



Care Alliance Ireland Exchange

Issue 29

February 2010

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Budget 2010

Budget 2010 was a tough one for all but thankfully direct financial supports for Family Carers were not specifically targeted. The strong campaign by several organisations in the Family Carer sector and beyond to protect the income of full-time Family Carers must be seen as a success.

Unfortunately, state funding for the not-for-profit sector as a whole has been cut by in the region of 10% and already we are seeing funding for specific carer support projects being reduced. It is likely that the impact will be real and noticeable in terms of reduced numbers of carer support groups, respite care, 1-2-1 support and phone line support. On a more positive note, we welcome the injection of additional funds towards home care support.

There appears to be a trend within the

sector towards a more significant funding role being played by various philanthropic organisations. This funding is generating a new level of dynamism and is providing opportunities for more strategic activities within the Family Carer sector.

Collaborative and partnership efforts are crucial in securing better and more integrated services for Family Carers and are being given a welcome boost from several quarters. High levels of interagency collaboration are evident. Examples of this include Carers Week 2010, joint submissions, the Family Carer Research Group, a strategy for Census 2011 – to name but a few. We in Care Alliance are well positioned to play our part in facilitating this collaboration for the good of all Family Carers



2 New Members

Care Alliance Ireland are delighted to welcome our new members Acquired Brain Injury Ireland (formally the Peter Bradley Foundation) and the Irish Osteoporosis Society.

We are looking forward to working with these organisations and will be highlighting them in the member profile section of our newsletter in the coming year.

MEMBER NEWS



The UK and Ireland Huntington's Alliance.

Huntington's Disease Association of Ireland (HDAI) has come together with Huntington's Disease Association of England and Wales (HDA), Scottish Huntington's Association (SHA) and Huntington's Disease Association of Northern Ireland (HDANI) to form The UK and Ireland Huntington's Alliance.

The Alliance hopes to make as many people as possible aware of this rare disease and its devastating effect on whole families. It aims to:

- Shape the debate on the care and support of people with HD and those affected by it
- Work with young people from HD families in order to support them for the years ahead
- Provide opportunities to share information and intelligence
- Act collectively where appropriate

The Alliance was celebrated at a reception in Belfast on October 12th. Mrs. Pat McKay, Chair of HDANI, welcomed President of Ireland Mary McAleese, patron of HDAI, her husband Dr Martin McAleese, Sarah Winckless, SHA patron along with executives and board members of the four associations, family members, health care professionals and those working in the field of Equality

The UK and Ireland Huntington's Alliance was launched in London on June 8th and was attended by Sarah Winckless, SHA patron with HDA patrons Tony Hadley and Shane Richie .



Introduction to Aromatherapy and Massage for Family Carers

This course will be held on Saturday 20th and Sunday 21st of February from 10am to 4pm, with light lunch included, in the Walmer College, Raheny. It is an introduction to the basics of massage and aromatherapy and upon completion participants will receive a certificate from the college. This course is free of charge

due to monies received through Dormant Account Funds. Places are limited. For further information on this and other training courses for Family Carers please contact Nora or Rosemary, Crosscare Carer Support Programme

01 8360011, nkirrane@crosscare.ie

Latest Research Reports

Research

Rural Carers in Australia

The Tyranny of Distance? report, funded by Commonwealth Financial Planning, is the first to examine the geographic spread and social, health and economic wellbeing of carers in outer regional and remote areas of Australia.

To see this report click on this link
[Report on Rural Carers in Australia](#)

Anxiety and Stress in Carers

“ 8 out of 10 people who care for a relative suffer from anxiety and stress, according to a study”—To see the full report click on the following link:

[University of Granada Science News](#)

Update on the Activities of the Family Carer Research Group

The group have been meeting now for over two years and in that time several major research reports relating to Family Carers have been produced by members of the group. Indeed, several have been submitted for consideration for presentation at the 5th International Carers Conference in Leeds in July 2010. [Click Here for Website](#) Indeed the reports are increasingly being referenced by policy makers, academics and are used to inform our own organisations submissions in various arena.

The November meeting looked at the complex area of Elder Abuse, with presentations by Dr Assumpta Ryan from the

University of Ulster and Dr. Emer Begley, Age Action Ireland. Both presentations are available to view on our website

[To view Dr Assumpta Ryan's Report Click Here](#)

[To view Dr Emer Begley's Report Click Here](#)

Other issues addressed at the meeting included the Law Reform Commission paper on the Regulation of Care Workers, HSE assessment tools, Updates on Eurocarers and Updates on various research funding Bids.

We are delighted to welcome Dr. Marianne Breen, Researcher, Trinity College

Dublin to the group. Marianne has recently begun a research project, co-funded by Care Alliance, that explores the area of post-caring. (Further details of the project are outlined elsewhere in this Newsletter.) We also welcome back Grainne McGettrick from The Alzheimer Society.

The next meeting of the group will take place on February 16th in Coleraine House from 10.30am-12pm. At this meeting Liam O'Sullivan, Care Alliance Ireland, will make a short presentation on Effective Interventions for Family Carers. As ever, all are welcome.

To attend please e-mail Esther on info@carealliance.ie

Life After Care – EU Dimension

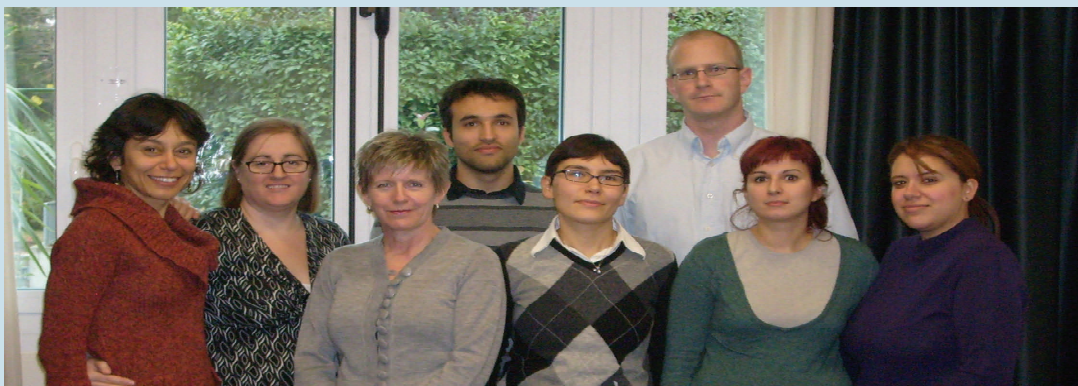


Care Alliance Ireland is committed to constantly reviewing, researching and disseminating good practices in Carer support. After identifying the gaps in our knowledge about the needs of people whose caring has ended, we have partnered with 4 other carer organisations in Europe to address this issue. Funding for this project has been secured through The EU Gruntvig programme.

The other partners in the project are Carers UK (UK), The Athens Alzheimer Association (Greece), Sofia Società Co-operative (Italy), and Arco (Italy). The first face to face meeting took Place in Bologna Italy in November. The meeting clarified each partners roles as well as the scope and timeframe of the project. We have committed to the following deliverables;

- Project Website – (Now up and running www.lifeaftercare.eu)
- Primary Research from Each Partner (Planned for February 23rd in Athlone)
- Overview of research on Post-Caring (Q1 2010)
- Handbook for Ex-carers (2011)
- Final Report on the Project. (2011)
- Dissemination Material (2011)

A further meeting will take place in London in May this year and will run in parallel with a study visit by a number of Irish ex-carers to London to meet other ex-Carers.



(From left to right) Barbara Leonardi (Arco) , Esther Kavanagh (Care Alliance Ireland) Madeline Starr (Carers UK) Marco Contavalli (Sofia) Licia Boccaletti (Sofia) Liam O’Sullivan (Care Alliance Ireland) Areti Eythimiou (Athens Association of Alzheimer’s Disease) Maria Panagiotou (Athens Association of Alzheimer’s Disease)

For further details on the project see www.lifeaftercare.eu



Does Europe Care? The Future of Carer Support in Europe



The conference, is being organised by **EUROCARERS in partnership with Scotland's national carer organisations.**

More than 100 million people in Europe care for a family member or friend with a disability, long-term illness, addiction or mental health problem, without pay and recognition, and often without support. As Europe's populations grow older, demand for family care will increase steeply in all countries over the next 20 years.

'**Does Europe Care?**' is a conference aimed at representatives of carers and carer organisations, and planners and policymakers who work in the field of health and social care and politics. The conference will focus on strategies to strengthen European policies for carer support and develop stronger carer representation at national and European level.

Through this conference, Eurocarers seeks to;

- **Promote awareness** of carers issues
- **Provide information** on relevant EU policy

developments

- **Support** the development of carer organisations
- **Develop** a united carers voice in Europe
- Developing an **informed research agenda**

The conference seeks to attract new countries and regions, present evidence of the positive benefits of carer policy and support, and lay the foundation for the development of a European Carers Manifesto.

Individual delegates are welcome to attend this event. We encourage small delegations. Where a delegation of THREE includes a carer representative, the carer's participation will be FREE and will qualify for free attendance and accommodation.

For more information about the conference please visit.

<http://www.hfevents.co.uk/DoesEuropeCare2010>



Building on the success of the 4th International Conference in Toronto, Carers UK and the University of Leeds are pleased to invite you to the 5th International Carers Conference, which will take place from 8-11 July 2010.

How we manage care and caring in a changing and ageing world is one of the world's greatest challenges, touching everyone's lives.

This conference again brings together the international community of researchers, practitioners and those with an interest in caring to debate the critical issues and exchange expertise and experience. Mapping the policy framework from around the world, the conference will explore innovation and seek real solutions to the care crunch.

The conference will focus on four key themes, identified through latest international debate:

New Frontiers in Caring: 2010 and Beyond

- Health, Social Care and Well-being Services
- Caring and Employment
- Technology, Design and the Built Environment
- Financial and Legal Planning, Products and Services

At this conference delegates will:

- Hear from a range of internationally renowned speakers
- Participate and present in workshops and poster sessions presenting cutting edge perspectives on the four key conference themes
- Learn about latest innovations at the conference exhibition
- Network with colleagues at a range of exciting social events

For more information about the conference please visit

www.carersconference.com

Research & Resources

Research on Migrant Care Workers

The role of migrant care workers in ageing societies context and experiences in Ireland

By Kieran Walsh, and Professor Eamon O'Shea

This study explores the implications of cultural changes in the care workforce due to the increase of migrant carers caring for Irish older people. Basing their findings on survey results the authors look at the implication of migrant carers from a number of angles including demand for migrant carers in older adult care, the impact of the current economic decline on future demand, the experiences of migrant carers caring for older people and the impact of employing migrant carers on the well being of older people. Based on

findings the authors recommend that, amongst other things, new regulations for home based care are necessary to protect older people and their carers and reform of existing processes is necessary to fully inform carers on what constitutes rights violations in the Irish labour market.

For further research reports on this topic [Click Here](#)

New Research on Post Caring



We are delighted to announce that Dr. Marianne Breen has commenced her research on post-caring. (See Biog below) Over the coming months she will be interviewing people around Ireland who have recently ceased caring. This project is co-funded by Care Alliance Ireland and the Irish Research Council for Humanities and Social Sciences. She has also joined the Family Carer Research group, led by Care Alliance Ireland. We welcome her to the Family Carer sector and look forward to supporting her with this important research.

Dr Marianne Breen is a research psychologist, specialising in the area of social inclusion. She is based in the School of Nursing and Midwifery, Trinity College Dublin. She is currently undertaking a study of post-caring among former family carers. This research will explore the needs and experiences of former carers whose loved one has recently been placed in a nursing home, hospice or has died. The project will also examine the supportive or educational implementations that could enhance former carers' quality of life after the cessation of caring.

The research team for the study includes Prof Mary McCarron, Dr Patricia Cronin and GERALYN HYNES. This project is co-funded by Care Alliance Ireland and the Irish Research Council for the Humanities and Social Sciences (IRCHSS).

Prior to this appointment at TCD, Dr Breen worked as a researcher both in the voluntary sector and academia. During this time, she completed a number of research projects examining a range of issues such as housing exclusion, educational disadvantage, problematic drug use and active citizenship. These studies were funded by a variety of statutory and voluntary bodies (e.g. Combat Poverty Agency and National Council for Ageing & Older People).

She was awarded a first class honours degree in Applied Psychology and the title of College Scholar for two consecutive years from University College Cork. She then went on to complete a PhD in Applied Social Psychology at Dublin City University. She was awarded a postgraduate scholarship from IRCHSS to support this work



Huntington's Disease Association of Ireland

Member Profile

Huntington's Disease Association of Ireland (HDAI) is a national voluntary organisation established to provide consultation, information and individualised support to those diagnosed with HD, their families and their health care teams. Confidentiality is respected. HDAI is a Registered Charity CHY 10130, formally launched in 1985 and incorporated in 1998.

HDAI exists to provide a unique service offering comfort, information and support to all those affected by HD

About HD

HD is an inherited disorder of the central nervous system. It is a multifaceted disorder, which involves changes in behaviour, cognitive decline, involuntary movements and speech impairment. Symptoms usually appear between the ages of 30 and 45, although they may appear earlier or later.

It is estimated there are 400-500 people in Ireland with HD and over 2000 at risk. Each child of a person with HD has a 50/50 chance of inheriting or not inheriting HD. People with the abnormal gene will always develop the disease, unless they die of other causes prior to developing symptoms. The illness usually lasts about 15-25 years and death is often due to the consequences of the immobility, general debilitation and malnutrition.

The hereditary nature of HD creates generational hardship within families and often brings feelings of shame, guilt, and social isolation. Cognitive and behavioural difficulties, dementia, and communication problems can lead to aggression and frustration for the person with HD and emotional stress and fear for family members. Many HD family carers face a continuing cycle of caring due to the hereditary nature of the condition. The potential for discrimination in employment, insurance and in personal relationships often results in an unwillingness to seek professional help. Depression is frequent in HD and suicide is a real concern.

HDAI is a niche organisation with experience in responding to issues arising from the complexities of HD and the impact it has on the core and extended family. HD-affected families are unique and require flexible support and understanding.

HDAI Offers

A national information and support service based in Dublin which provides information and support to families; individuals at risk of HD; carers and health care professionals; liaise with service providers; highlights the needs of members; creates awareness of HD.

- A Family Support Officer available to meet family members in crisis.
- Access to counseling for those in need.
- Support group meetings /carers workshops in Dublin, Cork, Mayo / Roscommon and Limerick
- An annual information meeting and respite weekend available to people with HD and their families.
- Publications including leaflets, booklets, and articles covering the many issues specific to HD available for families, social care and health professionals on request.
- A quarterly newsletter and annual magazine.
- The loan of a specialised HD Chair which helps protect against injury related to involuntary movements and debilitation.
- Talks and information seminars on request.
- Therapeutic treatments for patients in the mid stages of HD.
- HD ID cards provided on request.

For further information please contact:

Huntington's Disease Association of Ireland

Carmichael Centre,
North Brunswick St.
Dublin 7
Tel: (01) 872 1303
Freephone: 1800 393939
email: hdai@indigo.ie
www.huntingtons.ie



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 will achieve this by supporting organisations in their work with Family Carers through the provision of information, research, the sharing of resources and opportunities for collaboration.

Care Alliance Ireland was established in 1995 and our membership currently includes over 65 voluntary organisations concerned with the needs of Family Carers.

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

or contact us by at:

Tel: 01-8747776

E-mail: info@carealliance.ie

Care Alliance Ireland is a company limited by guarantee not having a share capital, registered in Dublin, Ireland, with registered office at:
Coleraine House, Coleraine Street, Dublin 7
www.carealliance.ie Telephone: (01) 8747776 E-mail: info@carealliance.ie
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