

# Care Alliance Ireland Exchange

Summer 2012 Issue 37

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## National Carers Strategy - Publication Back on Track

Having been suspended in early 2009, Minister Kathleen Lynch TD and the Department of Health have announced that the long-awaited National Carers Strategy will be published this year.

Care Alliance Ireland, together with other carer organisations, will be meeting with departmental officials on 10th May, and will have the opportunity to review and comment on a draft strategy. Whilst the consultation process remains somewhat unclear we are nonetheless happy that there is at last some progress.

As part of our remit as an alliance, we have invited all of our 88 member organisations to input to the process by identifying key issues they would like addressed in any strategy document. We have collated the responses and will ensure that this informs the Alliance’s position.

We look forward to being active participants in this process and hope that any strategy will have a clear timeframe for implementation and will improve the lives of Ireland’s 274,000 Family Carers.

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## National Carers Week - RTE’s Nuala Carey supporting the cause

Taking place from 18th – 24th June, we are delighted to have Nuala Carey (RTE) on board to support us with this year’s Carers Week.

Co-ordinator Jennifer Jackson has been joined by volunteer Katherine Mulfaul in ensuring Carers Week 2012 is the best yet. Exciting developments will include a Carers Week facebook page, visits to the national gallery, and a possible meeting with members of the Oireachtas.

Find us on Facebook



# Member News

## Irish Hospice Foundation Strategic Plan 2012-2015



The Irish Hospice Foundation (IHF) recently launched its new strategic plan. Over the next three years, the IHF want to see their vision further realised, namely that no one should face death or bereavement without the care and support they need.

This strategy of ensuring the sustainability of existing programmes and continuing to explore how to bring quality palliative care to the entire population, including the marginalised, is in line with their mission ‘to achieve dignity, comfort and choice for all people facing the end of life.’

The strategy details five key objectives under the following headings:

- Influencing and challenging
- Achieving change through capacity building and partnership
- Innovating and pioneering
- Communicating, educating and empowering
- Maintaining independence, organisational health and sustainability

You can download the full document from:

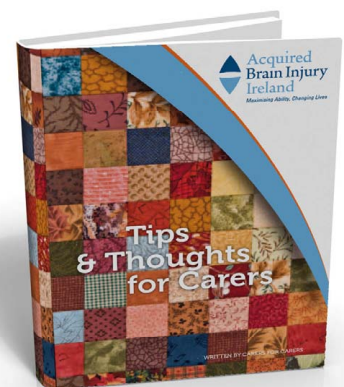
[http://www.hospice-foundation.ie/index.php?option=com\\_content&view=article&id=689&Itemid=416](http://www.hospice-foundation.ie/index.php?option=com_content&view=article&id=689&Itemid=416)

‘to achieve  
dignity, comfort  
and choice for all  
people facing the  
end of life’

## ABI Caring Booklet Available Now

Building on their successful and award winning Family Carer Training programme, Acquired Brain Injury Ireland have put together a booklet called ‘100 Tips and Thoughts for Carers’. Put together by carers of those affected by brain injuries, it is an insightful and easy read for all carers.

To order copies for €5 each please contact Aoife on (01) 280 4164 extn 207 or [aopredergast@abiireland.ie](mailto:aopredergast@abiireland.ie)



# Member News

## Young Carer Shares her Story of Caring with Nursing Students

On 27th April, the 2011 National Young Carer of the Year Kelly Farrell was welcomed to the Waterford Institute of Technology (WIT). Kelly related her experiences of family caring to a group of students, staff, lecturers and other interested parties. Kelly’s presentation offered valuable insights into the role of young child/teenage carers within our communities. This was an excellent source of learning for students, providing them with ‘real life’ expressions of caring within the world of a young carer.

Carers provide extensive care to family members in the home, ranging from physical care, administering medication, psychosocial and economic support, as well as assistance with a range of activities of living. The role of carer creates a further challenge to the young person’s participation in education, at a time when they are experiencing the milestones of childhood and adolescence.

Speaking at the event, Dr Paula Lane, a Board Member of Care Alliance Ireland, and a lecturer in the Department of Nursing, School of Health Sciences at WIT, said:

“Since health policy directions and Government initiatives are moving towards more community and primary health care settings, it is imperative that the roles and responsibilities of young carers are sufficiently understood and supported. Carers are very important contributors to social capital within the fabric of Irish life. Specifically, the need for research evidence examining young carers’ lives has become increasingly important towards informing our population health.”



Group of Waterford Institute of Technology student nurses with lecturers Miriam Cass, Brian Sharvin, Dr Paula Lane and Young Carer of the Year Kelley Farrell, with her parents Nuala and Sean Farrell, at a presentation to students and staff on the ‘experiences of a young family carer’.

# Member News

## Muscular Dystrophy Ireland Home from Home Apartment

Whether you are going to a hospital appointment, concert or social event, finding reasonably priced fully accessible accommodation in Dublin can be a challenge. With this in mind, Muscular Dystrophy Ireland (MDI) recently opened its new, purpose-built ‘Home from Home Apartment’ in Chapelizod, Dublin 20.

The Home from Home Apartment is a self-catering, wheelchair accessible, three bedroomed apartment adapted to the highest specification to empower and promote independent living for people with physical and sensory disabilities. This apartment provides breaks for people with disabilities and their families. It is about ensuring that the disabled person is part of the community. It also provides the opportunity to book the apartment as a whole family. As the project is based on the social model of disability it is based in the community with access to local services.

This self-contained apartment is available for short-term breaks ranging from one to seven nights. MDI’s Barry Buckley explains, “The purpose of the apartment is to provide stress-free accommodation for people with physical disabilities and their families visiting Dublin. We hope this might make it easier to attend an appointment, visit a friend in hospital, or simply enjoy a short break.”

Patrick Doocey, a member of MDI who has used the apartment on several occasions in recent months, is keen to encourage others to try the facility. “The philosophy of the accommodation is to promote independence for those who normally find themselves dependant on others. The apartment is modern and has all the resources you could need, including inter-room ceiling hoists, manual hoists, profile beds, air mattresses and accessible en suite bathrooms. When you arrive, the staff are friendly and welcoming, and there is also the option of availing of a self-drive accessible Volkswagen Transporter.”

The apartment includes three accessible twin and double rooms and one PA room. It can accommodate groups of one to six, and guests are asked to make a voluntary contribution of €25 per room, per night.

To find out more or to make a booking, call (01) 623 6414 or visit [www.mdi.ie](http://www.mdi.ie)



# Dates For Your Diary

## May - September 2012

### 23 May

Enabling Independent Living through advancing Universal Design of Telecare & Telehealth

When: 9:15– 13:00 Wednesday, 23rd May, 2012

Where: Croke Park Conference Centre, Dublin 1

The seminar will investigate the benefits of using telehealth/telecare technology within Irish health and social care settings and inform NDA research and advice to guide national policy.

More details, updates and speaker biographies, can be accessed at [www.universaldesign.ie](http://www.universaldesign.ie)



### 22-23 May

Eurocarers Annual General Meeting 2012 will be held in Varberg in Sweden (just south of Gothenburg) in May.

The AGM will be on 22 May and the Conference on 23 May.

For further details and to register please log-on to: [www.ahrisverige.se](http://www.ahrisverige.se)



### 28 May

Understanding the role of the Chair and the CEO

This one day training course is the perfect learning environment for both seasoned practitioners or those just stepping up to the top job.

Date: 28th May 2012

Venue: Arthur Cox, Earlsfort Plaza, Earlsfort Terrace, Dublin 2

To book, contact Eva Gurn in Boardmatch Ireland (01) 671 5005

Course fee of €395 must be paid prior to attending.

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

**Boardmatch Ireland**  
inspiring leadership and good governance



# Dates For Your Diary

## May - September 2012

30 May

World MS Day

MS Ireland are asking people to get involved in marking World MS Day. Find out about events and activities in your area at <http://worldmsday.ms-society.ie/world-ms-day>



18-24 June

National Carers Week is an annual celebration of the work of Family Carers in Ireland. It is co-ordinated by Care Alliance Ireland in partnership with eight other leading Irish charities who support family carers.

For more information, see [www.carersweek.ie](http://www.carersweek.ie)

To take part, contact: [info@carersweek.ie](mailto:info@carersweek.ie)



25 September

Young Carers Seminar

Date: 10am- 1pm, Tuesday 25th September

Venue: The Carmichael Centre, Dublin 7

The seminar is organised by Care Alliance Ireland, Crosscare and the Carers Association.

To book your place contact: [ndo@carealliance.ie](mailto:ndo@carealliance.ie)



INNOVATION & ACTION FOR SOCIAL CHANGE



# National News

## Governance Code Published for the Community and Voluntary Sector

The final version of the Governance Code has been published following extensive feedback during the public consultation phase (May to end July 2011). Over that period, a total of 112 written submissions were received and 140 additional inputs were made by groups/interests via workshops, webinars and emails.

The feedback represented a hugely diverse response, comprising input from individual charities, voluntary and community organisations, umbrella representative bodies, fundraisers, grant-makers, government departments, lawyers, trainers, educational institutions, students of post-graduate studies on the Third Sector, accountants, non-profit practitioners, retired public service officials, politicians and members of the public.

Care Alliance Ireland welcomes this Code and encourages its members and other relevant organisations to consider signing their organisation up to it.

For further information see [www.governancecode.ie](http://www.governancecode.ie)

Care Alliance Ireland encourages its members and other relevant organisations to consider signing up to the Code

## Care Alliance Executive Director becomes Senior Member of IMCV

Liam O’Sullivan, who has headed up Care Alliance Ireland since August 2004, has recently been accepted as a Senior Member of the Institute for Managers of Community and Voluntary Organisations (IMCV).

Speaking on his recent admission, Liam said “I am delighted and honoured to be accepted into the IMCV’s membership and encourage all managers in our sector to consider applying for membership. It’s long overdue that the sector has such an organisation, which will support professional development and will in time provide opportunities for accredited CPD.”

For further details see [www.imcv.ie](http://www.imcv.ie)



# Member Profile 1

## Hand in Hand

Hand in Hand is a non-profit organisation based in Galway. We support families in Donegal, Sligo, Mayo, Leitrim, Roscommon, Galway, Clare and Limerick who are affected by childhood cancer, by providing them with practical support. Hand in Hand (formerly CD’s Helping Hands) was established by a group of volunteers in 2006 who were inspired by a two-year-old Galway girl who was receiving treatment for leukaemia.



Today Hand in Hand seeks to help the families of children with cancer in the West of Ireland who have the added stress of travelling long distances to Dublin for their primary treatment. In most cases there are other siblings to care for while mum, dad or carer travels to hospital with their sick child. Our focus is to support the children and their carers in order to minimise the impact that both the diagnosis and frequent long distance travel has on family life. By availing of our services carers find they have more precious time to care for their ill child. We are a unique charity in that we are the only organisation in Ireland to support children and their families throughout the process of cancer treatment, which for many children will extend to years.

### What do we do?

We tailor our services to each family’s needs, engaging local services to provide the following support during and immediately after their child’s cancer treatment:

- Support with childcare
- Domestic cleaning services
- Household laundry
- Meal provision

### How does this help?

- Lessens the stress, worry and emotional trauma within the family
- Provides precious time for parents/carers to spend with the unwell child
- Gives peace of mind to parents/carers that their other children are being well cared for
- Helps one parent/carer to continue working throughout the treatment
- Provides the opportunity for parents/carers to take a ‘well earned break’ once in a while

“Hand in Hand seeks to help the families of children with cancer in the West of Ireland who have the added stress of travelling long distances to Dublin for their primary treatment”

For more information, please visit [www.handinhand.ie](http://www.handinhand.ie)

Find us on Facebook [www.facebook.com/handinhandwest](https://www.facebook.com/handinhandwest) or on [twitter@handinhandwest](https://twitter.com/handinhandwest)



## Member Profile 2

### The Brothers of Charity Services

The Brothers of Charity Services are committed to working with people with intellectual disability to claim their rightful place as valued and equal citizens. Our Services have their origin in the vision and dynamism of Canon Peter Triest (1760-1836) who founded the Congregation of the Brothers of Charity in 1807. In keeping with our ethos, we work to develop individualised supports and services based on the needs and choices of each person. We are the largest service provider for people with intellectual disability in the country. The Brothers of Charity Services in Ireland today are made up of an overall total of 6,000 people who use some form of our services and their families, and approximately 3,000 staff.

The Brothers of Charity Services is governed and directed by a national company whose directors are made up of Brother Members of the Congregation of the Brothers of Charity and lay people. The national company acts as the corporate entity representing the Congregation of the Brothers of Charity Services in Ireland. There are six subsidiary companies, one for each geographical region of the services, located throughout the West, Mid-West, South and South East of Ireland. Each company has responsibility for the management and provision of the services in the geographical region where that company is based. Each company has its own annual budget received mainly from the Health Service Executive. The national company and each of the service companies adhere to and promote the ethos and principles of the Brothers of Charity Congregation in the management and delivery of the services.

Service delivery is influenced by the stated needs of people who use our services. Services are designed around the individual and are measured using an accredited quality system. Personal Outcome Measures focus on the items and issues that matter most to individuals in their lives. We provide ‘individually based supports’ for people, in order that they may achieve their own life goals.

For further details please view our website [www.brothersofcharity.ie](http://www.brothersofcharity.ie)



“we work to develop individualised supports and services for the 6,000 people with intellectual disability who use our services”

# Resources

## Managing Carer Stress: Facts About Caring (US)

by Jane Hamilton (extract)

Although it's meaningful and gratifying, caring for others isn't easy. Over time, it can take a toll on body and mind, heart and soul, personal finances, family relationships, and work life. It can erode your immune system and increase susceptibility to disease, depression, or hospitalisation.

Approximately 20 to 30 percent of family carers suffer from mood disturbances and use prescription drugs for depression, anxiety, and insomnia : two to three times as often as the general population. If you're a carer, you need to preserve your health and capacity to care by managing your stress.

### Stress Management Suggestions

Like other carers who are coping with stress, you most likely try to keep your life in balance and do things to take care of yourself. What are ways you usually handle stress?

- ☐ Care for yourself as you care for others
- ☐ Avoid stress numbing behaviours
- ☐ Acknowledge that you're human, not a caring machine
- ☐ Conserve your energy
- ☐ Replenish your energy
- ☐ Cultivate community

When self-care is not enough, remember that professionals are able and willing to help. Seek their medical advice or psychological counselling services. Whatever you do to care for yourself will be good for both you and your loved ones. As you do so much for others, remember to take good care of yourself, too!

See the full article at <http://aginginaction.com/category/caring/family-caring/>

“Caring can take a toll on body and mind, heart and soul, personal finances, family relationships and work life”

“Acknowledge that you're human, not a caring machine”

# Caring in the News

## Media coverage on issues related to caring since March 2012

Carer's allowance not to be part of single welfare payment – The Irish Times – 6th May 2012  
<http://www.irishtimes.com/newspaper/ireland/2012/0426/1224315195411.html>

Taoiseach denies government targeting autistic children - The Irish Times - 25th April 2012  
<http://www.irishtimes.com/newspaper/ireland/2012/0425/1224315147918.html>

Legal challenge by mother of son with behavioural disorders - The Irish Times - 17th April 2012  
<http://www.irishtimes.com/newspaper/ireland/2012/0417/1224314823895.html>

Health Services for people with autism poorly developed - The Irish Times - 2nd April 2012  
<http://www.irishtimes.com/newspaper/opinion/2012/0402/1224314230574.html>

Smell ‘alarm’ prompts dementia sufferers to eat - The Irish Independent - 27th April 2012  
<http://www.independent.ie/health/health-news/smell-alarm-prompts-dementia-sufferers-to-eat-3094364.html>

Another trial for the children who can't take care of themselves - The Irish Independent - 27th April 2012  
<http://www.independent.ie/opinion/letters/another-trial-for-the-children-who-cant-take-care-of-themselves-3093698.html>

Start up of the Day - Neuro Hero - The Sunday Business Post - 4th April 2012  
<http://www.businesspost.ie/#!/story/Home/News/Start-up+of+the+day%3A+Neuro+Hero/id/19410615-5218-4f7b-ec20-0b2880890783>

Family Carers under Siege - The Bray People - 21st March 2012  
<http://www.braypeople.ie/news/family-carers-under-siege-3058255.html>

Westmeath's lady footballers team up for Family Carers - Westmeath Examiner - 15th March 2012  
<http://www.westmeathexaminer.ie/news/roundup/articles/2012/03/03/4009318-westmeaths-lady-footballers-team-up-for-family-carers/>

West Cork Carer is runner up in National Poetry Competition - West Cork Times - 5th March 2012  
<http://westcorktimes.com/home/?p=6500>

Common cholesterol medication can halt Alzheimer's progress say doctors - The Irish Independent - 4th April 2012  
<http://www.independent.ie/health/health-news/common-cholesterol-medication-can-halt-alzheimers-progress-doctors-3070238.html>

# Research & Practice

## Improving Transitional Care by Involving Family Carers (US)

Carol Levine, Director, Families and Health Care Project, United Hospital Fund



Current practice (with notable exceptions) assumes that the about-to-be-discharged hospital patient is well enough, strong enough, alert enough, and savvy enough to manage his or her own care, with a little information from hospital staff and a reminder to follow up with a primary care physician.

Many transition plans assume a considerable amount of family care. The best-laid transition plans will fall apart if one key partner—the family—cannot fulfil professional expectations.

- If family is not involved in planning, they may not understand what is expected of them.
- They also have no opportunity to refuse, or to have barriers accounted for in the care plan.

Collaborative-Wide Results, December 2010-May 2011

- 1,086 family carers identified; only a third had needs assessed
- Participation of family carers in medication reconciliation increased from 53% to 84%
- Average of 3 medication discrepancies identified
- Medication reconciliation took place one full day earlier
- 95% of carers had questions about medications
- Training and education took place earlier in care episode (day BEFORE discharge in hospital; week before discharge in SNF)
- Carers reported better prepared; staff reported fewer post-discharge “fires to put out”

### Conclusions

If family involvement in transitional care is really valued, then it must be:

- Recognised in specific actions
- Measured in meaningful ways
- Paid for appropriately
- Monitored for accountability

If family is not involved in discharge planning, they may not understand what is expected of them.

View full presentation of findings at <http://www.uhfnyc.org/publications/880807>

# Research & Practice

## Do baby-boomers care?

Nancy Guberman

extract of blog found at

<http://blog.oup.com/2012/03/baby-boomer-carers/>

Do baby-boomers see care as a normal, natural extension of family obligations? A recent study in Quebec, Canada reveals that if baby-boomers in that province do consider care a family responsibility, they have a much more limited understanding of what this care entails than their predecessors and the state.

Indeed, in a context where governments are expecting more and more from family carers, baby-boomer carers are telling researchers that they have a new concept of care. From their point of view, family members should be responsible for offering emotional and moral support, and accompanying the disabled or ill family member to appointments. In contrast, they believe that hands-on physical and nursing tasks (bathing, feeding, giving injections, etc.) should be assumed by home care services or assisted living residences.

These findings come from a study we undertook – “Baby Boom Carers: Care in the Age of Individualization” – to answer practitioners’ questions concerning the changing portrait of family carers they work with. To better understand the realities of this generation of carers, we met with thirty-nine carers (31 women and 8 men) born between 1945 and 1959 to talk about their caring experience.

The baby-boomers in our study appear to have a new conception of care whereby the documented, negative consequences of caring such as poor mental and physical health, sacrificed personal and family life, or impacts on employment, are no longer considered legitimate.

Additionally, many of our respondents spoke about the restrictions they put on the caring they do offer, particularly concerning the tasks they are willing to assume and the frequency of their help. They are thus very open to delegating much of the caring, particularly the hands-on tasks, to service providers.

So although baby-boomers don’t abdicate their responsibility to their ill and disabled family members, for most caring is not their only or even their dominant identity.

“the documented, negative consequences of caring such as poor mental and physical health, sacrificed personal and family life, or impacts on employment, are no longer considered legitimate”

# Research & Practice

## Report: Italians Rely on Mostly Immigrant Workforce for Caring

A recent report analyses the direct care workforce in Italy through interviews with direct care workers. The authors explain that the public provision of care is fairly limited, and while women had historically served as family carers, the changing economy means that fewer women are taking on this role. As a result, the main “pillar” of social care (not medical) for the elderly are the estimated 780,000 Personal Assistants (badanti), who are personally recruited by the family of the care recipient and are hired on an informal basis.

“Once there were wives and daughters, now there are badanti”

It is estimated that 90% of the badanti are foreign workers. The cost of hiring a personal assistant in the underground market is 30-40% less than going through the regular market channels. All of the experts interviewed for the paper explained that the largest issue related to these carers is the lack of a regulatory agency to monitor what happens in the home between the worker and care receiver.

The personal assistants who were interviewed preferred being directly hired by a family (rather than through a publicly-funded programme) because the publicly-funded programmes include an Individual Care Plan which specifies few and limited hours of assistance. In addition, there are means tests to qualify for publicly-funded care, meaning the recipient lives in poor social and housing conditions, as compared to working in a private household that has the financial capability to hire direct workers. For more information, visit:

[http://www.walqing.eu/fileadmin/download/external\\_website/WALQING\\_SocialPartnershipSeries\\_2011.14\\_ElderlyCare\\_ITA.pdf](http://www.walqing.eu/fileadmin/download/external_website/WALQING_SocialPartnershipSeries_2011.14_ElderlyCare_ITA.pdf)



# Research & Practice

## The social economy of ageing : Job quality and pathways beyond the labour market in Europe

Centre d'Economie de la Sorbonne

A recent report uses data on employed Europeans aged 50-65 to estimate the effect of job quality on participation in the labour market, social activities, and caring. Similar to past research, their model finds that women are more likely to be carers, and the model also finds that age had a negative impact on whether or not a person is employed.

While the model finds that the necessity to provide care did not appear to be a factor of people leaving jobs early, being employed full-time did reduce the chance of being a carer. The authors note that this may not account for the possibility of shared obligations within families, financial transfers, access to formal care, and the possibility of work/family arrangements.

In addition, while this study is focused on employed seniors, “the burden of informal care is to a large extent carried by inactive and unemployed females of this generation.” Participating in social activities increased the likelihood of being a carer, and the authors suggest that the positive rewards people receive from social activities may make them more likely to be a carer to members of their club, association, or network.

For more information, visit:

<ftp://mse.univ-paris1.fr/pub/mse/CES2011/11066.pdf>

“being employed full-time reduced the chance of the senior being a carer”

# 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 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:

<http://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](mailto:info@carealliance.ie)

**W** [www.carealliance.ie](http://www.carealliance.ie)

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**10** **Reasons  
To Join Us**

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