

# Care Alliance Ireland

## Exchange

Autumn 2015 Issue 48

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### 20 Year Celebrations

In 1995, a group of individuals and voluntary organisations, many condition or issue specific, came together with a view to forming an alliance. The idea was that the formation of such an alliance could be an effective way of raising the awareness both within their own organisations and externally, about the valuable role played by family carers.

Twenty years on, Care Alliance Ireland is now a leading actor in the field. We strive to positively influence research, policy and practice in family carer support, and work collaboratively with a wide range of partners. Currently we are engaged in a number of significant interagency projects, namely:

- National Carers Week
- National Carers' Strategy Implementation Monitoring Group
- Home Care Employment Standards Working Group (MRCI)
- Innovage - Online Portal for Carers of Older People
- InterRAI Single Assessment Tool/Carer Needs Assessment Working Group
- Lenus Working Group
- Family Carer Resilience/Dementia HRB Research (UCD)
- Benefit Finding Research (UL).

We also are involved in making regular submissions to a number of government departments and other agencies. We are also active internationally with Eurocarers and IACO. With in excess of 70,000 downloads from our website annually, we are the leading provider of information on family carer research, policy and practice in Ireland.

Founders and others who had supported our work were invited to a special 20 year anniversary, which took place in The Carmichael Centre on 15 September. With over 30 people in attendance, Senator Jillian van Turnhout and Diarmaid O'Corrbui both spoke eloquently on the topic of 'The Value of Federations and Alliances in the Not for Profit Sector'.

See page 2 for photos.

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We believe that our work over the past 20 years has contributed to:

1. Enabling the work of our 102 member organisations and others to be more informed and more family carer focused
2. Raising awareness of the valuable contribution family carers make to our community
3. Making the lives of family carers better.

# News

## 'Guiding Support for Family Carers'



Top left: Senator Jillian van Turnhout

Left: Liam O'Sullivan (Executive Director)

Bottom right: Frank Goodwin, (Founder of the Carers Movement in Ireland)

Bottom left: Liam O'Sullivan (Executive Director), Dr Gerry McCaffrey (Chair) and Deirdre Shanagher (Board Member)



## News

### Major Carer Research Conference set for 20 November in Dublin



#### 20 Years of Family Carer Research in Ireland

Care Alliance Ireland was established in 1995 to act as an umbrella organisation for organisations that support family carers directly.

In the course of those 20 years, there have been significant policy developments for family carers, most notably the publication of the National Carers' Strategy in 2012. Primary research relating to family carers is currently being undertaken in Ireland across a range of disciplines and third-level institutions. The time is right to bring together all this research and share it with a wide audience of interested parties. A review of historical research is also timely.

A one-day conference will take place on Friday 20 November and the date will coincide with International Carers Rights Day.

The call for papers can be downloaded [here](#).

Informal enquiries should be directed to Policy & Research Officer Zoe Hughes, by email ([zoe@carealliance.ie](mailto:zoe@carealliance.ie)) or by phone (086 883 4942).

### Policy and Research Officer Reporting

Zoe continues to expand her role as Policy & Research Officer. In addition to making contact and being available for discussions and consultations with members, she has developed a number of new pieces of work including:

- Submission to government of the Care Alliance Ireland Pre-Budget Statement (available at <http://bit.ly/1H6SoSN>) and attendance at the Department of Social Protection Pre-Budget Forum in June
- Analysis of more than 6,000 items of data gathered via an online survey regarding family carers' views on multiple topics
- Continued involvement with the Eurocarers Research Group
- Multiple funding applications for projects including a family carer oral history project
- Organisation of a family carer research conference entitled "20 Years of Family Caring in Ireland" to take place in November (see above for more details).

The next edition of the Research & Policy Ezine will be available in mid-October. To read previous editions please go to <http://bit.ly/1Q92Jnh>.



## News

### Care Alliance Ireland Presents Two Papers at the 6th International Carers Conference

As part of our Strategic Plan, we seek to engage at an international level, and in this regard, we presented two papers at the recent International Carers Conference in Gothenburg.

Our Policy and Research Officer, Zoe Hughes, presented a paper entitled **“Whose life is it anyway? The challenges of advocating for both people with intellectual disability and their family carers”**. The paper highlighted some of these challenges from the point of view of a policy worker who has recently moved from working in the intellectual disability sector to working with a national umbrella organisation concerned with improving the lives of family carers. Slides of her paper are available to read [here](#).

A selection of the 300+ papers at the International Carers Conference were recorded by video and are available to watch [here](#).

Our Executive Director, Liam O’Sullivan, presented a paper entitled **“10 years of National Carers Week in Ireland - A reflection”**, in which he detailed how the week began in 2007 and has evolved into a leading event in the calendar of many not for profit organisations here in Ireland, with planning underway for the 10th year in 2016. His paper reflected on the impetus, the beginnings of the initiative, its progression and its measurable outputs and outcomes. Slides of his paper are available to read [here](#). The full 14 minute audio/visual presentation is available to watch/listen to [here](#) (60 minutes into the file).



Zoe Hughes, Policy and Research Officer and Liam O’Sullivan, Executive Director, Care Alliance Ireland, attending the 6th International Carers Conference, Gothenburg.



## News

### 6th International Carers Conference (continued)

Alongside the conference, the annual meeting of Eurocarers took place ([www.eurocarers.org](http://www.eurocarers.org)) as well as the Annual meeting of the International Alliance of Caregiver Organizations ([www.internationalcarers.org](http://www.internationalcarers.org)). At the latter, Liam O'Sullivan, gave an overview of the development, led by Ireland of a new Carer Needs Assessment Tool within the internationally used InterRAI suite of Assessment Tools.



### UCD & Care Alliance Ireland to partner on new research

Care Alliance Ireland is delighted to announce a new research partnership with UCD and other collaborators, including St Vincent's University Hospital, on a project entitled "Towards resilience in family caregiving for people with dementia". The project is funded by the Health Research Board and will be led by Professor Gerard Fealy and a team of researchers from the UCD School of Nursing, Midwifery and Health Systems. The project will focus on the development and promotion of resilience in family carers of people with dementia. The findings of the study will provide important new evidence on carer resilience and will inform policy, carer supports and interventions.



We anticipate that the project will commence in the autumn, and we will be bringing you updates in coming editions of our Research and Policy e-zine. All enquiries should be directed to Dr Attracta Lafferty, UCD at [attracta.lafferty@ucd.ie](mailto:attracta.lafferty@ucd.ie).

## National News

### Review of Fair Deal Published

Review of the Nursing Homes Support Scheme, *A Fair Deal*

The long awaited review of the Nursing Home Support Scheme (Fair Deal) was published over the summer.

The official review is available to read [here](#).

The official Department of Health press release is available to read [here](#).  
See below some commentary on it.

**Care Alliance Ireland** – Commented on it in September eZine - Click [here](#).

**Age Action** – Comment on it by way of a press release <http://bit.ly/1OaDduW>

“More home and community supports would enable many of these people to stay at home longer. That’s a better outcome for the older people themselves and it would help to reduce the cost of the Nursing Home Support Scheme.”

**The Alzheimer Society** – Commented by way of a press release - <http://bit.ly/1FvXLXI>

“More dementia-specific home and community supports would enable many people with dementia to stay at home for much longer and continue to make a valuable contribution to society, which is a far better outcome for people with dementia. The provision of appropriate care in the community is far more beneficial than early admission to ill equipped residential care.”

**Ivan Yates** – Opinion Piece, full article: <http://bit.ly/1NZgEu3>

“Superficial announcement of “no hike” to 80pc income and 7.5pc asset charges to Fair Deal applicants. Short-term populism to get over expediency requirements of the imminent general election yet againfunking critical public policy issue. No party is prepared to confront this looming crisis, despite unambiguous analysis militating reform.”



Tús Áite do  
Shábháilteacht – Othar  
Patient Safety First

An Roinn Sláinte  
DEPARTMENT OF HEALTH



## National News

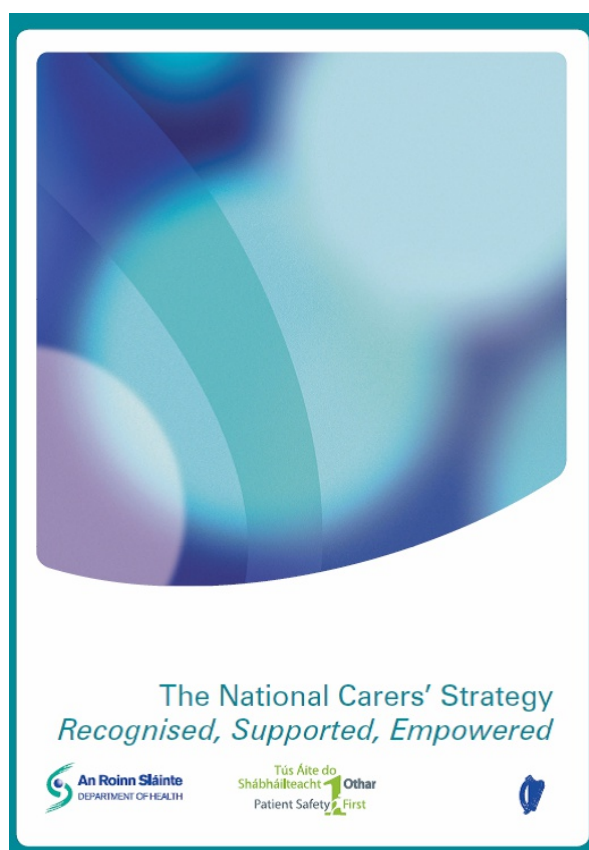
### Successful engagement with HSE Carer Strategy Implementation Group

Care Alliance Ireland is glad to report on recent positive engagement with key officials in the HSE in respect of progressing the implementation of the National Carers' Strategy. Both formal and shadow reviews of the implementation of the strategy have identified the slow progress on many of the commitments made in the report.

Meetings took place over the summer and were followed by intensive communication on key issues of hospital discharge, respite care and information provision. We look forward to continuing this engagement with officials in the HSE.

Meanwhile, officials from other named departments are continuing to work with the family carer sector in progressing issues identified in the Strategy.

Should any member organisation wish to discuss our work on this in more detail please do not hesitate to contact us directly.





## Member News

### Under the Hat Campaign Launched Internationally



Over the coming months, the European Headache Alliance membership, which includes the Migraine Association of Ireland, is asking the question 'What's Under The Hat?', encouraging patients to share their stories of the impact that headache disorders have on their lives. Their goal is to inspire public compassion for headache sufferers by making the invisible visible and providing a platform to give patients a voice.

By spreading their message across social media, they are hoping to get people talking about the disruptive and painful impact of headache so that headache can be given the priority it deserves. They can be contacted at [whats@underthehat.eu](mailto:whats@underthehat.eu) for more information and visit their [Facebook page](#) for updates. Watch the video [here](#).

### Details of Spina Bifida Hydrocephalus Conference Announced

The annual SBHI conference will take place in the Sheraton Hotel, Athlone from 16 to 18 October. For full details and booking information, please see [www.sbhi.ie](http://www.sbhi.ie).

## AGENDA

### FRIDAY 16<sup>TH</sup> OCTOBER:

- |                    |   |
|--------------------|---|
| 7.30pm - 8.30pm    | Opening Ceremony<br>Mayor Tom Farrell (TBC)<br>Meet & Greet |
| 8.30pm - 'til late | Evening Entertainment:<br>Provided by Hotel                 |

### SATURDAY 17<sup>TH</sup> OCTOBER:

- |                   |  |
|-------------------|--|
| 8.00am - 9.00am   | Breakfast  |
| 8.30am - 9.30am   | Registration   |
| 9.30am - 9.45am   | Conference Open<br>Mr. Frank Larkin, Chairman SBHI   |
| 9.45am - 10.15    | Presentation<br>Mr. Tom Scott, CEO<br><i>Tom who?</i>  |
| 10.15am - 11.15am | Bernadette Kerry<br><i>Burns Management</i>  |
| 11.15am - 11.30am | Morning Break  |
| 11.30am - 12.45pm | Panel: Siobhan Mungovan,<br><i>Me and My Back Bone</i><br>Ciara Hughes, <i>Healthy Living</i><br>Mary De Courcy, <i>My Journey</i> |
| 1.00pm - 2.00pm   | Lunch  |
| 2.00pm - 2.45pm   | Aine Harrington<br>presenting on behalf of FSV's<br><i>Caring For The Carer</i>  |
| 2.45pm - 3.15pm   | Gerry Maguire<br><i>Living A Full Life with Spina Bifida</i>   |

### SATURDAY 17<sup>TH</sup> OCTOBER: (cont)

- |                  |  |
|------------------|--|
| 3.15pm - 3.30pm  | Afternoon Break  |
| 3.30pm - 4.00pm  | Christy O'Neill<br><i>Sport - The Physical<br/>&amp; Social Aspects</i>                    |
| 4.00pm - 4.45pm  | Peer Support<br>Facilitated by Gerry Maguire<br>(SBH only)                                 |
| 6.00pm - 7.00pm  | Mass: A reflective<br>and celebratory Mass   |
| 8.30pm - 12.00am | Conference Close<br>Dinner & Evening Entertainment<br>Hosted by SBHI<br>Board of Directors |

All the sessions include 15mins Q & A session  
Andrea Fox: Children's Fun Club

### SUNDAY 18<sup>TH</sup> OCTOBER:

- |                   |  |
|-------------------|--|
| 8.00am - 10.00am  | Breakfast  |
| 10.15am - 10.45am | Registration: AGM Voting<br>Eligibility Registration |
| 11.00am - 1.00pm  | National AGM: Hosted by SBHI<br>Board of Directors   |
| 1.00pm - 2.00pm   | Lunch: Sunday Dinner                                 |

Programme subject to change. Early booking advisable.

Join us on Facebook! [f /SBHIreland](https://www.facebook.com/SBHIreland)

## Member News

### New Mentoring Programme for Family Carers

Are you new to a caring role?

- Do you require advice on your rights and entitlements?
- Would you like to access further information on supports and services in your locality?
- Or would you just like to talk to someone who has made a similar journey?



If you answered yes to any of the above, then this could be the programme for you!

The Carers Association is delighted to be launching a “peer-to-peer” mentoring programme to support family carers to address the significant challenges of caring for a loved one. Our wish is to devise a profile of current or former family carers who have developed specific skills in caring for a loved one, so that they can now advise family carers who are in similar roles and assist them with the challenges that they may face. These experienced family carers are people with lived caring experience; they truly understand what it is like, and are trained to use this knowledge to aid other family carers who are new to the caring role. These volunteers are referred to as “family carer mentors”. This is a pilot initiative for a 12 month period.

Everyone’s experience of caring is unique - however, it can be a great comfort to hear from others who have already been down the path yet to come. Discovering that you have become a family carer overnight can be a difficult experience - one that often leaves people overwhelmed, vulnerable and alone. The volunteer mentoring programme offers free, one-to-one, confidential support from someone who has made the same journey that you are about to begin.

This trained volunteer is an experienced family carer who will listen to and support you. The service is telephone-based, so you can be connected with a mentor anywhere in the country.

#### Objectives of the Mentoring Programme:

- To acknowledge the commitment and reduce the challenges for family carers.
  - To advise family carers on their qualifying rights and entitlements.
- To ensure family carers know about local supports and services available to them.
- To encourage family carers to engage in support groups and appropriate activities, helping reduce social and geographical isolation.
  - To provide this service for family carers at any stage of the caring journey.
- To develop, implement and evaluate an innovative and cost-effective approach to service provision in line with the strategic objectives of the Association.
- To support former family carers and to productively utilise their valuable expertise, skills and knowledge.
- To expand and strengthen the commitment of the Carers Association to volunteering, with clearly defined role descriptors, reporting lines and supports for volunteer mentors.

For more information on this mentoring programme, please contact: Arlene Carroll Email: [acarroll@carersireland.com](mailto:acarroll@carersireland.com) Mobile: 086 1731535. [Download Mentoring Referral Form](#)

## Member News

### Irish Hospice Foundation - Actions and Guidance on Communicating with People with Dementia

Hilary Maher, Education into Practice Advisor, the Irish Hospice Foundation, tells us about her organisation's support for family carers of people with dementia.

Communication is at the heart of our relationships. This applies too to people with dementia. Like other people, people with dementia need to relate and communicate with a range of people on a daily basis, including their relatives, healthcare staff, and others. Poor communication with people with dementia can put them at risk of unnecessary suffering. It can also mean that people with dementia are deprived of choice, control, and even respect.

The Irish Hospice Foundation (IHF) has long fought for the right of people to make choices about how they want their end of life to be – the freedom to choose for ourselves is a good indicator of the level of respect and dignity that we are generally afforded. Communicating with people with dementia is key to maintaining their personhood, right to the end.

Such communication can, however, be challenging. Dementia can make it difficult for them to concentrate, their language skills may vary from day to day, they may struggle to remember what has been said, they can find it difficult to make sense of local sayings and figures of speech, and they may also suffer from other age-related communication difficulties such as loss of hearing. We know that people with dementia may struggle with words and with understanding but their emotional memory remains live and active. The sorts of things that we normally rely on to make our communication effective may not always work when we are communicating with someone with dementia.

Here are some of IHF's offerings to make it easier to communicate with people with dementia and for their carers (family members, friends and care staff):

- The IHF offers a general tool for helping people to think and plan ahead and to record and document their preferences ('Think Ahead'). Obviously, this type of planning and documenting of what people want is best done when people are fully compos mentis. But there is evidence that people can still communicate their views and preferences about what is important to them even if they have some dementia or other cognitive impairment (Cahill & Diaz-Ponce (2011), Journal of Aging & Mental Health).
- The IHF offers a half-day workshop for staff working in residential care centres to help them improve their communication competence and confidence when working with people with dementia ('Communicating with People with Dementia') and, specifically for relatives, carers and friends of people living in residential care, the IHF has a four-session workshop programme ('Supporting Families') on various aspects of adjusting to having a loved one in a nursing home.
- The IHF has produced a variety of (mostly free) resources for the general public and for healthcare staff working with people with dementia, including a leaflet on 'loss and grief when a family member has dementia' and a leaflet on 'grieving following the death of someone with dementia'.



## Governance Corner

### Care Alliance Ireland registers as a Lobbying Organisation

As part of the Regulation of Lobbying Act 2015, many charities will be required to register and to submit returns detailing their lobbying activities three times a year. On August 10, Care Alliance Ireland registered. See [www.lobbying.ie](http://www.lobbying.ie).



### Board Review Progressing

As part of its commitment to constant review and reflection, our board of directors is undertaking a self-development assessment directed by Profs. Yvonne Harrison of SUNY Albany and Vic Murray of the University of Victoria. [Boardcheckup.com](http://Boardcheckup.com) is a Canadian free online system to assist with a board review. It involves the completion a Board Performance Self-Assessment Questionnaire. The summary report generated online has been distributed to all directors, and was discussed at the September board meeting.

### Financial Report

An update on our income/expenditure for 2015 was presented to the Board at its July meeting and as of September our income and expenditure profile is on target.

**Date for  
Remaining  
Board Meeting  
in 2015**

Tuesday 17 November

### Research Sub-Committee Set Up

As part of our ongoing commitment to supporting primary and applied research on family caring and the role of family carers, a new research sub-committee of the Board of Directors has been formed. This sub-committee, chaired by board member Deirdre Shanagher (Development Officer with the Irish Hospice Foundation), will ensure that research which is undertaken and supported by Care Alliance Ireland is of high quality and will have a positive impact on the lives of family carers. The task of the sub-committee will be to review research proposals, submissions, research reports and any other materials related to research associated with Care Alliance Ireland. The terms of reference of the group are available to read on [our website](#).

### New Organisation to support with Transparency in Charities Financial and Activity Reporting

Funded by both the state and philanthropy, Benefacts, seeks to 'provide a unique source of intelligence on Irish nonprofits'. Benefacts will build on the work of work (2007-2012) of the Irish Nonprofits Knowledge Exchange (INKEx), which began to build, test and launch an Irish database and free public website using regulatory disclosures by nonprofits, supplemented by voluntary disclosures. For further information, see [www.benefacts.ie](http://www.benefacts.ie).

Ireland's  
Nonprofit  
Data Portal

**Benefacts**

### As of 1 September 2015

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

# Member Profile

## Baile Mhuire Day Care Centre



Baile Mhuire Ltd was established in 1998 to provide a caring community facility where older people could be cared for and recuperate in the short term. It provided seven respite beds up until 2010. It was and is still based in Balloonagh, Tralee in the grounds of the Mercy Convent.

With the introduction of the HIQA Residential Care Standards it became clear to the group that the existing accommodation was no longer suitable to provide residential care services. With this in mind, the Board of Directors decided to change the focus of services from the provision of respite care to a day service for older people. This was consistent with the policy of the HSE and government in relation to the development of community services.

### Interim Centre

An interim Day Care Centre was opened in 2011 within the environs of the existing respite facility, a prefab which was renovated a number of years ago. Over the years, Baile Mhuire developed strong ties and relationships with the Mercy order and when the need arose for a larger facility the group was able to acquire St Johns Laundry from the Mercy Order, which is adjacent to the existing facility. A 35 year lease for a one acre site was signed. A new purpose built building was opened in April 2014.

Speaking about the service, Aidan Kelly, Chairperson of Baile Mhuire, said “another huge benefit is for family carers, who can take some time out from caring for their family member safe in the knowledge that their needs are being provided for in Baile Mhuire. Sometimes this may be the only respite the family carers get when the person goes to Baile Mhuire for five or six hours once a week”.

### Current Service

The centre, which operates five days a week (Monday, Tuesday, Wednesday, Thursday and Saturday) is working at capacity, with up to 30 clients attending each session. There are up to 130 older persons attending weekly. The centre provides a full range of care including social, clinical and ancillary services which are vital in supporting the older person to remain independent in their home or within their community environment for as long as possible. The centre is all about focusing on the older persons' needs and the service adapts to that daily. What cannot be measured is the social interaction that helps people lead a fulfilled life at home, but looked after in the community.

Aidan went on to say “Baile Mhuire will endeavour to upskill, enhance and develop the service provided to the Older Persons of Tralee and work with its core partners to continue this into the future”.

# Dates for Your Diary

## Budget 2016

13 October, Dail Eireann, Dublin

<http://bit.ly/1r2gUlu>



An Roinn Airgeadais  
Department of Finance

## 16th Healthcare Interdisciplinary Research Conference

Health, Wellbeing and Innovation: advancing research, practice and education

4 - 5 November 2015

Trinity College Dublin

<http://bit.ly/1KCb9RA>



TRINITY COLLEGE DUBLIN  
COLÁISTE NA TRÍONÓIDE

THE  
UNIVERSITY  
OF DUBLIN

## 20 years of Family Carer Research in Ireland

20 November 2015, 10am - 4pm

The Carmichael Centre, Dublin

To register, email [zoe@carealliance.ie](mailto:zoe@carealliance.ie) or phone 086 883 4942

The call for papers can be downloaded at [this link](#).





## International News

### InformCare Web Platform for Family Carers of Older people

**InformCare**  
The EU Information Hub on Informal Care

Carers

Care Alliance Ireland is pleased to announce the publication of the InformCare Innovage web platform. Along with colleagues from across Europe, we have been working with EuroCarers to create a large-scale and accessible website, which provides information for family and informal carers across 27 EU member states. The web platform focusses on information for family carers caring for older people.

The site includes details of supports available, information on specific medical needs of the person being cared for, managing family relationships, working whilst caring, and other topics. There is significant information for carers to understand how caring affects them personally, and how to cope with the stresses and challenges which caring can bring. This information is available for each member state, allowing carers to compare across member states and to understand what is available for carers across the EU.

For a short introductory film see the EuroCarers' YouTube channel (<https://youtu.be/rtffeyKJhj8>). The web platform can be accessed by navigating to <http://bit.ly/1HByScG>.



### Eurocarers Agrees Changes to its Structures and Agrees Research Priorities



At its AGM, the members of Eurocarers agreed changes to its statutes. In particular, the changes seek to widen the financial security of the organisation, with significant increases in membership contributions and changes to membership engagement processes. In addition, following a lengthy consultation process, a set of research priorities were agreed. For further details see [www.eurocarers.org](http://www.eurocarers.org).

To read Eurocarers' latest newsletter go to: <http://bit.ly/1g8Rg6V>.

# International News

## Progressive US Legislation Passed for Family Carers

The Caregiver Advise, Record, Enable (CARE) Act, is a new piece of legislation that is being enacted in more and more states across the US.

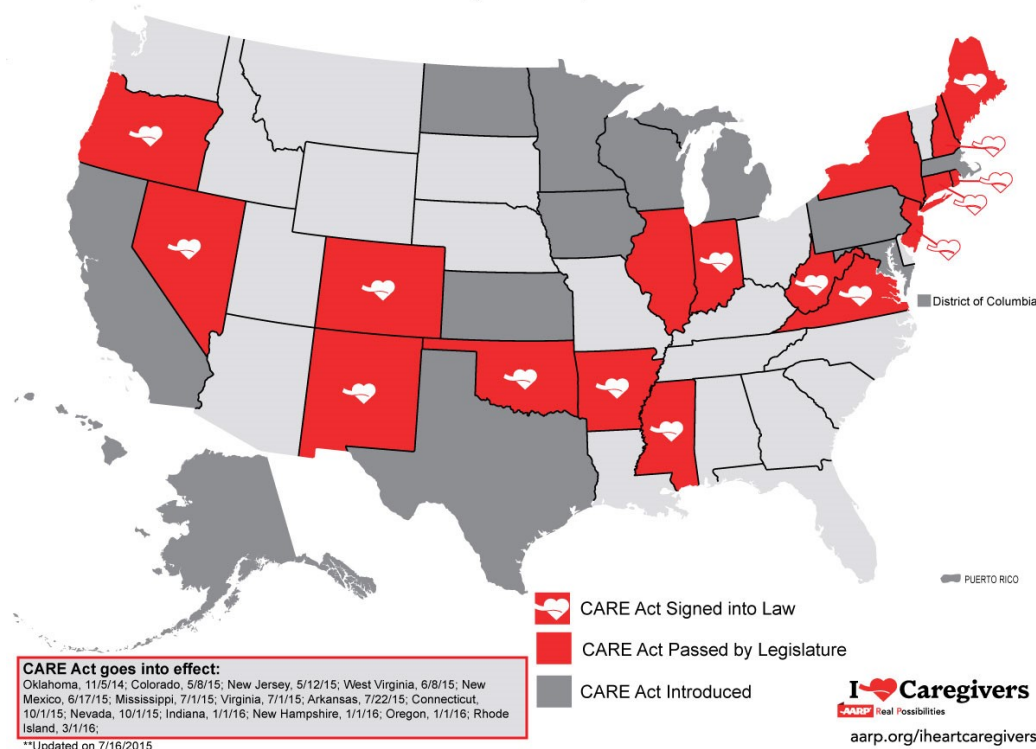
The CARE Act has three components:

- 1) It requires a recording of a family caregiver's name at admission to a hospital or rehabilitation facility
- 2) It notifies the family caregiver if a loved one is going to be discharged to another facility or home
- 3) It requires a facility to provide an explanation (and instruction) of the medical tasks a patient requires that the family caregiver will likely perform at home, like medication management, injections, wound care and transfers.

States that have passed the CARE Act in 2015 include: New Jersey, Oklahoma and Virginia. Read [here](#) about efforts advocates for family carers are undertaking to get the legislation passed in the Wisconsin Legislature.

## The Caregiver Advise, Record, Enable (CARE) Act

The CARE Act is a commonsense solution that supports family caregivers when their loved ones go into the hospital, and provides for instruction on the medical tasks they will need to perform when their loved one returns home.



# International Research

## Stress in Older Adult Caregivers

Many older adults find themselves serving as unpaid or informal caregivers to spouses or family members, and a growing body of research has shown how stress associated with caregiving can lead to negative health outcomes for these caregivers. A recent article on caregiving and stress in older adults examines caregivers' levels of stress compared to noncaregivers, compares the stress levels of high- and low-intensity caregivers, and examines how transitions in caregiving status may affect stress levels.

This study followed the stress levels of 992 women with an average age of 82 at the start of the study. Researchers classified participants into three groups: noncaregivers, low-intensity caregivers, and high-intensity caregivers. Low-intensity caregivers were those who performed assistance with fewer than two ADL (activities of daily living) tasks and fewer than six IADL (instrumental activities of daily living) tasks. High-intensity caregivers were those who assisted with either two or more ADL tasks or six or more IADL tasks. As they followed these women over a nine-year period, the researchers also looked at how transitions from one category of caregiving to another impacted on their stress levels.

Not surprisingly, those individuals who maintained the highest caregiving load from the start to the end of the study reported having the highest levels of stress, with an average score of 18.97 on the stress scale used in the study. Those caregivers providing a lower level of caregiving had a score of 16.47; this compares to an average stress score of 15.73 for noncaregivers.

When the researchers examined the impact of transitions in caregiving status, they found that those individuals who transitioned from being a lower-intensity caregiver into a high level of caregiving had the highest average stress score reported in the study of 19.41. This was higher than the 17.13 average stress score seen in those individuals who went from being a noncaregiver to a high-intensity caregiver. This comparison suggests that the stress of providing high intensity care may increase over time.

When caregivers transitioned to becoming noncaregivers, their stress levels decreased to scores similar to those who had been noncaregivers throughout the study; this latter group had the lowest average reported stress scores at 14.64, followed by those who transitioned from being a high-intensity caregiver to a noncaregiver, with an average score of 14.85. Those who transitioned from low-intensity caregiving to being a noncaregiver had an average score of 15.77. Interestingly, when a high-intensity caregiver transitioned to the reduced role of being a low-intensity caregiver, their levels of stress did not return to the average level for a low-intensity caregiver, instead only coming down to an average score of 17.50.

The study also examined how caring for individuals with different medical conditions impacted the likelihood of transitioning from low-intensity to high-intensity caregiving. Those caregivers who provided care to someone with a history of stroke, someone with memory problems, or who lived with the care recipient had significantly higher odds of becoming high-intensity caregivers.



## International Research

### Stress in Older Adult Caregivers (continued)

The study also examined how caring for individuals with different medical conditions impacted the likelihood of transitioning from low-intensity to high-intensity caregiving. Those caregivers who provided care to someone with a history of stroke, someone with memory problems, or who lived with the care recipient, had significantly higher odds of becoming high-intensity caregivers.

These findings support previous recommendations that greater attention needs to be paid to the needs of caregivers, so that the negative health effects of stress can be reduced or avoided. The authors of this study conclude that “Considering the adverse health outcomes of chronic stress, our results emphasise the importance of directing stress reduction interventions to high-intensity caregivers”. Moreover, this study also suggests that the types of caregiving transitions being made need to be taken into account when estimating caregiver stress. In particular, it should not be assumed that those high-intensity caregivers who remain caregivers but with a reduced caregiving load will return to a stress level associated with other low-intensity caregivers, and there should be follow-up with lower-intensity caregivers so that they can be provided with the additional psychological support needed if they transition to providing a higher level of care.

*Lyons JG, Cauley JA and Fredman L. The effect of transitions in caregiving status and intensity on perceived stress among 992 female caregivers and noncaregivers. Journals of Gerontology Series A: Biological Sciences (2015); 70(8): 1018–1023.*

To view the abstract go to <http://bit.ly/1IWexzz>

# International Research

## Cost of informal caregiving for patients with heart failure

### Background

Heart failure is a serious health condition that requires a significant amount of informal care. However, informal caregiving costs associated with heart failure are largely unknown.

### Methods

A study sample of noninstitutionalised US respondents aged  $\geq 50$  years ( $n = 19,762$ ) was used. Heart failure cases were defined by using self-reported information. The weekly informal caregiving hours were derived by a sequence of survey questions assessing (1) whether respondents had any difficulties in activities of daily living or instrumental activities of daily living, (2) whether they had caregivers because of reported difficulties, (3) the relationship between the patient and the caregiver, (4) whether caregivers were paid, and (5) how many hours per week each informal caregiver provided help. We used a two-part econometric model to estimate the informal caregiving hours associated with heart failure. The first part was a logit model to estimate the likelihood of using informal caregiving, and the second was a generalised linear model to estimate the amount of informal caregiving hours used among those who used informal caregiving. Replacement approach was used to estimate informal caregiving cost.

### Results

The 943 (3.9%) respondents who self-reported as ever being diagnosed with heart failure used about 1.6 more hours of informal caregiving per week than those who did not have heart failure ( $P < .001$ ). Informal caregiving hours associated with heart failure were higher among non-Hispanic blacks (3.9 hours/week) than non-Hispanic whites (1.4 hours/week). The estimated annual informal caregiving cost attributable to heart failure was \$3 billion in 2010.

### Conclusion

The cost of informal caregiving was substantial and should be included in estimating the economic burden of heart failure. The results should help public health decision makers in understanding the economic burden of heart failure and in setting public health priorities. To view full report go to <http://bit.ly/1K56bqc>.

## Practical Resources

### New 'thermometer' to assess carers' needs

Edge Hill University has launched a new tool for identifying the needs of carers - the 'Carers' Alert Thermometer' (CAT). It aims to identify and support the needs of unpaid carers providing end of life care at home. The thermometer is copyrighted, but free to use. The CAT has been developed with carers and professionals from across the North West of England. More information about the project can be found on [this website](#).



### Abstract to Research on Carers' Alert Thermometer

#### Background

There is an increasing international policy direction to promote home death for dying patients which will impact on the demands placed on family carers. The early identification of carer needs and appropriate intervention can help avoid crisis situations for the carer and avoidable hospital admissions which are reported to be a global concern. The aim of the study was to explore what professionals and carers of patients with cancer and advanced progressive illness, in their last year of life, find burdensome and to develop an alert system for use by non-specialist staff.

#### Methods

A mixed-method, multi-phased, consensus study sequentially utilising qualitative and quantitative data to develop and pilot the Carers' Alert Thermometer (CAT). 245 people (117 carers and 128 professionals) participated in the study across a range of health and social care settings in the North West of England (2011 - 2014).

#### Results

A number of key domains were identified and prioritised by consensus for inclusion in the CAT. The 8 domains fit within two overarching themes of the reported carer experience; the support needed by the carer to provide care and the support needed for the carer's own health and well-being. The resultant CAT is an evidence-based alert thermometer consisting of 10 questions, guidance on the possible actions for each alert and space for an action plan to be jointly agreed by the assessor and carer. Preliminary piloting of the CAT has shown it to be valued, fit for purpose and it can be administered by a range of personnel.

#### Conclusions

The CAT enables the identification of current and potential future needs so a proactive approach can be taken to supporting the carer as their role develops over time, with a view to enhancing their well-being and preventing avoidable hospital admissions; ultimately supporting patient choice to remain in their own home.

Professor Barbara Jack Director, EPRC.

Full Article <http://www.biomedcentral.com/1472-684X/14/22>

## About Us

Care Alliance Ireland is the national network of Voluntary Organisations supporting family carers. Our vision is that the role of family carers is fully recognised and valued by society in Ireland.

We exist to enhance the quality of life for family carers. We achieve this by supporting our member organisations in their direct work with family carers through the provision of information, developing research and policy in the field, sharing resources, and instigating opportunities for collaboration.

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

We work with our 102 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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## 10 Reasons To Join Us

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