Governance Awards <https://tinyurl.com/yag4klcs>.

Members Re-Appointed Directors at AGM

Following the AGM on 19 September, per good practice, four directors voluntarily resigned and put themselves forward for re-election. All four were re-elected at the AGM, namely Rosemary Daynes, Ann Walsh, Deirdre Shanagher and Phil Dunne. Barbara Barrett, who had been co-opted in June, and Annie Dillon, who had been co-opted in February, were both formally elected at the AGM.

Remaining board meetings for 2017

- 21 November

Lobbying

In early September we submitted our latest 4-monthly report to the Register of Lobbyists. You can read our submission [here](#).

Policies Under Review

In addition to our developing a Company Governance Handbook, over the coming months the following policies will be reviewed: Data Protection Policy, Division of Responsibilities between Chairperson of the Board and Executive Director, Code of Conduct for Directors, Schedule of Matters Reserved to the Board for Decision, and Protected Disclosures (Whistleblowers) Policy.

Governance Compliance Numbers Continue to Rise

As of 11 September, 436 organisations report being compliant with the Governance Code

1,196 organisations report being on the journey to adoption

For a full list of organisations see [here](#)

International News

Toolkit for Emerging Carer Organisations to Be Launched



The next meeting of IACO will take place on 3 October, on the fringes of the 7th International Carers Conference in Adelaide. The focus of the meeting will be to consider the next steps in the development of IACO and its ambitious work plan, and to launch a new Toolkit that seeks to support emerging carer organisations across the globe.

Collaboration on the Development of a Cancer Toolkit for Europe

In collaboration with the European Cancer Patient Coalition (ECPC), Eurocarers are developing a toolkit that aims to provide carers who provide care to someone suffering from cancer with the practical tips they need in their daily life, in their own language, through relevant information and advice.

Speaking about the initiative, Clare Champion, Eurocarers Project Officer said:

“Rather than giving off the peg responses, it will seek to help these carers become aware of the multiple aspects of their situation, maintain their own health and wellbeing, find some answers to the many questions they have, based on other carers’ experience, and invite them to use existing supporting tools in their country. This toolkit will address different aspects of the carer’s experience through the following specific sections”

Content will include:

- Coping with caregiving;
- Maintaining a good level of wellbeing (physical and mental health);
- Informing one’s employer/ maintaining work/life balance;
- Dealing with palliative and supporting care in cancer;
- Dealing with the financial burden of the disease;
- Resources and support networks in Member States.

The toolkit will be available initially in the following languages: French, German, Italian, Spanish and Polish. Some parts of the toolkit will be common to all versions, while the parts related to the resources and support available in Member States will be specific to France, Germany, Italy, Spain and Poland.

Care Alliance Ireland is working with other stakeholders to input useful content.

Eurocarers Annual Report

Eurocarers' latest Annual Report is available to read [here](#).





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 360,000 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 85 member organisations and other agencies to support them in their work with family carers. Our membership includes all the carers organisations and virtually all the condition-specific organisations currently providing services to many of Ireland's family carers.

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

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Charity Registration No 20048303

10 Reasons To Join Us

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