

# Care Alliance Ireland

## Exchange

Winter 2015 Issue 49

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### Budget 2016

#### **Welcome Response to Restoration of Level of Respite Care Grant Family Carers Unhappy with Being Described as "Not Working"**

Budget 2016 will deliver some real improvements in overall income supports for full-time family carers. This is to be welcomed. Not-for-profit organisations may at last be able to again build and develop their supports for family carers, confident that the cut-backs are behind us. This does not negate the need for all who deliver supports to family carers to deliver high quality evidenced-based supports, and to deliver them efficiently. Demographic pressures combined with increases in life expectancy will increase the overall quantum of care support needs for our community into the future. Family Carers are the bedrock of these supports.

Post-budget feedback from family carers on social media was interesting. Whilst the higher rate of Respite Care Grant and other small improvements in income supports were welcomed, a common thread was the feeling that as a family carer, to be labelled as non-working, was disrespectful and did not give expression to being fully valued. In addition, those family carers who were also in paid employment expressed their frustration at a lack of support and acknowledgement for the time spent balancing paid employment and caring responsibilities.

Concerns were also expressed about the ongoing challenges in accessing timely home care support as well as the so-called ancillary supports such as occupational therapy, physiotherapy, etc. We look forward to reviewing the 2016 HSE Service Plan and hope it will seek to prioritise the progression of a number of initiatives in the areas of carer information and carer needs assessment. We also look forward to the awarding of contracts to applicants for the family carer training funds (Dormant Accounts), announced nearly two years ago.

We look forward to reviewing the 2016 HSE Service Plan and hope it will seek to prioritise the progression of a number of initiatives in the areas of carer information and carer needs assessment.

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## News

### Care Alliance Ireland Full Response to Budget 2016

#### Budget 2016 Summary

Care Alliance Ireland is pleased to welcome a number of initiatives announced as part of Budget 2016 which will go some way to the realisation of Government's commitment to see family carers as "Partners in Care".

However, there are many families who will see minimal positive impacts from this Budget, for example young carers and family carers working full-time and juggling caring responsibilities in the home.

Key initiatives include:

- Restoration to 2012 levels of the Respite Care Grant (to €1,700 from €1,375). This grant is to be renamed the "Carer's Support Grant" to reflect the varied usage of the grant by family carers.
- Raise in the Home Carer Tax credit (by €190 to €1,000) and a raise in the income threshold to €7,200.
- €3 per week increase in Carers Allowance for those aged 66 and over (to €242 from €239).
- €2.50 per week increase in the Fuel Allowance (to €22.50 from €20).
- Upon the death of the person being cared for, Carers Allowance will continue to be paid for 12 weeks (an increase from 6 weeks). This only applies to Carers Allowance, not Carers Benefit.
- Increase in the Christmas Bonus to 75% (from 25%) of weekly payment.
- €15 million new funding to facilitate participation of children with disabilities in the Early Childhood Care and Education scheme.
- €940 million in funding to the Fair Deal nursing home scheme, with a guaranteed maximum 4 week wait time.
- Additional funding to expand speech and language therapy at primary care level.

We await the release of the 2016 HSE Service Plan to secure clarity as to where investment is being targeted and to see how the needs of older people and people with long-term illnesses and disabilities are proposed to be adequately met. This is particularly of concern given the level of funding for the Fair Deal nursing home scheme and the apparent focus on residential care versus care within the community. Minister Howlin said in his Budget 2016 speech that "a fair society is one where those who work hard receive decent rewards." We would ask Minister Howlin to remember that family carers in Ireland provide over 6 million hours of care every week, which equates to over €4 billion worth of care every year, and to then judge whether those family carers who "work hard" are indeed receiving those decent rewards.

While we welcome the initiatives for Family Carers announced for Budget 2016, Care Alliance Ireland remains concerned at the overall lack of enhanced investment for people with disabilities, long-term illnesses and mental health concerns. Family Carers support their loved-ones, often on a 24 hour a day, 7 day a week basis, with increasingly fewer supports available to those family members. Disability and Family Caring are two sides of the same coin. In particular we are disappointed at the lack of reinstatement of the motorised transport grant, mobility allowance, or the telephone allowance as part of the household benefits package- initiatives which our colleagues in the Carers Association and other groups have highlighted as of particular concern to older people and their Family Carers.

## News

### Defining Carers Discussion Paper Series Launched

As part of the enhancement of our Policy and Research work, we have a series of six discussion documents in the pipeline for publication over the next year. These publications will seek to engage a wide range of stakeholders in considering some of the emerging issues in the family carer field.

The purpose of this series is to introduce some new topics for reflection and consideration into the wider family carer discussion.

The first discussion document, entitled "Defining Carers" was launched on 19 October. Since that time it has been downloaded in excess of 700 times.

To date, the paper has stimulated some debate across the sector, including feedback from family carers themselves. Some comments from social media in response to the following question on publication of the discussion document are included below.

**How do you feel about being called a Family Carer? Care Alliance Ireland, one of the Carers Week partners, has just launched a discussion document on this very topic [bit.ly/1Lk4WHm](http://bit.ly/1Lk4WHm)**

*"Very interesting read and I would concur that I see my identity as a mother first - I took on the role of carer. I have no issue with this. I do have a big issue with others' perception of my role i.e. 'we get paid for not working' and that caring should be undertaken as an act of love i.e. not financially recognised."*

*"Don't mind being one in fact I wouldn't change a thing but what I do mind is been regarded as someone whom doesn't work. When I work harder than most people. I work 24/7 365 days a year without a day off ever. The government should see this and I shouldn't be seen as someone on the dole! Carers should have a wage after all we are saving this government a fortune."*

*"I'd do it all again in a heartbeat."*

One specific direct feedback we received about the report is given below:

*"I have read your piece of research "Defining Carers". I found it very interesting and thought provoking. It brought to light some vague feelings such as paternalism in the term and so on. It also opened my eyes as to how other people feel about the different terms as I was firm in my conviction of Family Carer (maybe not so now)."*

"Currently, for many, taking on the identity and label of 'family carer' is 'the gateway through which supports are accessed"

(page 4)



## News

### Care Alliance Ireland announce training collaboration with The Carmichael Centre on Implementing the Governance Code



**carmichaelcentre**  
**Training & Consultancy**

We are delighted to announce that thanks to funding under the Scheme to Support National Organisations we are now in a position to offer Care Alliance Ireland member organisations complimentary places for these one-day seminars. The seminars will take place in Dublin on 1 March and in Limerick on 8 March.

Speaking about the collaboration, Derek O'Reilly, Training Manager, Carmichael Centre for Voluntary Groups said "We are delighted to be partnering with Care Alliance Ireland on this initiative. This practical one-day workshop will go through the five principles of the Governance Code and explain how to implement it."

#### Content

##### **1: Leadership & Control**

Mission, vision and values. Planning. Managing staff and/or volunteers.  
Legal and regulatory requirements.  
Internal financial and management controls. Risk management. Policies.

##### **2. Transparency & Accountability**

Identify and communicate with stakeholders. Enable beneficiaries to engage with the organisation.

##### **3. Working Effectively**

Board roles and responsibilities. Managing meetings.  
Board recruitment, development and retirement.

##### **4. Integrity**

Honesty, fairness and independence. Conflicts of interests and loyalties.  
The organisation's reputation.

##### **5. Case Study**

Care Alliance Ireland to present on the journey to compliance.  
Actions required for full compliance with the Code.

Participants should familiarise themselves with the guidelines for types A, B or C organisations on [www.governancecode.ie](http://www.governancecode.ie) in advance of the workshop.

For enquiries and or to book contact us at [info@carealliance.ie](mailto:info@carealliance.ie).

## National News

### Family Carer Needs Assessment – Update

Care Alliance Ireland is currently acting as the conduit between the HSE and carer organisations with respect to the development of a new Carer Needs Assessment, as part of the introduction of a suite of assessment tools for the care of older people. Using the InterRAI Assessment model, Ireland is taking the lead in developing a comprehensive carer needs assessment tool. In recent weeks, 20 Family Carers have taken part in a pre-pilot, which has involved four HSE practitioners undertaking a person-to-person Carer Needs Assessment. This pre-pilot is being undertaken to get a sense of the usability and suitability of the tool. In 2016, an international pilot will be progressed, involving upwards of 1,000 family carers internationally, 200 of whom will be based in Ireland. This initiative is being undertaken in association with interRAI's Instrument and Systems Development Committee. For further details, see <http://www.interrai.org/welcome.html>.

Speaking on the development, Liam O'Sullivan, Executive Director, Care Alliance Ireland said:

"It is wonderful at last to see the Carer Needs Assessment tool being used here in Ireland. The initial verbal feedback from practitioners has been immensely positive to date. This augurs well for the wider roll out in 2016. They report the process as being positive for both themselves and for the family carers who have taken part so far. We acknowledge the leadership being shown by them and by the SAT team within the HSE and look forward to publishing the findings from this study in a future edition of our Newsletter. We also look forward to working with the HSE and other stakeholders in progressing a full international pilot in 2016."

#### Three reasons to introduce carer assessments

- 1) They give expression to family carers being Partners in Care (National Carers' Strategy, 2012)
- 2) They have a track record spanning twenty years in places such as the UK and USA.
- 3) They do not create a massive surge in demand for supports.



## National News

### Medical Research Charities Group/Health Research Board Announce Joint Funding Scheme for 2016



**MS Ireland** has recently launched its call for proposals. Details are available on their website. See [here](#).

MS Ireland will accept formal applications which follow the theme:

*'Mindfulness and Meditation based interventions for people with Multiple Sclerosis which can improve the quality of life for people with MS.'*

This programme awards funding to time-specific research projects. Projects of up to €50,000 investment for two years will be considered for this call (€25K in year one and €25K in year two). The closing date for applications to MS Ireland is 11 December 2015.



**Epilepsy Ireland** has recently launched its call for proposals. Details are available on their website. See [here](#).

Epilepsy Ireland encourages proposals for all types of research including basic, clinical, psychosocial and health services research.

Proposals that cover one or more of the following research areas are particularly welcome in the current funding round:

Development of improved diagnosis, treatments or support interventions. Genetics of epilepsy. Psychosocial aspects/impact of epilepsy. Epilepsy and education. Use of assistive technology in epilepsy. Sudden Unexpected Death in Epilepsy and other epilepsy deaths. Epilepsy in specific demographics such as children/young adults; the elderly; people with an intellectual disability; women; men. Rare epilepsy syndromes.

The closing date for applications to Epilepsy Ireland is 4 December 2015.

Supporting Charities carrying out medical research



## National News

### Consultations on the new National Disability Inclusion Strategy



Údarás Náisiúnta Míchumais  
National Disability Authority

The National Disability Authority is organising a series of regional meetings at the end of November and in early December on behalf of the Department of Justice and Equality. The purpose of the meetings is to consult people with disabilities and their families on objectives for the forthcoming National Disability Inclusion Strategy. Full details of the consultation document are being finalised, but the dates and times for your diary are:

- Tuesday, 24 November 2015 – Cork (10am to 1pm)
- Thursday 26 November 2015 – Dublin (10am to 1pm)
- Wednesday 2 December 2015 – Tullamore (10am to 1pm)

Further details and a link to the registration form from [dmomalley@nda.ie](mailto:dmomalley@nda.ie).

### Research and Policy Officer Reporting

Zoe Hughes continues to be available to member organisations and others for discussion and consultation on relevant issues. She will shortly be contacting member organisations that she has not had direct contact with to date to ensure that her work reflects the needs and interests of our member organisations.

A number of exciting new initiatives have been undertaken as part of the Policy & Research function of Care Alliance Ireland.

- Organisation of a very successful national research conference on 20 November celebrating “20 Years of Family Carer Research in Ireland”.
- Launch of the Care Alliance Ireland Discussion Paper series, with the publication of Paper 1: “Defining Carers” (<http://bit.ly/1W22sFC>)
- Collaboration with numerous sector colleagues in calling for increased funding to the sector in Budget 2016.
- Post-budget breakdown of developments of particular interest and relevance to Family Carers (<http://bit.ly/1X2QQil>).
- Further development of the Family Carer Research Group. Next meeting scheduled for February 2016.
- Continued participation on the Lenus Open Access working group, and 23 October presentation at “Opportunities to Work Together” event for International Open Access Week (slides available at <http://bit.ly/1SimdTO>).



Above, Zoe Hughes, Policy and Research Officer, (4th from left) at the Institute for Public Health/RIAN sponsored seminar, to mark International Open Access Week.

For more information on these, or any other policy and research matters, do not hesitate to contact Zoe ([zoe@carealliance.ie](mailto:zoe@carealliance.ie)).

## Governance Corner

### Policies Updated

Four organisational policies were reviewed, updated and approved by the board at the November board meeting. A new Whistle-blower Policy was also approved by the board. A continuity plan is being prepared.

### Care Alliance board reiterates compliance with The Governance Code

We have undertaken a review of our compliance with the Governance Code and the board reiterated our compliance at its recent board meeting.

#### As of 1 November 2015

**189** organisations report being compliant with the Governance Code

**711** organisations report being on the journey to adoption

For a full list of organisations, see <http://bit.ly/1aTs2ag>

#### Dates for 2016 Board Meetings

23 February

26 April

5 July

20 September  
(Followed by AGM)

15 November

#### Caring in Numbers

**69,455**

Number of downloads from Care Alliance Ireland Website - 1 Jan to 1 Nov 2015

**11,622**

Number of followers of National Carers Week Facebook page

**706**

Number of downloads of discussion document since its launch on 19 October

**86,000**

Numbers of family carers set to benefit in June 2016 from the restoration of the of the Respite Care grant (amount increased from €1,375 to €1,700, to be renamed Carer Support Grant)

**Up to 12 Weeks**

The length that The Carers Allowance can now be paid after caring ends.



## Member News

### Spotlight Shone on Carers of People with Dementia in Campaign by the Alzheimer Society of Ireland

More than 10% of all calls to the ASI Helpline in the first six months of 2015 were from carers struggling to cope with stress brought on by providing 24-hour care to loved ones. Overall, carer stress was the second most common topic of all calls to the helpline between the months of January and June of this year.

In a bid to raise awareness of the plight of the 50,000 family carers of people with dementia in this country the ASI launched its 'Impact of Caring' campaign in November. The campaign saw six members of the ASI's Dementia Carers Campaign Network, an advocacy group peopled by family carers, tell their stories of what life is like for carers of people with dementia. They were daughters, sons, wives and husbands and they provide a snapshot of the reality faced by carers every day in this country.

The aim of the campaign was to highlight the following:

- Almost half of the costs associated with dementia are borne by family carers
- Family carers of people with dementia save the Government €807 million every year
- Caring impacts on all aspects of a carer's life: financially; emotionally; relationships-wise
- Dementia carers can become isolated and need support
- There are 4,000 people under the age of 65 living with dementia in this country many of whom have young families with specific needs.

"The provision of quality, dementia-specific home care is of huge importance to enhance the lives of people with dementia and their carers."

Colette Kelleher, CEO

Among the campaigners was Katie Moran, 24 from Stillorgan in Co Dublin, who cares for her mother Loretta diagnosed with dementia at the age of 54, when Katie was just a teenager. *"Mom can't be left alone for a minute and she can no longer do anything for herself from eating to washing. Her limited words make it difficult to anticipate her needs. She has occasional moments of realisation too and nothing makes me sadder than seeing her tears when she realises what's happening to her. I think the Government needs to be made aware of the impact caring has on families. Not enough is being done to support people, particularly those who are quite isolated and without a support network."*

Laura Reid from Santry, who cares for her mother Nora who was diagnosed with dementia in her early fifties, said: *"Keeping life normal is the ultimate struggle for carers and fighting for their needs is often a battle in itself. Sadly, this isn't helped by our elected Government who is failing to honour its commitment to people with dementia. The Government needs to do more to enable people to keep living in their own homes and to resource their caregivers to provide much needed care."*

CEO of The ASI Colette Kelleher said: *"We are proud to launch our Impact of Caring campaign which seeks to shine a light on the plight of the 50,000 people who quietly provide 24-hour care to loved ones with dementia in homes all over the country 365 days a year. Most people diagnosed with dementia want to stay at home and most family members want to look after them, but keeping people at home requires support. It can be provided less expensively than in acute and residential settings and yet almost two in three people with dementia in Ireland are currently living at home with little or no supports. The Government is failing to create a real difference to the lives of people with dementia and as a result carers feel invisible and isolated."*

To view the case studies of the Impact of Caring Campaign please click [here](#).

The ASI Helpline 1800 341 341 is open Monday to Friday from 9am to 5pm and Saturday from 10am to 4pm.



## Member News

### Migraine Association win IMPACT Award

The Migraine Association of Ireland (MAI) was delighted to recently win a GSK Ireland IMPACT 2015 award for its work in providing information, support and reassurance to all of those affected by migraines and other headache disorders. The award will support the work MAI does in drawing attention to the impact of living with migraine on not just the person themselves but also on their families and carers. The burden on those caring for a person with a severe migraine disorder can be enormous and for the main part goes unrecognised.

A short video outlining the work of the association can be viewed [here](#). The Bradley Maher family kindly participated in the filming explaining how the association has helped them to deal with the impact of severe headache disorders on their lives.

This is the first year of the GSK Ireland IMPACT Awards, an expansion of the GSK IMPACT Awards in the UK and USA that have been running for 18 years, focusing solely on health and wellbeing charities in Ireland. Applicants were assessed on the following criteria – innovation, management, partnership, achievement, community focus and targeting need. The award was presented at a ceremony on 22 October.

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



Pictured above left:  
Left to right: Claire Bradley, Rown Maher, James Maher

Pictured above right:  
Left to right: Patrick Little, CEO MAI, Dr. Paddy Daly GP,  
Dr. Eddie O'Sullivan GP, Audrey Craven, President MAI,  
Mervyn Craven, Claire Bradley

## Member Profile

### Alzheimer Society of Ireland

**The leading dementia specific service provider in Ireland**



THE ALZHEIMER  
SOCIETY of IRELAND

The Alzheimer Society of Ireland (ASI) works across the country in the heart of local communities providing dementia specific services and supports and advocating for the rights and needs of all people living with dementia and their carers. Our vision is an Ireland where no one goes through dementia alone, and where policies and services respond appropriately to the person with dementia and their carers, at the times they need support.

A national non-profit organisation, the ASI is person centred, rights-based and grassroots led with the voice of the person with dementia and their carer at its core. There are 48,000 people living with dementia in Ireland and 50,000 family carers of people with dementia - even more when you include wider family and social networks.

The ASI has a number of grassroots advocacy groups such as the Dementia Carers Campaign Network (DCCN) which aims to represent, raise awareness and campaign on the distinct needs of people who care for someone with dementia. The group was established in 2013 and is supported and facilitated by the society.

The ASI also runs a five-week course aimed at supporting family members who are caring for loved ones with dementia. The five sessions are held on a weekly basis, usually in the evenings. Each session lasts about 2.5 hours. Go to [www.alzheimer.ie](http://www.alzheimer.ie) for more details.

Our helpline advisers and trained helpline volunteers are available to talk to you about:

- Different causes of dementia
- How a diagnosis is made
- Accessing our services and supports
- Practical tips for living well day-to-day
- Legal and financial affairs
- and much more...

We are open Monday to Friday 10am-5pm and Saturday 10am to 4pm. If you are contacting us outside these hours you can leave a brief message with your name and contact number and your call will be returned when the helpline re-opens.

#### National Helpline

The Alzheimer Society of Ireland's free, confidential service provides information, support and a listening ear. Our service is for people with dementia and their families as well as people who are concerned about their own or a loved one's memory. We also work with health and social care professionals.

#### Alzheimer Cafes

Alzheimer Cafes provide a warm and welcoming space for people with dementia, their carers, friends and health and social care professionals to meet and exchange ideas.

The cafe is based on an international model and usually meets in the early evening, although some cafes meet during the day. Contact our helpline at 1800 341 341 to find out more or visit [www.alzheimer.ie](http://www.alzheimer.ie) to find your nearest cafe.

# Irish Research and Practice Reports

## Irish Practitioners and Researchers publish on Impact of Carer Interventions

**The What:** Published in August in the British Journal of Health Psychology, this report found that there were significant effects of group (intervention vs. waiting list control) at the 3-month follow-up on carers' perceptions of stress and strain resulting from caring, and perceptions of criticism received by the carer from the person with an acquired brain injury (ABI). A subsequent per-protocol analysis showed an additional reduction at 3 months in levels of criticism expressed towards the person with an ABI by the carer. There was no significant effect of the intervention on psychological distress.

The structured multicomponent carers programme showed beneficial effects in terms of reducing carer strain and in the reduction of elements of perceived criticism at the 3-month follow-up; however, it did not significantly affect psychological distress in carers, suggesting the need for additional support for this group of carers.

**Our Take:** We in Care Alliance Ireland feel that it is great to see in this journal a move towards more applied presentation of the findings, specifically with regard to the 'so what' questions or more officially as the "Statement of Contribution" (detailed below). Unfortunately the full report is not available through Open Access (i.e. for free), which limits its accessibility.

### What is already known on this subject?

A number of studies have suggested that carers of people with ABI experience greater levels of carer burden and mental health difficulties than carers of other patient groups. Previous interventional studies on ABI are few, and such studies have diverged in the extent to which they have been oriented towards education, psychological support, or management of behavioural difficulties, making results somewhat difficult to apply in community health settings with this potential client group.

### What does this study add?

- We develop, describe, and evaluate a brief structured multicomponent carers' training and support programme for carers of people with ABI.
- Not all outcomes were affected positively by the intervention. While the intervention successfully reduced carer strain and critical comments, distress did not significantly reduce compared to people in a waiting list control group.
- Carers who were spouses/partners and carers who were parents exhibited comparable levels of strain, distress, and perceived criticism.
- Younger carers reported significantly higher levels of distress and carer strain at induction to the programme.
- The positive effects of the programme were maintained for at least 3 months, suggesting that it may have initial validity for improving some of the negative aspects of the carer experience.

The abstract report is available [here](#) (the full report is accessed by subscription only).

Well done to Carol Rogan (previously of Acquired Brain Injury Ireland, a member organisation of Care Alliance Ireland) and her colleagues on publishing this research!

Full Title of Report:

Fortune, D. G., Rogan, C. R. and Richards, H. L. (2015), A structured multicomponent group programme for carers of people with acquired brain injury: Effects on perceived criticism, strain, and psychological distress. British Journal of Health Psychology. doi: 10.1111/bjhp.12159.



# Irish Research and Practice Reports

## Launch of Report on Migrant Workers in the Home Care Sector

Migrant Workers in  
the Home Care Sector:  
Preparing for the Elder  
Boom in Ireland



This report was launched in September and Care Alliance

Ireland is happy to be involved in it and its associated outputs.

Many family carers have a keen interest in seeing that paid care workers are treated well and together both groups have a common interest in ensuring that care is valued irrespective of who delivers it.

Speaking about the report Gráinne O' Toole of the Migrant Rights Centre Ireland said: *"Care work is central to our society – everyone needs to be cared for at some point in their life. We cannot continue with the current ad-hoc and unregulated system of home care provision which undermines both the quality of care and the conditions for workers. Migrant workers reported having no employment contracts, working on call and night shifts without extra pay and many did not receive minimum wages, annual leave or public holidays. Being subjected to racism, working excessive hours and undertaking heavy workloads was also prevalent in this sector. Increasingly, many undocumented migrants are filling care roles and because of their irregular status are more vulnerable to exploitation. Care work needs to be valued and the needs of older people and care workers regardless of immigration status respected."*

The full report can be viewed [here](#).

In addition, Employment Guidelines for Home Care Workers have been prepared by a group of Irish not for profit organisations and will be launched by Dr. Mary Murphy of the Irish Human Rights and Equality Commission on Monday 30 November from 10.45 am to 1pm in the Mansion House. A film on the experience of home care workers will also be shown at the event. For further details contact [grainne@mrci.ie](mailto:grainne@mrci.ie).



# Practical Resources

## The Palliative Hub for Adults Launched



THE PALLIATIVE HUB

An All Ireland Gateway to  
Palliative Care Information

**The Palliative Hub – Adult** is a gateway to information about palliative care for adults on the island of Ireland. It is aimed at assisting people with palliative care needs, their family members, carers, friends and the wider public to understand what palliative care is.

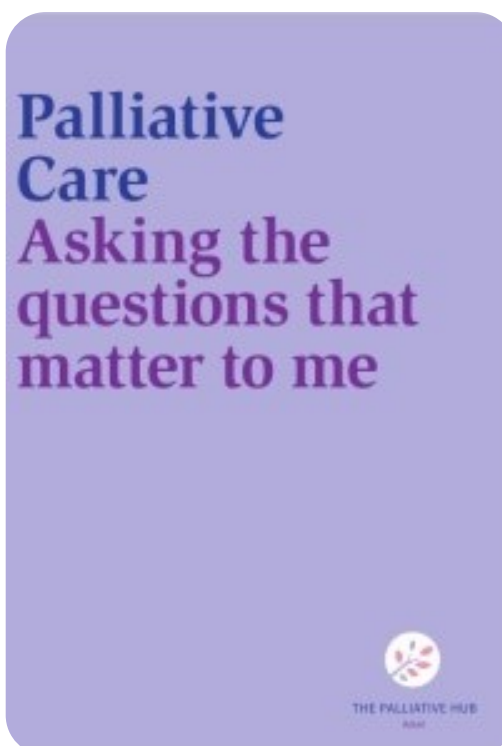
**The Palliative Journey** is a key part of the site. Each of the four stages set out has input from professionals who offer their experience and advice on caring for people with palliative care needs. The stages are also linked to relevant resources and to a range of organisations and services.

**The Palliative Journey – Care** seeks to offer people and their families advice about care decisions. It provides basic definitions on the different forms of care a person may receive and provides links to organisations that will be able help a family with caring for a loved one.

The Personal Stories section includes stories from people with palliative care needs, their family members and carers who have experienced, or are experiencing palliative care. It is hoped that the shared experience of these stories will help to support other people in a similar position.

A new 32-page information booklet called **Palliative Care: Asking the questions that matter to me** has also been launched to help people ask the right questions following diagnosis of a life-limiting condition. The booklet has been produced by AllHPC's Palliative Care Senior Nurse Network (PCSNN).

The Palliative Hub – Adult is the third of four websites that is being produced by AllHPC to help solve the information needs of the palliative sector as a whole. To access the other websites please visit [www.thepalliativehub.com](http://www.thepalliativehub.com).



# Practical Resources

## Eating Disorders / Relapse / Family Carers

### Relapsing

Relapsing is common a concern for those affected by eating disorders and for family members. When someone relapses it may feel as though they are returning to eating disorder behaviours and thought patterns.

A relapse may occur during or following recovery. The recovery and treatment process can sometimes feel stressful. A person may experience negative thoughts and fear in relation to issues such as weight gain. Thoughts may intensify and there may be occasional signs of behaviours indicating of a recurrence of the eating disorder. Over time, the thoughts increase and an individual may act on them more frequently, increasing behaviours. An individual may start to lose weight and their distress may be noticed by others. He/she may withdraw from family and friends.

Due to the individual nature of eating disorders, it may be difficult to predict the likelihood of a relapse. Research studies have identified stressful life events, social stressors such as the loss of a friend, challenges at work and dismissal from employment. Other contributory factors include intense obsessive compulsive symptoms, excessive exercise, residual concern about shape and weight following discharge from treatment, severity of checking behaviours prior to treatment and decreased motivation to recover.

Relapses are common, but are not an indication that a person has 'failed' at recovery. A relapse can be viewed as an opportunity to learn and to build on recovery. It is also important that parents, carers and friends not treat a relapse as a failure.

(Courtesy of Bodywhys: <https://bit.ly/1ZQ8pVN>)

Support for Families Affected by Eating Disorders is available [here](#).

**"Eating Disorders - a Resource for Parents"** is now available from Bodywhys.

Contact Bodywhys [here](#) to receive a copy in the post, or you can download the [PDF version](#) here.



# International News

## Executive Director takes on International Role



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

We are delighted to report that Liam O'Sullivan, Executive Director, Care Alliance Ireland, has accepted the invitation to take on the role of honorary Treasurer of the International Alliance for Carer Organizations (IACO). Already an active member of the communications committee, Liam previously served as Treasurer to Eurocarers and will bring to the role his considerable experience in financial management. IACO is currently seeking to deepen its existing relationship with a number of key strategic funders to enable it to implement its Strategic Plan.

### More about IACO

#### ***Vision***

IACO will establish a global understanding and recognition of the essential role of carers with respect to care recipients, health and social care systems and society.

#### ***Mission***

Through collaborative engagement IACO will improve the quality of life and support the needs of carers, through international partnerships and advocacy that strengthens and honors the voice of carers.

#### ***Goals***

The goals of IACO are to:

- Engage members to share and increase knowledge, expertise and experience.
- Act as a resource for carer organizations globally.
- Facilitate international advocacy to advance programs, policies and legislation that support caregivers.
- Increase awareness of the role and value of the Alliance.

<http://www.internationalcarers.org/>

# International Research

## Eurocarers

Presentations made at the recent Eurocarers AGM are now available to download here <http://eurocarers.org/AGM-2015->. The Eurocarers Annual Report is available to download [here](#).



### The latest Eurofound data relevant to carers

Robert Anderson presented the activities of the European Foundation for the Improvement of Living and Working Conditions (Eurofound) at the Eurocarers AGM in September in Gothenburg. He particularly highlighted the data recently collated by the Foundation regarding work-life balance and working carers. He also informed the group about two relevant articles to be released this year on carers and employment and work preferences after 50. Download presentation [here](#).



### The European Semester

Also presenting at the Eurocarers AGM was Stecy Yghemonos (Eurocarers) who underlined the growing importance of the European Semester in the political discussions around the reform of social protection, health and long-term care systems across the EU. He insisted that the Semester includes various entry points for policy influencing at EU and national level and that our EaSI agreement with the EC favourably positioned us as a credible knowledge broker. Download presentation [here](#).



## About Us

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

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

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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