

## In this issue

Young Carers 2

Caring at end of life 3

Neuro games 4

Dates for your Diary 5

Boardmatch 6

Joint Statement on Disability 7

Dail debates 8

Caring in the News 9

International News 10

Research and Practice 11-15

Quality Management course 15

About Care Alliance Ireland 16

## ‘Between Worlds’ Report on Former Family Carers Launched

A report on former family carers, ‘Between worlds: The Experiences and Needs of Former Family Carers’, by the School of Nursing and Midwifery at Trinity College Dublin and Care Alliance Ireland was launched on 29 September at Trinity College Dublin.

Principal investigator and Head of the School of Nursing & Midwifery, Professor Mary McCarron said: “This study, the first of its kind in Ireland, is an important first step in recognising the experiences and needs of people who are no longer caring for their loved ones. As one participant described it; ‘you’re in no world, your pre-caring world has gone, your caring world has gone, you’re left with no world’.”

The former carers who took part in this study pointed out that there are no statutory health or social care services in place for former carers.

This is a major issue and there appears to be a need for a formalised system of support that addresses the potential poverty trap and the risk of long-term unemployment as a consequence of opportunities lost during full-time caring. The report found that extending the Carer’s Allowance and more flexibility in social welfare regulations should be considered. There should also be a ‘toolkit’ to help prepare carers for when caring ends, with information on what to expect and where to go for help and advice.

Finally, former carers know a lot about the health and social care services system and health workers in their area. They would like to be able to share this with new and current carers who could benefit from their advice and guidance.



*“For the first time in an Irish context, this research documents the unmet needs of Ireland’s former Family Carers. We in Care Alliance Ireland will do all in our power to secure suitable supports and recognition for this group of people who have given so much of themselves to their loved ones.”*

Liam O’Sullivan, Executive Director of Care Alliance Ireland

**For a summary of the findings of the report, see page 10**

## Young Carers Seminar Well Received

Over 40 people from 25 organisations took part in a joint seminar on September 19th co-hosted by Care Alliance Ireland and Crosscare (Carer Support). A range of disciplines were represented from both the statutory and NGO sectors including education, health and social care, youth work to name but a few.

The seminar looked at the unmet needs of Young Carers in Ireland. The event went some way towards creating a greater understanding of the issues facing young carers today and the important role they play within their families and the contribution they make to the wider community. Significant media coverage was secured which added to the impact of the initiative.

Speakers at the seminar included Tony McGurk of Barnardos Northern Ireland, as well as other professionals involved in supporting young carers. A comprehensive seminar pack was given to all the participants and included various practice resources as well as the latest research on the issue.

The feedback received in the evaluation was very positive, with participants looking forward to using the information they got from the seminar to build momentum with regard to young carers initiatives within their own organisations.

A full report on the seminar will be available shortly.



*Sonya Brady and Jennifer Kavanagh, City of Dublin Youth Service, presenting at the Young Carers Seminar.*

## Supporting family carers at end of life

In June 2011 the Irish Hospice Foundation and Care Alliance Ireland hosted a lunchtime seminar for organisations supporting family carers of people with advancing life limiting disease. Over 30 people participated in the seminar which included representation from various carers and disability organisations.

When participants were asked to identify the issues that present for both paid and family carers, as they respond to the support people who are facing death, several helpful recommendations were made. These ranged from developing guides and fact sheets to help communication in sensitive areas, to accessing more up to date information on the health status of the people they are caring for. There was agreement that both paid and family carers experience acute sense of isolation and often burnout in this period of illness, and it was agreed that more specific training would help paid carers to understand the impact of caring for people with life limiting disease.

Progress has already been made on some issues presented at the seminar. In seeking to develop carers' information requirements, the Irish Hospice Foundation would like you to respond to the online survey on [www.carers.ie](http://www.carers.ie). The seminar report is also on the website. In addition, next spring the Irish Hospice Foundation is planning a full day workshop on 'Working with family carers facing death and bereavement'. If you wish to be added to a list of interested parties on this initiative contact: [marie.lynch@hospice-foundation.ie](mailto:marie.lynch@hospice-foundation.ie)



*Participants at the Caring at End of Life seminar co-hosted by Care Alliance Ireland and The Irish Hospice Foundation*

### Limerick News: Caring for Carers

Caring for Carers, Limerick Branch, are now in the process of training all our care workers to FETAC Level 5. The first group of our care workers has just completed the Care of The Older Person, FETAC Level 5. The carers' graduation night was a great success where their achievements were given the just recognition they deserved after months of studying and work experience.

We are busy organising two 'Caring in the Home' courses in both city and county. This course always proves to be very popular with family carers looking for more information on caring.

October 16th is the date of the ladies mini marathon here in Limerick. We are delighted with the number of entrants so far to run, hop or walk for us. This is a great day out for all the family. We can be contacted at 061 469484 regarding any of the above.

## Neuro Hero: games to rebuild relationships

A new company is developing a range of mobile games to help survivors of stroke and brain injury to replace feelings of isolation with fun and interaction.

Neuro Hero is the latest innovation from Dr Aviva Cohen who created the Research & Hope website that presents treatment options after a stroke and the Carers' Sanctuary online magazine for family carers. "When family and friends come to visit someone with brain injury or stroke they often find it difficult to sustain a conversation and unintentionally begin to talk around them. When my husband, Steve, refused to allow visitors over I began to realise why their presence was making him feel so excluded. I wanted to do something practical that would give friends and family members a way to engage and have fun with him and other people living with stroke or brain injury. I came up with the idea of games for mobile devices such as iPhones and iPads after talking to several other carers and realising that we were facing the same problem."

Aviva and her colleagues Catherine Sweeney and Vinny Reynolds have already won the support of NDRC who awarded them with a place on their prestigious LaunchPad program. The team now have the benefit of three months of intensive support and micro seed funding. "We are receiving so much help and encouragement that we are hoping to launch the first of our games into the App Store by Christmas" said Catherine.

"While the emphasis is on fun and collaboration we also want to make sure that every Neuro Hero game provides a therapeutic benefit" explained Vinny, "so we are working with a range of therapists from different disciplines and learning more every day".

It is still very early days for Neuro Hero but they are moving quickly. If you would like to find out more about the games and when they will be available, or if you know someone caring for a person affected by brain injury who has communication difficulties or problems with social interaction and would be willing to trial this game, please contact Aviva at [aviva.cohen@neurohero.com](mailto:aviva.cohen@neurohero.com)

*"I wanted to do something practical that would give friends and family members a way to engage and have fun with people living with stroke or brain injury."*



Tony McGurk, Barnardos Young Carers project, Northern Ireland with Nora Kirrane, Crosscare (Carer Support) at the September 19th Young Carers Seminar

# Dates for Your Diary

## 21 November 2011

The next **Family Carers Research Group** meeting will take place on Monday 21st November from 10.30am - 12.00 in the Carmichael Centre, Dublin 7.

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

## 2&3 November 2011

**CARDI (Centre for Ageing Research and Development in Ireland)  
Conference: Ageing Globally – Ageing Locally**

This event will promote the value and role of ageing-related research specifically for policy and practice. It has been designed to appeal to a range of stakeholders, including policy makers, health, housing and social services providers, industry, voluntary and community organisations, researchers with an interest in ageing, carers and older people.

President of Ireland, Mary McAleese, will officially open the Conference.

Venue: Croke Park, Dublin  
Registration closing: 24 October  
For details see [www.cardi.ie](http://www.cardi.ie)

**ageing  
globally –  
ageing  
locally**

## 17 November 2011



**ABI Information & Education Day For Carers - A One Day Conference for ABI Carers and Professionals**

Acquired Brain Injury Ireland's 2-year Brain Aware Family Carer Training Project has come to an end with the last programme taking place in Letterkenny in May/June this year. To wrap up the project ABI Ireland are planning a one-day ABI Information & Education Day on 17th November 2011 in the Citywest Hotel, Dublin.

The day will give family carers an opportunity to meet other carers and discuss issues of importance to them. For some it may be an opportunity for a reunion with carers they met during the Brain Aware Training programme. For professionals, it will be an opportunity for competency building in the area of ABI and issues for carers as well as a chance to meet with fellow professionals and family carers. The cost of attending is €15.

For further information or to book a place, contact ABI Ireland on (01) 280 4164. A booking form and brochure are available on our website: [www.abiireland.ie/events.html](http://www.abiireland.ie/events.html)



## Do you need new board members?

Getting the right mix of skills, experience and knowledge on your Board is essential to having an effective and high performing board and organisation. Boardmatch offers you an opportunity to recruit skilled and experienced people, from the business and professional, public and private sectors, for your Board. Boardmatch Ireland was established in 2005.

Through Boardmatch you can:

- Get access to skills sets that may not be readily available
- Increase the diversity of your board composition
- Strengthen your board, and your organisation
- Enhance the governance in your organisation
- Develop contacts and relationships with Business

The online service is free and easy to use. Register your organisation at [www.boardmatchireland.ie](http://www.boardmatchireland.ie) or contact Chris White for further information on (01) 671 5005 or [chris@boardmatchireland.ie](mailto:chris@boardmatchireland.ie)

Boardmatch also facilitates the **Chairs Network**, a peer support for chairpersons

of not-for-profit organisations in Ireland. The network was started in 2009 at the behest of some of the organisations we were working with. To date Boardmatch has hosted eight successful meetings, with sponsorship from Grant Thornton and Disability Federation Ireland. Meetings give a forum for chairs to network and to explore common problems and potential solutions.

Boardmatch will continue to co-ordinate the Chairs Network. Dates and times of future meetings will be posted on the website [www.boardmatchireland.ie](http://www.boardmatchireland.ie)

*"Boardmatch is a great resource. We needed to find a new board member who would bring strong financial and corporate governance skills. We filled the position on our first attempt with Boardmatch and have benefited hugely from his input."*

*EIRÍ Corca Baiscinn, West Clare*

## Valuing the Invaluable: 2011 Update

### The Growing Contributions and Costs of Family Caregiving (US)

This report, part of the Valuing the Invaluable series on the economic value of family caring, updates US national and individual state estimates of the economic value of family care using the most current available data. It finds that in 2009, about 42.1 million family carers in the United States provided care to an adult with limitations in daily activities at any given point in time, and about 61.6 million provided care at some time during the year. The estimated economic value of their unpaid contributions was approximately \$450 billion in 2009, up from an estimated \$375 billion in 2007. This report also explains the contributions of caregivers, details the costs and consequences of providing family care, and provides policy recommendations to better support caregiving families.

The full report can be viewed at:

<http://assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf>

# Organisations Representing 800,000 People with Disabilities issue Joint Statement to Government

Ten of the leading umbrella organisations in the Disability Sector met on 15th September in Buswell's Hotel, Dublin, to issue a joint statement of concern, regarding economic and service issues now confronting hundreds of thousands of people. The organisations involved are, Care Alliance Ireland, CIL Carmichael House, Disability Federation of Ireland, Genetic & Rare Disorders Organisation, Inclusion Ireland, Mental Health Reform, Neurological Alliance of Ireland, People with Disabilities in Ireland, The National Federation of Voluntary Bodies, The Not for Profit Business Association. The full text of the Joint Statement is as follows:

## **Preventing the Collapse of Ireland's Disability Strategy**

We the under-signed national voluntary disability organisations, representing the diversity of people with disabilities and disabling conditions including mental health, make this joint statement to Government regarding Budget 2012.

Disability is not a sectoral issue; it is a social issue. 18.5% of the Irish population have one or more disabilities, and the percentage is increasing as our population ages. The Taoiseach, the Tánaiste and the Programme for Government have named people with disabilities including mental health as the Government's social justice priority. Yet the Government cannot tell what has been the impact of the recession on this historically disadvantaged group. The adverse effects have been obscured by the absence of clear lines of accountability and ineffective monitoring of outcomes for people with disabilities.

Those of us in the sector however are acutely aware of the effect of the cumulative reductions in essential income and service supports on people with disabilities that have occurred since the onset of the recession in 2008. It is our view that further pressure on people with disabilities would be unsustainable. We consider Ireland's National Disability Strategy to be on the point of collapse into empty promises.

We jointly call on the Government, through the Comprehensive Review Expenditure and Budget 2012, to deliver on its social justice priority, and ensure that "the quality of life of people with disabilities is enhanced" in Budget 2012. [Programme for Government, page 54]

Action by the Government is urgently needed to:

- **Halt reductions in the income supports for people with disabilities dependent on benefits.**

People with disabilities are most likely to experience real poverty because on top of the recent cuts in benefit levels and new charges, they have to pay for extras required due to their disability.

- **Maintain funding for the services needed by people with disabilities.** Cutting the services required by people with disabilities not only undermines their lives, it also leads to a growing public burden in terms of hospital stays and expensive care costs

- **Publish and Implement Plan for the National Disability Strategy and incorporate it into Budget decision-making by all Departments and public agencies.**

Ireland must plan for this long period of austerity in a manner that protects services and supports for people with disabilities and ensures that real progress is achievable when economic conditions ease.

## Dail debates potential cuts to carers' benefits

During a Dáil Debate in July, Deputies Sandra McLellan and Richard Boyd Barrett asked the Minister for Social Protection in the Dail to confirm that there will be no further cuts to carers' payments in Budget 2012. Minister Joan Burton would not be drawn on this, as a comprehensive review of expenditure is currently under way in all Departments and decisions based on this will be made in December.

She clarified that the figure of 161,000 carers cited represented those identified in the 2006 census as providing as little as one hour of care per week, rather than those in receipt of payments. There are currently just over 51,000 full-time carers in receipt of a carers allowance payment from the Department. This includes almost 22,000 who are receiving half-rate carers allowance in addition to another social welfare payment. There are just over 1,700 people in receipt of carer's benefit. In addition, more than 17,000 people who are not in receipt of a carers payments received the annual respite care grant of €1,700 in June.

She stated that since their introduction, payments to carers have been expanded greatly. Carers allowance was increased in 2007, 2008 and 2009 and recipients are also eligible for household benefits, free travel and the respite care grant. She also suggested that the means test for carers is one of the most liberal means tests in the social welfare system, meaning a couple with two children can earn in the region of €35,400 and qualify for the maximum rate of carers allowance as well as the associated free travel and household benefits.

*carers save the State  
an estimated €2.5  
billion euro per year*

Deputy Aengus Ó Snodaigh raised the issue of a proposed cut in the household benefits package, claiming it has caused "huge anxiety among carers" and asked her to commit to maintaining current rates in payments. Deputy Boyd Barrett pointed out that carers save the State an estimated €2.5 billion euro per year and stated that the cost to the State would be massively higher if those being cared for had to be looked after fully by the State.

While Minister Burton agreed that carers do a very important job she reiterated she was not in a position to make any commitments regarding the outcome of the comprehensive review of expenditure. She noted that during the years when the economy was doing well, an opportunity was lost to develop services which were often as important to carers as cash amounts and she gave an assurance to "do everything I can to ensure carers are treated as fairly as possible within the system".

Deputy Derek Keating raised the issue of delays in applications for carer's allowance being processed. Minister Burton acknowledged this and said she had appointed an extra nine appeals officers who will not just be deciding on appeals from carers, but working throughout the entire appeals structure. She also responded to questions from Deputy David Stanton, Deputy Boyd Barrett and Deputy Ó Snodaigh, saying that the European Union and the IMF have not made any specific mention of carers payments, but that budget 2012 must achieve reductions of €3.6 billion in expenditure across the board. On a number of other matters related to carers, she would come back in more detail when she had looked into them.

**Irish Times - Forgetting about Illness for Arts Sake**

<http://www.irishtimes.com/newspaper/health/2011/0920/1224304402584.html>

**Irish Times - Accept Mental Illness as Part of the Human Condition**

<http://www.irishtimes.com/newspaper/opinion/2011/0914/1224304082253.html>

**Irish Times - 'I am terrified my daughter will die'**

<http://www.irishtimes.com/newspaper/health/2011/0816/1224302518054.html>

**The Examiner - Mandatory Student Community Work would address crisis in care for Elderly**

<http://www.examiner.ie/ireland/mandatory-student-community-service-would-address-crisis-in-care-for-elderly-166835.html>

**Irish Examiner - A broader platform to discuss mental health service concerns**

<http://www.examiner.ie/features/a-broader-platform-to-discuss-mental-health-service-concerns-163333.html>

**Irish Examiner - Young Carers in every community in Ireland**

<http://www.irishexaminer.com/breakingnews/ireland/young-carers-in-every-community-in-ireland-521101.html>

**The Irish Independent - Memory Test identifies Alzheimers early**

<http://www.independent.ie/health/latest-news/memory-test-identifies-alzheimers-early-2869338.html>

**Irish Times - Minister urged to reverse cuts in social welfare**

<http://www.irishtimes.com/newspaper/ireland/2011/0917/1224304267498.html>

**The Irish Independent - 'I just wanted my husband back': One woman shares her personal research into strokes**

<http://www.independent.co.uk/life-style/health-and-families/features/i-just-wanted-my-husband-back-one-woman-shares-her-personal-research-into-strokes-2338143.html>

*“There are only four kinds of people in the world – those who are caregivers, those who were caregivers, those who will be caregivers, and those who will need care.”*

**Rosalynn Carter, Former first lady of the United States,  
Board president of the Rosalynn Carter Institute for Caregiving**

## Providing and paying for long-term care

The OECD has published *Help Wanted? Providing and Paying for Long-Term Care*. It examines questions such as the future of long-term care given the ageing population and demographic and market trends. It also examines the reliance of older people on family and unpaid carers and whether or not these carers should be better supported.

The key points of the report can be summarised as:

The growing need for long-term care (LTC) has significant financing and labour-market implications

All OECD countries need a system providing formal LTC services

LTC workforce challenges appear manageable – though the report

acknowledges that this requires emphasis on improving working conditions

Moving towards universal LTC benefits is desirable irrespective of financing model

With growing cost pressure, seeking better value for money in long-term care is a priority

The report concludes that LTC services and settings are difficult to manage. Long-term care policies interact with other social policy issues such as health, housing, pensions and social infrastructure. The administrative and institutional-efficiency challenges are large. Possible useful approaches that have emerged from the assessment of country practices include:

- establishing good information platforms for LTC users and providers;
- setting guidelines to steer decision-making at local level or by practising providers;
- using care planning processes, based on individualised need assessments, involving health and care providers and linking need assessment to resource allocation;
- sharing data within government administrations to facilitate the management of potential interactions between LTC financing, targeted personal-income tax measures and transfers (e.g. pensions), and existing social-assistance or housing subsidy programmes;
- dealing with cost-shifting incentives across health and care.

You can read the summary and conclusions in full at:

<http://www.oecd.org/dataoecd/53/56/47887770.pdf>

## Overview of Family Carers in Turkey, Spain, Italy and Romania

As part of an EU-funded project (Leonardo Da Vinci, EU Education and Culture Dept), the RING -TransferRING Supports for Caregivers report reviews the situation of carers in four countries: Turkey, Romania, Italy and Spain. It highlights the main statistics, the legal framework and the available resources in each country.

Secondly, an analysis of carers' training needs is carried out based on the results of a survey conducted in the four countries. Both informal and formal carers responded to a questionnaire. Professional trainers and health practitioners were also surveyed.

The full report is available to view on the Care Alliance website:

<http://www.carealliance.ie/publications> (Overview Reports)

## Between worlds: The Experiences and Needs of Former Family Carers

McCarron, Breen, Cronin, Hynes, O'Sullivan and McCallion

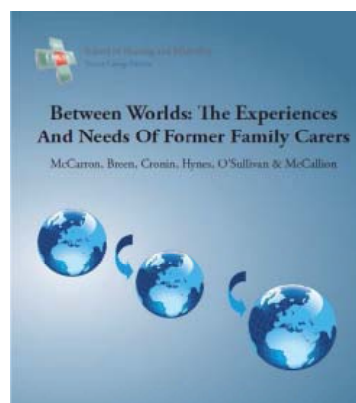
It is estimated that there are 274,000 family carers in the Republic of Ireland and while there has been significant progress made in the provision of state supports for carers, there is relatively little primary research on carers and none published on the post-caring / care transitions phase. The research that does exist points to the all-encompassing nature of informal caring, compromised earning potential and evidence of poor health and wellbeing amongst carers.

*"the skills and experiences of former carers can be an important resource within caring organisations through helping with sustaining others who are currently caring"*

These factors have ongoing significance for former carers and the first Irish study of its kind, undertaken by the School of Midwifery, Trinity College Dublin and Care Alliance Ireland, describes the experiences and needs of 40 former family carers. Former family carers were defined as those who cared for an ill or disabled family member at home for at least six months before they either died or moved into a nursing home or hospice. The length of time spent caring ranged from six months to 27 years and most people were caring for parents or a spouse.

In the study, former carers describe how becoming a full-time carer meant losing the life they had with all its social contacts, work and other opportunities. Subsequently, when the person they cared for died or moved to a care home, they experience further losses associated with their role and identity as a full-time carer. Losing both these worlds creates a profound sense of loss and emptiness. At the point where their 'caring world' has just ended carers often feel caught 'between worlds'.

They do not belong to any particular place and do not have any particular label or identity that applies to them.



They experience a range of emotional reactions, such as guilt, relief and anger. These are made worse often by the feeling that they have been 'dismissed' and devalued by State services and this can become a barrier to 'moving on' and creating a new world for themselves.

Other barriers include significant money problems and finding it hard to return to the workforce where previous skills for employment had been lost. The factors that help former carers to move on include family support and support from carers' organisations. In moving on they begin to care for themselves, keep active, become involved in their community, and 'get out of the house'. For some former carers, 'moving on' involves taking on other informal and/or formal caring roles giving the skills they had acquired while being full-time carers.

Most local carers' support groups are attended by more women than men but men make up 40% of carers in Ireland. They are under-represented in carer groups and other services. The male carers in the study described the support they received from self-initiated, small, emerging male support groups. The findings from the study may help carers' organisations and state services to develop options that may appeal to male former carers.

You can access the full report and an Executive Summary (in Plain English) at: <http://www.carealliance.ie/>

## Living through end-stage dementia: The experiences and expressed needs of family carers

Chris Shanley, Cherry Russell, Heather Middleton and Virginia Simpson-Young  
Dementia 2011 10: 325 originally published online 13 June 2011

The focus of this paper is the experiences and needs of family carers of people with end-stage dementia. The project involved in-depth, qualitative interviews with 15 carers. The major themes emerging from the accounts of participants' experiences were: getting support; having to trust others with care; managing the loneliness of being a carer; witnessing a loved one fade away; anticipating and experiencing death; and re-establishing life after the funeral. Carers expressed a range of instrumental and psychosocial needs.

The study has provided a more personal account of the caring experience than much of the related literature. It has emphasised the need of carers for genuine understanding and connection — from family and friends as well as healthcare staff. The study highlights the amount of support carers can provide to each other through support groups and associated friendships, and stresses the importance of healthcare staff acknowledging and respecting this capacity of carers.

The online version of this article can be found at:

<http://dem.sagepub.com/content/10/3/325>

Please note: only an extract of the article is free to access

### Family Carer 'Briefcase' for Psychologists

The American Psychologists Association has developed a user-friendly, online Family Carer resource to help psychologists and other health professionals assist family carers. This briefcase provides psychologists at all levels of training and experience with information about:

- How caring affects all of us
- Facts about family caring
- Common caring problems
- How to identify and reach carers
- The role of psychologists in working with family carers
- Assessment tools and effective interventions
- Conducting carer research
- Educating and teaching about caring
- Advocating for family carers
- Resources for diverse populations and age groups

The briefcase can be accessed at:

<http://www.apa.org/pi/about/publications/caregivers/>

### Alzheimer's Disease - Family Carer Interventions

The Veterans Association (VA) in the US has just completed a systematic review of all evidence-based Alzheimer's Disease caregiver interventions.

Watching the video is fascinating, especially the conclusions about the REACH programme. Also, the role of the caregiver assessment appears to be critical.

The full report can be accessed at:

<http://www.hsrd.research.va.gov/publications/esp/dementiacare.cfm>

## **New Clinical Practice Guidelines bereavement support in Palliative Care (Australia)**

Hudson, P., Remedios, C., Zordan, R., Thomas, K., Clifton, D., Crewdson, M., Hall, C., Trauer, T., Bolleter, A., and Clarke, D.

Clinical Practice Guidelines for the Psychosocial and Bereavement Support of Family Caregivers of Palliative Care Patients. Centre for Palliative Care, St Vincent's Hospital Melbourne: Melbourne, Australia (2010).

New Clinical Practice Guidelines in Australia outline a number of principles for family caregiver support. These principles and guidelines focus on the relative or friend who predominantly supports the patient – the Primary Family Caregiver.

- 1.** The crucial role of family caregivers in the care of the patient is acknowledged by the interdisciplinary team and accordingly family caregiver and bereavement support should be fully incorporated into service philosophy and standards of care.
- 2.** Family caregivers should be offered needs assessments and access to relevant psychosocial support.
- 3.** The focus of support should be the primary family caregiver(s), as identified by the patient. Where additional resources and skills are readily available, support is extended to other family caregivers.
- 4.** Family caregiver and bereavement support is provided using resources based on the available evidence and best practice guidelines.
- 5.** The focus of advice and support provided to the family caregiver(s) should be based on caregivers' choice and emphasise strategies to optimise their own well-being.
- 6.** Communication with family caregiver(s) should be conducted in a manner that provides direct and clear information in a language they understand via a combination of mediums including verbal, written or multimedia. Relevant confidentiality and legal requirements should be considered.

**7.** It is recommended that discussions around preparedness for the patient's death are responsive to the individual needs of the family caregiver(s). This may require discussing issues in stages according to the patient's declining physical condition.

**8.** Health care professionals and volunteers working with family caregivers should receive appropriate and ongoing training, support and supervision relevant to their level of involvement. Training should be based on National Standards and evidence-based guidelines.

**9.** Health care professionals, patients and family caregivers should be aware of the limits of palliative and bereavement services. Referral to external specialist services or individuals should be undertaken when appropriate.

**10.** Family caregiver and bereavement support is provided with respect to individuals and their needs within a safe, confidential and ethical approach that is sensitive to the caregivers' experience, culture and social environment.

**11.** Although poor bereavement outcomes are associated with identified risk factors, there is minimal evidence to support routine intervention with all bereaved people.

**12.** Comprehensive care planning by the interdisciplinary team, involving the patient and family caregiver(s), is an ongoing process, rather than a single event.

**13.** All relevant discussions, assessments and outcomes related to the patient and family caregiver(s) should be clearly documented in the most appropriate location (as per the service protocol).

**14.** A clear process for consumer complaints and feedback with regard to the quality of health professional support should be easily accessible to patients and family caregivers.

To download a complete version of the guidelines, please go to:

[www.centreforpallcare.org](http://www.centreforpallcare.org)

## Models of care - ROI/NI Review

Severe budgetary restraints, coupled with the rapidly ageing population on the island of Ireland, make the cost of care for older people, now and especially in the future, a major policy issue in both Northern Ireland (NI) and the Republic of Ireland (ROI).



There is a growing acknowledgement that although the current model of residential care suits people with particular requirements it does not always support those older people who wish to continue to exercise full control over their lives and lead a full life no matter what their level of dependency. There is a need to plan for different types of care in the future which can be adapted to suit individual needs as we grow older.

A recent article by the Centre for Ageing Research and Development in Ireland examines current research and policy on models of care on the island of Ireland. It also refers international best practice which can serve as examples for care of older people in ROI and NI.

The full article can be viewed at:

<http://www.cardi.ie/publications/cardifocusonmodelsofcare>

### e-Connected Family Caregiver: Bringing Caregiving into the 21st Century (US)

This report describes the results of a study conducted to examine family carers' receptivity to technology. In particular, the study assessed how helpful 12 technologies would be in supporting carers or helping them provide care.

These 12 technologies can be viewed as characteristic of the types of technologies that might be attractive to technology-using family carers.

The study also delved into barriers to the use of technology, factors influencing use of technology, and trusted sources of information about technology.

The report is based on a quantitative online survey of 1,000 technology-using family caregivers.

<http://www.caregiving.org/research/latest-research>

### End of life care (UK)

London Health Programmes (UK) has developed a range of tools is aimed at supporting NHS commissioners in planning end of life services.

End of life care has been identified as a national priority and was one of the original seven areas of focus of Healthcare for London: A Framework for Action.

The tools include a good practice guide; economic modelling tool; reference guide for commissioners; and QIPP tools.

To view the interactive resource, visit

[www.londonhp.nhs.uk/publications/end-of-life-care](http://www.londonhp.nhs.uk/publications/end-of-life-care)

# Intergenerational Family Care for and by Older People in Thailand

Knodel, J and Chayovan, N, Population Studies Centre, University of Michigan

Nationally representative surveys of the older population in Thailand clearly document the primary role of the family, especially adult children and spouses, in providing personal care to elderly members who are no longer able to function on their own. The role of the state, market and voluntary sectors, i.e. the other three points of the “care diamond” vary but are clearly subsidiary to the family although their relative contributions may shift in the future.

It is also clear that older persons, in their role as grandparents, make significant contributions to the care of young children, especially in situations where the child’s parents have migrated and left the grandchild in their care. Demographic trends are underway that pose important challenges for the future of intergenerational family care.

The future role of older persons in providing care to young dependent grandchildren is likely to be impacted by reduced fertility among persons of reproductive age and by the increased migration of working age adults although these are likely to operate in opposite directions.

The much smaller family sizes of the persons entering older age in the future and the increased migration of their adult children to find employment have serious implications for filial elder care and are already leading to shifts in living arrangements including a substantial decline in co-residence of elderly parents with a child. In terms of intra-generational family care, i.e. by spouses, the demographic underpinnings are far less subject to change.

The full report can be downloaded at: <http://www.psc.isr.umich.edu/pubs/pdf/rr11-732.pdf>

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## Quality Management for the Community & Voluntary Sector University of Limerick / DFI Accredited Course

The University of Limerick’s (UL) Enterprise Research Centre in conjunction with the Disability Federation of Ireland (DFI) are working together in developing and piloting an accredited course entitled ‘An Introduction to Quality Management for the Community & Voluntary Sector’, aimed at developing participants’ quality management knowledge. The programme consists of five days’ tuition staggered over eight weeks.

This programme aims to develop awareness in participants of the role of Quality Management in the development of an organisation, the management of change and the development of people and processes while keeping the service user at the forefront of the organisations activities.

Once successfully piloted, the course will be offered to those within the community & voluntary sector with a responsibility for governing, using or delivering service, coordinating activities, or with a role in the management of the organisation.

A further proposed element of the partnership project will be the development of a one-year Specialist Diploma, again to be accredited by UL. UL’s involvement is being headed-up by Professor of Quality and Applied Statistics, Eamonn Murphy.

For further information contact:

Michael Hennessy, Education Programme Manager, University of Limerick  
tel: (061) 213 037 e-mail: [michael.hennessy@ul.ie](mailto:michael.hennessy@ul.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 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 72 member organisations and other agencies to support them in their work with Family Carers. Our membership includes all the carers organisations and virtually all the condition specific organisations currently providing services to many of Ireland's Family Carers. A number of statutory groups are associate members.

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

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

**To find out more about Care Alliance Ireland, please visit our website:**  
[www.carealliance.ie](http://www.carealliance.ie)

**or contact:**

**(01) 874 7776      [info@carealliance.ie](mailto:info@carealliance.ie)**

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