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Membership Development Initiative Yields Big Response

Care Alliance Ireland's first formal membership development initiative has resulted in 10 organisations becoming members of Care Alliance Ireland. This brings our membership to well over 80.

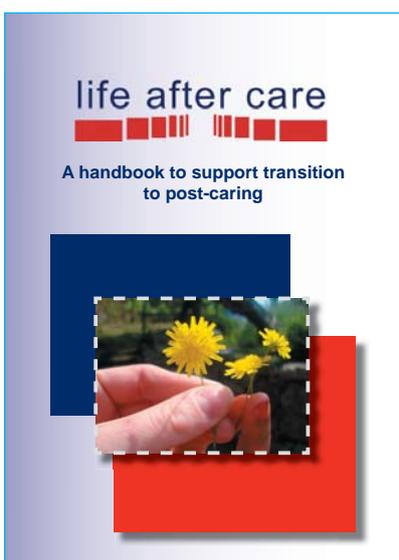
Speaking after the board of directors meeting on Tuesday 15th November, where membership applications were considered and formally approved, Colum Conway, Chair of Care Alliance said:

"The response to this initiative, from some of Ireland's leading non-governmental organisations, reflects the value they place on collaboration and alliances and the role they see Care Alliance Ireland plays in building cohesion and delivering positive outcomes in the Family Carer Sector.

On behalf of the board of Care Alliance Ireland, we look forward to engaging with our new members and in deepening the connections our members and other stakeholders make in the interests of Ireland's Family Carers."

The newest members of the Alliance are:

- Barnardo's
- Special Olympics Ireland
- St Andrews' Resource Centre
- Ability West
- Sunbeam House Services
- Clarecare
- St Aidan's Day Centre (Gorey)
- Plearaca Teo
- Rosses CDP
- Co. Roscommon Disability Support Group



Care Alliance Ireland has recently published a guide for Former Carers:

Life After Care - A handbook to support transition to post-caring

You can download the handbook from www.carealliance.ie or email info@carealliance.ie to request hard copies

Turn to page 2 for more information

Care Alliance Ireland publishes guide for Former Carers

Life After Care - A handbook to support transition to post-caring is a result of an EU project on former carers. The project has also funded an Overview Report on Former Carers in the EU, some country specific primary research on former carers, and a website www.lifeaftercare.eu

The handbook has been reproduced in three other EU countries, namely Italy, Greece and the UK, with modifications made for each country.

Throughout Europe, those whose caring role has come to an end face many challenges. We know that after caring ends many carers' health and wellbeing deteriorate. Recent research in this area has identified three stages of life after care: the loss of the caring world; living in loss; and moving on.

There are various opportunities for health and social care professionals, as well as family and friends, to reach out and offer support to former carers. A timely visit, a meal delivered, a kind letter or even a text, all can make a difference but need to be more than once-off. Ongoing support to former carers to engage in their new world is important.

The 2006-2016 National Partnership Agreement specifically identifies the need to give support to former carers. 'Consideration will also be given to enhancing economic and social inclusion supports to people whose caring responsibilities have concluded'. We hope this publication goes some small way towards this objective.

You can view and download the handbook at www.carealliance.ie/publications

Hard copies are available free of charge on request by email: info@carealliance.ie

Student Nurses from Waterford Institute of Technology Volunteer



Student nurses from WIT volunteered to do health screening for family carers in The Carers Association offices in Waterford. Their volunteering included blood pressure monitoring, blood glucose checks, listening and responding to general health queries from carers in areas of manual handling, activities of living, as well as coping strategies when caring for a loved one at home.

Pictured: Cathy Condon, Siobhan Conroy, Nuncie Murphy (Manager, Carer's Association, Waterford), Ceire Byrne, Dr Paula Lane (Lecturer, WIT, and board member Care Alliance Ireland), and Stephanie Hayes.

Irish Red Cross '2011 Carer of the Year' announced

Cork native Mary Brady was recently awarded the Irish Red Cross '2011 Carer of the Year' award for providing 40 years of full-time care for five of her six children.

Mrs Brady was nominated for the award by her neighbour Noreen O'Neill. Ms O'Neill described her neighbour as "an inspiration to all our community" saying that Mary is "always smiling and laughing and does lots of community work".

The Irish Red Cross Carer of The Year Award is an annual award open to all carers in Ireland.



Carer of the Year recipient, Mary Brady, Cork, with her husband and three sons

The award acknowledges the dedication of informal carers at home and in the community who provide an essential service to the vulnerable and display true humanitarian values.

On accepting her award Mrs Brady thanked her friends, neighbours, and the children that she cares for in particular saying "thank you Sean, Catherine, Evelyn, James and Thomas for being the unique people that you are. You have brought so much love and joy to us and made life-long caring so rewarding for your carers".

The Irish Red Cross publishes a Helping You to Care Handbook and provides training for Carers throughout the country. The 8 week course consists of modules such as mobility, adapting the home, and home hygiene. Both the handbook and the course are designed to give the carer the knowledge and skills they need to ensure that the person being cared for achieves the best quality of life. Anyone interested in the Carer Training course or handbook should contact the Irish Red Cross on (01) 642 4600 or visit www.redcross.ie

Irish Hospice Foundation Launches New E-Learning Course

The E Learning website allows subscribers to learn about best practice in bereavement support from recognised professionals in the field, and from the comfort of their home or workplace. All you need is a computer with good internet access.

The first course the E Learning website is offering is Lost For Words – an introductory training course on providing basic support to people who are bereaved. It is aimed at the general public and professionals who wish to learn more about the grieving process and how to provide effective support. It is particularly suitable and cost effective for organisations who wish to train staff in best practice bereavement support. The course is interactive and easy to use and participants receive a certificate of completion when they have finished.

To sign up for the course, go to: <http://elearningbook.hospice-foundation.ie>

If you would like to know more about the E Learning website and the Lost For Words course please contact Breffni Mc Guinness at (01) 673 0064 or breffni.mcguinness@hospice-foundation.ie

Young Carers Seminar Report Now Available

On 19th September, Care Alliance Ireland and Crosscare Carer Support Programme co-facilitated a seminar entitled 'Young Carers Support Initiative' in the Carmichael Centre. The report of the seminar is now available at www.carealliance.ie/publications

The Seminar was aimed at those who work with young people and their families in a range of settings with a view to gaining:

- A better understanding of issues facing young carers
- Connection with leading practitioners in this emerging area
- Enhanced collaboration between organisations
- Movement to set up and develop additional local young carer support projects

In attendance on the day were 37 people representing 24 agencies, the majority based in Dublin. A comprehensive seminar pack was given to each participant, included in it were various research and practice resources to support those interested in developing support services for young carers, together with copies of the presentations made by the various speakers.

The following links, which were presented at the seminar, may be of interest:

Young carers matter too: <http://www.youtube.com/watch?v=aR7Bk5VC1pc>

Young Carers Guardian Angels: <http://www.youtube.com/watch?v=-riqTuTS-mw>

Young Carers and school: <http://www.youtube.com/watch?v=7oHAvInYXDM&feature=related>

Young Carers festival 2011: <http://www.youtube.com/watch?v=S-7bqodzkdg>

Poems by the Young Carers Revolution: http://www.youtube.com/watch?v=7r_aRq90FY8

Stroke Survivors and Carers Campaign for Access to Rehabilitation Services

The Irish Heart Foundation held a stroke 'lobby day' in Leinster House on 10th November. About 70 stroke survivors and carers travelled to Dáil Eireann from every corner of the country to talk about their issues, mainly in relation to access to rehabilitation services, with their local representatives. The Irish Heart Foundation also appraised them of the national picture.

Some 50 TDs and Senators, including the Minister for Disability and Older People Kathleen Lynch, attended on the day.

The IHF would like to thank everyone who attended, especially those who travelled long distances. This lobby day will help to raise the issue of stroke rehabilitation within the corridors of power.



Dates for Your Diary

18 January 2012

Conference 2012 Developing a National Dementia Strategy

Trinity College Dublin and NUI Galway will host a conference on 18th January in the Science Gallery, Trinity College.

Findings from a new Irish research report on dementia will be presented, as well as international speakers. The conference will be of interest to policy makers, practitioners, researchers, advocates, service planners and providers, and all those living with dementia or caring for someone who is.

More information from www.socialwork-socialpolicy.tcd.ie/livingwithdementia or call (01) 896 2442

Trinity College Dublin (LiD) and NUI Galway (ICSG) present:



Conference 2012 Developing a National Dementia Strategy

Minister for Health, Dr James Reilly will open this conference at which findings from a new Irish report, based on an extensive research review on dementia, commissioned by the government will be presented. International guest speakers will include experts from Australia, France, Norway and the UK each of whom have played a critical role in the development of their respective National Dementia Strategies

The conference will address critical questions including:

- What are the current and future projected prevalence rates of dementia in Ireland?
- What are the main economic costs of care?
- What type of health and social care services are available to people with Alzheimer's disease and related dementias in Ireland?
- What lessons can Ireland learn from other countries now well advanced in the development and implementation of their National Dementia Strategies?

This conference will be of interest to policy makers, practitioners, researchers, advocates, service planners, service providers and all those living with Alzheimer's disease or the related dementias or caring for a relative diagnosed.

18th January 2012 - Science Gallery, Trinity College Dublin
Information and Bookings see: www.socialwork-socialpolicy.tcd.ie/livingwithdementia

Or Email: forsytc@tcd.ie/Phone: 01 8962442

TRINITY COLLEGE DUBLIN
COLAISTE NA TRIONOIDE, BAILE ÁTHA CLATH

living
with
dementia

NUI Galway
OÉ Gaillimh

ICSG
Irish Centre for Social Gerontology

DSIDC
Dementia Support and Information Centre

ATLANTIC
Philanthropies

16 January 2012

The next **Family Carers Research Group** meeting will take place on Monday 16th January from 10.30am - 12.00 in the Carmichael Centre, Dublin 7.

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

New Directors for Care Alliance Ireland

We are delighted to announce that, following a recruitment process through Boardmatch Ireland, Care Alliance Ireland has two new directors.

Dermot Maguire is currently General Manager, Human Resources at VHI Healthcare. Dermot has over 20 years experience in healthcare insurance in Ireland. Dermot is involved in all aspects of HR and particularly interested in performance management, employee development, coaching, employment law, and conflict resolution. Dermot is a graduate of the National College of Ireland (Management and Industrial Relations). He subsequently completed postgraduate qualifications with an MA in Industrial Relations from Keele University in the UK and a Master of Business Studies from Dublin City University. His professional qualifications include Fellow of the Chartered Institute of Personnel and Development (FCIPD). He has lectured in Human Resources on third-level courses at a number of Dublin universities.



Kevin O'Boyle qualified as a Chartered Accountant in London in 1976 and worked with members of the top four international accountancy firms in the UK and Ireland. Since 1988, he has been self-employed and has worked as a coach, mentor, consultant and accountant. He has been involved in a number of successful start-up businesses in Ireland and abroad and currently is a partner within a specialist unit of KSi Faulkner Orr, Accountants and Business Consultants, based in Dublin. In his roles as coach and mentor, Kevin has worked with executives, management groups and individuals within organisations, helping them to achieve their potential. He has worked in Ireland and abroad with a wide variety of organisations, from owner-managed businesses to multi-nationals. He has acted as 'speaking partner' to senior executives, over periods of years, in dissecting and analysing complex business issues and communicating action plans within their organisations. Through this involvement with people in organisations he has developed a strong interest in values-driven performance at all levels of society and business. Kevin is also a Director of NCBI and a number of commercial companies.



Organisations Encouraged to Sign Up to Fundraising Principles



by Sheila Nordon – Executive Director ICTR

Speaking at ICTR's Annual Conference *Whither or Wither Charities* on 10th November, Minister for Justice Alan Shatter outlined his approach to making progress on charities regulation and also expressed his disappointment at the low level of sign-up by charities to the **Guiding Principles for Fundraising** despite considerable investment by the state and the fact that the Principles are considered to be an integral part of the regulation process.

The Minister made the point that in the current economic climate it is not realistic to fully implement the Charities Act 2009 and therefore we need to be pragmatic and revisit the principles behind the Act. He is looking at what can be done to protect the sector, prevent abuse and maintain public confidence.

The Minister then challenged the sector to play its part by signing up to the Guiding Principles for Fundraising. He views involvement with the Fundraising Principles as crucial to the development of a better governed and more transparent charities sector and strongly challenged the sector to step up to the mark. The full text of the Minister's speech can be viewed at:

<http://www.justice.ie/en/JELR/Pages/SP11000216>

What does your organisation need to do to meet the requirements for signing up to the Fundraising Principles?

1. The Board or governing body of your Charity needs to formally commit to complying with the Principles and this should be noted in the minutes of the meeting. On the sign up form you will be asked to indicate that the commitment has been formally made and the date of the meeting at which the decision was recorded.
2. You should indicate in an accessible position on the website (i.e. not hidden away) that your charity is committed to compliance with the Statement of Guiding Principles for Fundraising.
3. You must have a Donor's Charter and complaints procedure easily available to the public – again this would normally be on your website (possibly on the fundraising page) and you should really give a named individual as the contact person for feedback/complaints.
4. Use the Checklist - <http://www.ictr.ie/files/Compliance%20Checklist.pdf> - to ensure that you have got everything in place before signing up.
5. Once you are satisfied that you are ready then sign up on our website at <http://www.ictr.ie/civicrm/profile/create?reset=1&gid=23>

NOTE: That there are sample templates for all the documents required on the website at <http://www.ictr.ie/content/list-resources-support-implementation-statement-guiding-principles-fundraising>

If you have any additional questions please email us at ictr@ictr.ie and we'll help you in any way that we can. Those that have already signed up have found the resource materials to be a great help in minimising the work you need to do, so get started today!

Average Processing Time for Carers Allowance Now at 14 Weeks - Minister

In response to a question from Patrick O'Donovan TD, the Minister for Social Protection Joan Burton stated that the average time taken to award a claim for carer's allowance in the first nine months of 2011 was 14 weeks. A total of 12,657 applications were made in this period and 10,499 were processed. There are currently 7,992 awaiting a decision. There are 51,659 carer's allowance claims in payment.

A major service delivery modernisation project is still underway to improve the efficiency of administration of the carer's allowance scheme which will provide a quicker and more responsive service to the customer. The first tranche of new carer's allowance claims began to be processed under the new system in August 2011.

However, the Minister pointed out that individual claims may still take some time to process. In determining entitlement to the allowance there are, in certain cases, unavoidable time lags involved in making the necessary investigations and enquiries to enable accurate decisions to be made. Delays can also arise if people applying for the allowance are not in a position to supply all the necessary information in support of their claim.

51,659 carers
currently
receive carer's
allowance

Figures from the Social Welfare Appeals Office show that, in 2010, the average processing time for carer's allowance appeals dealt with by way of summary decision was 26.9 weeks, while a case which required an oral hearing took an average of 47.3 weeks. A considerable period of time is added to the process when an oral hearing is required because of the logistics involved in this process.

No Timeframe Offered to Publish Carers Strategy

The following is a written response from Minister Joan Burton to a Dáil question about a National Carers Strategy from Luke Flanagan TD:

The Government is committed in the Programme for Government to developing a carers' strategy. It will consider how best to progress the development of the strategy, taking into account the prevailing economic realities and the work that was carried out previously.

The Department of the Taoiseach chaired an interdepartmental group in 2008 which undertook work to develop a National Carers' Strategy. The Departments of Finance, Enterprise, Trade and Employment, Health and Children, and Social and Family Affairs, as well as the Health Services Executive (HSE) and FÁS were represented on the group.

As my Department is responsible for providing income supports for carers, it will of course have a role in developing and implementing a strategy. However many of the issues of most concern to carers are the responsibility of other Departments, in particular the Department of Health.

The strategy will have to be developed within existing available resources. In developing and implementing the strategy, the Government will take account of our IMF and EU commitments, as well the outcomes of the comprehensive review of expenditure currently being undertaken by each Department.

Irish Examiner - Inspirational Mary takes carer of the year accolade for 'exceptional' work - 8th November

<http://www.examiner.ie/ireland/inspirational-mary-takes-carer-of-the-year-accolade-for-exceptional-work-173194.html#ixzz1dgpvuZwr>

Irish Independent - RTE's top stars 'must take the pain' says Marty Whelan at Carer Award - 22nd November

<http://www.independent.ie/national-news/rtes-top-stars-must-take-the-pain-says-marty-whelan-2941130.html>

Irish Independent - Why care for our loved ones could use a man's touch - 17th October

<http://www.independent.ie/health/health-news/why-care-for-our-loved-ones-could-use-a-mans-touch-2907787.html>

The Journal.ie - Social Welfare could be cut by up to 1bn - 12th October

<http://www.thejournal.ie/social-welfare-could-be-cut-by-up-to-e1bn-251727-Oct2011/>

Dublin People - Family's Budget Cut fears - 7th November

<http://www.southsidepeople.ie/article.php?id=536>

Irish Examiner - All of a sudden you are dealing with a stranger - 18th October

<http://www.irishexaminer.com/ireland/kfqlkfauqlq/rss2/>

Irish Examiner - Carers ask for protection and support in upcoming budget - 12th October

<http://www.examiner.ie/breakingnews/ireland/carers-ask-for-protection-and-support-in-upcoming-budget-524022.html>

Irish Examiner – Research: 10,000 are victims of Elder Abuse - 12th October

<http://www.examiner.ie/breakingnews/ireland/10000-are-victims-of-elder-abuse--research-524007.html>

Irish Independent - Huge loss for former carers - 17th October

<http://www.independent.ie/health/huge-loss-for-former-carers-2907785.html>

Irish Independent - Slow Progress on Palliative Care - 8th October

<http://www.independent.ie/breaking-news/world-news/slow-progress-on-palliative-care-2900044.html>

RTE News - Carers call on Government to protect allowance - 12th October

<http://www.rte.ie/news/2011/1012/carers.html>

Irish Times - President 'limited to shining light on issues' 18th October

<http://www.irishtimes.com/newspaper/ireland/2011/1018/1224305995520.html>

MS Carer of the Year Announced



MS Ireland was delighted to award Vanessa O'Donovan from Cork the prestigious MS Carer of the Year award at our national convention in September. Vanessa cares for her husband Bernard who has been living with MS for over 20 years. Bernard and Vanessa met 16 years ago when Bernard stayed at the MS Care Centre in Rathgar, Dublin. Vanessa worked at the centre as a care assistant. Seven months after meeting they got engaged and moved to Cork.

Vanessa says she is humbled to have received this Award: "It is difficult to put into words what this Award means to me. It represents so much to us – the journey Bernard and I have been on, and the journey so many others have experienced. I would love to be able to share this Award with all of those families and all at MS Ireland who have been such a huge support to Bernard and me over the years." Vanessa continued: "I firmly believe that where there is love, there is no such thing as sacrifice. My husband is an amazing man and it is a privilege to share my life with him. I wouldn't have it any other way."

Allen O'Connor, Chairperson, MS Ireland commented: "On behalf of MS Ireland, I would like to congratulate Vanessa on this wonderful achievement. Vanessa is a remarkable woman who provides an outstanding level of care for her husband. A very close and loving couple, Vanessa doesn't see caring for Bernard as something she has to do but rather as something she wants to do. I can't think of anyone more deserving of this Award."

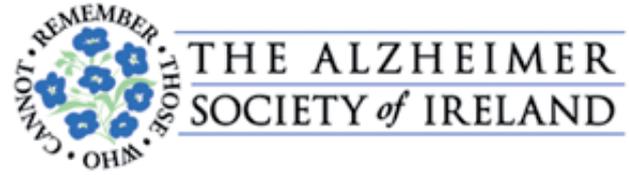
*"where there is love,
there is no such
thing as sacrifice"*

The awards ceremony took place at the MS Ireland's national convention in the Burlington Hotel, Dublin. The theme of this year's conference was MSLiving which included lectures, seminars, exhibitions and social opportunities providing information on research developments, practical ways to meet the challenges MS may bring, the products and services available to the MS community and a chance to meet other people living with MS. MS Ireland's patron and outgoing President of Ireland, Mary McAleese officially opened the event, which also marked MS Ireland's 50th anniversary.

Six seminars explored the practical aspects of living with MS: Benefits and Entitlements; Relationships, Sex and Intimacy; Emotions and Mindfulness; Fatigue Management; Young People and MS; Diet and Nutrition, with four exciting lectures delivered by national and international experts focussed on: Stem Cell Therapy; Vitamin D; New Emerging Therapies; Cognition and MS.

Copies of all the presentations and images from the conference are available on the website at www.ms-society.ie

Dementia diagnoses to rise sharply



CARERS of people with dementia are at crisis point and waiting lists for services have increased by 20% in the last year, The Alzheimer Society of Ireland has warned.

Launching its pre-budget submission on 18th October, the Alzheimer Society of Ireland said demographics for dementia are set to soar — yet Ireland has no cohesive plan to deal with the economic costs and health needs of the population living with the condition.

In the next 15 years alone, the number of people living with dementia will increase from 44,000 today to 70,115 in 2026.

Additionally, people under 65 years with early-onset dementia do not qualify for any HSE supports as they do not fall under the category for older people or for mental health services.

A spokesman for the society said this gap in services needed to be urgently addressed as part of a wider national dementia strategy, to which the government committed in its programme for government.

The society's head, Maurice O'Connell, said while the challenges of the current economic situation are recognised, the charity is "acutely aware" of the increasing numbers of people affected by dementia, their growing care needs and the cost to the State.

"We must act now to plan for the future. I firmly believe that the argument for our pre-budget demands for 2012 is not just a moral one but importantly an economic one too," he said.

"We recognise the fiscal difficulties that the government is facing and we wish to take a flexible response to working with policy makers regarding funding structures, service delivery and to ensuring the strategy is delivered successfully."

The society has now launched a campaign to encourage elected officials to drive the Programme for Government commitment through the roll out of an "Alzheimer pledge".

By encouraging elected officials to sign up to the Alzheimer pledge, the society hopes to mobilise further support for the National Dementia Strategy through the development of a Friends of Dementia cross-party group.

Consultant psychiatrist Dr Henry O'Connell who specialises in the psychiatry of later life, maintains that there are no clear pathways of referral for assessment, diagnosis and management of the disorder.

"The lack of a coherent and functioning dementia strategy in Ireland has a direct impact on people with dementia and their families and carers, who have no clear pathways for treatment of what is a profoundly life-changing and ultimately terminal disease," he said.

To register your support for a National Dementia Strategy log on to www.alzheimer.ie

This appeared in the printed version of the Irish Examiner Tuesday 18 October 2011
Read more: <http://www.irishexaminer.com/ireland/kfqlkfauqlid/rss2/#ixzz1cdDBY7BQ>

Irish Cancer Society Community Health Education Programme



According to the European Code Against Cancer, there are a number of lifestyle choices we can all make to reduce our risk of getting cancer by as much as 50%. These include:

- v Not smoking
- v Eating a healthy diet
- v Being a healthy weight
- v Limiting our intake of alcohol
- v Being smart in the sun

Early detection of cancer is also very important, as the earlier cancer is found and treated the greater your chance of survival.

In an effort to get these important messages out to communities across Ireland the Irish Cancer Society has developed its **Community Health Education Programme (CHEP)**. The programme trains volunteers to deliver cancer awareness information stands or talks on the following topics:

- v Cancer Smart Lifestyle
- v Smoking and Cancer
- v Skin and Cancer
- v Men and Cancer
- v Women and Cancer

The CHEP story so far

In 2011, the Irish Cancer Society trained 44 CHEP volunteers in the Dublin and Munster areas. To date they have been involved in over 50 cancer awareness talks and information stands. With the support of CHEP volunteers we hope to spread the positive side of the cancer story – that we can reduce our risk by making healthy lifestyle choices, and early detection is important as it gives you a better chance of surviving a cancer diagnosis.

Plans for 2012

The Society plans to expand the programme in 2012 to include two training events. The details are as follows:

- v Western Region: April
- v Dublin / North East: late Autumn

What do you need to become a CHEP volunteer?

If you are passionate about getting positive messages out to adults from all backgrounds and empowering them to make changes in their lives, this programme could be for you. You don't need to have medical training to become a CHEP volunteer, however a number of qualities are important. These include:

- Being able to either deliver a talk or provide information at a stand and stick to Irish Cancer Society messages
- Having good communication skills is a help but training will be given in this area so a willingness to learn is vital
- Reliability and being able to organise and keep records
- Having time available in your schedule to attend events

To host a CHEP event

Our health promotion team are always looking for opportunities to give talks or provide information to communities on how to live a cancer smart lifestyle. If you are interested in hosting an event, particularly in Munster and the Dublin area, we would like to hear from you.

Find out more

To find out more about becoming a CHEP volunteer or organising an event, contact:

Rosemary Scott, CHEP Co-ordinator
Irish Cancer Society
43-45 Northumberland Road, Dublin 4
rscott@irishcancer.ie
(01) 231 0579

Irish Family Carers meet Vice President of the European Commission



On 11th October, a group of Irish Family Carers attended a meeting in Brussels of the European Parliament Interest Group on Carers, which was arranged by Eurocarers. This meeting focused on Carers in the Active and Healthy Ageing Partnership. The group was led by Junette Dolan, Hon. Secretary of Caring for Carers Ireland.

The meeting, hosted by Independent MEP Marian Harkin, featured a keynote presentation from the EU Digital Agenda Commissioner Neelie Kroes, and explored ways in which EU innovation funding can explore new ways of using technology to support the work of carers.

Commissioner Kroes started out by underlining the value of carers to society, as carers provide for quality of life and protect the most vulnerable. They are the “not-so-visible engine powering society’s health and social care machine”. According to the Commissioner, the effective use of information and communications technologies (ICT) in the care sector benefits all those involved, as care recipients can stay in their own home, and remain independent and connected for longer. Commissioner Kroes expressed her hope that those who “care about caring” will engage with this Partnership, as their expertise, enthusiasm and input is vital; the voice of carers should be heard.

Marian Harkin MEP stated that the EU’s ‘Active and Healthy Ageing Innovation Partnership’ is one of the first initiatives that explicitly targets carers. This is an important step forward in recognising the growing number of older people and increasing care needs, and the huge and indispensable contribution of carers. Robert Anderson, President of Eurocarers, stated that the role of carers in the provision of daily care, ensuring independent living, is crucial and carers should play a role in all three pillars of the Partnership – prevention, care and cure, and independent living.

On the invitation of Marian Harkin MEP, Brigid Barron of Caring for Carers Ireland responded to Commissioner Kroes by providing a number of practical examples of the use of ICT in supporting Family Carers. These provided a real flavour of

what is happening and what can happen to improve quality of life and overcome isolation. Brigid underlined the importance of partnerships in this area; and that drivers are needed to progress the uptake and use of supporting ICT.

For more information please contact:
Brigid Barron, Caring for Carers Ireland
www.caringforcarers.ie
(086) 601 1971 or email
bbarron@caringforcarers.ie

For a full report of the meeting, see the Eurocarers website:
<http://www.eurocarers.org/news.php?id=26>



Mary McMahon, CEO Caring for Carers Irl, Neelie Kroes, Vice President of the Commission, Marian Harkin MEP, Brigid Barron, Caring for Carers Ireland

Road Map for European Ageing Research

FUTURAGE
A Road Map *for* Ageing Research

The **FUTURAGE Road Map for European Ageing Research** was formally launched at a conference in the European Parliament in Brussels on 18th October.

FUTURAGE is a two-year project funded by the European Commission to create the definitive road map for ageing research in Europe for the next 10-15 years, based on the widest possible consensus between key stakeholders.

The Road Map has been distilled into seven major priority themes:

- Healthy Ageing for More Life in Years
- Maintaining and Regaining Mental Capacity
- Inclusion and Participation in the Community and in the Labour Market
- Guaranteeing the Quality and Sustainability of Social Protection Systems
- Ageing Well at Home and in Community Environments
- Unequal Ageing and Age-Related Inequalities
- Biogerontology: from Mechanisms to Interventions

It is now available to download at <http://www.futurage.group.shef.ac.uk/road-map.html>

(UK) Not a one way street: Research into older people's experiences of support based on mutuality and reciprocity

Bowers, Mordey, Runnicles, Barker, Thomas and Wilkins, National Development Team for Inclusion, and Lockwood and Catley, Community Catalysts

This paper, published by the Joseph Rowntree Foundation, explores alternative approaches to planning, funding and providing long-term care for older people with high support needs.

It focuses on the ways older people with high support needs take up active roles based on 'mutuality and reciprocity'; provides stories and situations where those involved are giving and receiving support, rather than more traditional services provided by professionals / organisations; and contributes to emerging discussions and developments associated with 'mutuality and reciprocity'.

View the paper at: http://www.jrf.org.uk/sites/files/jrf/supporting-older-people-full_0.pdf

(UK) Older carers and involvement in research: why, what and when?

This briefing paper describes the views, experiences, motivations and plans of six older carers who decided to stay involved in research following their participation in a one year project at the University of Nottingham funded by Macmillan Cancer Support.

The project was set up to study the experiences and main support needs of older carers looking after someone with advanced cancer and was designed to also encourage and facilitate the active involvement of carers in the research process.

You can download the report from: <http://www.nottingham.ac.uk/nmp/documents/srcc-older-carers-and-involvement-in-research.pdf>

The role of telecare in supporting carers of older people (ROI/NI)

The proportion of over 65s on the island of Ireland is set to reach 29% of the population by 2041 (McGill, 2010). With the growing numbers of older people, new and innovative ways to help and support their carers are required. In order to explore the potential contribution of telecare in helping carers of older people, CARDI funded the development of a research network in 2009.

It was led by Brigid Barron of Caring for Carers Ireland, to assess the impact of telecare on carers of older people in terms of reducing stress and increasing quality of life. This research brief, published in September 2011, is based on the findings of the network as well as CARDI's own research in this area.

Telecare can be defined as the remote or enhanced delivery of health and social services to people in their own home by means of telecommunications and computerised systems. Telecare usually refers to equipment and detectors that provide continuous, automatic and remote monitoring of care needs, emergencies and lifestyle changes. It uses information and communication technology (ICT) to trigger human responses, or shut down equipment to prevent hazards. As well as helping older people to live in their own homes for longer, telecare has the potential to support and help family carers.

Key findings

- There are 160,917 carers in ROI, of whom 11% are aged 65 or over (Central Statistics Office, 2006). In NI, 185,066 people provide unpaid care, 12% of whom are aged 65 or over (NISRA, 2001).
- In ROI, half of 50-64 year olds with surviving parents provide help with household tasks to their parents (on average for 10 hours per week).



Over one-quarter provide their parents with personal care, on average for 18 hours per week (TILDA, 2011).

- 70% of carers in NI experience stress as a result of their caring responsibilities (DHSS&PS, 2006)
- In NI, 18% of carers feel they are always under stress, while 21% are stressed very often and 30% quite often (DHSS&PS, 2006). In ROI, two in every five carers report experiencing stress or nervous tension in the past year (Care Alliance Ireland, 2008).
- 1.6 million people across the UK use monitored personal alarms and between 60-70,000 use the devices in ROI (Cullen et al., 2009).
- Evidence from Scotland shows that almost three quarters of carers (74%) felt that telecare equipment had reduced their stress levels (Beale et al., 2010).

You can download the full report at:

[http://www.cardi.ie/userfiles/
Telecare%20\(Briefing%20Paper\)%20
Web.pdf](http://www.cardi.ie/userfiles/Telecare%20(Briefing%20Paper)%20Web.pdf)

Australia: Report on 2.6 Million Australian Family Carers

The Australian government recently released 2009 data on the country's 2.6 million family carers (defined as somebody aged 15 or older providing ongoing care for six months or more). Twenty-nine percent of carers identified themselves as the primary carer, defined as the person providing the most assistance, and women were about twice as likely to fill this role (5% of women, compared to 2% for men). One-third of carers reported having a disability themselves, as compared to 16% of non-carers who reported having a disability. Forty percent of primary carers were employed as compared to 66% of non-carers, and only nine percent of primary carers who cared for 40 hours a week were also able to work full time. Carers aged 15 years and older (49%) were more likely than non-carers (37%) to live in a household with income in the bottom two income quintiles, and 62% of primary carers were in the two bottom income quintiles.

In terms of duration, 12% of primary carers had been caring for less than two years, 28% had been caring for two to four years, and 6% had been caring for 25 years or more. Of the 98,300 primary carers who reported a need for respite care, only 36% had ever used it. Forty percent of primary carers providing 40 hours or more of care (per week) were likely to frequently feel worried or depressed, as compared to 27% for caregivers who provide 20 hours or less of care. Twenty-five percent of primary carers reported losing touch with their existing friends, while 61% of carers with a spouse or partner (who isn't the care recipient) reported that the relationship had been affected.

Of primary carers who reported a need for respite care, only 36% had ever used it

For more information, visit: <http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4436.0Main+Features12009?OpenDocument>

(UK) Royal College of Nursing Suggests Extending Hospital Hours So Carers Can Play Bigger Role

A proposal by the Royal College of Nursing (RCN) to extend hospital visiting hours to enable carers to become more involved in a patient's care created controversy over the roles of family carers and hospital staff. While the head of the RCN said he didn't want carers doing nurses' tasks, he did think that carers could assist with things like making mealtimes less stressful for patients. The chief executive of the Patients Association suggested that "it is just the tip of the iceberg," and said patient care, including feeding and toileting, should be carried out by nurses.

A critique of the proposal by a BBC journalist suggested that visitors can be disturbing for other patients on the ward and that lengthening visiting hours would exacerbate the problem. She also suggests that a stronger focus on providing care for people without acute medical problems outside of the hospital would do more to address the current burden on nursing staff for older people who shouldn't be in acute care hospital beds.

For more information, visit: <http://www.bbc.co.uk/news/health-15052636>

Stressed and strapped: Carers for friends, relatives suffer emotional and financial strain (US)

Source: Hoffman, G.J. and Mendez-Luck, C.A. (2011). "Stressed and Strapped: Caregivers in California." UCLA Center for Health Policy Research.

Family members or friends caring for aging or disabled individuals in California are under both financial and emotional strain and are likely to face even greater burdens, given recent cuts in state support for programmes and services that support in-home care, write the authors of a new policy brief by the UCLA Center for Health Policy Research.

The study looked at California's estimated 6 million-plus informal carers of all ages and found higher levels of serious psychological distress and negative health behaviours, such as smoking, compared with the general population. Of particular concern are an estimated 2.6 million carers between the ages of 45 and 64 who may be setting themselves up for an unhealthy future due to higher rates of poor health behaviours, compared with both non-carers in the same age range and older carers.

"This is the 'sandwich generation,' the group of people struggling to meet the needs of both growing children and ageing parents, often alone and while holding down full-time jobs," said Geoffrey Hoffman, the brief's lead author.

"We may be seeing an association between caring and stress, where carers are both more likely to be seriously depressed and to exhibit certain health behaviours that put them at risk."

Among the findings:

More than 1 million carers report moderate or serious distress levels, with almost one-third reporting that their emotions interfere a lot with their household chores (29.9 percent) or their social lives (32.9 percent).

Compared with both older carers and non-carers of the same age, middle-aged carers are more likely to binge drink (25.5 percent), smoke (15.9 percent) and/or be obese (30.1 percent).

Nearly one-third (29 percent) of middle-aged carers are single, divorced or widowed, and more than two-thirds (67.1 percent) hold down full- or part-time jobs. Nearly one-quarter (22.5 percent) are low-income.

Approximately one-third of carers who live with care recipients spend an average of 36 hours on caring — almost as much as a full-time job.

Read more at: <http://www.healthpolicy.ucla.edu/NewsReleaseDetails.aspx?id=90>

Research Examines Divorce And Genetic Ties In Making Caring Decisions (US)

Several professors at the University of Missouri are researching the effects of divorce on decision making around caring. Dr. Teresa Cooney and Dr. Christine Proulx are co-investigators on an exploratory study that will look at women who are carers for their ex-husbands and the unique challenges these women face. Dr. Lawrence Ganong is studying decision-making related to divorce, remarriage, and care for older relatives. In a study with Dr. Marilyn Coleman, study participants were presented with hypothetical caring scenarios, and while the majority of participants said biological factors are relevant, "they do not automatically require adult children to help older relatives." Relationship quality, a history of mutual assistance, and the availability of resources all influence caring decisions.

For more information, visit:

<http://munews.missouri.edu/news-releases/2011/1018-relationships-more-important-than-genetic-ties-when-deciding-who-cares-for-aging-family-members-mu-researchers-say/>

St Christopher's Caring for Carers DVD

Review by Jennifer Jackson

This DVD was created by St Christopher's Hospice (London) Complementary Therapy Team as part of their 'A Complement to Carers' project. The DVD is divided into two sections. The first section is a short film giving a background to the Complementary Therapy Programme and includes interviews with carers, complementary therapists and also the Director of Supportive Care in St Christopher's. It is useful from an organisation point of view to hear how the project began and how effective it has been.

The second section includes the self help guides specifically aimed at family carers including relaxation and massage techniques and also details of financial and support services. The relaxation and massage techniques are used in both group and one to one settings. While the details of the financial and support services are all UK-based, the Welfare Officer does talk generally about the advantages of being recognised by the state as a carer.

This DVD could be a very useful tool for complementary therapists or support group facilitators. But it also could be used in the home by a family carer to relax. As the DVD self help section is divided into 10 minute chapters, it could become something that a family carer could use on a daily basis to help to alleviate stress.



© St Christopher's Hospice

Available to watch at:

<http://www.stchristophers.org.uk/media/video/caring-for-carers-a-self-help-dvd>

Online resources for working with Family Carers (US-centric)

The **Rosalynn Carter Institute for Caregiving** (US) has identified several characteristics that appear to be shared by effective programmes that support carers. These factors have been associated with the most positive outcomes for family carers and should be built into efforts to support family carers:

http://www.rosalynncarter.org/what_makes_caregiver_programs_effective/

Fostering changes in individual and organisational practice and culture, **Transitions in Care–Quality Improvement Collaborative** (US) works to create better co-ordination and communication between health care organisations that share patients, and better integration of family carers in planning and implementing transition care plans. By building effective partnerships that recognise and support family carers and by developing better tools for critical tasks such as medication management, the initiative is helping providers avoid problems that undermine patient care and too often lead to preventable hospital readmissions.

<http://www.uhfnyc.org/initiatives/family-caregiving/TC-QulC>

Next Step in Care (US) provides easy-to-use guides to help family carers and health care providers work closely together to plan and implement safe and smooth transitions for chronically or seriously ill patients.

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

30 days of Caregiving - a message from across the Atlantic

In honour of America's National Family Caregiver Month in November, the Family Caregiver Alliance (USA) decided to feature a different perspective each day for the entire month this year. **30 days, 30 stories**. Some of the topics are practical with a focus on care, some are about policy and advocacy and some are personal experiences. They asked colleagues around the country to tell them about their latest programmes of note to caring, and ended on 30th November.

Day one, first story: So what does Family Caregiver Alliance know after 30 years of supporting family caregivers? While it might be tempting to give all the statistics current and future, I will resist. Caregiving is not about the average caregiver, it is a mosaic of narratives threading our country. It is a daughter, struggling to balance work, kids and care for her mom. It is a young wife providing care to her husband forever changed by combat in Iraq. It is neighbours picking up groceries, giving a lift to a medical appointment or stopping in for a cup of coffee for someone who needs some help and connection. It is a husband caring for his wife as she fades away from Alzheimer's disease.

Everyone it seems, has a story. But at the heart of the story is a person and a family and how communities come together to creatively meet the challenge of care. Care is a paradox: independence within an interdependent web of connections that means a person needing help can be in and can be a part of the community. We may need to confront some common notions of "ageing in place" too – maybe re-examine the anchor of the cherished family home, how we view inter-generational living arrangements and acknowledge isolation as a major threat to our health. And we need to be proactive – too often we see families reacting to a crisis when there are usually fewer options to consider because the conversation was too hard or, for most of us, denial is easier than deciding a course of action.

Because we see families – by birth or by choice – we see caring as a family issue. That is, it is never just one narrative – it is a reciprocal relationship between those needing assistance and those providing that assistance. The needs across the family require validation and respect. But too often, the focus is only on the family member who needs assistance while those who support that individual are ignored or worse, considered nuisances because they ask too many questions of professionals.

But we have also learned that not all families have the willingness or the capacity to take on caring for a host of reasons. And not all individuals needing assistance are safe within their families. Complex issues, complex families and no real simple solutions.

"carers are ignored or worse, considered nuisances because they ask too many questions of professionals"

So here is what we have learned: caring is a family issue and a healthy community is one that recognises that care demands may well

span younger and older members of a family. And since every family has a story of caring or will have very soon, communities need to support caregivers. We need to talk about caring and continue to talk about caring until it becomes a normalised activity in our communities.

What we do know from the statistics is that families, friends and communities will be facing a greater challenge in the future as the need for care increases. We need to act now with planning in our personal lives and with raising the public awareness in our communities and nationally about the importance of informal caregivers and the need to recognise and support their efforts.

**Courtesy of Kathleen Kelly, Family Caregiver Alliance (USA), with permission.*

You can read the 30 stories at:
<http://blog.caregiver.org/?p=319>
Day 23 features an article by Liam O'Sullivan of Care Alliance Ireland



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 82 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.

Click here to download a Membership Application form:
<http://www.carealliance.ie/membership>

Click here to read about the 10 reasons to join Care Alliance Ireland:
<http://www.carealliance.ie/userfiles/file/MembershipFlyer2011.pdf>

To find out more about Care Alliance Ireland, please visit our website:
www.carealliance.ie

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