

Care Alliance Ireland Exchange Spring 2013 Issue 40

Key Organisations Join Care Alliance Ireland

We are delighted that three key organisations have decided to join Care Alliance Ireland in recent months; namely the National Council for the Blind of Ireland (NCBI), RehabCare and the Irish Wheelchair Association (IWA).

Speaking on the occasion of board approval of these applications, Chairperson Kevin O'Boyle, said:

"Having three such strong and influential organisations as members is a wonderful opportunity for Care Alliance Ireland to increase its reach and impact in its work of guiding support for Family Carers."

We are currently working closely with the IWA and RebahCare around influencing the tendering process for home care provision. We also note with interest the recent NCBI report on the Cost of Sight Loss, and in particular the attempt to quantify in financial terms the value of informal/family support therein.

(See Member Profiles on pages 15 and 16)

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National Carers Week 2013 New Partner and New Developments

Now in its seventh year, and with support from EBS, this year's National Carers Week is shaping up to be the best yet. The Parkinson's Association has announced it will become a partner in National Carers Week for 2013. Speaking on the decision, Keith Adams, CEO, said:

carers week

"For us this is a superb fit – we were seeking out ways to better support families of those affected by Parkinson's, and in particular Family Carers, and so we are delighted to accept the invitation to join with the other eight national partners."



Thanks to Boardmatch Ireland we recruited a new independent Chairperson for the week, Jimmy McGrath. With a background in engineering and more recently HR, Jimmy has brought a new dimension to the project and we are delighted to have him on board.

One of the new developments for this year is a flier (below), which is being distributed through partners and other channels in advance of the week. An e-zine has also been created and widely disseminated through Facebook and other avenues. It can be read at http://tinyurl.com/c4ea4fk.www.carersweek.ie





National News

European Group Supporting Young Adult Carers to Meet in Dublin

As part of the Together for Young Adult Carers Project (TOYAC), the first face to face meeting will be hosted in Dublin by Care Alliance Ireland. The meeting will take place on May 13th, followed by an invite only round table discussion on May 14th.

Care Alliance Ireland is working with five European organisations on TOYAC, which is a partnership project funded by the European Commission and focused on the development of strategies and services for young and adult carers. Many of these young carers are vulnerable, and have limited opportunities, horizons and aspirations. Because of their caregiving responsibilities, many underperform in school and are at high risk of exclusion from the labour market. On the other hand, it has been demonstrated that caring develops knowledge, understanding, a sense of responsibility, maturity and a range of life, social and care-related skills in children and young adults.

Care Alliance Ireland has undertaken some preliminary investigation into the impact caring has on young adult carers' participation in third level education. Other project partners have taken on detailed investigation in their own countries on other specific aspects of young adult caring. These focus specifically in the area of siblings with disabilities, interventions by condition-specific NGOs, the role of youth services, the possibilities of social networking for supports, and young carers in employment. All partners will make a brief presentation of their findings at this seminar.

For more information see: www.youngadultcarers.eu



Numbers at a Glance

€325:

The reduction in the Respite Care Grant – payable each June.

6,287,510:

The number of hours of care provided each week by informal/Family Carers.

4.062:

The number of people who contacted The Alzheimer Society Helpline in 2012, an 18% increase on 2011.

187,112:

The number of people providing regular unpaid care according to the 2011 Census, an increase of 14% on the 2006 figures.

595,335:

The number of people reported to have a disability according to the 2011 Census, accounting for 13% of the population.

National News

Constitutional Convention votes to support all Family Carers

We welcome the recent vote by the Convention on the Constitution to include all Family Carers, both men and women, under Article 41.2, and to strengthen supports for carers.

Liam O'Sullivan, Executive Director, stated: "I welcome the clear vote of over 80% of the Convention to include carers and strengthen supports for them. Care Alliance Ireland looks forward to the development of the amendment which can be put to the people in a referendum. It is a clear step forward that the Constitutional Convention voted overwhelmingly not just to include carers, but to enshrine better support for them in the Constitution also. Forty per cent of carers are men and their caring role in the home is often forgotten".

Áine Uí Ghiollagáin of member organisation, Cúram, addressed the Convention on Article 41.2. "Cúram sought stronger protections for parents and carers at the Convention. Article 41.2 underpins supports, albeit indirectly, for carers in the tax, social welfare and health systems and is cited in relevant court cases and judgements.

40% of carers are men and their caring role in the home is often forgotten.

Cúram proposed a gender-neutral wording to the Convention which should strengthen support for carers. Poverty continues to be an issue for many carers, both men and women, whose risk of poverty also increases as they age. The need to better support carers was recognised by the All-Party Oireachtas Committee on the Constitution in 2006, but key financial supports such as the Carers' Respite Grant have been cut in Budget 2013."

Submissions and presentations to the Convention can be found on the website www.constitution.ie/Convention.aspx

Appeals to Family Carer Income

Details of appeals regarding applications for Carers Allowance and Domiciliary Care Allowance are now available to view online at

http://www.socialwelfareappeals.ie/pubs/cases/1_family.html

National News

Public Consultation: Review of the Mobility Allowance and Motorised Transport Grant Schemes An Roinn Sláinte DEPARTMENT OF HEALTH-

The Minister for Health, Dr. James Reilly T.D. and the Minister of State for Disability, Equality, Mental Health and Older People, Ms. Kathleen Lynch T.D., appointed a project group on 21 February 2013 to review the Mobility Allowance and Motorised Transport Grant schemes. The purpose of the review is find the most appropriate solution or solutions to address the priority transport needs of those who require supports, which will be fully compliant with equality legislation and can be delivered within available funding.

The review group is independently chaired and includes representatives of people with disabilities, relevant Government Departments, the HSE, the National Disability Authority, the Citizens Information Board, Pobal and other individuals with relevant expertise. It will report to the Government before the end of May.

As part of the review, a public consultation took place. Submissions were accepted until 17 April.

Emer Costello, Irish MEP, calls for Ratification of Domestic Workers Convention



Last week the draft EU decision on the International Labour Organisation's 2011 Convention on Domestic Workers (No.189) was presented by the European Commission in Brussels. Following its publication, Emer Costello called on the Irish Presidency to prioritise the adoption of this decision to ensure that all Member States can ratify the Domestic Workers Convention without further delay.

Ratification would commit signatory states to upholding fair and decent standards for domestic workers by protecting their fundamental labour rights, by preventing abuse and violence and by promoting safeguards for young domestic workers.

http://emercostellomep.newsweaver.com/f5c7aftu25te7gqo80ekzq?email=true&a=1&p=3388997 5&t=21424325

Research Study of Carers of Older People



Caring for Older Relatives: Caregivers' experiences of conflict, stress and coping Over the summer months, the National Centre for the Protection of Older People (NCPOP) at University College Dublin will be undertaking a national survey with a random sample of carers who provide care to older people. This anonymous postal survey aims to examine carers' experiences of conflict, stress and coping. For further information about the study, please contact Dr. Attracta Lafferty, Associate Centre Director, NCPOP by emailing attracta.lafferty@ucd.ie or telephoning on (01) 7166565.

Opportunities to Influence Policy

Call for Submissions on the 'Money Follows the Patient Policy Paper on Hospital Financing'



Deadline - May 3rd.

www.dohc.ie/consultations/open/Money Follows ThePatient/

Opportunity to join Voices4Care

The All Ireland Institute of Hospice and Palliative Care (AIIHPC) launched recruitment to Voices4Care in early March and reports a positive response from people interested in getting involved. Through the new Voices4Care group AIIHPC is committed to having the views of patients and their families at the heart of what they do.



Voices4Care will be a volunteer group made up of:

- patients (service users) receiving palliative care,
- their carers or former carers, and
- people interested in palliative care from the wider community.

AllHPC has produced a short video which gives more information in what Voices4Care will do and what will be involved as a member. Click http://aiihpc.org/policy-practice/42/users-carers-and-communities-forum to find out more.

Dates for Your Diary

Alzheimer Tea Day

9 May 2013 Nationwide www.alzheimer.ie/Get-Involved/Fundraising/Tea-Day.aspx/





Together for Young Adult Carers

13 & 14 May 2013
European meeting, Dublin.
www.youngadultcarers.eu



22 May 2013

Inaugural person-to-person meeting, Dublin

Email: ndo@carealliance.ie



EUROCARERS EUROPEAN ASSOCIATION

Eurocarers Conference

23 May 2013
Eurocarers Conference, Dublin.
www.eurocarers.org/events_agm2013.php

World MS Day

29 May 2013 Nationwide www.ms-society.ie/events/3760



National Carers Week

10 to 16 June 2013 Nationwide www.carersweek.je



Members' News

Alzheimer National Helpline responds to increased demand

The Alzheimer Society of Ireland, ASI, is delighted to confirm it is extending the Alzheimer National Helpline opening hours to meet increasing demand from our service users. In 2012, 4,062 people contacted our service representing an 18% increase on the previous year and a 39% increase on 2010.



From May 1st, the Helpline will open six days a week, Monday to Friday from 10 am to 5 pm and Saturday from 10 am to 4 pm. Our two dedicated Helpline Advisors alongside our trained Helpline volunteers respond to calls and emails from all over Ireland. Many callers have remarked that it is a great reassurance to know that there is someone at the end of the phone when they need to talk.

The Helpline provides practical information and emotional support to people with dementia, their family and friends as well as to people who are concerned about their own or a loved one's cognitive health. The Helpline also works with health and social care professionals. This free and confidential service provides a vital link to ASI's network of dementia-specific specialist supports and services throughout Ireland as well as to a wide range of information and publications.

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To contact us call 1800 341 341 or email helpline@alzheimer.ie.

Testimonials

"It's great to know I can pick up the phone whenever things are getting too much."

Family Carer

"Many thanks for your fast reply and encouraging words."

A person worried about their memory

"This is great; I'll pass all the information to my client and talk it through with them."

Health care professional



Members' News

World MS Day

Multiple Sclerosis Ireland is delighted to be part of National Carers Week 2013. Many people who use our services rely on the support and care of their family to lead healthy and independent lives. We believe that the contribution of carers should be recognised and celebrated. Throughout the country we are organising and supporting events that promote and celebrate the role of carers. As part of our week of activities we will be launching a MS Carers Toolkit. Full of practical advice and information, the toolkit looks at the physical and emotional aspects of caring for someone with MS.



The fifth World MS day takes place on Wednesday the 29th of May. MS Ireland will be joining with MS organisations and groups around the world to raise awareness of MS and the challenges people face. This year's theme is young people with MS. MS Ireland's activities include a young people's Gathering in Dublin on the 11th of May; local information and support events around the country; Oireachtas campaign to highlight severe deficiencies in neurological and neurorehabilitation care; a music auction; and a call for people to raise funds locally by organising a McVitie's Digestive Tea Party in their homes, communities and workplaces. More information at www.ms-society.ie

The Carers Association Latest Newsletter

The Carers Association has published the latest edition of Take Care, its quarterly newsletter.

www.carersireland.com/newsletters recent.php



Members' News

Roscommon Disability Support Group Congratulates Client on her 90th Birthday



Congratulations to Kitty Burke of Roscommon who is a regular visitor to the Roscommon Disability Support group in Derrane. She celebrated her 90th Birthday on 15 February in the Resource Centre.

Providing Supports to People with Disabilities and the Older people of Roscommon

T: 090 66 25852 Email: info@rosdisabilities.ie



Project DAWN

The official launch of Project DAWN took place on 17 April at the newly constructed, purpose-built DALE Centre in Derrane. The project will act as a one-stop-shop for training and business incubation. Its aim is to increase the capacity and potential of people who receive disability and illness payments to participate in the labour market using a case management approach.

Project DAWN is a fully funded programme managed by Pobal and funded by the European Social Fund and the Department of Social Protection.

Practical Resources

10 Tips for Family Caregivers

With links to specific tools

- Seek support from other caregivers. You are not alone!
- Take care of your own health so that you can be strong enough to take care of your loved one
- Accept offers of help and suggest specific things people can do to help you.
- · Learn how to communicate effectively with doctors.
- Caregiving is hard work so take respite breaks often.
- Watch out for signs of depression and don't delay in getting professional help when you need it.
- Be open to new technologies that can help you care for your loved one.
- · Organise medical information so it's up to date and easy to find.
- · Make sure legal documents are in order.
- Give yourself credit for doing the best you can in one of the toughest jobs there is!

Source: http://caregiveraction.org/resources/ten-tips/

New Carer Assessment Resource for Practitioners Launched



Selected Caregiver Assessment Measures: A Resource Inventory for Practitioners. 2nd Edition, December 2012.

This timely resource we hope will encourage health and social care practitioners to think more about the added value in assessing Family Carers needs.

The authors give some background to the resource:

"Given the current interest in caregiver assessment across health and social service settings, it seemed fitting to update the caregiver assessment measures for the next generation of deployment in the field. As health care continues to move into home setting, it is important to assess not only the knowledge, skills and capacity of the caregiver to provide care but also to address caregiver well-being and health in order to prevent more serious health problems for families in the long-term."

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www.carealliance.ie/userfiles/file/SelCGAssmtMeas ResInv FINAL 12 10 12.pdf

Life After Care

A guidebook for those whose caring has recently ceased. Hard copies available on request from info@carealliance.ie



Research and Practice Reports

Family Caregiving and Transitional Care: A Critical Review



Mary Jo Gibson, Kathleen A. Kelly and Alan K. Kaplan October 2012

This review and critical synthesis demonstrates that promising approaches and tools exist to make family caregivers integral partners with professionals during transitions between health care and community settings, such as from hospital to home. However, it finds that engaging family caregivers deserves higher priority in most transitional care programs. In addition, it makes a case for greater coordination between medical services and long-term services and supports in transitional care. It concludes with recommendations for research, quality measurement and public policy to more meaningfully engage family caregivers as partners in transitions across settings.

www.caregiver.org/caregiver/jsp/content/pdfs/FamCGing_TransCare_CritRvw_FINAL10.31.2012.pdf

"Even when a caregiver was present, hospital staff frequently directed teaching exclusively toward the patient. For example, a nurse and patient sat side-by-side to review instructions; the highly motivated caregiver, seated across the room due to lack of space, was unable to see the written material. The integral role of caregivers in helping patients at home contrasted with their often peripheral role in inhospital transition processes".

Carol H. Cain, 2012

Feelings of loneliness, but not social isolation, predict dementia onset: results from the Amsterdam Study of the Elderly (AMSTEL)

J Neurol Neurosurg Psychiatry doi:10.1136/jnnp-2012-302755

Feeling lonely rather than being alone is associated with an increased risk of clinical dementia in later life and can be considered a major risk factor that, independently of vascular disease, depression and other confounding factors, deserves clinical attention. Feelings of loneliness may signal a prodromal stage of dementia. A better understanding of the background of feeling lonely may help us to identify vulnerable persons and develop interventions to improve outcome in older persons at risk of dementia.

To read the full report see http://tinyurl.com/abb9nzt

Research and Practice Reports

Joint Report by the Alzheimer Society of Ireland and the Irish Hospice Foundation

Building Consensus for the Future: Report of the Feasibility Study on Palliative Care for People with Dementia.

To view the report, see www.alzheimer.ie/About-Us/Research.aspx



Carer Assessments

You Have Two Clients

When you assess an older client with a family caregiver, you really have two clients. The needs of the family caregiver are different than the needs of the care receiver and the geriatric care manager or aging professional must differentiate those needs to make sure the care receiver's functional and psychosocial needs are met. The care receiver and the family caregiver are one homeostatic system encompassing the whole aging family.

To keep that family healthy and whole, in the middle of swirling care crisis, the care manager must first recognize that there are multiple clients including the person who gives or supervises care. In a health care insult, family members who give care are often referred to by the inanimate wooden term "resources". They have also been referred to as "informants".

My Geriatric Care Management Agency

> Operations Manual

Cathy Jo Cress MSW



www.cathycress.com/my-blog/categories/listings/aging

This stripping of personhood denudes them of their status as individuals and melts them into the caregivers, thus breeds professional ignorance, like the crowd who watched the emperor with no clothes. We are blind to caregiver's humanity and thus their own needs.

Member Profiles

Irish Wheelchair Association



Irish Wheelchair Association (IWA) is a national organisation dedicated to the achievement of full social, economic and educational integration of people with physical disabilities as equal, independent and participative members of the community.

IWA has played a key role in bringing many improvements and changes to the lives of people with physical disabilities, in the areas of equality, access, employment, housing, sport, independent living, education, the built environment and advocating for legislative changes. We work to achieve greater independence, freedom and choice for people living with a disability.



IWA has a presence in every county in Ireland. The range of services provided by the Association include: Resource and Outreach Centres, Assisted Living Services, Motoring and Transport, Youth Services, Training and Education, Holidays, Wheelchair Sales, Repairs and Rental, and Sport.

Assisted Living Service

IWA has played a pioneering role in the development of in-home services, and the Assisted Living Service is the Association's largest service area, enabling people with disabilities across the country to live more independent lives.



The Assisted Living Service provides person-centered, individualised and practical support to people in their own homes.

This ranges from assisting people to carry out daily tasks like getting ready in the morning, household duties and preparing meals, to supporting them in social, educational or employment settings.

Resource & Outreach Centres

The aim of IWA's Resource and Outreach Centres is to provide opportunities and support services to people with physical disabilities so that they can lead full, active and independent lives in their own communities. Each Resource and Outreach Centre aims to deliver a customised programme of education, training and social activities for every individual.

For further information log on to www.iwa.ie or contact the Information Department on 01 818 6485 or email info@iwa.ie

Member Profiles

RehabCare

RehabCare operates a wide variety of responsive health and social care services which reach into communities the length and breadth of Ireland. Each year more than 3,000 people of all ages and from all walks of life avail of these services which range from resource centre activities to support provided to individuals within their own homes.



Clients include people with disabilities and their families, older people, children and people who have been long-term unemployed. Choice, quality and personalised services are the cornerstones of RehabCare. The organisation prides itself on the flexibility of its activities, which are all designed to meet the individual wishes and requirements of each client. RehabCare is also committed to ensuring that clients play a full and active role in the decisions that shape the services they use through its client representative body, the National RehabCare Advocacy Council (NRAC).

RehabCare is the health and social care division of Rehab Group, an independent international group of charities and commercial companies which works towards a world where every person has the opportunity to achieve their potential. Rehab's 3,800 staff provide health and social care, training and education, and rehabilitation, employment and commercial services in Ireland, England, Scotland, Wales, the Netherlands and Poland. Every year, more than 80,000 people and their families benefit from the supports provided by Rehab in almost 250 locations. These services enhance the quality of people's lives, by supporting people in fulfilling personal goals, in accessing new opportunities and in playing a more active role in their communities. Rehab enables people to make the most of their skills and talents, to take up employment or further education and to live more independent lives.

For further details please view our website www.rehab.ie

Caring in the News

Media coverage of caring-related issues since December 2012

20% Budget cut to Respite Care Grant alienates carers – Inclusion Ireland, 5 December 2012 www.inclusionireland.ie/content/media/1006/20-budget-cut-respite-care-grant-alienates-carers

Budget 2013 Social Protection: Call to reverse 20% cut to respite support for carers – www.breakingnews.ie, 6 December 2012

www.breakingnews.ie/budget/news/budget-2013-social-protection-call-to-reverse-20-cut-to-respite-support-for-carers-216169.html

Tánaiste dismisses calls for reversal of Budget measures – RTÉ News, 7 December 2012 www.rte.ie/news/2012/1207/357284-carers-to-stage-protest-outside-leinster-house/

Family Carers Protest Outside the Dáil – Irish Independent, 11 December 2012 www.independent.ie/videos/irish-news/family-carers-protest-outside-the-dail-28946190.html

It's only looking back that we realise what the warning signs were – The Irish Times, 29 December 2012

www.irishtimes.com/news/it-s-only-looking-back-that-we-realise-what-the-warning-signs-were-1.5359?page=1

Ten minutes in court that decided one family's destiny – The Irish Times, 11 January 2013 www.irishtimes.com/news/ten-minutes-in-court-that-decided-one-family-s-destiny-1.956660

Ask Mary O'Rourke.... My mum has cancer, and my siblings are not helping – Irish Independent, 19 January 2013

www.independent.ie/woman/love-sex/ask-mary-orourke-28960685.html

Carer application backlog drops - Irish Independent, 28 January 2013 www.independent.ie/lifestyle/health/carer-application-backlog-drops-29024441.html

Finding a new place for women in our 'fantasy' Constitution – The Irish Times, 16 February 2013 www.irishtimes.com/news/finding-a-new-place-for-women-in-our-fantasy-constitution-1.1252639

800 under 4s act as unpaid carers – Irish Examiner, 18 March 2013 www.irishexaminer.com/archives/2013/0318/world/800-under-4s-act-as-unpaid-carers-225821.html

Stuck in the Middle – The Irish Times, 30 March 2013 www.irishtimes.com/life-and-style/people/stuck-in-the-middle-1.1343260

International News

More recognition for informal carers in Italy

By Licia Boccaletti

Something is happening in Italy these days regarding carers' rights. First of all, a group of associations and stakeholders is promoting a class action for the acknowledgment of rights for carers. Even though maybe not all of the requests made so far can be shared, it is still very good news, as newspapers are reporting the news and have started talking about carers and the problems they face.

Secondly, one of the most important Italian newspapers (II Corriere della Sera) is hosting a blog named "Invisibles" which is focused on disability. In the article they published on 13 December 2012 they talked about carers, also mentioning our organization Anziani e non solo, our website on carers www.caregiverfamiliare.it and the Carers Day we are promoting in Carpi (Modena): http://invisibili.corriere.it/2012/12/13/hanno-cura-di-chi-amano-ma-per-la-politica-non-esistono/. This gave us great satisfaction, and is a step forward for Italian carers.

For more information please contact Licia Boccaletti at: progetti@anzianienonsolo.it.

Rhode Island Assembly Considers Bill to Mandate Carer Assessments

If enacted, the Family Caregivers Support Act of 2013 would require a caregiver assessment if the plan of care involves a family caregiver. A plan of care would then be developed, which would take into account the needs of the caregiver and the recipient. The Act was submitted In January 2013, and is currently under consideration.

UK Census reveals major rise in numbers of unpaid family carers

www.carersuk.org/newsroom/item/2890-census-reveals-major-rise-in-numbers-of-unpaid-family-carers?dm i=74C,17U03,PF3WJ,447FU,1

International News

European Parliament majority support for 2014 European Year for Reconciling Work and Family Life



COFACE, the Confederation of Family Organisations, is proud to announce that on 7 February 2013, the European Parliament officially adopted Written Declaration Nr. 32 calling for the designation of 2014 as the European Year for Reconciling Work and Family Life. More than half (388) of MEPs signed the Declaration.

We are particularly indebted to the 4 co-signers of the Written Declaration, MEPs Marian Harkin, Jutta Steinruck, Roberta Angelilli and Elisabeth Morin Chartier, for believing in the project and for being instrumental in the process. We also thank our members and supporters, who came from the four corners of Europe, often spontaneously offering help and support in convincing MEPs to sign the Written Declaration.

After the support of the Trio Presidency (Ireland, Lithuania and Greece), we now have the endorsement from the European Parliament, thus sending a very strong signal to the President of the European Commission and the heads of Member States to designate 2014.

COFACE is ready to lead the 2014 Alliance of Civil Society Organisations to prepare and implement successfully the European Year, which we believe will make a difference in the lives of all families, women, men and children in Europe.

About the campaign: http://eyf2014.wordpress.com/

Eurocarers Latest Newsletter

The most recent edition of the Eurocarers newsletter (March 2013) is available and includes details of the upcoming AGM and conference to be held in Dublin in May. www.eurocarers.org/News_Newsletters.php





About Us

Care Alliance Ireland is the National Network of Voluntary Organisations supporting Family Carers. Our vision is that the role of Family Carers is fully recognised and valued by society in Ireland.

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

1 O Reasons To Join Us

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 88 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.

Become a member of Care Alliance Ireland: www.carealliance.ie/membership

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