

Care Alliance Ireland

Exchange

Summer 2015 Issue 47

Update on Membership Development Initiative

Key National Organisations Join Care Alliance Ireland - Membership Now Exceeds 100

Following a recent membership development initiative, a number of national condition-specific organisations have become members of Care Alliance Ireland, namely the Migraine Association of Ireland, Epilepsy Ireland and ASPIRE (Asperger Syndrome Association).

Speaking on the occasion of board approval of these applications, Chairperson Gerry McCaffrey, said:

"Having these three national organisations as members is a wonderful opportunity for Care Alliance Ireland to increase its reach and impact in its work of guiding support for family carers."

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

"These conditions can be quite hidden, and as such, the understanding, care and support provided by family members is often insufficiently acknowledged by the wider community. We look forward to seeking out ways to work with these organisations to help them deliver on their visions and missions."

At the May board meeting a number of other membership applications were also approved. These are: Breffni Family Resource Centre (Carrick on Shannon), Baile Mhuire Ltd (Tralee), GROW, Congregation of the Sisters of Mercy, Cairdeas Centre (Carlow) and St Hilda's Services (Athlone).

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Senator Jillian van Turnhout pictured at the launch of National Carers Week 2015

National News

Funding Extension Announced for 25 Disability and Caring Groups

In recent weeks a further 12-month extension to funding was announced for 25 disability and caring organisations, many of whom are members of Care Alliance Ireland. We welcome the announcement.

Below are excerpts from a joint response to the news from the Disability Federation of Ireland (DFI) and the Neurological Alliance of Ireland (NAI).

John Dolan, CEO of DFI stated: *"We are relieved that the SSNO funding has been reinstated to the 25 disability and caring organisations. These organisations run essential services in the community, including family support work, primary and acute health services, advocacy services, national help-lines, early intervention services and information provision; vital services to enable people with disabilities and their families to live with security, flexibility and well-being in their own communities. This one year continuation of funding means that these organisations can continue to support thousands of people with disabilities across the country".*

He continued: *"The announcement on the Claire Byrne Show last night is just plugging a gap in the short term - the organisations affected will face another year of uncertainty as a permanent solution to the chronic underfunding of disability services and supports hasn't been addressed, to date, by our Government. The forthcoming budget is their final opportunity to leave a positive legacy and give a much needed start to the still awaited recovery for disabled people and their families".*

Talking about the impact on the neurological sector, Mags Rogers, Development Manager with NAI said, *"Last June 12 neurological charities supporting the 700,000 Irish people with neurological conditions such as stroke, dementia and multiple sclerosis were facing closure or the loss of vital frontline services due to the decision by the Minister for the Environment not to renew existing funding to all the neurological charities which were in receipt of funding under the SSNO scheme to support national voluntary organisations. Today they have a temporary reprieve but we will be back here again next year unless a proper solution is found. This is very poor reassurance to the people who depend on these charities".*

You can read the official statement at <http://bit.ly/1dgC0TP>

National News

Criticism of Pace of Implementation of the National Carers Strategy

Scorecard Highlights Limited Progress

On 19 May the Carers Association published the "Family Carers' Scorecard". The report looks at each action contained in the 2012 National Carers Strategy and tracks its progress to date. Care Alliance Ireland Executive Director, Liam O'Sullivan, was a member of the Monitoring Group for this project.

Each action within the Strategy was graded according to a 5-point scale of action as follows:

- 1) Objective Achieved: making a real difference
- 2) Good Progress: positive results for family carers
- 3) Initial Progress: but slow pace/delayed start
- 4) No progress
- 5) Regressive.



Summary



Family Carers' Scorecard

What has the National Carers' Strategy Achieved? An assessment of progress from the perspective of Family Carers.



Out of 42 actions in the Strategy:

- 1 action received an "Objective Achieved" score
- 4 actions received a "Good Progress" score
- 19 actions received an "Initial Progress" score
- 10 actions received a "No Progress" score
- 8 actions received a "Regressive" score

Care Alliance Ireland remains committed to working alongside our colleagues in the Carers Association to influence the full implementation of the National Carers Strategy.

If you have any questions regarding the Scorecard (available to read [here](#)), please contact the Carers Association directly.

National News

Family Carer Research Group Meeting

On Wednesday 3 June, 24 researchers with an interest in family carer issues gathered in the Carmichael Centre, hosted by Care Alliance Ireland as part of the renewal of the Family Carer Research Group.

The group was delighted to have a chance to hear from Prof. Sue Yeandle, Director of the Centre for International Research on Care Labour and Equalities (CIRCLE) at the University of Leeds; Dr. Paula Devine, Deputy Director of the ARK (Access, Research, Knowledge) Ageing Programme; and Prof. Gillian Robinson, Ulster Co-ordinator of ARK. Prof. Yeandle shared her knowledge in linking and using research outputs to changing policy in the area of caring; something which the group agreed can be challenging! In addition, the group received a wonderful outline of the work of the ARK programme, and an overview of some of their research. A spirited discussion followed the presentations, and allowed the attendees to discuss their own experiences in varied fields such as intellectual disability, dementia care, psychology, nursing and general carer support.

We look forward to the next group meeting, which will take place on 14 September. If you are interested in joining the group, please contact our Policy & Research Officer, Zoe Hughes (zoe@carealliance.ie).



Members of the Family Carer Research Group, including right, Daragh Rodger, HSE and Professor Sue Yeandle, University of Leeds

National News

Pictures from the 9th National Carers Week



National Carers Week took place from 8 - 14 June 2015



National News

Pictures from the 9th National Carers Week



National Carers Week took place from 8 - 14 June 2015



A full report on the week will be in the next edition of our Newsletter.
See www.carersweek.ie Facebook: [nationalcarersweek](https://www.facebook.com/nationalcarersweek)

National News

Absence of Home Care Regulation 'a risk to elderly'

The HSE is paying millions to homecare providers but the sector remains unregulated, leaving thousands of elderly people at risk of poor quality care, abuse and medication errors, an expert in quality healthcare compliance has warned.

Despite a public outcry five years ago after a Prime Time programme revealed appalling standards of care by a number of private home care providers (caring for people in their own homes), the health watchdog, Hiqa, still has no remit to inspect the sector. This is despite a commitment in the 2011 Programme for Government "to develop and implement national standards for home support services which are subject to inspection by the Health Information and Quality Authority" and a recommendation by the Law Reform Commission in 2012 that the Health Act 2007 be extended to allow Hiqa regulate professional home carers.

The Department of Health said "primary legislation and resources will be required for the introduction of a statutory regulation system for home care services" and that this "will be considered by Government on a prioritised and phased basis as resources, legislative and planning processes allow".

John Sweeney, CEO of Healthcare Informed, a company with expertise in international regulatory compliance, patient safety and quality improvement, said anyone could set up a homecare organisation "from their bedroom, tomorrow, if they wished" — even though elderly people availing of the service often had highly complex needs. This was against a backdrop of the majority of the 50-plus private providers in Ireland not having relevant external quality assurance, Mr Sweeney said. "We hear advertisements on the radio that various homecare organisations are quality-certified, but in reality, the certification relates to their business processes and systems rather than the actual quality of care," Mr Sweeney said.

Bláthnait Ní Mhurchú, national service manager with Myhomecare.ie, who are contracted by the HSE to provide services, said vulnerable adults and older persons were "being ignored by the Government by failing to implement minimum standards without delay".

"When someone is crossing the threshold of your home, you need to be confident that they are going to adhere to quality care standards," Ms Ní Mhurchú said.

Research shows that those availing of homecare were far more likely to suffer an "adverse event" compared to hospital inpatients — 17% of hospital inpatients versus 66.5% of homecare clients, according to research carried out in 2013 by the Canadian International Journal for Quality in Health Care, Mr Sweeney said.

Continued on page 8.

National News

Absence of Home Care Regulation 'a risk to elderly' (con't)

Mr Sweeney said while media investigations and Hiqa had unearthed recent scandals in a number of residential care homes, "nobody knows what's happening in homecare".

The HSE said its approved providers were selected through a tender process in 2011/12 and a new tendering process was "nearing completion".

It said the 2014 tender requires providers to meet "quality standards" building on the 2012 tender and covering areas such as a client-focused service, appropriate complaints process and training and supervision of staff: "The purpose of these measures is to promote quality and safety."

It said arrangements for provision of homecare packages (HCPs) by approved providers are "monitored at local level" and that it is "in the process of implementing the Safer Better Healthcare Standards across all health services, including a range of measures to standardise home care services across the country".

The HSE estimates that in excess of 13,000 people are in receipt of a HCP from approved providers. Among homecare providers in receipt of HSE funding in 2013, were Home Instead Senior Care (€10m); Bluebird Care (€4.6m); Comfort Keepers Ltd (€11m); and Irish Homecare Services (€6.5m).

This article first appeared in the Irish Examiner on 28 May 2015, authored by Catherine Shanahan.

Policy and Research Officer Reporting

Zoe Hughes has settled in well to her new role and has established contact with many member organisations and other organisations who are interested in family carer issues. She has initiated several new pieces of work and is ensuring that we maximise our impact in the policy and research areas. Some examples of our work in this space include:

- Collaboration with 27 European countries on an innovative web support platform for the dissemination of information to family carers.
- A number of research and project proposals to various funding schemes on topics including support for family carers and supporters of people with intellectual disabilities.
- Submissions to government, including a submission on the impact of the Disability Act 2005 and the National Disability Strategy Implementation Plan (2013-2015) on family carers.
- Re-convening of the Family Carer Research Group (see report on page 4).

The next edition of our Policy and Research eZine will be out in early July. To read previous editions go to <http://bit.ly/1Q92Jnh>.

If you want to speak with Zoe about any policy or research issue she can be contacted via email (zoe@carealliance.ie) or by phone (086 883 4942).

Member News

Stigma Reduction in Dementia

Launched in early June, the Alzheimer Society of Ireland is focussing on stigma reduction.

There are a few ways to get involved:

- Watch the video and share it: <https://youtu.be/CIJc3jRsJNE>
- Sign up to Learn Listen Link: <http://alzheimer.ie/Get-Involved/Campaigning/Forget-the-Stigma.aspx>
- Share on social media: [#forgetthestigma](https://twitter.com/forgetthestigma)



Careline collaborating with The Samaritans

Expansion of National Careline Coverage — 24/7 Coverage Now on Offer

The Carers Association provides a free Careline on 1800 24 07 24. It is now expanding the support available to carers.

Samaritans provides a 24/7 service countrywide, which is staffed entirely by volunteers. It has offered to take calls from carers who wish to speak to someone during the hours that the Carers Association is not presently covering. If someone calls the Careline out-of-hours, s/he will be given the option to stay on the line and be diverted to a volunteer from the Samaritans.

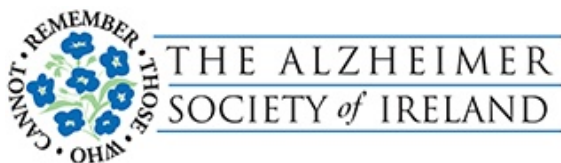
There will be no charge to the caller.

The organisation reports that a number of calls that come through its Careline are people who want to 'have a chat'. They have taken the decision to make a call, and this may not have been easy for them as they may be feeling stressed or very vulnerable. **NOTE:** The volunteers from Samaritans will not however, be in a position to provide information on rights and entitlements, training or other services.



Member News

New Resources for Carers of People with Dementia



The Irish Hospice Foundation and the Alzheimer's Society of Ireland have developed three new leaflets aimed at family members/carers of people with dementia. These were formally launched as part of the 9th National Carers Week on 8 June. The leaflets are as follows:

1. Understanding late stage dementia

This factsheet provides information about what to expect as dementia progresses to late stage. It aims to help families to understand some of the issues that can arise and to know where they can go for support and services.

2. Loss and grief when a family member has dementia

This leaflet provides information to family members on the different types of grief which can occur when someone has dementia. It also gives some tips on looking after yourself if your loved one moves into a nursing home.

3. Grieving after the death of a family member with dementia

This leaflet talks about grief and how people can be affected after the death of someone who had dementia. It also gives some practical tips to support carers through their grief.

These leaflets are available from the Alzheimer Society of Ireland, telephone 1800 341 341, or download from <http://bit.ly/1fzGr5>

Irish Family Carer Research

ClinicalTrials.gov

Benefit Finding Research Progressing

As reported in the previous edition of our Newsletter, this joint research with the University of Limerick is progressing to the next stage. Dr Stephen Gallagher who is leading the project says: "the intervention is the first of its kind in the world and aims to use writing exercises as a way of improving well-being in caregivers. It is only requires caregivers to write in a diary three times a week for two-weeks. They also will be invited to fill in a well-being survey before and after they take part and again three months later".

In recent weeks, with the support of Care Alliance Ireland and the Carers Association, over 100 family carers have been recruited to take part in the research. Details about the research have been registered with clinicaltrials.gov. See <http://1.usa.gov/1Qsbxzw>.

Caring in the News

Selection of media coverage of caring related issues since January

Carers honoured by President Higgins in Dublin – RTÉ News – 11 February 2015
<http://bit.ly/1E0aYlc>

Care grant is 'a lifeline' – Irish Independent – 21 February 2015
<http://bit.ly/1KnKa7O>

No follow-up services for stroke patients, say families and carers – Nationalist – 18 March 2015
<http://bit.ly/1JVkQbi>

Adams calls for full restoration of Respite Care Grant – Talk of The Town (Dundalk) – 27 March 2015
<http://bit.ly/1G8rv0l>

Dementia strategy needs more funding, Independent TD says – The Irish Times – 1 April 2015
<http://bit.ly/1lr3lag>

'Sandwich generation' on the rise says carers' group – Irish Examiner – 14 May 2015
<http://bit.ly/1dOiWgP>

Government Strategy makes poor progress, says Carers Association – BreakingNews.ie – 19 May 2015
<http://bit.ly/1JVh1mw>

Carers' Association criticises Department of Jobs – The Irish Times – 19 May 2015
<http://bit.ly/1R6fCLX>

Down syndrome and dementia: 'Don't break the link between the carers and the client' – Irish Times – 19 May 2015
<http://bit.ly/1PGYyyl>

Calls for better Government-funded resources for carers – RTÉ News – 20 May 2015
<http://bit.ly/1S8egBZ>

Family carers who provide palliative and end of life care need to be supported – eHospice – 20 May 2015
<http://bit.ly/1HLbrkl>

Carers and cared-for now have a freephone helpline – Wexford People – 26 May 2015
<http://bit.ly/1dgyPeX>

Pain of stigma 'a reality' for people with dementia – Irish Examiner – 4 June 2015
<http://bit.ly/1FvP27D>

Governance Corner

Important News for HSE Funded Organisations and the Governance Code



Organisations in receipt of funding from the Health Service Executive under Grant Aid Agreements Section 39 Health Act 2004 (up to €250,000)

As a condition of endorsing the Governance Code, the HSE additionally requires organisations funded under a **Grant Aid Agreement** of up to €250,000 to demonstrate compliance with the following:

- Written Constitution/Memorandum and Articles of Association
- Separate bank account in the name of the organisation
- Financial procedures regarding cash handling/payments
- Tax clearance requirements must be met
- Adherence to public and EU procurement policies
- Complaints policy in line with Part 9 of the Health Act 2004 (if services to children and/or vulnerable adults are provided)
- Freedom from abuse policy (if services to children and/or vulnerable adults are provided).
- Safeguarding of children and vulnerable adults policy, including Garda Vetting (if services to children and/or vulnerable adults are provided).

Once the above are included, the HSE accepts that an organisation that is in compliance with the Governance Code is also compliant with the HSE governance requirements for Grant Aid (under €150,000).

Where the Grant Aid amounts to €150,000 up to €249,999, Audited Financial Statements are an additional requirement.

The HSE would still require information returns but the organisation could be assured that the HSE governance requirements would be fulfilled by their adoption of the Governance Code.

Please note: The governance requirements for organisations managed by the HSE's Service Arrangements are much more extensive and are not fully covered by the Governance Code. Although compliance with the Governance Code may provide evidence of good governance practice it is not sufficient to be in compliance with the extensive additional governance requirements that the HSE mandate under their Governance Framework.

Source: The Governance Code website 12 May 2015. See <http://bit.ly/1HwzvF6>.

Governance Corner

Organisational Governance Update

- We continue to engage with the Charities Regulatory Authority around concerns we have with its website. Our specific concerns relate to directors not being able to readily review proposed changes to organisational details. We have also expressed concerns around potential for confusion in regards to terminology as well as the requirements for using the CHY number into the future. (Update, June 18th: Charities Regulatory Authority System Upgrade - Draft details of your charity can now be shared with directors as a pdf file for their review prior to submission.
- A budget for 2015 was approved by the Board at its November meeting and as of June our income and expenditure profile is on target. We are hopeful of some positive news in respect of project proposals later this year, which may have a materially positive impact on our income into 2016.
- The Board have signed off on the 2014 Directors Report and Financial Statements. We managed to report a balanced budget for 2014. A clean audit letter was secured and the financial statements are fully SORP compliant. The report and statements will be presented at our AGM on 15 September and put on our website soon thereafter. In the meantime, a summary of the year can be read at <http://bit.ly/1M7adAS>.
- In May, the Risk Register/Matrix was reviewed and updated by the Audit and Risk Committee.
- The next Board meeting will take place on 14 July.

Dates for Remaining Board Meetings in 2015

Tuesday 14 July
(Board Review/Update)

Tuesday 15 September
(Followed by AGM, 20 year anniversary)

Tuesday 17 November

As of 4 June 2015

126 organisations report being compliant with the Governance Code

615 organisations report being on the journey to adoption

For a full list of organisations, see <http://bit.ly/1aTs2age>

Member Profile

Migraine Association of Ireland

There are an estimated 500,000 migraineurs in Ireland. Around 20,000 of these suffer from chronic daily headache (15 days or more per month). According to the most recent major WHO global disease burden study published in the Lancet in December 2012, migraine is reported as the seventh most disabling disease overall and the fourth amongst women. Migraine affects around 10% of children. In children it presents in different forms and is 50:50 boys and girls. After puberty migraine is three times more common in women and in 60% of cases migraine is hereditary.



The exact cause of migraine is unknown but symptoms include nausea and vomiting, severe throbbing, usually one-sided headache and extreme sensitivity to light, noise and smell. Attacks can last from four to 72 hours.

The Migraine Association of Ireland (MAI) is a registered charity and established as a company limited by guarantee. From small beginnings in 1994, it has grown to become recognised as one of Europe's leading headache patient associations. MAI provides support, information and reassurance on a range of migraine and other headache disorder issues while promoting awareness on these to migraineurs, health professionals and the general public. Services provided by MAI include:

- A confidential helpline service for sufferers of migraine and other headache disorders to provide on-the-spot information and support - 1800 200 378
- A specialist nurse advice line
- BrainStorm newsletter, published three times a year and circulated to migraineurs and health professionals
- Information leaflets and fact sheets on specific aspects of migraine
- Migraine diaries to educate and to assist migraineur in learning to manage their life with migraine
- Publications for health professionals
- An electronic newsletter is produced six times per year
- Award winning website, www.migraine.ie providing useful up-to-date on-line information
- Public information seminars and awareness events
- Migraine Action Week, an annual campaign during September to highlight migraine issues
- There are Migraine Clinics in Dublin (Beaumont, the Dublin Neurological Institute and St Vincent's Hospital), in Cork and more recently in Galway, which were established largely due to campaigning and support from MAI.

Migraine and Carers

Migraine not only impacts on the people affected but also their family and carers. For parents watching their child suffer severe pain often leads to a feeling of helplessness and despair. The impact in families of adult sufferers can be enormous also. Having to cancel outings and social events at short notice, children unable to bring friends into their home during a sufferer's attack and becoming regular carers with increased responsibilities and impact on marital relationships are just some of the issues affecting family members. A quality of life study carried out a few years ago which included carers and family members will be published during Migraine Action Week this September.

The Migraine Association recognises the need to support not just the migraine sufferer but also their carers and family and encourages them to attend our seminars and information events and to make use of our helplines and support groups.

Dates for Your Diary

6th International Carers Conference

Care and caring: future proofing the new demographics

3 – 6 September 2015

Gothenburg, Sweden

<http://bit.ly/1BX7Ryf>



Seminar on Home Care Employment Standards

MRCI

9 September 2015

Details to be confirmed



Care Alliance Ireland

Annual General Meeting

15 September 2015, 3pm – 4pm

The Carmichael Centre

www.carealliance.ie



16th Healthcare Interdisciplinary Research Conference

4 – 5 September 2015

Trinity College Dublin

<http://trinityhirc.com/>



Resources

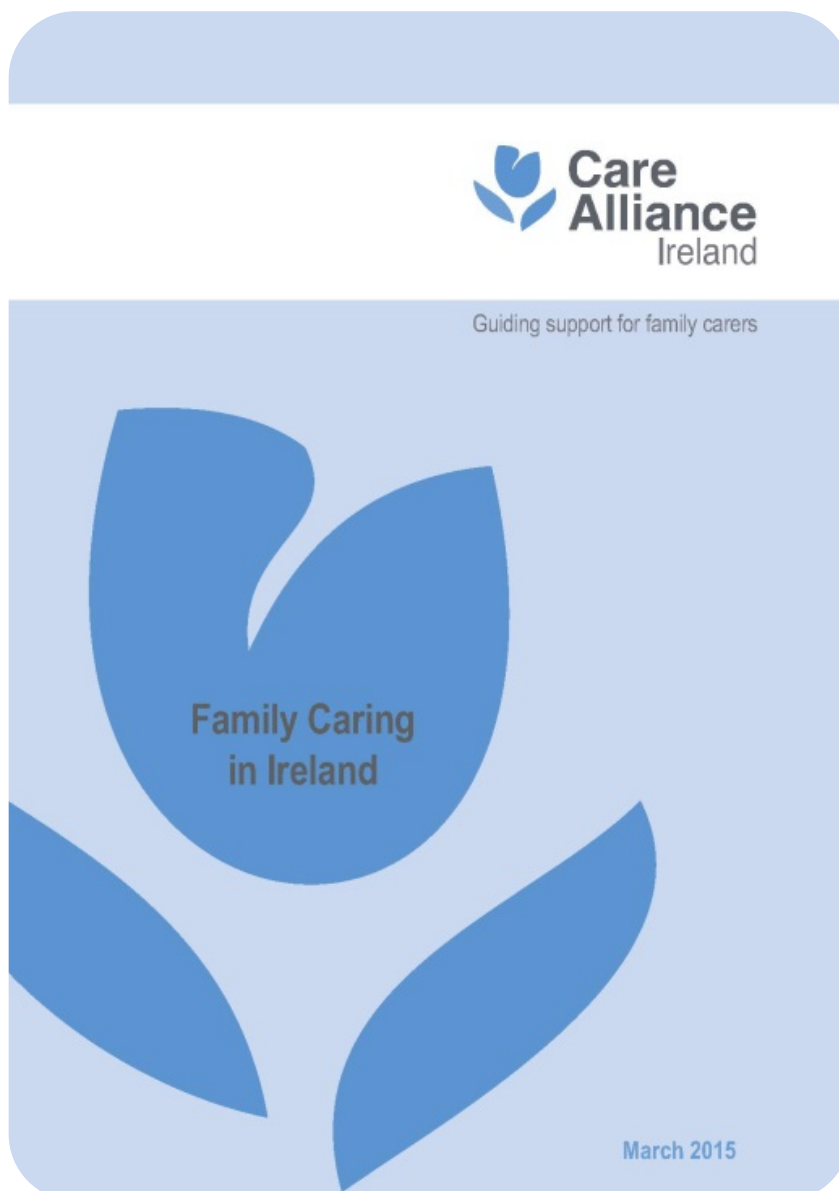
Publication of overview Report on Family Caring in Ireland

First published in 2010, the third edition of this report was published in March 2015. Since its publication in March there have been in excess of 1,000 downloads. 500 hard copies have also been distributed to key service providers and voluntary organisations throughout the country. The report can be downloaded at <http://bit.ly/1EcjR4V>.

The report brings together the key research, policy and practice developments on family caring in Ireland and abroad in one succinct publication.

This report is a great resource for those working with and supporting family carers. It will support students interested in the topic and will be a reference book for many years to come.

A small number of hard copies are available on request, e-mail info@carealliance.ie.



International News

International Alliance of Carer Organizations

New Website and Toolkit being Devised

The Alliance has launched a revamped website. New content includes blogs, country-specific information and other resources. See <http://internationalcarers.org>.

In addition, work is beginning on a new toolkit, designed for nations without a carer infrastructure. The intent is to develop a series of fact sheets on different aspects of caregiving to provide an overview of possibilities for policy-makers and NGOs to consider as they begin to develop services in their nation. Some of the proposed factsheets include:

- Carer assessment
- Employed carers
- Impact of caregiving on health
- Lexicon or glossary of common carer terms
- Carers of persons with disabilities
- Youth carers
- Respite care
- Adult day services
- Home care
- Carer education
- Rural carers
- Technology to support carers
- Male carers
- Legislation to support carers.

Care Alliance Ireland is an active member of the Alliance and sits on its Communications Committee. Its AGM will take place in Gothenberg on 2 September.

European Parliament Interest Group on Carers

"Family vs. state responsibility in long-term care provision - The feasibility of one model" **6 May 2015 Report**

The Interest Group on Carers and Eurocarers met on 6 May and addressed family versus state responsibility for long-term care across the EU.

Despite the huge variety of approaches, challenges and levels of progress, all Member States are engaged in political discussions on this topic. Whilst the EU cannot legislate in this area, it can facilitate discussion and exchange of good practice and experience and the area of long-term care seems to lend itself well for this type of informal cooperation.

A comprehensive meeting report is available at <http://bit.ly/1KUWzAt>.

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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