



# Care Alliance Ireland Exchange

Spring 2011

Issue 32

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## New Government, New Direction?

Further to the recent coalition agreement for government, Programme for National Government 2011-2016, Care Alliance welcomes the commitment to developing a National Carers Strategy. We also welcome the commitment to an Alzheimer's Strategy, a Positive Ageing Strategy and the full implementation of the existing Disability Strategy.

Ideally, these four interrelated commitments would complement each other and there would be ongoing communication between the stakeholders to ensure the best possible outcome. Unfortunately, history tells us otherwise.

The voluntary and disability sectors need to ensure that each of these commitments is progressed and that the rhetoric of valuing interdisciplinary and multi-agency approaches throughout our health and social care services is actually delivered on.

There remain some dilemmas and even more unanswered questions:

- Which department is best positioned and best resourced to progress these commitments?
- How will the implementation of these commitments be financed?
- How will Universal Health Insurance impact on access to carer support services?
- What impact will the implementation of Home Care standards have on Family Carers?
- Will Family Carers be prioritised with respect to accessing free GP Care?
- How will a move towards a personal budget model in disability services impact on the relationship between Family Carers and those they care for?

The Programme for Government says *"By the end of our term in Government, Ireland will be recognised as a modern, fair, socially inclusive and equal society supported by a productive and prosperous economy."* We in Care Alliance Ireland will work with our member organisations and other stakeholders to ensure that the new government keeps to these pledges.



## Acquired Brain Injury Ireland Wins Award for its Family Carer Training Programme

ABI Ireland is delighted to announce that its Brain Aware family carer training programme was a winner in the recent Astellas Changing Tomorrow Awards, in the category of Hope. Brain Aware is a training programme for Family Carers who are caring for loved ones with an acquired brain injury. Full story page 9.

## Voluntary organisations best source of information and support

**First nationwide survey on state of neurological care reveals 81% view voluntary organisations as essential or very important in providing services and support**

“The first nationwide survey on neurological care carried out by the Neurological Alliance Ireland (NAI) is an indictment of the Irish health system and evidence of a mounting crisis in neurological care,” said Professor Orla Hardiman, Consultant Neurologist in Beaumont Hospital and spokesperson for THINKING AHEAD, the NAI Campaign for Neurological Care. NAI represents 30 neurological charities.

The survey findings reveal that more than 38 per cent of people with neurological conditions waited longer than six months to be diagnosed at a deeply worrying time for them and their families. 42 per cent experienced more than a six month delay in receiving vital services with the majority waiting for consultant neurology services. Neurological conditions include stroke, epilepsy, migraine, Alzheimer’s disease, acquired brain injury and multiple sclerosis.

Significantly, 49 per cent of respondents reported that voluntary organisations were their best source of information and support in relation to their condition. 48 per cent viewed voluntary organisations as essential and a further 33% as important or very important in terms of the services and support they provide.

Commenting on the survey results, Anne Winslow, Chair of the NAI said: “We have repeatedly pointed out that further cuts to State funding for neurological charities will compound the dreadful state of neurological care experienced by 700,000 people and their families in Ireland. The incoming government must engage with our Action Plan for Neurological Care and realise its obligations to more than 700,000 people with neurological conditions and their families. It can do that by putting in place the framework of statutory and voluntary services that is so desperately needed”.

For more information on the campaign, visit [www.thinkingahead.ie](http://www.thinkingahead.ie)

Full report at [http://www.headway.ie/download/pdf/nai\\_full\\_survey\\_report1.pdf](http://www.headway.ie/download/pdf/nai_full_survey_report1.pdf)

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## Home Care Regulation

In December, the previous Minister for Older People, Áine Brady TD, made the following comments on home care services in response to the Primetime Investigates programme which examined the lack of regulation in the home care sector.

“The central focus of Government policy for older people who need care is that they should be able to receive quality care and they should be at the centre of all decisions regarding their care. The key element that must exist between providers of care be they public or private, and the recipient of that care, has to be trust. This is fundamental to any service and particularly so in the case of health or personal social services where recipients will in all likelihood be vulnerable. In relation to the four cases highlighted the HSE is investigating these now and if there was a lack of suitable care the HSE will terminate the contracts and/or change providers. The HSE has been working with the Department of Health and Children on a number of key initiatives which will strengthen overall governance in this area and will be implemented and published in the first half of 2011. HSE also has complaint mechanisms and an Elder Abuse Network.”

The **HSE’s Information Line 1850 24 1850** is available Monday to Saturday 8am-8pm for those who wish to make a complaint or access the Elder Abuse reporting service.

The full statement can be viewed at: <http://www.dohc.ie/press/releases/2010/20101213.html>

## Launch of Training Events by HSE West, Galway, Croí & The Carers Association



The Carers Department, HSE West, Galway have teamed up with The Carers Association to deliver 15 FETAC Level 5 'Practical Home Care Skills' Modules for Family Carers in Galway this year.

Sharon Deering, Training Manager, The Carers Association explains: "The aim of this course is to provide family carers with an overview of the roles and responsibilities of caring, the practical care skills and knowledge essential for quality care provision, to raise awareness of the supports that are available to family carers and to look at ways to cope with the caring role."

Attending the Launch of the Training Calendar of Events of Heartsaver CPR Training Courses and FETAC Level 5 Practical Home Care Skills Modules in Galway for 2011, in partnership with the HSE West, The Carers Association and Croí, West of Ireland Cardiac Foundation were:

Left to right: Agnes Durkin, Regional Training Facilitator, The Carers Association; Michelle Harrison, Manager, Carers Department, HSE West, Galway; Sharon Deering, Training Manager, The Carers Association.

For more information about these courses, please contact the **Carers Department, HSE West, PCCC Services, Galway on (091) 548333**

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## Share your caring story

The European Federation of Associations of Families of People with Mental Illness (EUFAMI) is currently compiling a library of personal stories of carers who look after family members with mental health problems. EUFAMI have asked Shine to see if anyone would be interested in taking part in this project by sharing their personal experience with regards to their role as a carer and family member of someone who has a mental illness.

***"We believe that sharing these stories – inspiring ones and touching ones and also examples of best practice – would provide a great source of support to our members."***

Sigrid Steffen, President of EUFAMI

The survey can be accessed at:

<http://ts.ktrmr.com/survey.asp?i.project=CXBXX&s=GEN24&id=1&chk=na&pid=auto>

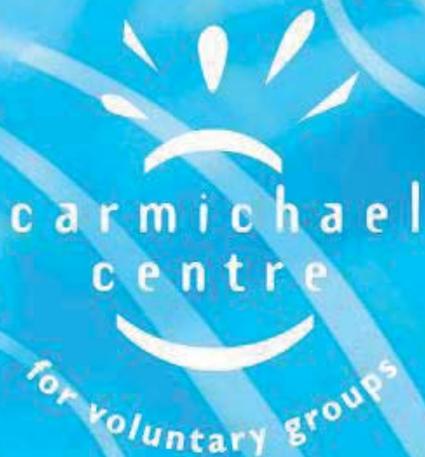
or from the EUFAMI website [www.eufami.org](http://www.eufami.org)

Responses can also be sent by post to Shine and we will send it on to EUFAMI. Please send to: Dolores Kavanagh, Shine, 38 Blessington Street, Dublin 7. For more information, see [www.shineonline.ie](http://www.shineonline.ie)

**There are currently  
50,833 people in  
receipt of Carer's  
Allowance and  
1,625 in receipt of  
Carer's Benefit**

*source: DPS, March 2011*

Carmichael Centre for Voluntary Groups presents  
**Dublin's Good Friday Concert**



## **Johannes Brahms Requiem**

**Saint Patrick's Cathedral, Dublin**  
**Friday April 22<sup>nd</sup> 2011 at 8pm**

Doors open at 7pm. All seats must be taken by 7.45pm.  
Unreserved seating. Some seats restricted view.

**Soprano:** *Virginia Kerr*

**Bass:** *Philip O'Reilly*

*The Goethe-Institut Choir and Orchestra*

**Conductor:** *John Dexter*

**Master of Ceremonies:** *Senator David Norris*

Also featuring pieces by J.S. Bach, Th. Tallis and F. Liszt

If you would like to make an online donation go to  
**[www.carmichaelcentre.ie](http://www.carmichaelcentre.ie)**

Follow us on   

# **a day to Remember**

**Thursday 5th May**

## **Alzheimer's Tea Day**

Alzheimer's Tea Day - a day to Remember - is an opportunity for people to come together and raise funds by hosting a tea party in their home, office or school.

Invite your guests along for a cup of tea and a biscuit and then ask them to make a small contribution to The Alzheimer Society of Ireland.

Taking part is easy and funds raised are allocated to the closest service/branch of The Society. All money raised locally, stays locally.

Tea Day is critical to people who care for loved ones with Alzheimer's - because it funds real, tangible, hands-on services that make an enormous difference to their everyday lives.

See 'dates for your diary' for details of how to take part or visit [www.teaday.ie](http://www.teaday.ie)

## **HSE Service Plan Published**

The HSE has published its 2011 Service Plan, outlining its budget reduction framework.  
The full document can be viewed at:

<http://www.hse.ie/eng/services/Publications/corporate/nsp2011.pdf>

# Dates for Your Diary

## 5-6 May 2011

**EUROCARERS Annual General Meeting (AGM)** will take place in the Ashling Hotel, Dublin on 5-6th May.

Some of the topics to be discussed include:

- Focus on carers in Central and Eastern European Countries (two speakers)
- Opening address by Marian Harkin (MEP) on "Working together for an EU Strategy for Carers"
- Presentation of the "Irish Strategy for Carers" (Enda Egan)
- The role of ICT for caregivers (EU-officer Clara Centeno)
- Long-term care across Europe (Jolanda Elferink)
- Caregivers quality of life and managing incontinence (Giovanni Lamura)

You can now register online at [www.eurocarers.org/conference2011](http://www.eurocarers.org/conference2011)

## 27 April 2011

The next **Family Carers Research Group** meeting will take place on Wednesday 27th April from 10.30am - 12.00 at the Carmichael Centre, Dublin 7.

If you would like to attend or are interested in 'skype-ing' in, please email [ndo@carealliance.ie](mailto:ndo@carealliance.ie)

## 5 May 2011

This year, **Alzheimer's Tea Day** is on Thursday 5th May.

For more information on hosting a tea party to raise funds for the Alzheimer Society of Ireland:

Call 01 2073800

Email [teaday@alzheimer.ie](mailto:teaday@alzheimer.ie)

or submit your registration form online at [www.teaday.ie](http://www.teaday.ie)

## 20 June 2011

### **Caring at End of Life – Supporting Carers in this Complex and Difficult Journey**

The Irish Hospice Foundation, in partnership with Care Alliance Ireland, are hosting a **Lunch and Learn** seminar for professionals involved in supporting family and friends who are caring for someone nearing the end of life on Monday 20th June at the Irish Hospice Foundation, Nassau Street, Dublin 2.

The aim of the session is to provide an initial forum to discuss the issues that present for professionals supporting this group of carers, as well as outlining existing supports and resources that are available for them in their work.

For more information contact Marie Lynch at [marie.lynch@hospice-foundation.ie](mailto:marie.lynch@hospice-foundation.ie) or Liam O'Sullivan at [ndo@carealliance.ie](mailto:ndo@carealliance.ie) or check [www.carers.ie](http://www.carers.ie)

## 27 April 2011

### **National Dog Walk 2011 – for Family Carers**

This year, the Petmania National Dog Walk will take place on Easter Monday, 25th April 2011, at 2pm at 13 locations around the country. The 5km sponsored walk is open to dogs of all shapes, sizes and breeds and we hope that they will bring all the family along to what is guaranteed to be a fun day out!

Petmania has nominated The Carers Association as our official people-charity, and will use this event to help raise vital funds for this organisation. Register today at

<http://www.petmania.ie/national-dog-walk/?id=316>

## New Hope for Stroke Survivors – 24 treatments most doctors don't offer

A unique website, just launched, offers hope to people suffering with devastating problems due to stroke. Research & Hope ([www.researchandhope.com](http://www.researchandhope.com)) presents survivors with 24 potential stroke treatments. Despite passing clinical trials, most of these are rarely offered by doctors in the aftermath of a stroke.

The website was created by Dr Aviva Cohen, a researcher and lecturer whose husband, Steve, suffered a serious stroke in 2006. Still nursing their second baby, Aviva watched as her 'bullet-proof' karate instructor dissolved into a paralysed, speechless stranger overnight.

Refusing to accept the prognosis that Steve would be severely disabled for life, Aviva searched the internet and trawled through the millions of entries under 'stroke'. When mainstream medicine had done all it could for Steve, she sent him for numerous therapies that had not been on offer in hospital. These included acupuncture, hyperbaric oxygen therapy, and a range of experimental drugs. Success rates have varied but overall, Steve has made significant progress. Since exploring unusual therapies, Aviva says,

***“the light has come back into Steve’s eyes, the movement has come back into his paralysed arm, and hope has come back into our lives.”***

Aviva created the Research & Hope website to make it easier for fellow stroke survivors and carers to find high quality, unbiased information on uncommon but clinically tested therapies.

Research & Hope is simple to navigate. It presents a clear overview of how each treatment works and provides a summary of arguments for and against using that particular treatment for stroke. It also describes what happens when the patient arrives at the clinic or hospital offering the therapy. If the reader decides to find out more, an online map displays the location of his or her nearest practitioner. Use of the site is free. Research & Hope is not just a website; it is a gateway that empowers people to take action and to find hope.

**STOP PRESS: Social Entrepreneurs Ireland have announced that Research & Hope is one of the final 18 candidates for their 2011 Awards.**

## Hospice Friendly Hospitals – Design & Dignity

The Hospice Friendly Hospitals (HFH) Programme aims to make end-of-life care central to hospital care. While the majority of people would like to die at home, most people now die in a hospital. Despite this, end-of-life care is still not seen as a core activity of hospitals and is not adequately reflected in hospital cultures, systems and structures.

HFH has produced a video on the need for “design and dignity” in end of life care in hospitals. Seamus Heaney and Gabriel Byrne, among others, talk about the need for “sacred spaces in public places”. It makes the case for privacy, quiet and facilities such as meeting rooms and tea/coffee for family members. You can watch the video on youtube at:

<http://www.youtube.com/watch?v=zr4hSAVdNwU>

## Carer of the Year 2011

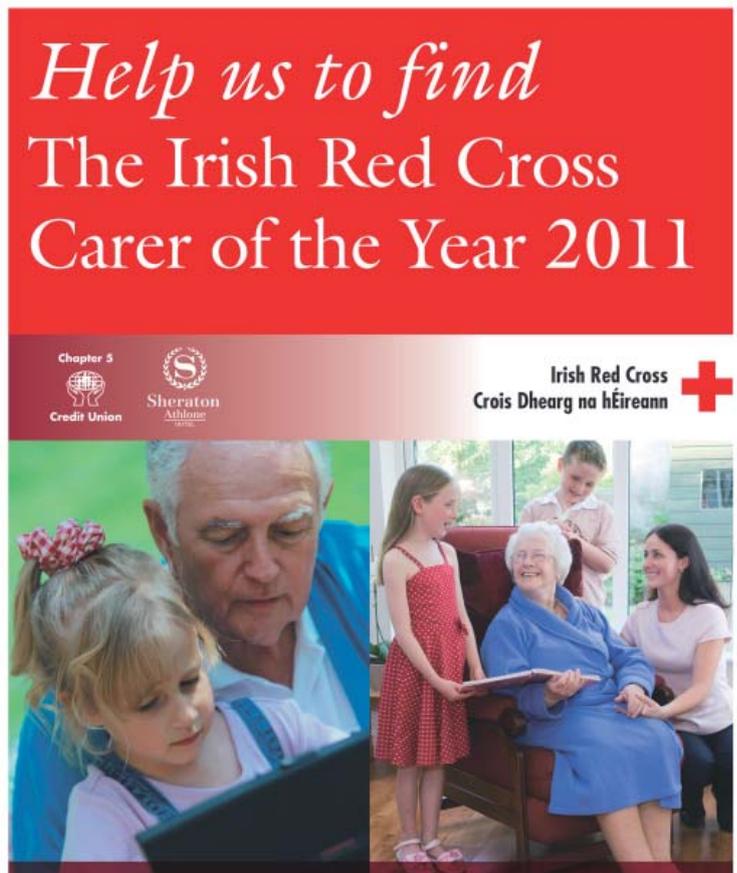
The Irish Red Cross would like to acknowledge the hard work and dedication of all Carers at home and in the community through its Carer of the Year Award 2011.

The critical act of caring for others is often taken for granted and this valuable work goes unnoticed. The winner of the Carer of the Year Award will receive a gift cheque for €2,000 sponsored by Chapter 5 Credit Union and a luxury spa break for two in the Sheraton Athlone Hotel. Certificates will also be awarded to Carers who deserve special recognition.

The closing date for receipt of entries is 12th May 2011. You can download applications from the Irish Red Cross website

[www.redcross.ie](http://www.redcross.ie)

or request one by phone on (01) 642 4600 or from the Irish Red Cross Head Office, 16 Merrion Square, Dublin 2.



The Irish Red Cross also supports Carers through its community services such as the **Helping You to Care** training course and **Therapeutic Hand Care Service**.

They have also produced a **Helping You to Care Handbook** which is a practical fully illustrated guide for those looking after someone who is ill, elderly or is disabled, with comprehensive advice on all aspects of care. Helping You to Care Handbooks are available to buy from

[www.redcrossshop.ie](http://www.redcrossshop.ie)

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## Irish Cancer Society Night Nursing Service

The Irish Cancer Society provides a free night nursing service to cancer patients who wish to remain at home for end of life care. Each patient and family can receive up to 10 nights of care between the hours of 11pm to 7am.

The service is delivered by registered general nurses and their role involves supporting the family through giving advice and reassurance at what is a very difficult time for them. They provide nursing care and symptom management for the patient together with psychological and spiritual care.

There are approx 230 Night Nurses located around the country delivering the service.

The service is essential in order to allow palliative cancer patients to remain at home at the end of life surrounded by their family and loved ones.

The service can be accessed through the local community palliative care team, GP or Public Health Nurse. The service is funded through monies raised on Daffodil Day and in 2010 over 7000 nights of care were provided to over 2000 families nationwide.

The Irish Cancer Society also provides a **Cancer Information Helpline on Freephone 1800 200 700**

## MS Carers Support Tool Study

The importance of addressing issues of concern to carers is evident in the new government's commitment to develop a National Carers Strategy. In particular, this is a welcome development for carers of People with Multiple Sclerosis (PwMS). National and international research is consistent in its findings that providing and developing services, including access to support and information, are important to this group of carers. Despite the ongoing evidence identifying such needs internationally, there is a lack of well developed and tested nursing interventions.

In an attempt to address the needs of carers of PwMS, Margarita Corry, a lecturer in nursing at the School of Nursing & Midwifery, Trinity College Dublin, as part of a research degree, is developing and testing an intervention that will enable nurse specialists in multiple sclerosis to provide proactive support to carers of people diagnosed with Multiple Sclerosis. If the intervention is found to be of benefit to these carers and their care recipients, it is anticipated that it can be tested for more widespread use by nurses as part of the service they offer to carers.

The purpose of the study is to evaluate if a telephone support service delivered by MS nurse specialists results in better care outcomes for both people with multiple sclerosis and their carers. The potential benefits for the carers include being empowered to manage problems encountered as a result of caring and being better prepared to provide care. It is anticipated that these outcomes will contribute to an overall improvement in the wellbeing of carers and in the experiences of the people they provide care for.

Margarita would like to acknowledge the support received for this study from the members of the Irish Network of Multiple Sclerosis Nurses, Multiple Sclerosis Ireland and Care Alliance Ireland. Margarita can be contacted at [macorry@tcd.ie](mailto:macorry@tcd.ie)

### Cognitive Impairment and Dementia: A Practical Guide to Daily Living for Family Caregivers



Compiled by Suzanne Cahill PhD & Vanessa Moore

In association with  
The Living with Dementia (LiD) Programme,  
School of Social Work and Social Policy, Trinity College Dublin  
and the  
Dementia Services Information and Development Centre (DSIDC),  
St James' Hospital, Dublin.

### Cognitive Impairment and Dementia: A Practical Guide to Daily Living for Family Caregivers

This guide provides practical information to family care-givers of people living at home with a cognitive impairment or a dementia, to help them better cope with the day-to-day choices and dilemmas they may confront.

When someone is caring for a person diagnosed with dementia or a cognitive impairment, the home and negotiating its surroundings can pose difficulties and can be dangerous. This guide makes simple suggestions about changes/ adaptations they can make which may make daily life at home safer and more simple for the carer and family members.

Download your copy at:

[http://www.cardi.ie/userfiles/PracticalGuide191110\(inal\)\[1\]\[1\].pdf](http://www.cardi.ie/userfiles/PracticalGuide191110(final)[1][1].pdf)

## Acquired Brain Injury Ireland Wins Astellas 'Changing Tomorrow' Award

ABI Ireland is delighted to announce that its Brain Aware family carer training programme was a winner in the recent Astellas Changing Tomorrow Awards, in the category of Hope.

In 2008, ABI Ireland was successful in receiving funding from Pobal to provide training for Family Carers who are caring for loved ones with an acquired brain injury.

The 'Changing Tomorrow' award, developed by Astellas Pharma, aims to reward those who aspire and work towards a vision of a healthier world. Brain Aware was one of over 100 projects reviewed by the Changing Tomorrow judging panel with just 16 shortlisted for the five categories of Hope, Leadership, Commitment, Innovation and Environmental/Social Responsibility.

Future Brain Aware Training Programmes for Family Carers will take place as follows:

**Macroom, Cork – April/May 2011**

**Thurles, Co. Tipperary – April/May 2011**

**Letterkenny, Co. Donegal – May/June 2011**

All enquires to Una Kinane at (087) 257 8235 or [ukinane@abiireland.ie](mailto:ukinane@abiireland.ie)



Patricia Kelly, General Manager of Astellas Ireland Pharma Co. Ltd presented the Changing Tomorrow Award to ABI Ireland's CEO, Barbara O'Connell. In photo left to right are: Carol Rogan, Training Manager; Barbara O'Connell, CEO; Una Kinane, Project Co-ordinator

Winning projects also received prize monies of €1,000. ABI Ireland is currently using this fund to deliver additional training to Family Carers under the Brain Aware Programme.

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## Database Launched to collate decisions of Social Welfare Appeals Office

The Northside Community Law Centre has created a database of decisions of the Social Welfare Appeals Office. Called **Casebase**, the database is the first of its kind in Ireland.

Of particular interest to Family Carers is this case relating to Carers Allowance:

Carer's Allowance (Casebase no.: G0008)

Publication date: 14-March-2011

Case summary: Carer's Allowance claim. The Appellant (the carer) cared for his wife who is in receipt of Disability Allowance. The Appellant applied for Carer's Allowance in September 2005 and was refused on the grounds that the evidence did not support his claim that his wife required "continual supervision" to meet her needs. The Appellant appealed the decision. The Appeal was disallowed.

To access Casebase, go to:  
<http://www.nclc.ie/casebase>



## Young Carers Pilot Project in Cork

Having completed my research dissertation on the subject of young carers in Ireland, which focussed specifically on the impact of that caring role on the young person's mental health and education, I felt that something needed to be done in order to support young carers in Cork. As part of my work with the Community Development Unit of Cork City Partnership, we felt that the best way to start was to organise a meeting with representatives of any agency that is engaging with families and young people, such as youth work organisations, HSE, etc.

As a result of this meeting a Community Worker from South Lee Community Work Department and a Primary Care Social Worker are now working with me on the project. It was agreed that the issue needed to be addressed in two ways. Firstly, there should be an awareness raising element. This involves attending regional or team meetings of public health nurses, occupational therapists, physiotherapists etc. and delivering a presentation on the issue.

The second approach is a pilot project in an area of the city where all of the relevant services are well established, such as Springboard, Barnardos, primary health care team etc. This should help us to more easily identify young carers and, in turn, the supports they may need should be easier to access. Initially, the project will take place over a smaller area, as communication between the services would be better than city-wide.

Article by Linda Mc Kernan, Community Development Worker, Cork City Partnership. For more information about the project, contact:

[lmckernan@partnershipcork.ie](mailto:lmckernan@partnershipcork.ie)

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## OECD study shows that valuable unpaid work is under-accounted for by between one-third and one-half

Household production constitutes an important aspect of economic activity and ignoring it may lead to incorrect inferences about levels and changes in well-being. This paper sheds light on the importance of unpaid work by making use of detailed time-use surveys for 26 OECD member countries and three emerging economies.

The calculations suggest that between one-third and half of all valuable economic activity in the countries under consideration is not accounted for in the traditional measures of well-being, such as GDP per capita. In all countries, women do more of such work than men, although to some degree balanced – by an amount varying across countries – by the fact that they do less market work.

While unpaid work – and especially the gender division of unpaid work – is to some extent related to a country's development level, country cross-sectional data suggest that demographic factors and public policies tend to exercise a much larger impact. The regular collection of time-use data can thus be of tremendous value for government agencies to monitor and design public policies, and give a more balanced view of wellbeing across different societies.

For more information, see: <http://www.oecd.org/dataoecd/41/37/47258230.pdf>

## Member Profile

cúram



**Cúram** is this year celebrating our 30th anniversary. Founded by Norah T. Gilligan in Dublin in 1981, Cúram is a national, non-denominational, non-party political voluntary organisation open to all men and women who support our aims of recognition and support for the unpaid work of parents and carers. Most of our members, however, are at-home mums and dads or family carers, or both.

Cúram is part-funded by the Department of Equality and has recently joined Care Alliance Ireland, having worked together with many other organisations on campaigns such as the Carers Count Campaign, and towards a National Carers' Strategy, which should provide better structures and supports for family care.

Cúram is also active in the EU, in our federation organisation FEFAP ([www.fefaf.be](http://www.fefaf.be)). We represent FEFAP at conferences and at meetings on women's and care issues, including the Commission for the Status of Women meetings in New York. This year we were able to meet with UN officials in the Statistics Department, Social Affairs and in the new division, UN Women.

We looked for improved statistics on unpaid work (which is otherwise invisible – making recognition and support difficult!) and sought specific supports, including services and funding, to enable parents and carers to fulfil their care responsibilities but not be impoverished as a result. We also met many other NGO representatives working in other parts of the world on the same issues, with a view to working together towards a common goal.

Most of Cúram's work is on policy issues and we represent parents and carers in the media and other public forums. We also provide an information service to members and the general public. Search Cúram on Facebook to keep up to date with our activities and links to research of interest to parents and carers.

Curám was involved in the Carers Count Campaign to encourage carers to answer Question 22 in Census 2011. As we know from research, carers underclaim the hours they spend supporting the people for whom they care. Groups like Cúram can represent carers, but the government needs to know directly from carers how many hours are involved or, especially given the current economic climate, support won't happen.

As part of this campaign, Cúram launched the **myCareTime** iPhone app, developed to help carers count their hours, on Friday 8 April 2011. You can download it from the iTunes store for free.



For more information on Cúram or our activities, please contact:  
Áine Uí Ghiollagáin on  
Tel: 087 68 22 517  
Email: [withcare@eircom.net](mailto:withcare@eircom.net)  
Search Cúram on Facebook



## Family Carers receive “slap in the face” in Budget 2011

The Carers Association is appalled that all the assurances they received from backbench TDs that the Carers Allowance would not be touched in the Budget have come to nought. Family Carers who look after their loved ones in the home save the State an estimated €2.8 billion per year.

In return Carers received €12.00 per week, which in most cases barely enabled them to make ends meet. This latest cut of 4%, €8.48 per week, will have a real impact on the welfare of a very substantial proportion of family carers, already finding it difficult to meet everyday bills like heat and electricity, essential to maintaining the well-being of their loved ones.

“The Government has reneged on its promise to protect the most vulnerable in our society by hitting Family Carers, for whom a cut of 4% is the enormous amount of €440.96 per year” says Enda Egan, CEO, The Carers Association.

“This goes against the stated Government policy to provide care for older people and people with disabilities in the home for as long as possible. It is another case of a massive chasm between Government policy and practice, a gap that has widened in each of the last three budgets” concluded Egan.

The Carers Association is the National voluntary organisation of family carers in the home, providing support services, respite, training and information to carers throughout Ireland. The Carers Association can be contacted on the National Careline Freefone 1800 24 07 24 or see [www.carersireland.com](http://www.carersireland.com)

## Government decision not to appoint a Minister for Older People “defies logic”

Age Action is shocked at the Government’s decision not to appoint a junior minister with responsibility for older people or ageing in the new administration.

“This is the first time in 14 years that a government has not appointed somebody to this important position,” Age Action spokesman Eamon Timmins said. “It is very difficult to understand the rationale behind the decision, considering the huge challenges which face policy makers as a result of Ireland’s ageing population, and the considerable amount of policy regarding older people in the programme for government.”

The older people’s charity said a minister for older people was essential to steer key elements of policy through, such as the National Positive Ageing Strategy. “The programme for government, states this strategy will be completed and implemented, but without a minister for older people it is now unclear who will do this work,” Mr Timmins said.

“The failure to appoint a minister with responsibility for this area places a major question mark over how much of the age-related policies in the programme for government will be delivered,” he added. “At a time when other countries are getting to grips with the challenges of ageing, today’s decision defies logic. It does not inspire confidence that the new government will address ageing issues in a joined-up, comprehensive fashion.”

**Age Action**

**IRELAND**

*For All Older People*

A round up of media coverage on issues related to caring since end November 2010.

### **Heads up... drop-in centre opens its doors**

<http://www.irishtimes.com/newspaper/health/2011/0308/1224291573352.html>

### **A strategy for end of life**

<http://www.irishtimes.com/newspaper/opinion/2011/0218/1224290139083.html>

### **The two sides of coping with depression**

<http://www.irishtimes.com/newspaper/health/2011/0208/1224289248838.html>

### **Dignity can be retained in Alzheimer's**

<http://www.irishtimes.com/newspaper/health/2011/0201/1224288677543.html>

### **Direct payments for disabilities more effective, says report**

<http://www.irishtimes.com/newspaper/health/2011/0111/1224287231754.html>

### **Concerns over home care**

<http://www.irishtimes.com/newspaper/letters/2010/1217/1224285736285.html>

### **Homecare complaints received by HSE**

<http://www.irishtimes.com/newspaper/ireland/2010/1215/1224285580391.html>

### **End-of-life issues do not just end with death**

<http://www.irishtimes.com/newspaper/health/2011/0322/1224292769725.html>

### **I was in twilight zone for a year**

<http://www.irishtimes.com/newspaper/health/2011/0308/1224291571328.html>

### **Carers protest over Budget cuts**

<http://www.irishtimes.com/newspaper/breaking/2010/1210/breaking40.html>

### **Care 'should not be linked to location'**

<http://www.irishtimes.com/newspaper/ireland/2011/0223/1224290628376.html>

### **Homecare provision must be vetted and regulated**

<http://www.irishtimes.com/newspaper/opinion/2010/1215/1224285578156.html>

### **Harsh lessons learned from looking after our mother**

<http://www.independent.ie/opinion/columnists/martina-devlin/martina-devlin-harsh-lessons-learned-from-looking-after-our-mother-2462538.html>

### **Vital census question for carers**

<http://www.irishexaminer.com/opinion/letters/vital-census-question-for-carers-150857.html>

## Eurocarers

The organisation is going from strength to strength, thanks in part to recent financial support from a long-standing corporate supporter (SCA/Tena). The Executive continues to meet monthly, with a strong Irish representation. The organisation's AGM will take place in Dublin on 5-6th May, as advertised on page 5.

### Carers Assessments – Grundtvig Learning Partnership update

Since August 2010, Eurocarers has been participating in a European project on Family Carers. The name of the project is "Self-assessment of their needs by Family Carers: The pathway to support". It brings together 14 national NGOs, including The Carers Association, and two European umbrella organisations.

The objective of the partnership is to identify, at EU level, good practices in the field of awareness raising and training aimed at promoting the self-assessment of their needs by Family Carers. Family Carers often neglect their own needs and the outside support they could seek and they have no knowledge of their rights.

The project will lead to the development, by summer 2012, of recommendations for the design of tools aimed at meeting the needs of carers. For more information, see [www.eurocarers.org](http://www.eurocarers.org)



## European Parliament agrees Citizens' Initiative

On 15 December 2010, MEPs gave the green light to the Citizens' Initiative, which will make it possible for one million citizens or more to demand new EU legislative acts. Member States will adapt their legislation by the end of this year to facilitate this.

The agreed procedure is as follows:

- To start matters, a committee of at least seven citizens needs to approach the Commission to register the request for an initiative.
- The Commission will determine whether it is admissible, basing itself on the EU Treaty.
- If the petition is admissible and collects at least one million signatures, its initiators will have the right to be received by the Commission and to take part in a public hearing.
- In accordance with the Treaty, the Commission will be the sole judge of the possibility of giving a legislative follow-up to a citizens' initiative.

For more information, see:

<http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+TA+P7-TA-2010-0480+0+DOC+XML+V0//EN&language=EN#BKMD-16>

## Research on Incontinence Care “Quality of life in caregivers of dependent people affected by incontinence in Europe”

By Sabrina Quattrini (INRCA, Italy) and Giovanni Lamura (INRCA, Italy and European Centre for Social Welfare Policy and Research, Vienna, Austria)

After a long preparation phase, in Spring 2010 EUROCARERS and SCA (a multinational company in the field of hygiene products) agreed to co-operate to carry out a qualitative survey (based on face-to-face interviews) on “Quality of life in caregivers of dependent older people affected by incontinence in Europe”.

The study, funded by SCA and co-ordinated on behalf of Eurocarers by INRCA, is now coming to a conclusion. It has involved research teams and field studies in four countries, each representing a different macro-area of the European continent: Southern Europe (Italy, INRCA, Italian National Research Centre on Aging), Eastern Europe (Slovak Republic, Institute for Labour and Family Research), Scandinavia (Sweden, The National Competence Centre for Family Care) and Western Europe (The Netherlands, Vilans).

The aim of the study was to explore the experiences of adult partners and children in caring for dependent older persons aged 65 and over, living at home and suffering from urinary and/or faecal incontinence on a daily basis, in order to gain a better understanding of which measures and interventions might improve the current situation of caregivers.

The data collection, concluded in January 2011, has involved between ten and 16 in-depth interviews per country. After the qualitative analysis the national reports have now been completed, and currently the final comparative report is being finalised. The final meeting among the project partners will take place on 8 – 9th March 2011 at INRCA in Ancona, where the final version of the comparative report will be discussed, and appropriate dissemination strategies agreed.

The findings emerging from the study will be presented for the first time at the next **EUROCARERS Annual General Meeting**, to take place in Dublin 5-6th May.

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## Coping styles within the family system in the chronic phase following acquired brain injury: its relation to families’ and patients’ functioning

**Objective:** To investigate how the functioning of family members and the coping styles they use are related to the psychosocial functioning both of the family members and of the person who has sustained a brain injury.

**Results:** Primary caregivers who had a preference for passive coping styles reported that they experienced a lower level of family functioning, a lower quality of life, and a higher strain. Neither the coping styles nor the psychosocial outcomes of the primary caregivers were significantly associated with patients’ self-reported quality of life. Furthermore, there was no correlation between the level of family functioning and a patient’s quality of life.

For more information, see: <http://www.ncbi.nlm.nih.gov/pubmed/21305233>

## Characteristics of caregiver perceptions of end-of-life caregiving experiences in cancer survivorship: in-depth interview study

**Objective:** Little is known about caregiver experiences during the end-of-life period. Our objective was to characterise caregiver perceptions of their experiences in cancer survivorship with special reference to the end-of-life stage considering depression in bereavement. Methods: Qualitative research using in-depth interviews of 34 caregivers from two palliative care units in Japan. Data were analyzed inductively using framework analysis. Depression and personality traits were measured using the Center for Epidemiological Studies Depression (CES-D) and Sense of Coherence (SOC) scales, respectively.

**Results:** Caregiver perceptions were characterised along two axes. One axis involved four caregiver-cancer patient relationships: strengthening, reconstruction, intimacy-maintained, and estrangement-maintained. The core concept was transformation of relationships: caregivers reappraised aspects of caregiver-patient interactions through caregiving. The other axis involved subjective caregiving experiences divided into five concepts: spontaneity of care, discussing death, sympathy for patient emotions, impressions on first witnessing death, and introspective reflections in bereavement. Strengthening and reconstruction relationships appeared similar among the four relationship types, but only the former tended to overcompensate by sacrificing private time. Although median CES-D scores in each relationship type were under the cut-off for possible depression, four of eight caregivers suspected to have depressive tendencies belonged to the strengthening type. The mean SOC score for all caregivers was intermediate relative to scores previously reported in Japanese studies.

**Conclusions:** While caregivers' subjective experiences can be classified, their relationship to depression in bereavement needs future research. The present findings indicate that caregivers should also be considered in clinicians' views of cancer survivorship.

Full ref: Psycho-Oncology (2011) Characteristics of caregiver perceptions of end-of-life caregiving experiences in cancer survivorship: in-depth interview study. Hiroko Mori, Risa Fukuda, Akitoshi Hayashi, Kazunari Yamamoto, Chizuru Misago and Takeo Nakayama. Published online in Wiley Online Library ([wileyonlinelibrary.com](http://wileyonlinelibrary.com)). DOI: 10.1002/pon.1964

## Study Demonstrates Effectiveness of Online Support Groups for Caregivers

As the prevalence of dementia increases, so does the prevalence of unpaid caregiving, as family members need to assume caregiving roles with their loved ones. Research has shown that this unpaid labor puts caregivers at significantly higher risk of mental and physical distress. A recent Canadian study demonstrated the viability of using internet-based intervention programmes to manage caregiver distress by encouraging improved self-efficacy and social support (Marziali and Garcia 2011).

To read the full article, please visit:

[http://aginginaction.com/2011/03/study-demonstrates-effectiveness-of-online-support-groups-for-caregivers/?utm\\_source=feedburner&utm\\_medium=feed&utm\\_campaign=Feed%3A+AgingInAction+%28Aging+In+Action%29&utm\\_content=Google+Reader](http://aginginaction.com/2011/03/study-demonstrates-effectiveness-of-online-support-groups-for-caregivers/?utm_source=feedburner&utm_medium=feed&utm_campaign=Feed%3A+AgingInAction+%28Aging+In+Action%29&utm_content=Google+Reader)

## New Study Reveals Balance of Positive and Negative Aspects for Caregivers of Individuals with Alzheimer's Disease or Dementia

### Research and Practice

#### Caregivers' Views Related to Stage of Loved One's Illness and Whether Caregiver Had a Choice in Assuming Responsibility

One-half of caregivers of individuals with Alzheimer's disease or dementia surveyed for a new caregiver study find an equal balance of positive and negative experiences in their caregiving. One-third (33 percent) say their caregiving experience is more positive than negative.

The 2011 report, "Caregivers of Individuals with Alzheimer's or Dementia," which was presented at a briefing on Capitol Hill today, examines both positive and negative feelings associated with caregiving for individuals with progressive deterioration of their abilities and faculties. Conducted by the National Alliance for Caregiving and sponsored by Pfizer Inc., the study found that:

- Two out of three caregivers feel that caring for their loved one gives them the opportunity to "give back" (65 percent)
- Nearly one-half of caregivers feel they now have a closer personal relationship with the person to whom they provide care (46 percent)
- More than four in 10 feel they now live more "in the moment" than they did before (44 percent)

When asked how they have been changed by their caregiving experience, 67 percent are more grateful, 60 percent are more accepting, 56 percent are more patient and 51 percent are more assertive.

Emotional stress appeared as one of the prevalent negative feelings associated with caregiving. In fact, 61 percent of caregivers reported feeling highly stressed. Forty percent indicated feelings of guilt that they were not doing more to help their loved one and 39 percent reported anger with themselves for becoming frustrated with their loved one.

When looking at the initial signs of the disease, the study found that nine of 10 caregivers observed events and situations that led them to believe their loved one probably had Alzheimer's or dementia. Only three in 10 say a doctor's examination or questioning was one of the events that initially contributed to their thought that Alzheimer's or dementia was present (31 percent).

"I think that it's revealing that 70 percent of family caregivers recognized the symptoms of Alzheimer's on their own, without a doctor's questioning," says Gail Hunt, CEO and president of the National Alliance for Caregiving. "This shows me that the public is beginning to understand the signs and symptoms of Alzheimer's. Primary care physicians may need more education to help in screening older patients."

The study looked at the care recipients' condition, diagnosis of the illness, actions taken and information sources used, the impact of the caregiving situation, profiles of caregivers and background on the caregiving situation. Results found that caregivers' views of their situations were related to two factors: the stage of their loved one's illness and the choice they felt they had in assuming their caregiver role.

The "Caregivers of Individuals with Alzheimer's or Dementia 2011" report is based on a quantitative survey of 1,000 family caregivers, age 18 or older, who provide unpaid care to an individual with Alzheimer's, dementia or age-related mental confusion or forgetfulness. Respondents were screened to ensure their care recipient was at least 40 years old. The on-line questionnaire was fielded from September 14 to September 27, 2010.

To view the full report, visit:  
[www.caregiving.org](http://www.caregiving.org)



# Care Alliance Ireland

The National Network of Voluntary Organisations for Family Carers

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 72 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. A number of statutory groups are associate members.

**To find out more about Care Alliance Ireland, please visit our website:**  
[www.carealliance.ie](http://www.carealliance.ie)

**or contact:**  
**(01) 874 7776**      [info@carealliance.ie](mailto:info@carealliance.ie)

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