



Care Alliance Ireland Exchange

Summer 2018 Issue 59

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National Carers Week – 11 – 17 June, 2018

National Carers Week is now in its 12th year, and we look forward to another week of celebrations and recognition of the care provided by Ireland's 360,000 family carers. This year we have two new partners, Spina Bifida Hydrocephalus Ireland and the CRC (Central Remedial Clinic).

Speaking about being a partner in the week and what it means to the CRC, Stephanie Manahan, CEO said: *"The CRC is proud to partner with Care Alliance Ireland in celebrating Carer's Week 2018. As one of the largest disability organisations in the country we are indebted to those family carers who give up their time to care for a loved one, and selflessly put someone else's needs above their own. This week is about celebrating our heroes, and recognising the unseen work they are dedicated to."*

There are twelve organisations who are partners in the week this year and who will be organising events around the country to acknowledge the valuable work and contribution that family carers make not only to their individual families but to Irish society more widely. Partners this year are: Acquired Brain Injury Ireland, the Alzheimer Society of Ireland, Care Alliance Ireland, the CRC, the Disability Federation of Ireland, Family Carers Ireland, the Irish Cancer Society, the Irish Hospice Foundation, MS Ireland, Special Needs Parents Association, Spina Bifida Hydrocephalus Ireland and St. Michael's House.

For details on events being organised or tips on how to organise an event, see www.carersweek.ie or our facebook page www.facebook.com/nationalcarersweek over the coming weeks.



News

Resource for Former Family Carers Reaches Across Ireland

Since the launch in March of our new publication *The Way Ahead* – a resource to support former family carers – we have been inundated with requests from across Ireland for hard copies.

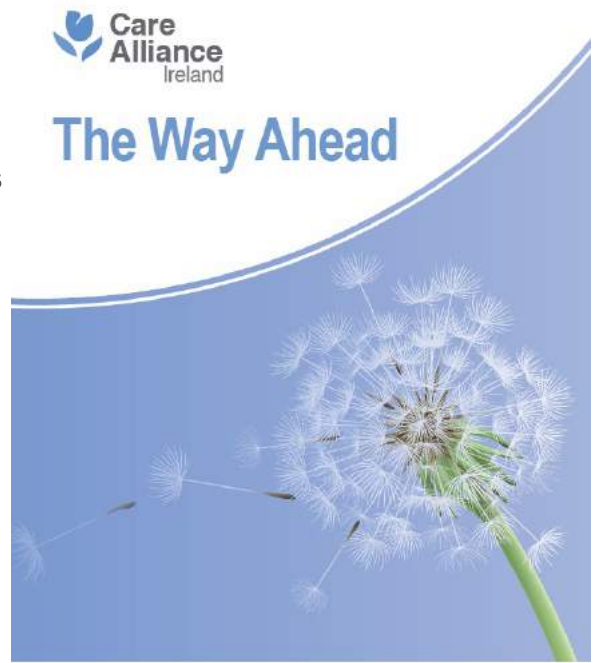
Just under 2,000 copies have been distributed to individuals and organisations in every county in Ireland. Copies have been sent to Citizens Information Centres and to Intreo Centres, as well as to our member organisations. Several hundred copies have been given to Family Carers Ireland, as they begin the roll out of their Plan C Programme for former family carers. Enquires about the resource have been made from as far away as Australia.

There have been over 3,000 direct downloads of the resource and we are now seeking funds to get more hard copies printed and distributed across Ireland.

Annie McGuinness took part in a number of radio interviews since the launch, promoting the booklet and discussing life as a former family carer.

Feedback about the booklet has been very positive to date.

A small number of complimentary copies are remaining and available for individual former family carers on request from info@carealliance.ie. The booklet is also available to download at www.carealliance.ie.



A resource to support former family carers



“Please may I have some hard copies of this excellent booklet. This will be a wonderful resource for carers and contains a lot of valuable information that healthcare professionals may not know, for example, the 12 week rule in relation to the carers allowance. Thank you and congratulations to all the team involved in developing this very worthwhile resource.”

Clinical Nurse Specialist Palliative Care

News

Care Alliance Ireland Welcomes a New Staff Member

Following a very competitive recruitment process, a new appointment has been made to the Care Alliance Ireland team.

Kevin Deegan will work primarily on the HRB/Dementia/EnCaRe project, in collaboration with UCD, specifically in the area of research dissemination to a lay audience. He will also co-ordinate the delivery of six regional meetings, involving current and former dementia carers, who will be given the opportunity to discuss the research findings emanating from the HRB-Dem/EnCare project.



Kevin will also be involved in supporting National Carers Week in June and with various other projects currently ongoing. As well as his work in Care Alliance Ireland, Kevin is currently pursuing his MA in International Relations with UCD. His thesis focuses on the effects climate change has on human rights in developing nations.

Kevin graduated with a BA in History & Politics in 2017. Alongside this, he completed his BSc in Computer Science in 2013 with IT Tallaght. Kevin has worked with a number of charity organisations in the past, such as Temple Street Hospital and UNESCO. Kevin has a keen interest in running; having completed the Dublin marathon in 2013, Kevin will be running the Dublin marathon again in October to help raise awareness of the work done by the Irish Hospice Foundation.

Kevin can be contacted by email on kevin@carealliance.ie or by phone on 085 852 9352.

News

Meeting with Mental Health Ireland



**Mental Health
Ireland**

Our recent meetings with leaders of our membership organisations serve to keep us aware of the issues they face in their support of families.

In the area of mental health, we are particularly aware of the sensitivities around the use of terminology, noting the extensive use of the term 'supporter' as opposed to family carer. This was one of the many issues we discussed with Martin Rogan, CEO, Mental Health Ireland, and his colleague Catherine Brogan, when we met together at their head-quarters in April. One specific outcome of the meeting is that we have agreed to look at working together on a possible new discussion paper for publication in the future. Martin reports that Mental Health Ireland is committed to co- production which actively involves people with personal experience of mental health issues, family members and health professionals in the design, delivery and evaluation of mental health services.

Social Policy Network Meeting

On Tuesday 17th April, Care Alliance Ireland was delighted to welcome members of the Social Policy Network to the Carmichael Centre for their quarterly meeting. The group meets to share information and ideas on the respective work of the member organisations in relation to social policy, and to act as a support and learning network for those doing social policy work. The group has a rotating Chair, and members take turns hosting meetings in their respective locations. The April meeting welcomed Laura Ronney Ferris, Systems Librarian at Dr. Steevens Library, HSE, to discuss how Open Access publishing can be used for social policy purposes.

If you are interested in learning more about the Network, you can contact Zoe (zoe@carealliance.ie), who can connect you with the current Chair.



News

Research and Policy Officer Reporting



Zoe Hughes continues to work with member organisations to increase collaboration across the policy and research brief of Care Alliance Ireland.

Work undertaken on research and policy issues recently includes:

- Continued involvement with the Invest in Homecare campaign and with the National Patient Forum and Lenus working Group
- Submissions made to date in 2018 include:
 - National Action Plan for Social Inclusion 2018 to 2021 Public Consultation
 - Loneliness Taskforce
 - Consultation on Proposed Guiding Principles to Frame the State's Economic Migration Policy
 - Advance Healthcare Directives Codes of Practice Consultation
- Actively involved in the Public Patient Involvement (PPI) project with the University of Limerick
- Continued support and collaboration with University College Dublin on Family Carers and Dementia (HRB-funded project)
- Continued facilitation of the Family Carer Research Group. Most recent group meeting took place March 2018
- Continuing to meet with a number of member organisations, in particular following on from the engagement drive in Q1.
- Developing material re: Care Alliance Pre-Budget priorities to share with member organisations to get feedback for Budget 2019
- Ongoing drafting of further papers in the Discussion Paper Series. As always, Zoe welcomes any feedback on the papers in this series, and suggestions for upcoming topics to be addressed.
- Support of student projects on the topic of family care where appropriate.
- 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

Resilience in Caregivers of People with Dementia – UCD/ Care Alliance Research Update



Over the last few months, the EnCaRe Network Group of family carers and the team at UCD have been putting the finishing touches to the online information and support resource they have been developing. Called *'Take Care of Yourself: Enhancing the Resilience of Family Carers of People with Dementia'*, the resource is being prepared for testing as part of the final evaluation phase of this three-year project.

As well as the evaluation of the resource, the next few months will see Care Alliance Ireland and the team at UCD roll out a number of information-sharing events to ensure that knowledge gathered over the course of the project is disseminated widely. To assist with this work we are delighted to welcome Mr Kevin Deegan

(for more see page 3) to the Care Alliance Ireland and HRB DEM team and look forward to keeping you up to date on the project's dissemination activities over the coming months. Kevin can be contacted about his work by email at kevin@carealliance.ie.



Empowering Professionals to support Young Carers – Project Update



The work of EPYC is ongoing, with the final partner face-to-face meeting having taken place in Edinburgh in March. At the meeting we discussed our outputs to date, how to frame our final guidance report, and how we might be able to build on the work of the group into the future. The final guidance report, which is being delivered by Carers Trust in Scotland with support from Care Alliance Ireland, will reflect the experiences of the EPYC project and highlight the work done by the partners. We anticipate the report will be a useful guide for organisations new to working with young carers, and will demonstrate the challenges and successes of the partners through the EPYC experience.

The meeting in Edinburgh was timed to coincide with a young carer showcase event being hosted by our Scottish partners, Carers Trust. This event brought together young carer support organisations to discuss the work they are doing and how they are building and developing their services. The showcase was an excellent opportunity to learn from our contemporaries in a jurisdiction with significant knowledge of and investment in family carers and young carers.

The EPYC project will be highlighted during National Carers Week with a seminar on young carers taking place in the Carmichael Centre, Dublin 7 on Tuesday morning 12 June. Book [here](#).

For more details, please email Denise on denise@carealliance.ie.



News

A Change in Judging Criteria for 2018 Good Governance Awards



The Good Governance Awards (GGA) is an initiative that recognises and encourages adherence to good governance practice by Nonprofit organisations in Ireland.

The Awards were developed in 2016 by Carmichael and are supported by the Charities Institute Ireland, Boardmatch, Dóchas, Enclude, Volunteer Ireland, The Wheel, together with our corporate partners; Davy, Governance-Online, Mason Hayes & Curran and Mazars Ireland.

Annual Reports

The Good Governance Award seek to acknowledge, encourage and promote good governance practice primarily in the area of annual reports.

A New Governance Award in 2018 - Best Governance Improvement Initiative

This new award will recognise initiatives that have been taken in the last 12-18 months to improve the quality of the nonprofit's governance. Nonprofits can submit their good governance initiatives, setting out (briefly – max 750 words) the governance issue(s) they addressed, the actions they took and the impact that this has had for the organisation.

Entry Criteria

- To enter, the organisation must be an Irish nonprofit organisation (i.e. it has a registered office in the Republic of Ireland).
- There are 2 award types and 5 entry categories based on the income size of the organisation from those with an annual income of under €250k to those with an annual income of over €15m. Organisations may enter for either award type or for both.
- A nonprofit organisation must upload their entry to the GGA website by the closing date (14th Sept, 2018).
- Shortlisted listed organisations may be asked to supply additional information to assist the judges in their adjudications.
- See www.goodgovernanceawards.ie for more information.

Member News

The Alzheimer Society of Ireland Launches Regional Group for Dementia Carers Advocacy Network in Munster

The Alzheimer Society of Ireland (ASI) has launched the regional group of its carer advocacy network, the Dementia Carers Campaign Network (DCCN), in Munster and the first meeting of the Southern DCCN took place at the Clayton Hotel in Limerick back in March.

The DCCN, which was set up in 2013, is a national campaigning group and is made up of people who have experience of caring for a loved one with dementia. This group is open to anyone who is interested in advocacy and has experience caring for a friend or family member with dementia.

The DCCN aims to be a voice of and for dementia carers in Ireland and to raise awareness of issues affecting families living with dementia. The group is supported and facilitated by the ASI. Since the DCCN's inception, members of the network have been involved in monitoring the implementation of Ireland's first National Dementia Strategy (NDS); taken part in awareness-raising activities, including national and local media work; contributed to research programmes; and spoken at conferences and events across Ireland.

There are 500,000 people across Ireland whose families have been affected by dementia. In order to adequately reflect the experiences of dementia carers in Munster, the ASI has established the Southern DCCN, which will focus on highlighting the issues affecting dementia carers in the region. DCCN committee member from Cork Ann Twomey said: "Since working with the Dementia Carers Campaign Network (DCCN) I have used my own experiences as a carer for my late husband to the benefit of other carers – by raising awareness of issues facing families caring for a loved one with dementia and by lobbying for policy change. Being a part of the Dementia Carers Campaign Network gives you a voice that may otherwise have gone unheard."

For more information on the DCCN, please contact advocacy@alzheimer.ie.

Pictured are members of the Southern Dementia Working Group in Limerick.



Member Profile

CRC – Central Remedial Clinic



The CRC is one of the largest national disability organisations, working with approximately 4,000 children and adults with disabilities in Ireland. We employ over 300 highly talented and committed people and we are supported by over 100 passionate and enthusiastic volunteers. Our mission is to work together to make a positive difference to the lives of people with disabilities, their families and carers.

We provide multidisciplinary assessment and treatment services to children from the greater Dublin area. We also provide specialist services to children with physical disabilities who access our specialist service from every county in Ireland and provide a range of specialist medical, therapeutic and assistive technology services to children and adults with complex disabilities and rare conditions. With innovative medical and surgical interventions, evidence-based therapies and assistive technologies, children and adults with disability are supported to achieve their maximum potential.

Our adult services are located in Dublin and we operate them from five different centres. We are committed to supporting young people and adults with disabilities to have a life with opportunities to develop new skills, realise their potential, achieve academically, advocate for disability rights, build relationships and participate in their local communities and in wider society, through valued social roles.

We are also Trustees for two special schools in Clontarf and Clondalkin for over 150 children with physical and other complex disabilities. The CRC Schools provide differentiated and individualised education to pupils with physical and multiple disabilities. Pupils also access health and social services and other essential services, mainly during the school day. All pupils have multiple disabilities but a primary physical disability, in line with our official school designation.

We have an ambitious strategic plan that is focused on continuous improvement and growth of services in line with national policy. Every day, in every service we aim to realise our vision of people with disabilities achieving their potential and living full lives as equal and valued citizens.

The CRC can be contacted as below:

Central Remedial Clinic, Penny Ansley Building, Vernon Avenue, Clontarf, Dublin 3.

Tel: (01) 854 2200

Email: info@crc.ie

Facebook: [www.facebook.com/CRC Central Remedial Clinic](https://www.facebook.com/CRC%20Central%20Remedial%20Clinic)

Twitter: [@centralremedial](https://twitter.com/centralremedial)

Governance Corner

New Strategic Plan on the Cards



Our current Strategic Plan (2014–2017) has come to an end. At the March 2018 board meeting, the Chair, the Executive Director and three other board members were directed to begin the process of developing a new strategic plan. The first step has been to undertake a review of the existing plan. The review found that the plan was implemented to a large degree and that the organisation is well positioned to build on its achievements in the context of a highly functioning and moderately resourced organisation. A strong staff and director team, deeper and more engaged membership base, and exemplary governance, together with strong collaborative relationships that have been built up across the statutory, not-for-profit and academic sectors, augur well for the development of a new and impactful Strategic Plan. Over the coming months, many of our stakeholders will be invited to feed into this process by way of phone conversations and surveys.

Policies Under Review

At the May board meeting, the board considered a new Company Governance Handbook. The handbook incorporates most of the organisation's policies and procedures, and is a useful resource to support director and staff induction. Upon final review by the board, it will be available on our website at www.carealliance.ie/howweare_governance.



Lobbying

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

2017 Audit Approved

Our 2017 Directors Report and Audited Financial Statements were reviewed by the Audit and Risk Committee in April and were approved for signing by the board of directors at the 8 May meeting. The full report will be presented to our members at our AGM on 18 September, and then put up on our website.

Board Meeting Dates, 2018

3 July

18 September
(followed by AGM)

20 November

Governance Compliance Numbers Continue to Rise

As of May, 493 (up 6 on March) organisations report being compliant with the Governance Code and 1,360 (up 29 on March) organisations report being on the journey to adoption.

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

Research

New Carer-Related Research and Evidence Exchange Network (CAREN)



Speaking on the recent launch of a repository of significant family carer research, Dr. Mary Larkin, the lead researcher behind this project, said:

“this freely accessible resource seeks to meet the needs of ALL those across the globe who require any form of carer-related knowledge – be this research evidence, and/or information about practice and policy. It is for national and international use by governments, carers, employers, policy makers, practitioners, researchers, NGOs/third sector organisations and research funders. Not only does CAREN provide a reliable, regularly updated, independent, searchable and coherently organised database of information and evidence about carers, it also allows those accessing it to communicate and exchange knowledge“.

The resources within this network are organised into 62 themes, which are listed under the four major categories (see below). Clicking on a theme will take you to a list of all resources within that theme. You can click on an author's name to find further resources by that author, and use other links to access the original source material.

In addition, clicking on the title of any individual resource shows details about the source of the information, such as the type of reference, ISBN/ISSN, publication year, keywords. A number of these fields can then be used to find further resources, i.e. with the same keywords, or by the same author using the links on the right-hand side and within the Key Information box.

Carer variables

The characteristics and features of different types of carer and caring situations.

Impact of care

The consequences and sequela of caring.

Support and carers

The provision and impact of general and specific help and support.

Type of care

The nature of needs of the cared-for person, and the features of the care situation.

To access this database go to www.open.ac.uk/caren

Feedback is welcome – contact mary.larkin@open.ac.uk

(Note much of the primary research referenced is behind journal paywalls. This will limit access to abstracts unless you have a subscription to the relevant journal.)

Dates for your Diary

National Carers Week

11 – 17 June, Nationwide
12th National Carers Week
For more information see: www.carersweek.ie and
www.facebook.com/nationalcarersweek



Empowering Professionals to support Young Carers (EPYC) Seminar

12 June, Carmichael Centre, Dublin 7
10.30am–12.30pm (followed by light lunch)

This free seminar is aimed at anyone working with or around young people who may have additional caring responsibilities.

For more information or to book, click [here](#).



International Social Work, Education and Social Development Conference

4–7 July, RDS Dublin



Good Governance Awards – Application Deadline

14 September, online



Care Alliance Ireland AGM

18 September, Dublin
3.00pm–5.00pm



Resources

Family Carers Ireland Launch New Online Care Guide

Recently launched, this guide seeks to provide relevant and tailored information and advice to family carers.

For more information see www.familycarers.ie/careguide.



Care Alliance Ireland Discussion Paper Series

All of our publications are available now in hard copy or to [download](#).



International News

Eurocarers

As part of their annual work programme, Eurocarers are organising a Study Visit on the topic of “Carers, human rights and associative discrimination” in cooperation with colleagues from Anziani e Non Solo and the Department of Law of Modena University (Italy). The event is taking place in Modena on the 5–6 June. We are delighted that a wonderful advocate for family carers and a former family carer herself, Annie McGuinness, will be taking part in the Study Visit.



Associative discrimination comes about when someone is treated unfavourably on the basis of another person's protected characteristic. In relation to carers, it is probably best understood where a disadvantage can be expressed in the following simple statement: *'but for my relationship with a dependent person, this would not have happened.'* For example, a candidate who has been told she is getting a job is suddenly deselected after revealing that she has a severely disabled child with complicated care arrangements. The withdrawal of the job offer could amount to discrimination based on her association with a disabled person (disability being a protected characteristic).

This Study Visit will benefit from the expertise of external guests, including Professor Luke Clements (from the School of Law at the University of Leeds), representatives from the School of Law at the University of Modena, colleagues from the Regional Carers Association in Italy (who will share their experience about the development of the regional and national law on carers). The Study Visits provide an opportunity for Eurocarers members to learn from each other, take stock of the network's knowledge and good practices and lay the ground for future common initiatives at policy and/or practice level. As always, participants will therefore be expected to actively contribute to the discussion by presenting either their organisation's work and/or views on the topic or the legal environment for work in their country/region.

IACO



Care Alliance Ireland was represented by our Executive Director, Liam O'Sullivan, at the most recent IACO meeting in London on 9 – 10 May. Members agreed to a new strategic plan which will forge deeper and wider relationships with other international NGOs as well as with a number of pharmaceutical companies.



IACO delegates in London, May 2018





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](#).

Contact Us:

T +353 (0)1 874 7776

M +353 (0)87 207 3265

A Coleraine House, Coleraine Street, Dublin 7

E info@carealliance.ie

W www.carealliance.ie

Company Limited By Guarantee

Registered in Dublin, Ireland, company address as above

Company Registration No 461315 CHY No 1464

Charity Registration No 20048303

10 Reasons To Join Us

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