

Care Alliance Ireland

Exchange

Winter 2013 Issue 42

Membership set to reach 100 Organisations as leading Charities join Care Alliance Ireland

Following the recent approval by the Board of Directors of eleven applications for membership, the Alliance membership is set to reach 100 over the coming months.

Speaking after the board meeting, Gerry McCaffrey, Chair said: "The latest membership applications demonstrate the added value such organisations see in being part of an Alliance of organisations supporting Family Carers." The new members are:

Bryson Care West
Cairdeas / Kilmovee Family Resource Centre
Carlow Day Care Centre
Cobh Family Resource Centre / Cobh Carers Group
Cork Mental Health Housing Association
Enable Ireland
LauraLynn
St Michael's House
Tabor Lodge Addiction and Housing Services
Rotunda Hospital (Social Work Department)
WALK

He added, "I'm particularly glad to see a wide representation of new members, from north and south, from home care to hospital based providers, and from those caring for the young and those caring for the old. With a number of further applications having been received in recent days, it's likely that our membership will exceed 100 before the year is out."

Liam O'Sullivan, Executive Director, said "We will now engage with these organisations and look to identify specific ways of supporting them in their valuable work with Family Carers."

For full membership details see www.carealliance.ie/membership.

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Young Carer of the Year
thirteen year old Niamh
Duffy who helps with the
care for her brother Finn.
Congratulations Niamh!

National News

Budget 2014 – Family Carers not specifically targeted, but further cuts will impact nonetheless

Some responses from member organisations and other stakeholders to the 2014 Budget announced on 15 October 2013.

The Carers Association

"This year our main aim was to protect the Half Rate Carer's Allowance and we are pleased to say this has been achieved. It hasn't been all good news however – we're particularly concerned about the abolition of the Telephone Allowance for older people and carers (in particular the impact this will have on the use of personal alarms), the abolition of the Bereavement Grant, the hike in prescription charges and the tightening on the eligibility criteria for Medical Card holders. The Association will continue to engage with Government on these matters."



For the full response see: www.carersireland.com/emailtemplates/2013_10/newsletter.htm.

Disability Federation of Ireland

"This Budget and Government policy in general fails to coherently integrate people with disabilities into public service reform. DFI welcomes some positive measures for people with disabilities and their families, including the beginning of the process of universal healthcare, €20 million for community mental health services and the allocation (albeit only a fraction of what is required) to support accessible housing for people with disabilities. Disability, chronic illness and mental health needs are experienced by individuals and families across the life course."



For the full response see: www.disability-federation.ie/index.php?uniqueID=10742#f7.

National News

Budget 2014 responses, continued

Irish Heart Foundation

"The Government is giving a profits boost to the tobacco industry by failing to substantially increase tax on cigarettes on the grounds that it will fuel smuggling. The fact is that the tobacco smuggling rate is vastly overestimated by the tobacco industry and the real rate fell last year from 15% to 13% according to Revenue research."



For the full response see:

www.irishheart.ie/iopen24/condemns-paltry-budget-increase-cigarettes-n-440.html.

The Wheel

"It is projected that (government) spending will fall again in 2015, down to €48.25 billion, which will give us an overall reduction since 2008 of 9.64%. This contrasts with the overall loss of funding for the voluntary and community sector in the order of -8% to -10% a year."



For the full response see: www.wheel.ie/sites/default/files/Wheel%20budget%202014.pdf.

Age Action Ireland

"The combination of measures contained in Budget 2014 will cause increased hardship for the most vulnerable of older people."



For the full response see:

www.ageaction.ie/sickest-poorest-and-most-vulnerable-older-people-hit-hardest-budget.

National News

Research Study on the Health and Wellbeing of Dementia Caregivers Launched

There is a growing need for dementia care in Ireland as the average age of the population is increasing and the prevalence of dementia increases with age. Currently much of this care is provided by informal caregivers who are frequently spouses or partners of those with dementia. Whilst this type of care is often associated with better outcomes and quality of life for the person with dementia, it can be challenging for caregivers. It is therefore very important that the impact of caregiving is considered and that the health and wellbeing of caregivers is understood and protected.

De-Stress is a new three year study that will provide, for the first time in Ireland, information on the determinants of the health of spousal dementia caregivers. The study is being carried out by researchers in Trinity College Dublin's NEIL (Neuro-Enhancement for Independent Lives) programme and is funded by the Alzheimer Society of Ireland and the Health Research Board under the Medical Research Group funding scheme. It is hoped that the research findings will inform policy and the development of targeted interventions to improve caregiver health and make care in the community a viable option for both the caregiver and the person with dementia.

If you would like additional information about the study, if you can help to raise awareness about this research, or if you are interested in participating yourself, please contact Dr. Maria Pertl on maria.pertl@tcd.ie or call 01-896-8414. Further information about the study is also available on the NEIL website: www.tcd.ie/Neuroscience/neil.

Post-doctoral research fellow Dr. Maria Pertl has been appointed to run the study, which will follow a group of about 300 spousal dementia caregivers over time and collect data on psychological and cognitive wellbeing (for example, memory or attention), physical health and genetic and physiological factors that may be linked to healthy ageing.

Informal caregivers over the age of 50, who are providing care at home for their spouse or partner with dementia, can participate.



National News

Establishing and addressing the palliative care needs of people with advancing neurological disease

The Neurological Alliance of Ireland (NAI) in partnership with the Irish Hospice Foundation (IHF) are embarking upon an exciting project that aims to examine the palliative care needs of people with advancing neurological disease from the perspective of NAI member organisations. Over 700,000 people in Ireland are affected by neurological conditions (conditions affecting the brain and spinal cord). Due to the uncertain nature, duration and progressive course of some of these illnesses, there is a requirement to consider end-of-life issues and the need for palliative care.

The Health Service Executive Service Plan for 2013 and the Department of Health's 2012 document Future Health recognise that the palliative care needs of those with advancing neurological disease is an area requiring attention. Some information exists about the palliative care needs of those with specific neurological illnesses such as Parkinson's and Motor Neurone Disease. There is however, little Irish information available about the palliative care needs of those with advancing neurological disease as a group. As a result, there is a lack of consensus and direction with regard to how the palliative care needs of people with these diseases can be identified or met.

In consideration of this, a joint project has been commenced that will examine the end-of-life issues pertinent to NAI member organisations that are involved in the care of those with advancing neurological disease. It is anticipated that this piece of work will provide direction on meeting the end-of-life and palliative care needs of those with advancing neurological disease. It will also be a means of signalling the support and guidance required for staff working with this target group.

For more information see: www.nai.ie or www.hospicefoundation.ie.



National News

The Disability Federation to Co-Host an Event on Quality and Innovation with the University of Limerick

"Developing Quality and Innovation through Strategic Operations and Alliances in the Voluntary Disability Sector"

The Pavillion, University of Limerick.
Friday, 29 November 2013, 10.15am – 3.30pm

There is an open invitation to this one-day symposium hosted jointly by the Disability Federation of Ireland (DFI) and the Enterprise Research Centre at the University of Limerick (UL).

Key speakers set to address the event include Marie Keogh O'Sullivan, Director of Safety and Quality Improvement at the Health Information and Quality Authority, Professor Eamonn Murphy of the Department of Mathematics and Statistics in UL and contributors from DFI, UL, Cork Centre for Independent Living, Wexford Disability Services (CIL) and Fighting Blindness.

The key objectives of the symposium are:

- To discuss quality principles and thinking in the community and voluntary sector, examining the shared partnership which has grown between DFI and UL over the past three years.
- To exchange knowledge of quality tools, lean thinking and "value add" in consideration of how best to create and sustain a culture of quality within an organisation.
- To examine opportunities for improved quality across the community and voluntary sector through increased co-operation and sharing of information.
- To review the research and case studies undertaken by three post-graduate students in UL, outlining the challenges and efficiencies learned through the process.
- To celebrate the accomplishments and achievements of the graduates of "An Introduction to Quality Management for Community and Voluntary Organisations" on the successful completion of their course.

View the full symposium brochure at: www.disability-federation.ie

Register online at: www.regonline.co.uk/Register/Checkin.aspx?EventID=1320799

Symposium registration fee of €45 with concessions available.



National News

2013-2015 National Disability Strategy Implementation Plan Announced



The four high level goals of the National Disability Strategy Implementation Plan 2013- 2015 have been announced recently:

- Equal citizens
- Independence and choice
- Participation
- Maximising potential.

The highlights of the Plan include:

- Publication and enactment of the Assisted Decision Making (Capacity) Bill to give full legal capacity to people with disabilities
- Implementation of the suite of reforms arising from the value for money and policy review of disability services, the phased closure of residential institutions and campuses, new models of day services and supports, and roll-out of early intervention and school-age therapy services for children
- Implementation of the housing strategy for people with disabilities
- A focus on accessibility in the arts, culture and sports areas
- All Departments to deliver disability and mental health awareness training to staff, including via the National Disability Authority's e-learning disability course (<http://elearning.nda.ie>)

The Plan was developed by, and is overseen by the National Disability Strategy Implementation Group, Chaired by Minister Kathleen Lynch TD, and comprising senior officials, the Disability Stakeholders Group, and the National Disability Authority.

Read the full National Disability Strategy Implementation Plan 2013-2015

Member News

The Alzheimer Society of Ireland establishes Ireland's first Dementia Carers Campaign Network



THE ALZHEIMER
SOCIETY of IRELAND

Introduction

A core objective of the Alzheimer Society of Ireland (ASI) is to ensure that people living with dementia and family carers are at the heart of the organisation. One of the structures put in place to achieve this was the formation of the first Irish Working Group of People with Dementia. The aim of this working group is to ensure the engagement of people living with dementia, not only in the work we do, but also at a national policy level. The working group has been active in both fields since it formed in early 2013.

In relation to family carers, who have always been involved in the organisation, we wanted to put a similar structure in place to facilitate the better sharing of their experiences and ensure their voice is heard at a national policy level. In response we are now forming the first Ireland-based Dementia Carers Campaign Network. This will involve people who have experience caring for someone with dementia and are interested in collective lobbying and campaigning with the ASI.

Network Aim

The aim of the network is to represent and raise awareness of the distinct needs and experiences of carers of people living with dementia. Dementia carers, whether they are partners, children, other family members or friends of the person with dementia, have unique insights into the psychological, emotional, physical and financial impacts of caring. The aim of the network is to facilitate the ASI to harness these experiences into one collective voice and to instigate change at a national policy level.

Network Tasks

The ASI will coordinate the network. It is hoped that network members will be involved in raising awareness of dementia and the experiences of being a dementia carer. In the early stages we will propose that members decide on a shared political advocacy agenda and determine actions around these. In addition, members will be asked to support and work with the ASI in developing lobbying and campaigning tools and engage in related activities, for example meeting with political representatives as well as lobbying/campaigning in the run-up to European and local elections in 2014.

If you or the people you work with would like to learn more about the Network or are interested in getting involved, contact:
Emer Begley,
Advocacy Officer, at
emer.begley@alzheimer.ie
or telephone 01 2073805

Crosscare - Carer Support - You-Tube Video Launched

Over the summer, Crosscare carer support created a super online video with three carers in their programme who talk about caring, the impact on their lives and the role of the Carer Support Programme.

You can view the video by [clicking here](#).



Member News

CareBright Receives Quality Award

CareBright has been providing homecare services to rural and urban communities in Munster since 1998. It is a not-for-profit organisation which focuses on caring for, and supporting, people to live independently in their own homes. CareBright, formerly known as Rural Community Care Network, was formed not only to provide care in the community but also to provide employment to those who deliver care. It has a team of 250 paid carers managed and supported by a team of care managers who are all qualified nurses with many years' experience. They work closely with family carers, clients, families, public health and community nurses, physiotherapists, occupational therapists and general practitioners to ensure person-centred care is delivered in the home.

CareBright also offers courses in Cardiac First Responder, Manual Handling and Patient Moving and healthcare training programmes including FETAC accredited Level 5 Healthcare modules such as Care Skills and Occupational First Aid.



Above: Careworkers
Amanda Kelly and Alison
O'Dwyer marking
CareBright's 15 years of
providing care in the home.

Below: Micheal
O'Muircheartaigh was the
guest speaker in the
Dunraven Arms Hotel,
Adare for the launch of
Carebright's new brand
earlier in the year.



Above:
Martin Roper, Technical Director of the Excellence
Ireland Quality Association, with Colette Ryan,
General Manager of CareBright and Noreen
Kennedy, Care Manager of CareBright, at the Q
Mark awards.



Member News

Irish Red Cross launches the 'Carers Handbook'



The Health and Social Care Programme of Irish Red Cross (IRC) National Services aims to deliver, across the country, humanitarian services to individuals and communities in need. IRC continuously strives to assist those who selflessly and tirelessly give help and care to the most vulnerable people in society, and who, in doing so, make a real difference to people's lives and an enormous contribution to our communities.

To develop this, The Irish Red Cross recently launched the second edition of the 'Carers Handbook', which offers a practical and useful resource to carers across the country. Those people who take on the role of carer, often without any formal training, may feel overwhelmed and indeed vulnerable themselves. This handbook provides practical support and advice for such people, and the wonderful work that they do in looking after someone who is ill, elderly or has a disability.

The handbook is laid out in an extremely accessible format, allowing people 'dip in' to read the relevant section for them as challenges arise. With sections on home hygiene and care skills, and advice on personal care and communication, the handbook will assist in the provision of a better quality of care and a happy, safe environment for both the recipient and the carer.



The Carers Handbook was officially launched on 4 November 2013 in the Mansion House Dublin and is available from the Irish Red Cross online shop: www.redcrossshop.ie/Carers_Handbook/289/.

MS Ireland signs up to Deal Effect



MS Ireland is delighted to be a founding partner of Deal Effect, a new daily deals website with a charitable twist.

Commenting on the initiative, they said: "We saw this as an opportunity to offer our community a quick and easy way to get involved with MS Ireland. Essentially people can show their support while benefiting from deals they would possibly be buying anyway so it's a win-win!" Visit www.dealeffect.ie/msireland to sign up.

Practical Resources

The Words to Explain Why Caregivers Need Self-Care

As a caregiver, you assume additional responsibilities, absorb stress, and often minimise its impact:

- "I won't be long. I'm just taking my mum to the doctor."
- "No big deal. I'll find someone to watch the kids while I go to the appointment."
- "How difficult is it to stop on the way home and get the incontinence pads?"
- "Sure, I can chip in to help pay for these new prescriptions."
- "She's the one who is sick, so why am I having such a hard time?"



Is your Self Care being nurtured?

If others don't understand what you're going through, or if you have lost sight of your own needs, here are some words to help clarify why you need self-care.

Stop minimising or denying how caregiving impacts your life.

When you say things like, "I'm just..." "Not a problem..." "Sure..." "I'll manage..." "No big deal..." you communicate that what you're doing has no significant impact on your life. That's not true! Caregiving is stressful; over time it takes a toll on body and mind, heart and soul, on finances, family, and work life. Don't diminish or hide the effects of caregiving. Use accurate, honest words to help everyone, you included, recognise why caregiving is difficult and why you need self-care.

Name sources of your caregiver stress.

Below are common caregiver stressors. See which apply, and name additional stressors in your life.

- Physical problems: my own insomnia, exhaustion, illnesses, aches, and pains
- Emotions: fear, sadness, guilt, anxiety, anger, depression, frustration, loneliness
- Mental concerns: worry, uncertainty, conflicting advice on what to do
- Financial problems: loss of income, new expenses
- Time pressures: juggling work/personal life, always on-call, too much to do, no help
- Caregiving responsibilities: lack of skill in providing care, out of comfort zone, unexpected crises, never get a break, don't want these responsibilities
- Suffering: witness pain/illness/disability, unable to relieve suffering, worsening condition.

Practical Resources

The Words to Explain Why Caregivers Need Self-Care, continued

All healthy self-care begins with self-awareness. Be sure to tell others about your situation, to help them grasp what you're going through.

- Acknowledge losses

One reason caregivers feel so alone: the many invisible, often painful losses that come along with caregiving. Few people see these, and no one else can bear them for you. Some examples:

- "Because of Alzheimer's, I've lost the close relationship I enjoyed with Mom."
- "My son's genetic disorder robbed our family of the future for him that we'd hoped for."
- "Because of my dad's terrible accident, my parents are no longer financially secure."

Recognising losses like these can help you understand the deeper reasons why caregiving is so difficult. Use these questions to name the losses you're experiencing, and find words to share them with others.

- How has this caregiving situation affected relationships with family, friends, or people at work?
- How has it affected my self-image or how I see myself?

Because of this caregiving situation, what:

- Hopes and dreams for the future are changed or lost?
- Familiar routines and expectations are difficult to let go?
- Personal or professional goals must be put aside?
- Ways of contributing, or meaningful aspects of life, are ending?
- Makes me feel a loss of power, control, prestige, or position?

Use these words to help others understand what you're going through, and remind you why you need self-care. As you do so much for others, remember to take good care of yourself, too.

About the author

Jane Meier Hamilton, MSN, RN, is CEO and founder of Partners on the Path, LLC, a leader in providing corporate-sponsored caregiver support programs to businesses that employ, and nonprofits that support, caregivers. She has been a nurse for 40 years and family caregiver for 20. Learn about Jane's research-based, resilience-building resources at www.PartnersonthePath.com. Find her book, *The Caregiver's Guide to Self-Care* (Infinity 2011) in print, one-hour audio, and e-book formats at your favourite online provider.

Source: www.AgeingInAction.com (17 October 2013)

Research and Practice Reports

Why do Family Carers Live Longer?

A new study from Johns Hopkins and other universities shows that family caregivers have a substantial survival advantage, contrary to what is usually thought. Read more at: www.stonehearthnewsletters.com/caregivers-live-longer/caregivers/.

Seniors who don't sleep well have higher levels of an Alzheimer's biomarker, study says

Seniors who don't sleep well are more likely to have high levels of beta-amyloid, a biomarker for Alzheimer's, in their brains. Previous studies had linked disturbed sleep to cognitive impairment in older people. The new findings, published in JAMA Neurology, suggest that sleep problems may contribute to its development.

Adam Spira, the lead author, says that his study doesn't prove a causal link between poor sleep and Alzheimer's disease. Longitudinal studies with objective sleep measures are needed to further examine whether poor sleep actually can contribute to or accelerate Alzheimer's disease.

For further details see: www.washingtonpost.com/national/health-science/seniors-who-dont-sleep-well-have-higher-levels-of-an-alzheimers-biomarker-study-says/2013/10/28/5cf96d98-3c23-11e3-a94f-b58017bfee6c_story.html.



Member Profile

LauraLynn, Ireland's Children's Hospice



LauraLynn, the Republic of Ireland's first Children's Hospice, was opened by President Mary McAleese in September 2011. At the heart its vision is all children who need us can access us. The landmark development and the opening of LauraLynn House in 2011 was the beginning of a journey for greater development of palliative care services for children and has encouraged national debate into the issues surrounding equality of access to services, with the goal of ensuring that all children with life-limiting conditions and their families can access services that they need close to their home.

For those children and families that are referred to us, in addition to medical, nursing and care staff, LauraLynn has a **multidisciplinary team** which consists of psychology, social work, chaplaincy, dietetics, occupational therapy, physiotherapy and music and play therapy. Our mission is to work holistically with families that are referred and we have close liaison with referring agencies and other services. Our focus on putting life into a child's day rather than days into a child's life enables us to create a fun and friendly environment for the children and their families and other carers. This year we piloted a **sibling programme** with individual days for siblings of children who are in our care. These activities, which included music, dance, sailing, treasure hunt, Halloween Party, arts and crafts and other fun activities, allowed these siblings to have a break from the daily routine of living with a child with a life-limiting condition. A **family fun day** was also facilitated in Barrettstown by our occupational therapy, physiotherapy and psychology team in July 2013.

On 16 November 2013 a bereavement support day took place for parents who availed of LauraLynn's services and whose children had died as a result of a life-limiting condition; this was facilitated by social work, psychology and chaplaincy.

Ireland's first dedicated **Children's Palliative Care Conference** will take place at the Royal Hospital, Kilmainham, on 29 and 30 November 2013. This conference is a collaboration between LauraLynn, the Jack & Jill Foundation, Our Lady's Hospital for Sick Children, Crumlin, the Irish Association for Palliative Care, and the HSE. Open to all healthcare professionals working in children's palliative care, this conference will bring together experts in the field and provide an opportunity for delegates to hear the latest research, be challenged by keynote speakers and build valuable networks. For further information see www.irishcpconf.ie.

By working together and sharing our knowledge and experience, all of us can play a part in improving and developing services for children with life-limiting conditions and their families.

For more information, see: www.lauralynn.ie.



Caring in the News

Media coverage of caring-related issues since August 2013

Change in services provided to profoundly disabled teenagers "totally unfair" says Carers Association – The Irish Times – 1 August 2013

www.irishtimes.com/news/social-affairs/change-in-services-provided-to-profoundly-disabled-teenagers-totally-unfair-says-carers-association-1.1481171

Family Carers Pleased with HSE Agreement – Dublin Gazette – 29 August 2013

www.gazettegroup.com/news/news-lucan/family-carers-pleased-with-hse-agreement

Male carers, Ireland's unsung heroes – Irish Examiner – 29 August 2013

www.irishexaminer.com/archives/2013/0829/features/male-carers-irelandaposs-unsung-heroes-241296.html

Lack of support keeps Carers in 'Crisis Mode' – The Clare Champion – 6 September 2013

www.clarechampion.ie/index.php/lack-of-support-keeps-carers-in-crisis-mode-2/

My husband didn't ask for this and I'm in it for the long haul – Irish Independent – 8 October 2013

www.independent.ie/lifestyle/health/mental-health/my-husband-didnt-ask-for-this-and-im-in-it-for-the-long-haul-29641647.html

Dog mood monitor could alert family that elderly relative needs help – Breaking News.ie – 10 October 2013

www.breakingnews.ie/world/dog-mood-monitor-could-alert-family-that-elderly-relative-needs-help-609371.html

The Carer: I dread the budget every year - we can't take anymore cut backs – Irish Independent – 11 October 2013

www.independent.ie/irish-news/the-carer-i-dread-the-budget-every-year-we-cant-take-any-more-cutbacks-29653089.html

Carers 'failed' says husband of right to die campaigner – Irish Independent – 17 October 2013

www.independent.ie/business/budget/carers-failed-says-husband-of-righttodie-campaigner-29667348.html

Tom Curran: Carers have been treated shamefully by this government, we deserve a break – Irish Independent – 17 October 2013

www.independent.ie/opinion/analysis/tom-curran-carers-have-been-treated-shamefully-by-this-government-we-deserve-a-break-29667601.html

Caring in the News

Lack of Hospice beds leaves terminal patients out in the cold – Irish Times – 22 October 2013
www.irishtimes.com/life-and-style/health-family/lack-of-hospice-beds-leaves-terminal-patients-out-in-the-cold-1.1568194

Invisible Carers need our support and recognition – Irish Independent – 27 October 2013
www.independent.ie/lifestyle/health/invisible-carers-need-our-support-and-recognition-29703001.html

Cuts and Austerity in Disability and Other Services – Dail Eireann Debates – 29 October 2013
(courtesy of Oireachtas Report, Brian Harvey)
www.oireachtasbrief.ie/people/taoiseach/1-debates-cuts-and-austerity-in-disability-and-other-services/?lang=en

Anne is Limerick's Carer of the Year – Limerick Post – 31 October 2013
www.limerickpost.ie/2013/10/31/anne-is-limericks-carer-of-the-year/

Carers 'deserve better' than budget cuts, says award winner – The Irish Times – 5 November 2013
www.irishtimes.com/news/politics/carers-deserve-better-than-budget-cuts-says-award-winner-1.1584975

Selfless teen with arthritis wins carer award for looking after autistic brother – The Irish Independent – 6 November 2013
www.independent.ie/irish-news/selfless-teen-with-arthritis-wins-carer-award-for-looking-after-autistic-brother-29730376.html

International News

NHS Scotland Launches Carers Training Initiative

The Scottish national carers strategy Caring Together 2010-15 contained specific actions on workforce education and training.

Gill Ryan (former editor of this newsletter) is leading the Equal Partners in Care (EPiC) project to ensure a joint approach across NHS and social services staff.



A nationally agreed framework to support workforce learning has been developed, based on key outcomes for carers. The EPiC Core Principles for Working with Carers and Young Carers are supported by online learning resources which can be used to plan workforce training in various settings or for staff to reflect on their practice. They are free to access and may be useful to educators or organisations planning similar training in Ireland.

For more information see: www.knowledge.scot.nhs.uk/equalpartnersincare.

EU Social Platform Makes Clear Recommendations around Informal Care

Recommendations for informal care givers to have an adequate balance between care, work and private life



The platform argues that reconciliation policies require a comprehensive approach, based on the five fundamental rights protected by the Charter of Fundamental Rights of the European Union: the right to equality between men and women (art. 23), the right to private and family life (art. 7), the right to fair and just working conditions (art. 31), the right to quality public services (art. 36) and the right to a high level of social protection (art. 34).

Members of the platform want to ensure that reconciliation policies:

- Guarantee that responsibility for care is based on equality for all, and that informal care work is shared between men and women and generations
- Ensure the respect of fundamental rights of caregivers
- Recognise and support informal and family care
- Recognise and support the role that volunteers bring to formal and informal care.

About the Social Platform

It is the largest civil society alliance fighting for social justice and participatory democracy in Europe. It consists of 46 pan-European networks of NGOs. It campaigns to ensure that EU policies are developed in partnership with the people they affect, respecting fundamental rights, promoting solidarity and improving lives.

See more at: www.socialplatform.org.

International News

Why an EU strategy on carers would work



The Social Platform was invited to the European Parliament interest group on carers on 15 October 2013 by Marian Harkin MEP, chair of this interest group, to discuss an EU strategy on carers.

Informal and family care is a largely ignored sector of the economy and virtually invisible to policy makers. Approximately 80% of all care across the EU is given by Family Carers. They are currently some 19 million informal care givers in Europe.

Pierre Baussand, Director of the Social Platform, highlighted key issues relative to carers' situations. Nowadays an overwhelming **majority of carers are women**. They represent about 80% of carers. This is a clear infringement of the equality between men and women legislation, and it prevents women from achieving their full human development potential.

The effects of the crisis and austerity measures have dramatically affected carers in the past few years. The crisis has worsened the social situation of many people: more and more of them have been in the need of care while at the same time, numerous cuts have been made on many supports such as disability benefit, child benefit and pension reforms.

First carers should be **recognised** and **supported** through legislative measures such as more flexible working time arrangements.

But the future should not rely on informal care. We need more **social protection**.

Public policies should urgently give people more independence, for example, by reducing the high cost of the health system or facilitating the accessibility of housing.

This phenomenon is actually occurring in all member states. **Therefore it becomes a European issue and an EU level answer should be given.**

See more at: www.socialplatform.org/news/why-a-eu-strategy-on-carers-would-work.

International News

Rates of Pay for Care Workers Under Threat in the UK



**Council funding cuts force care firms to pay less than the minimum wage
120 providers to be investigated by HM Revenue & Customs over contract bids that are too cheap to pay legal minimum**

Randeep Ramesh, 22 October 2013, The Guardian

Cuts in council funding mean that rising numbers of care firms are having to break the law by employing workers at below the minimum wage, the head of the Low Pay Commission has warned.

David Norgrove told the Guardian that councils were sometimes dramatically slashing the rates that they paid care companies to wash, feed and dress the elderly and frail; and this was happening so fast that the firms concerned were using ruses to get round the £6.31-an-hour minimum pay rate.

The commission has been told that Her Majesty's Revenue and Customs has identified 120 care providers – almost equivalent to one in every English local authority area – for investigation. "HMRC are working on this as a priority. People should not be bidding for contracts at rates which cannot pay the legislated national minimum wage," said Norgrove, the chair of the commission.

To cut costs, he added, care companies were in "increasing numbers" hitting on a number of tactics, such as not paying for travel time between visits. He could not condone this behaviour, but added: "We are hearing from companies who say that they cannot pay for travel time on the rates that local authorities are paying them. This is a growing problem which is a consequence of rates being dropped, sometimes dramatically, by councils."

Care workers interviewed by the Guardian confirm that companies are blaming cuts in local authority funding for deteriorating pay. Alex, 21, is a carer in the West Midlands who left college two years ago because the money "was real good a few years ago. I was earning £1,300 a month".

However, after cuts in social care budgets, his employer has squeezed his wages to just £900 a month by using zero-hour contracts and tracking devices to ensure that the time, location and duration of visits are logged. In Alex's case, this means he is paid by the minute.

"I am only paid for the time I spent with the client. So even though my timesheet says I am booked for a 30-minute slot, if I work 21 minutes then that's all I get paid for. With the travel time I am making less than the minimum wage," he said. "The company just says it's the council who are to blame because they are cutting their spending."

To read the full article, see: www.theguardian.com/society/2013/oct/22/council-funding-cuts-care-homes-minimum-wage.

International News

The 10 Most Important Attributes of a Care Home



1) Values must be held at the top

The culture is crucial. The views of the chief executive, expressed privately behind their office door, must reflect the fundamentals of integrity, honesty, mutual respect and humanity in relation to the management of their business.

2) Qualities of the manager

Managers need to:

- be confident, empathetic, energetic, capable and kind;
- lead bravely and understand their own accountability and their staff's;
- know when to ask for help, and be fully supported, practically and emotionally.

3) Staff must be supported

Staff in a good care home are its heart and model its values. They must be respected, supported, well treated and valued. Their emotional as well as employment needs should be recognised and understood. They must be fairly paid – at least the Living Wage.

4) Clarity of purpose

Good care homes manage risk, regulation and paperwork in an adult way and focus on relationships and people. They never allow the 'system' and 'bureaucracy' to become their main purpose.

5) A community of people

Good care homes try not to refer to 'the residents' as there is no such homogeneous group. There is no such thing as a 'good 42-bed care home'. There are, however, places where 42 individuals live well together and share some communal space, time and company.

6) A home is 'lived in'

The environment is clean, tidy and well designed but any tendency to look and feel like a clinic is resisted. It is obvious that individuals have control over their own space.

7) Engagement

Good care homes are engaged with their community. The local community takes responsibility too and encourages, cherishes and supports. Good care homes are welcoming places to visit.

8) Working with the health community

Good care homes have good relationships with the local health community – GPs, district nurses, hospital, consultants. They have respect for each other and work together to find solutions with the person at the centre.

9) Working with relatives

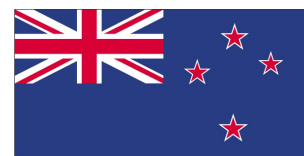
Relatives are confident in the values of the care home. They are able to challenge when needed and to thank. They can let the staff do their job with confidence. They understand that staff are people too and have their own relationships with the people who live there.

10) Regulatory support

Commissioners and regulators trust the care home and engage in an appreciative way, supporting it as a valued part of the 'whole' system. They share their knowledge, experiences and good ideas. They challenge and hold to account but they don't place bureaucratic and ineffectual burdens on them.

International News

New Zealand Government's Payment for Family Carers Introduced



The New Zealand Carers Alliance is a coalition of 45 not-for-profit organisations formed to advocate for the rights of Family Carers. It says a new Government payment scheme for Family Carers will create more problems than it solves. Its Chairman, John Forman, said it will do nothing other than pit disabled people against their closest loved ones, by introducing an employer dimension into family relationships.

“It takes no account of the fact that the 1600 carers who qualify are in many cases also the disabled person’s parent – putting the decision-making on the shoulders of a person who may be severely or profoundly disabled. In addition, there are so many service and compliance layers that it will cost a fortune to monitor,” John Forman said.

“In its announcement the Government makes much of the fact that it consulted with experts to craft this policy. The feedback we provided was ignored, and the result is the Funded Family Care payment is a dog’s breakfast. It’s not nice, it’s not right, and it won’t work,” he said. He said the best that could be said of the scheme is that there are 1600 carers who will be paid the minimum wage for some of their work. However, he said it was a ‘cheap and dirty’ response to a major social policy issue, and a raw deal for carers and those they support. He said a more workable solution would have been for Family Carers to be paid directly by the Government as independent contractors. This would have been far more practical, and respectful of people with disabilities and their families, he said.

Released without fanfare, the new Funded Family Care scheme will see high-needs disabled people having to employ their parents or other close family members, as well as oversee compliance tasks such as ACC levies and Kiwisaver contributions. The Government has been secretive about details on how it will work, perhaps knowing it would get an unfavourable response from carers and their advocates.

Family Carers, who support New Zealand’s ill, elderly, and disabled loved ones at home, had hoped for better following a long-running human rights battle to recognise their unpaid work. Last year the Government agreed to take the issue out of the courts and work with affected parties to find a solution. Following a public consultation, it announced that it would pay 1600 parents of disabled adults who have high support needs the minimum wage for up to 40 hours per week, injecting \$92 million over four years into the new payment.

For more information about the NZ Carers Alliance, go to www.carers.net.nz/home.



International News

Carers and Employment in the UK – 13 Specific Recommendations Made



A recent report by the UK Government, Employers for Carers and Carers UK, sets out the economic case for supporting the growing number of workers who also care for older or disabled relatives.

The report states: “(we) believe that the issue of supporting carers to remain in work is not only a problem, but also an economic opportunity. Supporting carers to remain in work can bring considerable benefits to carers themselves, employers and the wider economy. The Group therefore believes that there are a number of concrete, realistic and affordable steps that the Government, local authorities and employers can and should take to support carers to remain in work.”

To view the full report go to: www.employersforcarers.org/resources/research/item/808-supporting-working-carers-the-benefits-to-families-business-and-the-economy.

US - Caregiving Commission on Long-Term Care releases Final Report



In recent weeks, the [Commission on Long-Term Care](#) released its much awaited Final Report to the US Congress. The US based National Alliance of Caregiving is pleased that it emphasises the valuable role of family caregivers in the care process. The report contains 28 public policy recommendations for improving the delivery of long-term care services and supports. The report does not offer recommendations for reforming long-term care financing.

For more information on the Commission's work:

- Review the [report's recommendations](#) on family caregiving (pages 51-54).
- Review a [PowerPoint presentation](#) on the report.
- [Read the report](#) in its entirety (115 pages).
- [Watch the briefing](#) on the report's release (webcast).

About Us

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

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

There are approximately 274,000 Family Carers in the Republic of Ireland. Family Carer support is provided by a number of organisations, including those dedicated solely to carer support and others who support carers as part of their response to individuals with specific conditions.

We work with our 99 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

Contact Us:

T +353 1 874 7776
M +353 87 207 3265
A Coleraine House, Coleraine Street, Dublin 7
E info@carealliance.ie
W www.carealliance.ie
Company Limited By Guarantee
Registered in Dublin, Ireland, company address as above
Company Registration No 461315 CHY No 1464

10 Reasons To Join Us

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