

# Care Alliance Ireland

## Exchange

Autumn 2016 Issue 52

### Home Care — Briefing Paper Disseminated Widely with over 1,000 Downloads

High-quality home care can be a key support to Family Carers and to people with disabilities. Currently, in the region of 55,000 people aged 65 and over and approximately 8,000 people under 65 in Ireland receive publically funded home care; others buy in home care, often from members of Care Alliance Ireland.

There continues to be considerable coverage in the media of home care and we in Care Alliance Ireland felt the time was right to attempt to assess the quantum of publically funded home care in Ireland over the period 2008-2016. Due to time and resource limitations, the report focusses on home care for older people.

We have disseminated the report widely to our various stakeholders and were invited to pen an Opinion Editorial on the topic, which appeared in the Irish Examiner on 26 August. We are also collaborating with a number of not-for-profit organisations in campaigning, in advance of Budget 2017, for improvements to home care support.

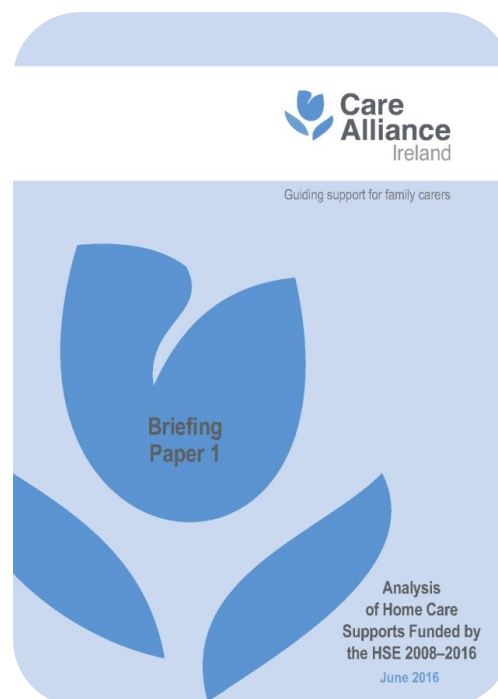
To date, the report has been downloaded in excess of 1,000 times and a small number of hard copies are available on on request.

We endeavoured to keep the report objective and the following recommendations were made:

- We recommend that the HSE sets a 2016 goal of reaching the 2011 target level of public provision of home care per person aged 65+. Our figures suggest that this will require additional resourcing of €31m in 2016 equating to an additional 1.55m home care hours over and above current published targets. This will also require the collection of data at a national level that details actual hours of home care delivered through Home Care Packages.

#### In this issue

News	3
Member News	9
Research & Policy Officer Report	13
Governance Corner	14
Irish Research	15
Practical Resources	15
International News	16
Policy and Research Briefs	17
About Us	20



## Briefing Paper Update Continued

- In the medium term, we recommend that the HSE sets a goal of reaching the 2008 level of public provision of home care per person aged 65+. Our figures suggest that this would require additional resourcing of €72m in 2016, rising to €116m in 2019.
- We recommend that all HSE publications use consistent terminology when describing home care provision.
- We recommend that considered attempts be made to assess the current volume of privately provided home care.
- We recommend that the move towards the regulation of home care is progressed during 2016.
- We recommend that home care provision is set up on a statutory basis.
- We recommend that further analysis is undertaken to explore the apparent material reduction in home help hours delivered per client.
- We strongly recommend that the Department of Health liaise with the HSE and other interested parties in developing more sophisticated models of assessing appropriate levels of home care provision based on international norms and agreed levels of dependency. The utilisation ratio in itself, while helpful, does not tell the whole picture in terms of adequacy of coverage and service provision, particularly in light of data that suggests a trend towards fewer hours of home care delivered per client.
- Home care support needs are on a continuum from low to high. The rollout of the InterRAI assessment tool, proposed as a suitable model for assessing such needs, must be an organisational priority within the HSE. Progress on this initiative has been slow. We believe that with the development of this tool comes an opportunity to recalibrate baseline home care support needs and to better inform planning for our ageing population.

## Zoe Hughes' Op Ed in the Irish Examiner, 26 August

Read article here  
<http://bit.ly/2bS5xUZ>



## News

### Dates Set for National Carers Week: 12 — 19 June 2017



Following a review of National Carers Week 2016 and the production of a comprehensive report for all partners, we can confirm that the 11th National Carers Week will take place on June 12 — 19 2017. We recently received news of the success of our application for €10,000 to the National Lottery to support National Carers Week 2017.

### Funding Secured for Three Years

Following a competitive process Care Alliance Ireland secured funds under the Scheme to Support National Organisations in the Community and Voluntary Sector (SSNO). The funding, of €253,000 over a three-year period (2016—2019), is awarded by the Department of Housing, Planning, Community and Local Government and is administered by Pobal.



An Roinn Tithíochta, Pleanála,  
Pobail agus Rialtais Áitiúil  
Department of Housing, Planning,  
Community and Local Government

Speaking about the award, outgoing Chair Dr Gerry McCaffrey said:

“This funding from the state yet again validates the work of Care Alliance Ireland. It will enable us to continue with our work in supporting our member organisations, delivering high-quality briefing papers and discussion documents, making submissions and being active players in the domestic and international carers movement.”

## News

### Family Carer Training Seminars

Third in series to take place 17 November

The third and final seminar in our series of three training seminars will take place in the Carmichael Centre on 17 November. The focus of this final seminar, which has been created based on suggestions from previous attendees, will be on peer—peer learning: participants will be encouraged to share their experiences in providing training for Family Carers. We will also be launching the Family Carer training website ([www.familycarertraining.ie](http://www.familycarertraining.ie)) during the seminar. For more information contact Zoe ([zoe@carealliance.ie](mailto:zoe@carealliance.ie)).

### Meeting with Minister McEntee

Care Alliance Ireland and a number of other not-for-profit organisations met with Minister Helen McEntee (with responsibility for older people's services and mental health) on 8 September. The discussions were wide ranging and much discussion took place about home care, and about how our health and social care services can better support Family Carers and older people. The Minister invited organisations to get back to her with written priorities and suggestions on how we would see a forum on older people's issues moving forward.

### Discussion Documents

We recently printed some hard copies of our collection of Discussion Documents that have been published in recent times. Please email [zoe@carealliance.ie](mailto:zoe@carealliance.ie) to request copies.



## News

### National Carers Strategy

#### Four years on — Third Scorecard launched

Family Carers Ireland launched a Scorecard on 14 July that measures progress in respect of the 2012 National Carers' Strategy.

The Scorecard highlights some examples of good progress and good engagements, together with areas where little or no progress appears to have been made.

Of the 42 objectives outlined in the National Carers' Strategy, Family Carers Ireland have found:

- 1 objective achieved thus far
- 14 with good progress made
- 7 with initial progress made
- 17 with no progress made
- 3 having regressed

“While we find just one objective fully achieved, we have seen some good progress on the National Carers' Strategy over the past three years, particularly given its cost-neutral limitations” said Catherine Cox, Head of Communications, Family Carers Ireland. “Good engagement with Government departments has brought meaningful progress. However, critical areas such as respite provision and discharge from hospital to home remain significantly under-resourced, resulting in negative impacts on family carers' lives, and correspondingly regressive scores. With the upturn in our economy, we are now asking Government to adequately resource and fund the next phase of the Strategy in order to make a real impact on the lives of family carers.”

We in Care Alliance Ireland have been involved in reviewing the progress made and look forward to more progress being made over the coming months and years. A further meeting with officials from the HSE took place on 14 September and Family Carers Ireland have set up a number of other meetings with a range of government departments to ensure that Carers issues are given the consideration they deserve. Care Alliance Ireland will participate in a number of these meetings over the coming months. Should any member organisation wish to input into this process please contact Zoe Hughes directly.

### Executive Director to Undertake TCD Course in Implementation Science

One of the roles of Care Alliance Ireland is to help bridge the gap between policy, research and practice. In this regard, our Executive Director, Liam O'Sullivan, will be undertaking a Post-graduate Certificate in Implementation Science, delivered by the Department of Public Health in Trinity College Dublin. For more details on the course read [here](#).





## News

### Care Alliance Ireland Makes Application for Good Governance Award



The Good Governance Awards is a new initiative that recognises and encourages adherence to good governance practice by community, voluntary and charitable organisations in Ireland. The Awards have been developed by the Carmichael Centre with the support of the Irish Charities Tax Reform (ICTR), Volunteer Ireland, The Wheel, Davy and Mazars Ireland.

#### Aims

In this inaugural year the Good Governance Awards seek to acknowledge, encourage and promote good governance practice and will recognise and provide practical examples to organisations of excellent or very good directors' reports & financial statements.

As such, the Good Governance Awards aim to support and encourage the CVC sector to use their annual reports and financial statements to showcase their embracement of and adherence to good governance.

Governance extends far beyond board composition and the frequency of board meetings. It is intrinsic to an organisation's culture, its people and how it operates, and is recognisable in its public face. Good governance is about being transparent and open: it encourages trust in and relationships with an organisation. As the CVC sector works for the public benefit it needs to be in a position to demonstrate good governance.

#### Format

The Carmichael Centre Good Governance Awards will initially focus on annual reports, examining how they demonstrate adherence to good governance. Over time they will also include demonstration of good governance on organisations' websites and other areas.

The Governance Code for CVC organisations (the Governance Code) will provide the framework for assessment. A panel of judges with appropriate experience and expertise has been established to adjudicate shortlisted entries and select the winners. The awards will be adjudicated on a desk-based evaluation with a screening, shortlisting and judging process. They will be based on the information published in annual reports & financial statements. There will be an award for the best volunteer-only (Type A) organisation, small (Type B) organisation and large (Type C) organisation, as defined and described in the Governance Code. The award for Type C will be further sub-divided into organisations with an annual turnover under €500,000 and annual turnover of more than €500,000.

The inaugural Good Governance Awards recognises excellence in the area of the annual report. It should not be taken that these awards imply a wider compliance with Good Governance practice by any of the winners or shortlisted entries. An organisation's Annual Report and Financial Statements is just one aspect of good governance and there many other practice areas that an organisation needs to comply with if it is to achieve excellence in governance.

Organisations will be able to self-nominate or be nominated. A dedicated website [www.goodgovernanceawards.ie](http://www.goodgovernanceawards.ie) will act as a central hub. It will outline the entry criteria and categories, the panel of judges and guidance on how to take part.

## News

### Young Carers Collaboration

The development of supports for young people with significant caring responsibilities is more urgent than ever in light of the recent findings from the collaborative Cross-National Health Behaviour in School Age Children, published recently by NUI Galway.

Upwards of 11% of young people aged 10—17 reported having caring responsibilities and extrapolation of this data points to a potential 56,000 young people with caring responsibilities.

Representatives from Care Alliance Ireland, Crosscare, Family Carers Ireland and the City of Dublin Youth Service have been meeting recently to discuss ways to collaborate more in this area into the future. Representatives from West Cork Carers have also expressed an interest in coming on board. Terms of Reference have been drawn up and the next meeting will take place in Dublin on 6 October. If you are interested in finding out more about the work of this group email [info@carealliance.ie](mailto:info@carealliance.ie).

### EPYC Update - New Project Executive Appointed

The project is now up and running, in conjunction with the five other EU partners. We are delighted to announce the appointment of Denise Dunne as Project Executive. Contact Denise at [denise@carealliance.ie](mailto:denise@carealliance.ie) or on 085 806 2392

The first formal output of the project, which Care Alliance Ireland is leading on, will be a set of resources (including templates for leaflets, successful slogans, communication campaigns, etc.) to raise awareness among teachers, youth workers, healthcare professionals and other practitioners dealing with young people regarding the existence and recognition of young carers and the problems they face. This output will be based on resources currently in use in partner organisations and local contexts, including tools currently applying to different target groups but possibly adaptable to young carers.

Over the coming months Care Alliance Ireland will be taking the lead in collecting, systematising and sharing these tools with our project partners, who will then assess their potential for transferability.



# News

## Collaboration Is at Our Core

## Care Alliance Ireland is active in 17 collaborative projects

Collaboration is at the core of much of our organisation's work. We thought it timely to take a step back and list the projects initiatives that we are currently involved in:

Project	Partners	Other Stakeholders
HRB Dementia Research	UCD, St Vincent's Hospital	Family Carers, Other NGOs
National Carers Week	8 National NGOS	HSE, Other NGOs, Medical SWs
Erasmus Plus Project (Empowering Professionals to Support Young Carers)	5 European Not-for-profit Orgs.	To Be Agreed
Carer Needs Assessment	HSE, InterRAI, Family Carers Ireland, Rehabcare	Family Carers
Joint Pre-Budget Events	The Wheel, Disability Federation, other NGOs	Family Carers
Family Carer Training	Whitebarn Consulting, Eurocarers	Family Carer Training Providers, Other NGOs
Carers/Palliative Care Online Project	All-Ireland Institute of Hospice and Palliative Care	Other NGOs and State Providers
Family Carer Research Group	10 NGOs, 4 Academic Institutions	
Neurology Campaign (2016)	Neurological Alliance of Ireland, Other NGOs	Family Carers
Governance Training	The Carmichael Centre	Member Organisations, Other NGOs
Lenus Working Group	HSE, Other NGOs	
Annual Carers Forum	Dept. of Social Protection, other NGOs	Govt. Departments and State Bodies
National Patient Forum	HSE, other NGOs	
National Carers Strategy Implementation Monitoring Group	Family Carers Ireland	
Social Policy Network	10 NGOs	
Campaign for Home Care Change	Age Action, Alone, ASI, MS Ireland, other NGOs	
Family Carer Survey (2015)	UCC (Tentative)	





## Member News

### Walking with WALK

Gale Gilbert from Walkinstown Association for People with an Intellectual Disability tells us about their upcoming Halloween events:

"Our Annual Halloween Frightnight will see WALK transform the local historic Norman landmark, Drimnagh Castle, into a spooktacular fest on Wednesday 26th and Thursday 27th October 2016 from 4pm – 8pm. Last year's Halloween Frightnight saw WALK welcome 440 people to the event, which sold out in record time. This year due to popular demand we have added an extra date!"

"The community event will be a fright fest of spooky thrills and chills at the Haunted Halloween Castle tour. Visit the ghostly gardens. This is not for the faint-hearted, with spooky characters, scary noises, eerie fog and many a strange sight to behold! A Halloween show starts at the Haunted Castle where you will find plenty of thrilling treats and surprises. The paranormal parade of the gardens makes one wonder about the real history of this Castle!!

WALK hosts a number of community projects annually. This is done in recognition of the need to build stronger community ties, strengthen partnerships and provide opportunities for the people we support to engage further with their local communities. This event to date has been a huge success that has only been made possible by the involvement of many other groups coming together in the form of volunteering and sponsorship."

Austin O'Sullivan, Director of Resources at WALK said: "Following on from its great success over the last years, this event night continues to be improved upon to be even bigger and better. This is a real opportunity for the people we support and our staff team to be really involved in their local community. The hosting of the event in the surrounds of Drimnagh Castle shows how with a little initiative and partnership working, local community facilities can support each other for the greater good."

**This event is recommended for age 5+. Visit our events page for more information, call Sevak on (01) 4650388 or email [events@walk.ie](mailto:events@walk.ie).**

Fundraising is not the main focus of WALK's events. The main motivation in the event is in the opportunities that arise through the experiences of participating at all levels right from the set up to the take down of the event. However, where proceeds are raised from the event, they go directly to the "WALK Community Project Fund". This fund supports community projects whereby people can develop local events or projects that are inclusive and benefit service users and the local community; capital equipment whereby people can buy equipment, small or large, that would benefit the people we support and potentially the local community; and through part-funding individuals we support through accessing training, education or recreation facilities.

Previous proceeds raised from the fund concentrated mainly on the development of the community facility at Walkinstown Green. This had been a derelict site and a breeding ground for anti-social behaviour. It is now home to a social enterprise consisting of The Green Kitchen Café (2016 finalist in Dublin 98fm's Best of Dublin Awards), the Green Garden Centre, community training facilities and a men's shed.

Joe Mason, CEO, WALK said, "This community facility in Walkinstown Green has huge benefits not only for the people that we support but for the whole community. The bigger picture is that it allows us to open our doors to the wider public. This in turn gives people an opportunity to see for themselves the value and the contribution that people with disabilities have and continue to make within their local community. This is invaluable and anything that helps us achieve this is tremendous."

## Reporting on Migraine Action Week 12—18 September



The Migraine Association of Ireland (MAI) marked Migraine Action Week which ran from 12 to 18 September 2016 with a launch event at the Mansion House, Dublin. The theme of the launch event on 12 September (European Migraine Day of Action), was 'New and emerging therapies'. Presentations included a moving talk by Claire Bradley who not only lives with migraine herself but also cares for a daughter with severe migraine. Claire shared her family's experience of the impact and burden of migraine on their family life.

A public awareness billboard campaign highlighting the common, disabling, yet treatable nature of migraine, was launched on the same day in 9 DART stations in Dublin. Other activities during Migraine Action Week included a keynote event focusing on Young People and Migraine in Castletroy, Co. Limerick at which there was a great family turnout.

Visit [www.migraine.ie](http://www.migraine.ie) for further information or contact the association on 1850 200 378 or [info@migraine.ie](mailto:info@migraine.ie).



## Palliative Care Week Highlights Need for More Resources Particularly in Midlands and North East

Palliative Care Week commences on October 2nd and is a unified week of action to celebrate and support hospice and palliative care around the world. During this period, The Irish Hospice Foundation (IHF) will highlight the difficulties some patients in Ireland have in accessing palliative care.

Sharon Foley, CEO of the IHF said, "In Ireland we have an ageing population and we need to respond to this need and ensure that not only are we living well, but we are dying well. We only get one chance at a good death and a person's geographical location should have no bearing on this. There are currently unacceptable gaps in existence in the availability of specialist palliative care services in the country.

"The fact that there remains no inpatient Level III hospice in the Midlands and North East regions means patients have no option but to be admitted to an acute hospital for care – where the majority do not want to be. Homecare teams do not have the dedicated support of a full multi-disciplinary team including social workers, occupational therapists and physiotherapists. This is unacceptable and we continue to call on the Government to prioritise the development of firm actions plans for these regions as a matter of urgency."

Ms Foley concluded, "Palliative care is a human right. As part of World Day we are calling for the best care at end of life for all people, regardless of what illness they suffer from or where they live. Everyone deserves the best possible care on their final journey."

## Member News

### Irish Hospice Foundation Announces Dates of Four Death Café Conversations

The Irish Hospice Foundation (IHF) has announced the dates for four Death Café Conversations

taking place in September and October. The Death Café Conversations over tea and cake encourage gentle but meaningful interactions on death, dying and bereavement; provide useful tools; and encourage interaction.



"The output of this engagement will allow us to create a 'Charter for Dying, Death and Bereavement in Ireland' which we hope to launch in early 2017. This is the first ever charter of its type in Ireland. We are pleased to be leading such an important public discussion," said Sharon Foley, CEO of The Irish Hospice Foundation.

"At the cafes, people will be asked to complete a survey asking five questions on their end of life wishes, bereavement, death, loss and grief. You can also complete the survey online and join our [#haveyoursayirl](#) social media campaign to help inform the charter. We're encouraging people everywhere to ensure they and their families and friends have their say. We're also engaging with non-government organisations and healthcare professionals as their input is integral to the charter".

"To ensure the project is a success we're asking people to promote Death Café conversations in their area, display a poster, fill in the survey and engage in the social media campaign, help us go viral. This is such an important issue we all need to think about. We want to drive debate on end of life and bereavement and finally speak on your behalf in a charter for the Irish people. We partnered with Limerick Compassionate Communities, whose experience has been instrumental for these initiatives," concluded the CEO.

It's free of charge to come along and all are welcome. We are encouraging people to invite their family, friends, colleagues and neighbours to drop in for a chat. There will be cake.

Death Café Conversation Dates:

**CORK:** Thursday 29th September 11.00am – 1.00pm  
SNA Hall, Wilton, Cork

**MULLINGAR:** Friday 30th September 11.00am – 1.00pm  
Annabrook House Hotel, Mullingar

**TALLAGHT:** Monday 10th October 11.00am – 1.00pm  
Redrua, Tallaght

**DUBLIN:** Monday 17th October 11.00am – 1.00pm,  
Woodquay



Since I was a kid I have always wanted to travel, and if I die while I am traveling I have fulfilled my dream. I am 20, I don't think about death as there is not much point as it will happen anyway.

Hector, Arthur's Quay

For more information please contact Rebecca on 085 106 4808.  
Fill in the survey today: [www.surveymonkey.com/r/haveyoursayirl](http://www.surveymonkey.com/r/haveyoursayirl)



## Member News

### Alzheimer Society Campaigning on Dementia Care

The Alzheimer Society of Ireland (ASI) has received a fantastic response to its pre-budget campaign, 'Dementia Care Begins at Home', and to date over 19,500 people have signed a petition calling on the Government to invest €67 million in 2017 for home care supports for people with dementia.

Not only that, but a wonderful campaign video made by Kathy Ryan, a Vice-Chair of the Irish Dementia Working Group, and her sons Matt and Andrew, has gone viral and has been viewed by over half a million people. To watch go to <https://youtu.be/o5QxK0M8OVg>.

Launching the campaign in June, Senator Colette Kelleher, former ASI CEO, said, "It's time to look at home care in a new way. Home care should not be seen simply as a solution to the hospital crises, but as an integral part of long-term care in its own right. Appropriate home care should be provided as a choice to help keep people well in the community and out of hospital and long-term residential care. It is also vital in supporting family carers, who provide the vast majority of home-based care for people with dementia."

To sign the ASI's petition and for more information on the campaign please visit [www.alzheimer.ie](http://www.alzheimer.ie).



Pictured L-R: Minister Helen McEntee, Senator Colette Kelleher, ASI CEO, and Ms Helen Rochford-Brennan, Chair of the Irish Dementia Working Group at the launch of the Alzheimer Society of Ireland's 2017 Pre-Budget Submission on 30th June 2016.



## Policy and Research Officer Reporting

Zoe continues to work with member organisations to increase collaboration across the policy and research brief of Care Alliance Ireland. If you would like to raise any issues with her, please don't hesitate to get in contact. Work undertaken on research and policy issues recently include:

- Submissions to Government on the new DSP Statement of Strategy 2016–2019, and to the Oireachtas Committee on the Future of Healthcare.
- Submission of our Pre-Budget Statement for Budget 2017, incorporating feedback from member organisations.
- Participation in, and collation of, member organisation feedback to the Department of Social Protection-facilitated Pre-Budget Forum in June.
- Two meetings of the Family Carer Research Group, with presentations from members on the topics of Home Care and Mental Health and Family Care.
- Presentation of two papers at the International Long-term Care Policy Network Conference in London.
- Publication of Briefing Paper 1: An Analysis of Home Care Supports Funded by the HSE 2008–2016.
- Continued collaboration with the National Carers Strategy (NCS) Monitoring Group and the HSE National Carers Strategy Group to progress the National Carers Strategy actions. The third annual report of the NCS Monitoring Group was launched on 14 July.
- Meeting with Minister for Mental Health & Older People, Helen McEntee to progress issues relating to Family Carers.
- Continued availability to member organisations to consult on key policy & research issues.

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



### Caring in Numbers

**37,000**

Number of full-time Family Carers in receipt of the Carers Allowance

**29,000**

Number of full-time Carers in receipt of the Half-Rate Carers Allowance

**2,312**

Unique visitors during August 2016 to [www.carealliance.ie](http://www.carealliance.ie), the highest level recorded to date

**7,781**

Number of downloads in August 2016 from [www.carealliance.ie](http://www.carealliance.ie)

**56,000**

Potential number of Young Carers in Ireland

**14,024**

Number of Followers on National Carers Week Facebook page

Right: Zoe Hughes, Care Alliance Ireland, with Anil Patil, Carers Worldwide, at the International Conference on Evidence-based Policy in Long-term Care, London, September 2016. The slides from Zoe's paper can be read [here](#).



## Governance Corner

### New Director

We are delighted to announce the co-option on 15 July of Hazel Mulligan onto the Board of Directors. Hazel is a graduate of UCD with a degree in Social Science and has also studied Management with the Open Training College. She has been employed in St. Michael's House for almost twenty years, during which time she has fulfilled a variety of roles.

She is currently the Service Manager of Individualised Supports and is undertaking a reconfiguration of some existing services and development of new individual support services. This entails working with the individual and their family/network of support to design and deliver supports based on their expressed needs and wishes.



### Governance Awards

This award has been set up in collaboration with a number of not-for-profit organisations. We have entered these awards and look forward to the winners being announced on 18 October. See [www.goodgovernanceawards.ie](http://www.goodgovernanceawards.ie).

### Statement Issued to Reassure Stakeholders

Following the extensive media coverage of governance issues in a number of not-for-profit organisations our board issued a statement. You can read the statement [here](#).

### 2015 Directors' Report and Financial Statements

Following a review by our Risk and Audit Committee the Board approved the 2015 Directors' Report and Audited Financial Statements. You can read them [here](#).

### Policies Reviewed and Updated

In recent weeks the Board considered and approved updates to our Equality and Diversity Policy, Finance Policy and Procedures, and the Terms of Reference for the Audit and Risk Committee.

### Compliance with the Governance Code

As of 1 September 2016, 296 organisations report being compliant with the Governance Code 923 organisations report being on the journey to adoption. For a full list of organisations, see <http://bit.ly/1aTs2ag>.

#### Dates for your Diary

**27 September**

"Invest in Home Care Now"  
Campaign Media Launch

**29 September**

NGO Pre-Budget Press  
Conference

**29 September**

Joint NGO Federations  
Pre-Budget Press Conference

**11 October**

Budget 2017

**18 October**

Good Governance Awards

#### Remaining Dates for 2016 Board meetings

Tuesday 15 November

# Irish Research

Our website has a range of Irish research on Family Carers issues. Go to [http://www.carealliance.ie/publications\\_resources](http://www.carealliance.ie/publications_resources).



'Guiding support for family carers'

[Home](#) [Who We Are](#) [Activities](#) [Membership](#) [Publications & Resources](#) [Strategic Plan](#) [Links](#) [Contact Us](#)



## Practical Resources

### Irish Red Cross Carers Handbook

Under the remit of the Irish Red Cross National Services, their Health and Social Care Programme aims to deliver humanitarian services to vulnerable people and communities in need across the country.

“We are continuously striving to assist those members of communities who selflessly and tirelessly give, help and care for those most vulnerable people in society, and who undoubtedly make an enormous contribution to our communities and make a real difference to people’s lives” says the Irish Red Cross.

To develop this, the Irish Red Cross has a ‘Carers Handbook’, which offers a practical and useful resource to carers across the country. Those people who take on the role of carer, often without any formal training, may feel overwhelmed and indeed vulnerable themselves.

The Carers Handbook is laid out in an extremely accessible format, allowing people to ‘dip in’ to read the relevant section for them as challenges arise. With sections on home hygiene and care skills, and advice on personal care and communication, the handbook will assist in the provision of a better quality of care and a happy, safe environment for both the recipient and the carer.



This handbook provides practical support and advice for such people, and the wonderful work that they do in looking after someone who is ill, elderly or who has a disability.

The Carers Handbook is €6.99 and is available from the Irish Red Cross by contacting 01 6424600.

## International News

### Eurocarers

Eurocarers is currently preparing its submission to the European Commission on the European Pillar of Social Rights.



Commenting on the initiative, Claire Champeix of Eurocarers said, “Though uncertainties remain as to what extent this initiative will be able to introduce a major step towards a truly social Europe, it is obviously a positive development. This initiative, likely to set up the European social agenda in the coming years, highly concerns Eurocarers as it touches upon key areas such as education and lifelong learning, gender equality and work—life balance, health and safety at work, health care and long-term care.”

For more information on this process see [here](#).

### IACO

We are delighted to report that IACO’s application for consultative status at the United Nations Economic and Social Council has been successful. This will enable IACO to further give voice to Family Carer issues in this significant forum.

The annual meeting of IACO will take place in Copenhagen on 5 and 6 October. Care Alliance Ireland will be represented by Zoe Hughes. A particular focus of the meeting will be issues around caring for someone with Parkinsons, a topic that Care Alliance Ireland has produced primary research on. Read this research [here](#).



International Alliance  
of Carer Organizations

Building a global understanding and respect for the vital role of carers



## Policy and Research Briefs

### **Training Home Care Workers Associated with Significant Reduction in A&E Visits**

US researchers have recently found that low-income Californians who are elderly and disabled were less likely to go to the emergency room or be hospitalized after their in-home caregivers participated in an intensive training programme. Under a pilot programme, nearly 6,000 aides in Los Angeles, San Bernardino and Contra Costa counties were trained in CPR and first aid, as well as infection control, medications, chronic diseases and other areas. All were workers of the In-Home Supportive Services programme, who are paid by the state to care for low-income seniors and people with disabilities, many of them being relatives of those they cared for.

Researchers at the University of California, San Francisco based their analysis on the results in Contra Costa County, which they said produced the most complete and reliable data. UCSF professor emeritus Bob Newcomer said they compared insurance claims on 136 at-risk elderly and disabled residents whose caregivers were trained with the claims from more than 2,000 similar residents whose caregivers did not receive the training. Though the sample was small, Newcomer said he was encouraged by the findings. "Training shows a lot of promise," he said.

The rate of repeated emergency room visits declined by 24 percent, on average, in the first year after caregivers were trained and 41 percent in the second year, according to the UCSF analysis.

The goal of the pilot program was to determine whether educating paid caregivers and integrating them into the medical team would improve the health of their patients. The caregivers in all three counties, 44 percent of whom did not have a high school education, voluntarily attended about 60 hours of classes and completed 13 hours of related work at home. The people they cared for also took part in some of the classes, which were conducted in several languages. Caregivers who were trained told researchers they felt better equipped to do their jobs and communicate with clients and their doctors, according to the report.

Newcomer said that because the caregivers are in the patients' homes for hours, they can be the "eyes and the ears" for physicians and other medical providers. They can tell the doctors "if the person is more confused, or is refusing to eat, or that the status is changing," he said.

"The results of the study show that caregivers play a pivotal role in helping keep people out of the hospital," said Corinne Eldridge, executive director of the California Long-Term Care Education Center. The nonprofit center was founded in 2000 by members of the Service Employees International Union, which represents many IHSS workers.

See <http://californiahealthline.org/news/teaching-in-home-caregivers-seems-to-pay-off/>.

## Policy and Research Briefs

### Article: "Give Me a Break: How Adult Day Services Impact Caregivers' Stress"

Many studies have shown that family caregivers are at greater risk for a variety of poor health outcomes due to the stressful nature of caregiving. One attempt to reduce caregiver stress is through respite services such as adult day services that provide a break for caregiver. A recent (US) study looked at the impact of respite services on caregivers of individuals with dementia by measuring the caregivers' levels of the stress hormone cortisol.

The researchers found that individual caregivers who showed cortisol patterns associated with "burn out" on days with without day services were also showing cortisol responses that were much more normal on days when they had access to day services. The days when respite services were available restored normal cortisol functions from patterns that research has associated with high chronic stress, but these benefits did not extend to those days in which the caregivers provided most or all of the dementia care themselves. However, even though these more normal responses were limited to days with day services, the researchers still categorised such days as "providing an opportunity for physiological recovery, which ultimately can improve health outcomes".

One interesting aspect of these findings was that the improved cortisol patterns began before the caregiver dropped off the care recipient at day services. This suggests that just the anticipation of relief and receiving assistance was providing stress relief to these individuals.

In addition to the biological benefits of adult day services, the caregivers benefitting from them reported fewer care-related stresses and more positive experiences overall, providing confirmation that biological responses are connected with more positive subjective experiences on days with caregiving relief.

These findings provide direct biological evidence of the benefits of respite care for caregivers who are at risk of negative health outcomes associated with the act of caregiving.

While such respite does not erase the stressful effects of days without adult day services, it allows caregivers' stress hormone systems time to recover, which has been shown to reduce risks associated with unhealthy chronic cortisol patterns.

Source: Klein LC, Kim K, Almeida DM, et al. "Anticipating an easier day: effects of adult day services on daily cortisol and stress" *The Gerontologist* (2016); 56(2): 303–312.

<http://www.investigage.com/2016/04/04/give-me-a-break-how-adult-day-services-impact-caregivers-stress/>

## Policy and Research Briefs

### Intergenerational Linkages in the Family: How Policies Shape the Organisation of Caring and Financial Supports for Family Members

This policy brief highlights recent research findings from the project FamiliesAndSocieties on the role of laws and policies in shaping gendered interdependencies in families; the way the “sandwich generation” (those who are likely to raise a child or a grandchild and care for parents at the same time) cares for older parents across countries; transfers in Europe from ageing parents to adult children and vice versa; and the extent to which the financial crisis has affected intergenerational patterns of family support across households. It also presents suggestions for policy interventions that can be derived from the findings.

Read more: [www.familiesandsocieties.eu/?page\\_id=120](http://www.familiesandsocieties.eu/?page_id=120)

### Website Launched for Dementia Research

The Institute of Public Health in Ireland (IPH) has created a new web resource called [www.dementiaresearch.ie](http://www.dementiaresearch.ie) to support those working in the field of dementia. The site provides a summary and overview of data, research and policy on dementia across the island of Ireland (between 2010 and 2014). It allows users to search by keywords or undertake a more specific advanced search. The results will provide a summary and an indication of where to access further details.

### Caring for Elderly Stroke Survivors Costs an Estimated US\$40 Billion per Year

The report finds that more than half of elderly stroke survivors receive help from a caregiver, requiring 22.3 hours of assistance per week on average. That's nearly double the amount that elderly patients who have not had a stroke require, at an average of 11.8 hours of help.

“Previous studies underestimated the caregiving resources that are used, and we expect the cost of caregiving will only increase as baby boomers age,” said first author Lesli Skolarus, M.D., M.S., a neurologist with the U-M Comprehensive Stroke Center.

Caregivers could include unpaid caregivers, like family and friends, along with paid caregivers, as about one-third of stroke survivors with informal care also receive paid care. Activities included in the estimate are accompanying the patient to physician appointments, cooking, cleaning, helping the patient to eat, bathe and dress, and helping with money matters and insurance decisions.

#### Elderly patients' care needs



“Stroke survivors need a caregiver to spend the equivalent of half of a full-time job each week to help them,” said senior author James Burke, M.D., M.S., a neurologist with U-M’s Comprehensive Stroke Center and the Ann Arbor Department of Veterans Affairs. “Caregiving is an especially big burden in patients with neurological conditions.”

Skolarus added, “We need to plan for other mechanisms to support caregivers and survivors. Hopefully planning now will reduce the future burden.”

Reference: “Care Received by Elderly US Stroke Survivors May Be Underestimated,” *Stroke*, August 2016. doi: 10.1161/STROKEAHA.116.012704

See link [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 providing information, developing research and policy in the field, sharing resources, and instigating opportunities for collaboration.

There are approximately 274,000 family carers in the Republic of Ireland. Family carer support is provided by a number of organisations, including those dedicated solely to carer support and others who support carers as part of their response to individuals with specific conditions.

We work with our 104 member organisations and other agencies to support them in their work with family carers. Our membership includes all the carer organisations and virtually all the condition-specific organisations currently providing services to 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](mailto:info@carealliance.ie)

**W** [www.carealliance.ie](http://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

**Disclaimer:** This newsletter is for information only and does not constitute endorsement of any service or product referred to. The views expressed are those of the authors/ organisations and are not necessarily shared by Care Alliance Ireland. No responsibility is accepted for any errors, omissions or statements in this newsletter, or on any website or publication referenced.