

Good Governance AWARDS WINNER 2016

Care Alliance Ireland Exchange Summer 2017 Issue 55

National Carers Week 2017

The 11th National Carers Week took place 12–18 June and yet again succeeded in delivering over 100 events for Family Carers across every county in Ireland. This year the week included a number of new initiatives including a live Twitter discussion on Family Carer issues in collaboration with Dr. Liam Farrell.

We were particularly happy with the print/online media coverage; RTE's Marian Finucane Show had three male family carers on the Saturday morning show on 17 June (listen here). We were also happy with the increase in involvement by health centres and private companies. The week was the fourth-highest trending topic on Twitter Ireland on 12 June. This year also represented a significant increase in merchandise with thousands of stress balls, hand warmers, shopping bags, trolley coins, T-shirts and pens dispersed nationally.

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A full review of the week has been completed and involved Family Carers, event organisers, partners and others who were involved in the week. Photos from the week can be seen on pages 3, 4 & 5.

National Carers Week 2018 takes place 11 - 17 June.

"A delayed thank you from me on all the work completed in Carers Week 2017. It was St. Michael's House's first experience of being an official partner and it was a welcome and positive one. The Carers Week is part of the communication plan for 2018. We look forward to engaging more of our teams on the ground. It was lovely to meet and work with you all."

Barbara Wiseman, St Michael's House.

National News

Care Alliance Ireland Successful Co-Applicants with University of Limerick (UL) in Public Patient Involvement Project

We are delighted to be partnering with UL and others in building capacity in the area of Public Patient Involvement. This programme of work will change the way research proposals are written by researchers, by engagment with patients and the public at the design stage. While researchers may need patients or the public to be involved in the research, they rarely ask for their input. According to a recent HRB study, this is not because researchers don't want to, but because they don't know how to go about it. This funding scheme is designed to help institutions supply the right environment, training, support and processes to help researchers engage the public and patients in their research from the start.

Speaking on the news, Zoe Hughes, Policy and Research Officer, said: "Care Alliance Ireland is looking forward to working with UL and other not-for-profit organisations in the area of PPI. Ensuring that patients and their carers are fully involved in any research that affects them is crucial to the success of any applied project that holds them at the core of that research."

Work begins on the project in January 2018. For more details see here.

Census Carers Figures Surprise

Preliminary data from the 2016 Census reports a modest increase in respondents who report providing unpaid care



"Some 195,263 people (4.1% of the population) report providing unpaid care in **RESUI** the Republic of Ireland in 2016, an increase of 8,151 on 2011. As well as the growth in the number of carers, Census 2016 shows that the time spent caring is also on the increase, with 83,754 people providing care for up to 2 hours per day (up from 80,891), while 41,185 people provided care for more than 6 hours a day (up from 39,982)." (CSO, 15 June 2017).

We in Care Alliance Ireland do not believe this to be an accurate account of the prevalence of Family Caring. Indeed, the 2015 Health Survey reported that 10% of the adult population provided care. This equates to in the region of 360,000 people.

Commenting on the disparity, Liam O'Sullivan, Executive Director, said:

"This disparity is so big that we in Care Alliance Ireland will shortly be publishing an analysis of the data, in the context of international data from Eurocarers that suggests that up to 23% of some adult populations in Europe report providing unpaid family care. Data matters, but having accurate data matters even more."

See full details of census data here.

National Carers Week continued

A selection of images from events throughout the week













National Carers Week continued













National Carers Week continued



Caring teaches me how to find the silver lining each day









Major Seminar on Family Carer Research to take place - 31 August





Registration Now Open

Conference: Family Carer Research in Ireland

UCD, Dublin. Thursday 31 August 2017

Care Alliance Ireland invite you to their 2nd biannual Family Carer Research conference, taking place in collaboration with the UCD School of Nursing, Midwifery and Health Systems on Thursday August 31st 2017.

The conference will take place in The Red Room in the UCD student centre, Belfield, Dublin 4.

Full conference programme will be released closer to the date, and will include oral and poster presentations from a wide range of speakers from across the not-for-profit, academic, and statutory sectors. In addition, a number of Family Carers will be speaking and making presentations throughout the day.

Registration for the full day costs €30 per person, which includes lunch and refreshments. There are a limited number of reduced price tickets for Family Carers and students.

You can find out more details, and register for the conference at http://bit.ly/2rJNpnl

Care Alliance Ireland Secures Nominating Rights to Seanad Eireann

We are delighted to report that we have been successful in our application to secure nominating rights to the Administrative Panel of Seanad Éireann.

The most recent elections to the Seanad (2016) were notable for the successful election through this panel of John Dolan (CEO of the Disability Federation of Ireland). We are keen that future elections through this panel will secure representation on both disability and Family Carer issues as we see disability and caring as two sides of the same coin.

We believe that our longstanding collaborative work with the Disability Federation of Ireland and other federations is resulting in a more effective way of influencing health and social care policies and practices that seek to improve the lives of Family Carers and people with disabilities.

Further Discussion Paper Published

Disability and Caring-Over 1,000 downloads since launch in April

Published in April, this discussion document attempts to open up the discussion around the challenges of advocacy for individuals with a wide range of disabilities. With the emergence in Ireland of a new organisation (Profound) aiming to articulate the particular needs of those with profound disabilities, the discussion document challenges some of the prevailing messages around individual capacity to self-advocate. The full paper can be read at http://bit.ly/2o0J51K



"Briefly, three main theoretical frameworks currently co-exist (somewhat uneasily) in the field of disability (lezzoni & Freedman, 2008). These are the medical model, the social model and (to a lesser extent) the ecological model. Historically there are other models which have been at the forefront at different times, such as the moral (Barnes, 2010) and religious models (Miles, 1995)."

"Disability is a complex phenomenon that is both a 'problem' at the level of a person's body and a complex and primarily social phenomenon. Disability is always an interaction between features of the person and features of the overall context in which the person lives, but some aspects of disability are almost entirely internal to the person, while other aspects are almost entirely external."

"The difficulty is also arguably reflected in the significant 'silo' mind-set that appears dominant in many aspects of health and social care delivery and leadership. This is entirely at odds with the concept of integrated care, one of the concepts currently ubiquitous in health care policy documents."

"This overreliance on the social model of disability, without acknowledgement of the high medical and support needs that some individuals have, risks people with these higher support needs and their families being increasingly left out of the dominant narrative around self-advocacy and independent living."

"Overarching disability policy – in direct contrast to policy specifically concerning Family Carers – may direct those same services to exclude parents of adults with intellectual disabilities from decisions."

AllHPC Carers Online Palliative Care Resource Launched



Over 30,000 people die in Ireland each year, and as more and more people spend the last part of their lives at home, families are often the primary caregivers.

Launched during National Carers Week, Caring for Carers is a new website dedicated to carers and family caring, providing core information for family members or friends who are providing support to a person who needs palliative care.

The website has eight sections and contains videos, downloads, links and information gathered by a group of experts, including carers, from across the island of Ireland.

Created by a team led by Professor Peter Hudson from Queen's University Belfast in collaboration with AIIHPC and a working group made up of family carers and former carers, carer organisations, health and social care professionals and charities, the site is hosted on www.thepalliativehub.com, an all-island gateway to palliative care information.

Speaking at the launch of the website, Karen Charnley, AIIHPC Head of Institute, said: "We are delighted to announce the launch of Caring for Carers, which represents another key stepping stone in providing information to the public on palliative care. Family carers play a huge and critical role in caring for people with palliative care needs and it is fitting we should launch this website during Carers Week 2017. which is dedicated to the amazing work that carers do on a daily basis. One of the core goals of AIIHPC is to foster strong cross-sector partnership and collaboration, and Caring for















Carers provides another example of the strength of this approach. It also adds another core component to the Palliative Hub and brings it closer to being the comprehensive resource for people with palliative care needs."

Professor Peter Hudson, Queen's University Belfast, who led on the development of the resource, stated:

"One of the most important things people confronting the end of their lives want is to be assured that their family will be well supported. Family caregivers need to know how to access support services and where to obtain key information to assist them in managing the role of supporting their relative or friend. This new resource 'Caring for Carers' meets these needs by offering an evidence-based, reliable and easily accessible resource for family caregivers of people with life limiting conditions."

Over the coming months Caring for Carers will continue to be developed with additional information and stories from people who have cared for or are caring for someone with palliative care needs. The site is available at carers.thepalliativehub.com.

€500,000 to Be Provided to **Support Former Carers/Carers** in Transition

Pobal, on behalf of the Department of Arts, Heritage, Regional, Rural and Gaeltacht Affairs, the Department of Justice and Equality and the Department of Social Protection, is inviting applications for funding from eligible organisations under the Dormant Accounts Fund (DAF) Measures. The closing date for receipt of applications is 3pm on Wednesday 26th July 2017. The recent information session provided further details of the intended focus of these grants, which is proposals that will:

- Support carers to cope with post-care transitions and to participate as fully as possible in economic and social life
- Recognie the unique journey of carers post caring
- Support carers in dealing with their loss and the challenges and changes in routines and activities
- Make the journey to re-entering social and economic life easier.

Full details of the measures are outlined in the DAF Measures Guidelines document which can be found on the Dormant Accounts page of Pobal's website here.

We in Care Alliance Ireland welcome the final publication of details of this grant scheme.

End of Life Forum

FORUM 2017

Your Life Your Death Your Say

Forum on End of Life in Ireland Conference

Tuesday 10th October 2017 **Dublin Castle Conference Centre**

Take the opportunity to have your say, and hear what others (expert and personal) have to say about dying, death and bereavement in Ireland.

- A Taste of Death Café: Eat cake, drink tea and share thoughts on dying,

- B. Planning for Your Future: What should we ask ourselves?
 C. Children Grieve Too: Helping children cope with grief
 D. Working with Grief: Supporting staff through loss and grief
 E. Ageing Matters: Living and dying well in residential care

Open to the public and professionals interested in end-of-life care.

Book now www.hospicefoundation.ie





Young Carers Interventions–Collection of Resources Now Live

Empowering Professionals to support Young Carers (EPYC)



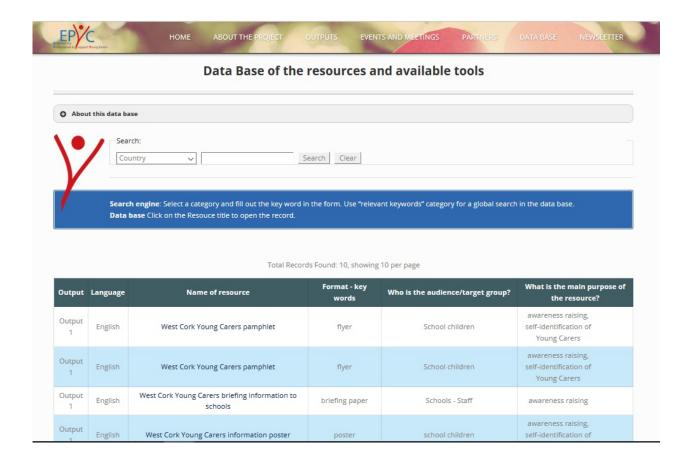
In recent days, the online resource that the project partners have been working on over the past 12 months has been launched. To view the resources go to http://www.ep-yc.org/data base/.

Speaking about the launch, Benjamin Salzmann, Pflege in Not and EPYC Project Co-ordinator, said: "Together with the five other partners from across Europe we are proud to be making this resource available online. With 87 separate resources, we see this as the beginning of a concerted effort to disseminate widely proven and dynamic resources and interventions that will act as a significant asset to those currently and or interested in supporting young carers across Europe."

Denise Dunne is project co-ordinator for EPYC. To contact her about her work or other young carer issues, please email denise@carealliance.ie.

EPYC is co-funded by the Erasmus+ programme of the European Union.





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. Work undertaken on research and policy issues recently includes:



- Continued involvement with the Invest In Homecare campaign, the National Patient Forum, and the Lenus Working Group.
- Ongoing involvement in the National Carers Strategy Monitoring Group along with colleagues from Family Carers Ireland to progress reporting and actions in the National Carers Strategy.
- Submission to the Citizens Assembly re: "How we best respond to the challenges and opportunities of an ageing population". (Read here)
- Ongoing collation of relevant material in the Research & Policy Roundup. (Read here)
- Participation in disability umbrella organisations' pre-budget statement. (Read here)
- Submission of final draft of paper to the Journal of Care and Caring. This has been accepted and will be published in October 2017.
- Continued strategic use of the National Carers Week Facebook page and Twitter to highlight current and upcoming research and policy events which may be of interest to Family Carers across the country (including recruitment for research projects, HSE Focus Groups, consultations, etc.).
- Member organisations supported to attend the Annual Carers Forum alongside Care Alliance Ireland.
- Member organisations invited to feed into submissions such as our Pre-Budget Submission, using Survey Monkey to collect opinions as appropriate.

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

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

Sandra McCarthy, Research Assistant

It has been a busy few months for Sandra and the HRB-DEM project team. The family carers group has been established and they had their first meeting on May 2 in UCD. Called the EnCaRe Network (Enhancing Carer Resilience), the group is made up of 6 people with experience of family caregiving for a person with dementia and 2 members from the UCD research team. Over the next few months they will be working together to develop a programme to help to enhance resilience among family carers of people with dementia. Drawing on their own experiences of family caregiving for a person with dementia, the network will start by exploring what it means to be resilient and from there, identify things they think would enhance resilience in other family carers of people with dementia.

Sandra met the members of the EnCaRe Network at the first two meetings and will continue to support them throughout the process. Sandra has also been busy working with the UCD team on a dissemination event that took place on the 22nd June in the Ashling Hotel. The event was booked out with over 60 participants and featured updates from the HRB-DEM project, presentations from two family carers on their experiences of caring for a person with dementia and a review of service provision for family caregivers by our member organisation Family Carers Ireland. Also featured was a presentation by Prof Eamon O'Shea looking at some of the new directions in dementia care in Ireland.

As part of the current dissemination strategy, a Twitter handle has been created for the project, which can be found at https://twitter.com/EnCaReDementia.





Sandra can be contacted on 085 252 4978 or by email sandra@carealliance.ie.











International Foundation

for Integrated Care

Resources

Papers from Conference on Integrated Care Available to Download

The conference took place in Dublin between May 8 and 10, and brought together researchers, clinicians and managers from around the world who are engaged in the design and delivery of integrated health and social care. They shared experience and the latest evidence about integrating public health, health and social care and the new roles and possibilities for hospitals, producing positive and curative integrated mental and physical care, mobilising key enablers like policy making and mobile and digital health solutions, and investment in an integrated care workforce, clinical leadership and coproduction with individuals, careers, communities and populations.

The presentations and other resources from the conference can be downloaded from here.

Care Alliance Ireland was delighted to co-present a paper on Carer Needs Assessments with Dr. Natalie Vereker form the HSE.

For more about integrated care see here.

Family Carer Training Website

Additional resource material has been added and the site also provides details of more up-to-date training available for Family Carers.

www.familycarertraining.ie



FAMILY CARER TRAINING

Welcome to www.familycarertraining.ie. On this website you will find information about training for Family Carers.

If you are a Family Carer you can find information about current training happening across the country and online, along with further information that you may find interesting.

If you are from an organisation who supports Family Carers you will find information on good practice nationally and internationally and useful research on topics related to training and education of Family Carers.

Please click on the relevant section for more information





Resources

Family Carer Ireland Booklets Available





HSE Carers Website

The site has been reviewed, with input from Care Alliance Ireland, and will be updated in the near future.

The site can be viewed by clicking here.



Dates for Your Diary

20 July

Disability Federation of Ireland AGM at 11am



31 August

Family Carer Research Seminar–UCD Register here.



15 September

Good Governance Awards Application Deadline



19 September

Care Alliance Ireland AGM



10 October

Forum on End of Life in Ireland 2017 Dublin Castle, details available here. See also page 9.



Research and Practice

Leading Health Care Manager Publishes Findings on a Community Virtual Ward Model to Support Older Persons with Complex Health Care Needs

Clare Lewis, Clinical Case Manager for Older Persons in the HSE, has recently published a paper detailing her practice findings.

Background: Globally the older population is increasing rapidly. As a result there is an increase in frail older persons living within the community, with increased risks of a hospital admission and higher mortality and morbidity rates. Due to complexity of care, health care professionals face challenges in providing effective case management and avoiding unplanned admissions to hospital. A community virtual ward (CVW) model was developed to assist health care professionals to support older persons at home during periods of illness and/or functional decline.

Methods: A quantitative observational study was conducted to examine if a CVW model of care reduced unplanned hospital admissions and emergency department (ED) presentations in 54 patients over a 12-month period. The sign-rank test examined matched data on bed days, ED presentations, and unplanned hospital admissions pre- and post-CVW implementation. Other risk factors for admission to hospital were examined using the Mann–Whitney test pre- and post-CVW admission, including falls, living alone, and cognition. Correlations between hospital admission avoidances and unplanned hospital admissions and ED presentations were tested using Spearman's p test.

Results: There was a reduction in ED presentations post-CVW admission (P<0.001), and median unscheduled admissions were reduced (P=0.001). Those living alone had a lower number of ED presentations (median 0.5, interquartile range 0–1) prior to admission in comparison to those living with a caregiver, with no differences observed during admission to CVW. For those who experienced a fall during CVW admission, the odds ratio (OR) of requiring long-term care doubled for each extra fall (OR =2.24, 95% CI 1.11 to 4.52, P=0.025). Reduced cognition was associated with an increased risk of ED presentations (ρ =0.292, P<0.05) but not associated with increased risks of unplanned hospital admissions (ρ =0.09, P=0.546). There were no significant correlations seen between admission avoidance and the number of unplanned hospital admissions or ED presentations.

Conclusion: Through an integrated approach to care, a CVW model in the care of older persons can reduce ED presentations and unplanned hospital admissions.

The report is published in an open access format and can be read here.

Research and Practice

Male Caregivers Less Likely to Seek Support, US Research Shows

One of the most unpleasant responsibilities Mike Beaty faced as a family caregiver was changing his father's diapers. As a professional care provider, he says it wasn't unusual for him to handle such tasks, "but when it's your parent, when it's your father, when it's someone that you looked up to, that you respected... to reverse that and allow them to become the child and take care of the most intimate needs they have, it's difficult to do that."

Many male caregivers are thrust into a role that can challenge their notions of masculinity and push their emotional boundaries to breaking point, and they often have little knowledge of how to proceed or seek help. According to a 2015 survey by the American Association of Retired Persons (AARP), there are 16 million men acting as caregivers in the U.S., 40 percent of all caregivers. These men are the target of a new campaign to provide recognition and resources, as many may face steeper emotional challenges than women, struggling with the most intimate aspects of caregiving and facing a stigma that might stop them from seeking help.

The AARP campaign features a video public service announcement featuring "Breaking Bad" star Danny Trejo imparting the story of a "warrior" caregiver providing for his ailing father using the tagline, "Caregiving is tougher than tough." To see this short one minute video click here.

Jean Accius, an AARP policy expert in caregiving, authored a report published in March to draw attention to male caregivers and to dispute stereotypes about them. One of the biggest misconceptions about male family caregivers is that they're only taking on tasks like financial assistance, household chores and shopping, according to Accius.

But he says that, like Beaty, they are often taking on the most personal tasks of caregiving, helping patients with eating, bathing and dressing, and even handling nursing tasks like giving injections, tube feedings or wound care. It's these deeply personal tasks that men tend to struggle with more than women, Accius says. Many men the AARP surveyed said they felt unprepared or uncomfortable doing those types of tasks.

Complicating matters, men are also less likely to seek help and talk about the emotional challenges they face with caregiving. Accius says he's heard from men throughout the U.S. that they tend to "suck it up" rather than seek help. But by not expressing their experiences, these men are at greater risk of anxiety, isolation and depression. "Most of the male family caregivers agree that caregiving is stressful, but very few reached out for help," Accius notes.

Recognizing that issue, Beaty helped establish a support group for men acting as caregivers at his church in the Dallas, Texas, area. He says he's found other men going through similar circumstances there and together they've managed to have more frank, candid discussions about their experiences.

For some men like Stephen Chee, now the director of wellness at Lifetime Wellness, serving as a personal caregiver can even foster a lifelong passion for helping people in similar situations. After becoming his father's primary caregiver, Chee left the business world and now works directly with professional caregivers to help them maintain their energy and compassion.

Caregiver burnout is a big risk – caregivers often give too much of themselves while not taking care of their own needs in turn. Chee says a lack of sleep, a lack of proper nutrition or inattention to other personal needs can lead to feelings of guilt, withdrawal, or depression. "That can all be defined as the cost of caring," he says.

For anyone suddenly thrown into a new carergiver role, Chee says, "Evaluate your support system, be honest with yourself with your capacity... To do that due diligence is very important, it's going to get tested."

Full article available here.

Governance Corner

Regulator to Seek Views on Governance

The Charities Regulatory Authority (CRA) has established a consultative panel on the Governance of Charities: details here. It is likely that they will seek input from NGO's in the near future. We recently surveyed member organisations on their view in this matter.



The feedback will be shared with the board of directors and will inform our work in driving good governance going forward.

Care Alliance Applies Again for Good Governance Award

As you will know, the staff and board of directors of Care Alliance Ireland place a high value on good governance and this was demonstrated by our winning the inaugural Good Governance Awards last October. We have entered for the award again this year. For further details see www.goodgovernanceawards.ie.



Full Compliance with Updated Governance Code

At our April 25 board meeting, the board of directors reiterated our organisation's full compliance with the Governance Code. The new code operates a "Comply or Explain" system. See here to read our Comply or Explain statement.



Complaints Reporting

Per our agreement with the HSE, we submit a biannual statement of complaints. This was done most recently in early July.



Lobbying

In May we submitted our latest four-monthly report to the Register of Lobbyists. You can read our report here.



Governance Corner

Audit Completed

Our auditors DCON prepared our 2016 Audited Financial Statements. The Directors' Report and Audited Financial Statements were approved by the board of directors at the 25 April board meeting.



Board of Directors

Co-option of Barbara Barrett

Following recruitment and consideration by the board of directors, Barbara was co-opted onto the board in June. Barbara cared for her mother, who recently passed away. Barbara brings with her extensive experience in the legal sector, has volunteered with various organisation for over 40 years and is a qualified counsellor.

Remaining board meetings for 2017

- 19 September (Followed by AGM)
 - 21 November

Policies Under Review

At its April board meeting, the board reviewed and approved updates to the Code of Conduct for Board Members, the Procedures for the Election of Directors and a number of other policies that were due for review.



Governance Compliance Numbers Continue to Rise

As of 28 June 410 organisations report being compliant with the Governance Code

1,136 organisations report being on the journey to adoption

For a full list of organisations see here

International News















Coalition of EU NGOs Endorses European Commission's Comprehensive Work-Life Balance Package

In April the European Commission put forward an ambitious and comprehensive proposal on work-life balance for working parents and carers.

A group of European NGOs responded by saying:

"We are pleased to see it reflects our demands for a life-cycle and transversal approach, and contains many of the elements we called for in the past. We are convinced that this initiative has the potential to bring real change in the lives of many Europeans. We are a Coalition of European networks of NGOs working since 2012 in order to put work-life balance high on the EU agenda and, while regretting the withdrawal of the maternity leave directive proposal in 2015, we warmly welcome today the work-life balance initiative proposed by the European Commission. First, we welcome the mix of legislative and non-legislative initiatives covering leave schemes as well as provisions for quality, affordable and accessible care services and flexible working arrangements. We believe that this is the right direction. This is what the EU is about, putting the European project into the lives of women, men and children in Europe, showing that Europe does care. The Package must be followed up with serious enforcement and real monitoring across the EU. We would stress that some of the measures included are particularly helpful, notably the introduction of a paid paternity leave of ten days and a minimum payment at sick leave level of a non-transferable parental leave. Payment, increased flexibility and non-transferability have been proven crucial to increase take- up among fathers. The Directive introduces also a new carers' leave of 5 days per year paid also at sick pay level. This is a welcome step. However, it is regrettable that no legislative measures have been taken to extend protection against dismissal of women returning to work from a period of leave, beyond a better enforcement of existing legislation."

To view the Commission proposal see here and to read the full response to the initiative by the group of NGOs see 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.

Reasons
To Join Us

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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