

*Dear readers,*

*Here we are with the second issue of 2014 of EuCaNews, the Newsletter of EUROCARERS (or EuCa), the European Association Working for Carers! In the first section (“News from the Executive”), you will find an overview of the newly elected Executive Committee, with a brief bio-sketch of its three new members and a note from the new President, John Dunne. After a visual glimpse of some nice moments spent at the Annual General Meeting in Helsinki, Christine Marking provides us with the usual update on EU policy developments, followed by the Manifesto set up by Eurocarers to promote the engagement of the new members of the European Parliament. The section on “Carers in Action” delivers the latest news on initiatives undertaken by our members, including a survey on informal care in the Netherlands, the last Global Forum on Incontinence as experienced by a carer, and two relevant events taking place in Scotland. The section dedicated to research provides you with some “food for thought” from recent publications on different subjects such as the role of prisoners as carers of inmates, volunteering in older age in different European countries and caring for a mother with Alzheimer’s disease. Finally, the “In brief” section presents some short “snippets” of information about various issues.*

*Please keep in mind that **your feedback, comments and ideas for the Newsletter are important** to help us to improve it. So please do not hesitate to send us any contribution relating to your own organisation, experiences or relevant events, which you would like to disseminate to a larger audience interested in caregiving issues in Europe. Please try to keep your contributions as concise as possible (i.e. 1.500 words maximum).*

*We wish you a good read and a good summer,*

**Giovanni Lamura**  
(INRCA, Italy)  
e-mail: [g.lamura@inrca.it](mailto:g.lamura@inrca.it)

**&**

**Hilary Arksey**  
(freelance consultant;  
e-mail: [hilary.arksey@virgin.net](mailto:hilary.arksey@virgin.net))

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## NEWS FROM THE EXECUTIVE COMMITTEE

*In this section of the Newsletter, we report the core issues discussed during the (tele)conferences that take place periodically between the members of the EUROCARERS Executive Committee. This time, however, we are going to briefly present its new members; during the last Annual General Meeting (AGM) held in Helsinki on 5-6 May, two of the seven executive positions came to an end of their term and were subject to election.*

### The new Executive Committee

The newly elected Executive Committee now comprises: John Dunne (President), Hanneli Döhner (Vice President Carers Associations), Elizabeth Hanson (Vice President Research), Marijke Steenbergen (Treasurer), Licia Boccaletti, Helle Lepik and Marja Tuomi. In addition, the Executive is supported by four advisers: Christine Marking, Frank Goodwin, Giovanni Lamura and Katherine Wilson.

Following the photographs of all members, you find a short profile describing the two new elected members of the Executive (John Dunne and Elizabeth Hanson) and the new adviser (Katherine Wilson). For a more detailed description of all members' profiles, please go the EUROCARERS website [http://www.eurocarers.org/about\\_executive.php](http://www.eurocarers.org/about_executive.php).

**John Dunne**  
(President)



**Hanneli Döhner**  
(Vice President Carers Associations)



**Elizabeth Hanson**  
(Vice President Research)



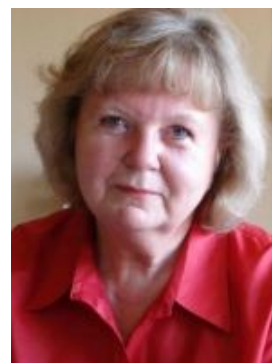
**Marijke Steenbergen**  
(Treasurer)



**Licia Boccaletti**



**Helle Lepik**



**Marja Tuomi**



**Christine Marking**  
(Adviser)



**Frank Goodwin**  
(Adviser)



**Giovanni Lamura**  
(Adviser)



**Katherine Wilson**  
(Adviser)



Here's a brief profile of the new members of the Executive, to help you get to know them better.

**John Dunne (President):** John is currently (since 2011) Chief Executive of The Carers Association, Ireland's national voluntary organisation for and of carers in the home, which exists to:

- Empower family carers with relevant knowledge, skills and personal support;
- Ensure that family carers have the fullest and best quality supports possible;
- Provide an effective and representative voice for family carers; and
- Achieve greater public awareness of and support for family carers and care issues.

John's previous appointments include: Chief Executive of the Chambers of Commerce of Ireland; Chief Executive of the National Youth Federation (Ireland's largest youth work organisation); Deputy Director-General of the International Fund for Ireland and *Chef de Cabinet* to the Minister for Foreign Affairs. Whilst working with Chambers Ireland, John

also served as a director of *Eurochambres* – the European network of Chambers of Commerce. He was a member of Ireland's National Economic and Social Council from 2001 to 2009, and currently chairs a major 10-year Prevention and Early Intervention Programme designed to increase the efficiency of major public expenditure programmes through area-based systemic change. John's primary degree is in Public Administration (Trinity College, Dublin); he also has an MBA (University College Dublin) and a post-graduate Diploma in Policy Evaluation (Brunel University, London).

**Elizabeth Hanson (Vice President Research):** Elizabeth (Liz) Hanson is Scientific Leader of the Swedish National Family Care Competence Centre (*Nationellt kompetenscentrum anhöriga*), a centre of excellence in the area of family (informal) care. She is a Professor at the Linnaeus University, Department of Health and Care Sciences, Kalmar, South-East Sweden and a Visiting Reader at the University of Sheffield, School of Nursing. Elizabeth started her working career in palliative and hospice care and has an international background, having worked for four years as an assistant professor at the University of Manitoba and as clinical research associate at the St Boniface Research hospital in Winnipeg, Canada. Since 2000 she has lived and worked in Sweden together with her husband, Lennart Magnusson and their two children, Emma and Richard. She has a long standing interest in carer issues and has had personal experience of being a carer for both her parents and father-in-law.

Since 1997, Elizabeth has led and carried out research and development work in partnership with older people, carers, practitioners and decision makers to enhance and/or stimulate innovative service provision. Her work has included a variety of national, EU and international projects which have largely focused on service development, user and carer involvement and the role of Information and Communication Technologies to help empower carers and older people with long-standing conditions living at home. A notable example is the ACTION (Assisting Carers using Telematics Interventions to meet Older People's Needs) service which is acknowledged by the EC (Information Society & Media) as an example of best practice in the area of ehealth in Europe. Elizabeth is a steering board member of Anhörigas Riksförbund (AHR: Carers Sweden) and has been an active member of Eurocarers since 2006, representing AHR (2006-) and Nka (2008-). She has always been actively involved in voluntary work and served as a board member for a community hospice organisation in Winnipeg, Canada and subsequently for Crossroads Care sitting services in Sheffield, UK. Elizabeth currently works in a voluntary capacity on behalf of Eurocarers in the WP3 of the current INNOVAGE project.

**Katherine Wilson (Adviser):** Katherine is Strategic Manager of Employers for Carers (EfC) at the charity Carers UK. EfC is a forum for employers committed to developing good practice to support staff who are caring for ill, frail or disabled relatives, partners or friends. Supported by a leadership group of businesses and the specialist knowledge of Carers UK, EfC provides practical help and advice for employers and promotes the business benefits of supporting carers in the workplace. Formally launched as a membership forum in 2009 (after many years of earlier work with employers supported by the European Social Fund), EfC now has over 75 member organisations covering at least 1 million employees and is currently developing an international platform.



## **A note from the new elected President on EUROCARERS' priorities for the coming year**

**by John Dunne (President Eurocarers)**

The following represents a short overview of the 'manifesto' I presented to the AGM in Helsinki, setting out my key priorities for the coming year. Having just signed a funding agreement under the EU PROGRESS initiative, the coming year will see significant change and development within the Association. There are four main strands to what we have to deliver operationally:

### **1. Governance:**

The Association's legal registration is moving from Luxembourg to Belgium, we are opening an office in Brussels and will have appointed two key staff before the end of the year. As a result of these developments, the Executive Board will review its Statutes with a view to bringing proposals for change to next year's AGM.

### **2. Project Delivery:**

Our credibility with the EU Commission is now heavily dependent on our effectiveness in delivering what we have promised in our PROGRESS application as well as meeting the (onerous) administration and reporting requirements. In addition, we are being approached more frequently about joining other project consortia based on EU or commercial funding, and need to ensure that we join the right projects and then contribute to their success.

### **3. Lobbying and Policy Development:**

We need to build on our successes to date in promoting an EU Carers Strategy, working through our EP Interest Group as well as member organisations at national level. We will prepare a major response to the Social Policy Committee's report on Long Term Care before the end of the year. This will address three elements of the report:

- (i) its proposals in regard to policy;
- (ii) its profile of the situation of family carers in each member state; and
- (iii) its analysis of research gaps in regard to knowledge about informal carers.

We are also committed to promoting measures to reconcile working life with caring responsibilities through 2014-5.

### **4. Network Capacity-Building:**

As part of our PROGRESS funding we hope to be in a position to begin capacity-building with interested member organisations in the coming year. We envisage that this will happen in two ways:

- (i) Invitations to participate in regional and/or functional training and networking events; and
- (ii) The opportunity to invite senior managers from other member organisations to carry out a 'peer review' of their organisation.

Underpinning all of these activities, however, we must ensure that Eurocarers uses its new resources to become more relevant to its member organisations. A key challenge in this regard will be to find ways of overcoming distance and language barriers to more inclusive

and effective networking. Overall, I believe that the only way we will know whether we are being successful is when our members are willing to 'invest' more time and funding into Eurocarers, because of the value of what they get back in return. This is important because the final challenge we will face in adapting to PROGRESS funding is to build a sustainable core within the organisation that is not entirely dependent on EU funding.

## **Some visual impressions from the Annual General Meeting in Helsinki on 5-6 June 2014**

**By Giovanni Lamura (text), Henk Bakkerode and Sebastian Fischer (photos)**

Below, we're delighted to show you photographs kindly taken and shared with us by our colleagues Henk Bakkerode (Eurocarers) and Sebastian Fischer (Vocal, Scotland) during the excellent social events organised by our Finnish colleagues during the last AGM in Helsinki: thanks again to Marja Tuomi and all her colleagues for the wonderful hospitality!

**Fig. 1: Marja Tuomi opening the AGM and welcoming all participants**





**Fig. 2: John Dunne presenting himself before the election**



**Fig. 3: The welcoming toast during the dinner cruise in the bay of Helsinki organised by the Central Association of Carers in Finland**





**Fig. 4: Frank Goodwin and Giovanni Lamura receiving tokens of appreciation from the Executive (here displayed: Hanneli Döhner), at the end of their terms served as EUROCARERS President and Vice-President Research respectively**



**Fig. 5: The attentive audience of the AGM...**



**Fig. 6: ... and during a lunch break of the Conference on 6 June (from the left: Frank Goodwin, Eurocarers; Sebastian Fischer, Vocal-Scotland; Jolanda Elfenrink, Movisie-Netherlands; Marja Pijl, adviser to Eurocarers, who ended her term in Helsinki: many thanks to Marja for all her work, too!)**



## EU POLICY DEVELOPMENTS

### Updates on recent EU policy developments

**By Christine Marking (adviser to the Executive Board)**

#### **European elections: the outcome at a glance**

European elections were held across the EU at the end of May. The main outcome can be summarised as follows:

- The political balance remains broadly unchanged in the European Parliament, despite a rise in anti-European MEPs. It looks like the centre-right and centre-left parties are on track for a grand coalition;
- Out of the 751 seats, the centre-right European People's Party (EPP) now has 212 seats in the European Parliament as opposed to 265 in the previous Parliament), followed by the Socialists and Democrats (S&D), with 186 seats (previous Parliament: 184);
- This is the fourth time that the EPP has the largest number of seats. The Alliance of Liberals and Democrats for Europe (ALDE, the (centrist liberal group) obtained 70 seats, the Green parties 55 and the right-wing Conservatives and Reformist Group (ECR) 44. The far-left Confederal Group of the European United Left obtained 43 seats, while the far-right Europe of Freedom and Democracy Group ended up with 36 seats.

There are 38 non-affiliated MEPs and the 67 “other” MEPs who do not yet belong to any political group; most of those belong to populist and extremist anti-European parties. It looks unlikely that these will unite into one anti-European block; for instance, the UK Independence Party has already indicated that it will not form an alliance with the French Front National and Dutch Freedom Party. The process of allocating MEPs to the various Committees and Working Groups will now start and will probably be concluded in July, during the first plenary session, which is to be held between 1-3 July.

*For more information:*

<https://www.theparliamentmagazine.eu/articles/news/european-elections-mep-lists-country-country>

#### **Commission Communication on effectiveness, accessibility and resilience for EU's health systems**

On 14 April, the Commission adopted a Communication proposing an EU agenda to ensure that Europe's health systems can face current challenges and pressures. It highlights a number of initiatives the EU can develop and build upon to support Member States in meeting the expectations of citizens in relation to quality care. The focus is on methods and tools that will help Member States to achieve greater effectiveness, accessibility and resilience of their health systems, in line with reform recommendations addressed to them in the context of the European Semester.



Member States are also encouraged to make good use of European funding instruments, such as the structural funds.

The Communication recommends Member States to:

- **Strengthen effectiveness**, keeping in mind that the first objective of a health system is to improve the health of the population. This can be done through applying performance assessment results, ensuring safety and quality of care for patients, and developing an integrated approach to care so as to avoid over reliance on hospitals.
- **Increase accessibility**, so that health systems provide healthcare services to the whole population. This result can be achieved through better planning of the health workforce and a more effective use of medicines. Furthermore, the Directive on cross-border care will provide increased transparency, and better affordability and availability of care.
- **Improve resilience**, so health systems are capable of adapting to changing environments and identifying innovative solutions. This capacity can be strengthened by choosing more effective and efficient treatments which respond to patients' needs. Of equal importance is building efficient information flows and innovative Information and Communication Technologies in health.

The Commission's Communication is backed by several studies, in particular on access to healthcare, effectiveness of health systems, and reforms of the hospital sector.

Eurocarers has prepared a response to this document.

*For more information:*

[http://ec.europa.eu/health/healthcare/health\\_systems\\_organisation/index\\_en.htm](http://ec.europa.eu/health/healthcare/health_systems_organisation/index_en.htm)

Commissioner Borg's website:

[http://ec.europa.eu/commission\\_2010-2014/borg/index\\_en.htm](http://ec.europa.eu/commission_2010-2014/borg/index_en.htm)

[http://ec.europa.eu/health/healthcare/health\\_systems\\_organisation/index\\_en.htm](http://ec.europa.eu/health/healthcare/health_systems_organisation/index_en.htm)

### **Social Protection Committee produces report on long term care**

The Social Protection Committee (SPC) has recently produced an extensive report on long term care provision in the EU. This Committee acts as an EU advisory policy committee, which:

- Monitors social conditions in the EU and the development of social protection policies in member countries. It reports on social inclusion, [health care](#), [long-term care](#) and [pensions](#);
- Promotes discussion and coordination of policy approaches among national governments and the Commission.

It prepares discussions for the Ministers responsible for social protection (the Council of Ministers) and publishes reports and opinions on its own initiative or at the request of the Council of Ministers or the European Commission.



The SPC consists of (high-level) civil servants from relevant Ministries from all Member States and has put in place various Working Groups, one of which is the Social Protection Committee Working Group on Ageing (SPC-WG-AGE). Despite the vast differences between EU Member States when it comes to demography, economy, traditions and the development of systems for long term care, the SPC-WG-AGE is trying to find common ground for cooperation and action. While there is no one-size-fits-all solution to cope with the increasing demands resulting from the ageing of our societies, it is felt that there is much value in mutual learning between Member States.

Therefore, the report aims:

- To re-emphasize the case for social protection against the risk of long term care needs;
- To identify existing evidence about possible ways to contain and address present and future demands on long term care provision;
- To identify where there is lack of knowledge and need for further evidence;
- To give examples of good practices around the EU that could also be considered in other Member States;
- To suggest to the SPC where policy action could be taken to increase EU support to the efforts of Member States.

It consists of two parts:

- A general part where an overview of the challenges and potential solutions is provided;
- An annex consisting of 28 Member States country profiles as regards their long term care provision.

The report does not claim to be completely comprehensive, but it is hoped that it will lead to constructive discussions within the SPC and in single Member States and stimulate further cooperation between EU Member States in this important area.

It contains seven key messages:

1. Social protection against the risk of long-term care dependency is needed for equity and efficiency reasons;
2. A large and widening gap between the need for and the supply of long-term care is likely to develop;
3. Closing this gap requires proactive approaches to contain the growth in needs and to meet them in the most efficient way;
4. There are many examples of good proactive practices: a more systematic assessment of what works and what is most cost-effective will add further value;
5. Adequate social protection against LTC dependency is a major aspect of gender equality in old age as well as in working age;
6. Given the diversity of LTC policies there is scope for better mutual learning and for a common European knowledge base;
7. There is a need to further clarify the common objective of adequate social protection against LTC dependency and to set out how EU support for the LTC efforts of Member

States can be enhanced including through better collaboration between ministers of health and ministers of social affairs.

The report explicitly recognises the huge role and contribution made by carers. Eurocarers is working on a detailed response to the SPC report, as part of the activities funded by the PROGRESS programme. Eurocarers members will be approached to provide their comments on the individual country profiles, and a briefing for members is currently being prepared.

*For the full report: [Full report \(EN\)http://ec.europa.eu/social/main.jsp?catId=758](http://ec.europa.eu/social/main.jsp?catId=758)*

**Fig. 7: Meeting held by the Informal Group on Carers of the European Parliament on 9 April 2014 in Brussels, with (from left to right) European Commissioner Tonio Borg (Malta), Marian Harkin (chair, Ireland), Jean Lambert (UK) and Sirpa Pietikäinen (Finland).**



## Eurocarers Manifesto for the new Members of the European Parliament

Please find below the Eurocarers election Manifesto, which defines what the new Members of the European Parliament (MEPs) can do, including a call on them to join the Interest Group on Carers.

### Informal carers: invaluable but under pressure

#### Why do informal carers matter?

- **80% of care** across the EU is provided informally by spouses, relatives and friends – **usually unpaid**.
- These carers will become even more important as the number of older people **increases**.
- The **economic value** of unpaid informal care - as a percentage of the overall cost of formal long-term care provision - ranges from **50% to 90%** across the EU.
- Caring can be a source of personal **satisfaction** and emotional gratification....
- ...but it can also have **challenging health, financial, social and employment** consequences.
- The increasing labour market participation of the main carers, i.e. women and older workers and other demographic developments are leading to **decreasing availability of carers**.
- Carers cannot do their work without proper **recognition and support (in policy and practice)**.

→ **All Member States face the same challenges in terms of long-term care provision**

→ **All Member States need the informal care resource to prevent social security systems collapsing**

### Despite their relevance, carers are rarely considered in policies that impact on them.

#### What can **you** as a member of the European Parliament do?

The Parliament can urge the Commission to make use of the various possibilities to address and support carers, such as:

- **Including carers issues in social policy development**, i.e. to actively target carers in initiatives like the European Innovation Partnership on Active and Healthy Ageing, the Employment Package and the Social Investment Package, the PROGRESS programme, the European Social Fund, the Health programme, gender equality initiatives, the social OMC etc..
- **Formulating a specific EU action programme** to ensure and coordinate an effective exchange of information, experience and good practice between relevant stakeholders.
- **Activating EU funding** to contribute to capacity building of carers in relation to provision of support and advocacy as well as support exchange of information, research and networking.
- **Promoting data collection and monitoring** to support sound policy development (e.g. Horizon2020).
- **Adopting legislative measures** to explore the possibility of binding measures, while respecting national competence and the principle of solidarity (e.g. a Directive on carers leave).

### Carers are the largest contributors to sustainable health and social security systems.

**If carers are expected to keep providing care – and they are – their needs and requirements should be an inherent part of health and social policy development.**

**Their contribution needs to be properly considered as part of the economic equation.**

**The Interest Group on Carers works to ensure the development of a comprehensive EU strategy on carers, and your support is urgently needed:**

**Join the European Parliament Interest Group on Carers and enable carers across the EU to care!**

## CARERS IN ACTION

### Challenges and opportunities in informal care in The Netherlands 2014

**By Anita Peters and Jolanda Elferink (Senior project leaders “Social Care, Informal care and Welfare”; Researchers at Movisie, Expertise Centre Informal care, Netherlands)**

Family carers and voluntary caregivers in the Netherlands make an important and indispensable contribution to long-term care. It is almost impossible to set a monetary value on the care that they provide. They contribute time, quality and attention that professional carers cannot provide to the same extent. The Netherlands is shifting from a welfare state to a participatory society of citizens; to encourage this, the Dutch government has put a national emphasis on informal care and prepared a ‘Future Agenda for Informal Care’, jointly with various stakeholders. It also plans to invest strongly in stimulating teamwork between professionals, volunteers, family carers and patients. Movisie, the national expertise centre, developed new ways of working between professionals, informal carers and volunteers.

#### *Informal care*

A distinction needs to be made between informal carers and volunteers. Informal carers are usually family members or other people (friends, neighbours) who have a strong bond with the person in need of care. The economic value of informal care in the Netherlands (around 75 per cent of all care) is estimated at approximately 7 billion Euros (450 Euros per capita). The most recent figures from the Netherlands Institute for Social Research (SCP) report ‘Informal care in the Netherlands’ (2013) indicate that in 2008:

- Almost one third of people over 15 years of age provide informal care to people outside their own household, for instance to ill people, relatives, friends, neighbours or acquaintances. This also includes people who are not ill;
- 20 per cent of the adult Dutch population (2,6 million people) provides care to significant others in need for longer than three months or more than eight hours per week;
- 1,1 million people provide both long-term care and intensive care;
- The number of family carers is expected to increase by 5 per cent until 2025.

Figures from a new study into informal care conducted by SCP will be available shortly. Volunteers perform unpaid activities in an organised context to support patients in need, for instance through organisations such as Red Cross and Humanitas. They offer services such as outings, visiting, buddy projects and help with (financial) administration. Increasingly there are also citizens’ initiatives at local or community level, organised either with professional help or existing only through volunteer effort. Usually the volunteer does not have a personal connection with the patient at the outset, but some of them do get acquainted and become part of the patient’s personal network.

#### *Challenges*

The Netherlands is a strongly ageing society, with growing numbers of chronic patients. Dutch society sees a decrease in family size. Younger generations can no longer share caring duties with many siblings to ease the pressure. The pressure on paid labour is increasing, as more women –



traditionally the carers in family care and voluntary care – are also joining the paid workforce. We also see increased geographic distances between family members. Other challenges are that people in need of care and support stay in their own homes longer and that there is more focus on an integrated offer of care and support services at neighbourhood and community level. With the introduction of the Dutch Social Support Act in 2007, informal care policy became an issue for local authorities. Together with informal carers and support organisations, Movisie defined guidelines for family care support functions that needed to be addressed in local policies: information; advice and guidance; emotional support; education; practical support; respite care; financial support and instrumental help. Attention was paid to supporting volunteer organisations. National policy is calling on people to become volunteers. Also unemployed people are stimulated to volunteer. These new groups – with may be different motivations to be active – do need professional guidance, especially when they are engaging in care work.

### *Focus on teamwork*

In the Netherlands, we see a firm investment in stimulating teamwork between professionals, volunteers, family carers and patients. Professionals play a key role in this process. This teamwork is subject to research and development to create effective work methods in both residential care and home care. When an elderly person needs professional care, it is very important that the informal carer remains in the picture. Also, when a family member is admitted to a residential facility, the informal carers ought to stay involved. Family members can assist in caring in a residential institution as well, but they need some guidance. Often they are confronted with the institution's regime and do not know if they are allowed to help their relative or other residents. They may find it difficult to let go and hand responsibility to professionals. On the other hand, they may be too exhausted to be involved on a regular basis.

### *National impulse for informal care*

Recently, an additional national impulse for informal care has been given. A special programme (2014-2016) will promote informal care in the Netherlands, concentrating on residential care institutions, municipalities and informal carers. Particular attention will be paid to the distribution of good practices. A 'Future Agenda for Informal Care' is also being prepared, aiming to develop concrete actions for strengthening, facilitating and connecting informal care, including family care, jointly with various stakeholders in informal care. Joint efforts by policy makers and practitioners on every level are essential. Priorities are:

- Improved cooperation between informal and formal care;
- The promotion and training of carers' expertise by professionals;
- Better equipment for carers and volunteers to enable them to continue caring;
- Voluntary work-new-style should play a role in sustaining informal care.

### *Municipalities*

A central role is reserved for the municipalities. They have to organise, sustain and facilitate by all means the upcoming informal care-giving networks in local communities. They have to look for local and tailor-made individual solutions. National expertise centres and carers' interest groups will be available for support and advice when needed.

### *New directions*

The organisational structure of long-term care for the elderly, as well as for people with intellectual and mental disabilities and people with psychiatric care needs, is rapidly changing.

Responsibilities for paid staff and civil society need to be redefined. Budget cuts might result in organisations replacing paid staff by volunteers. Under the right conditions, volunteers can contribute to quality of care for residential patients. But care professionals have little experience in working together with family carers or volunteers, and very little time to explore how to work as a team with relatives. The family carer needs to be approached in a professional way to realise a constructive relationship between professional carer and family carer. A support plan for family carers can also be beneficial to the professional carer. Additional care by family carers can lighten the workload of the professional carer.

Movisie developed a partnership model for professionals in residential care to use in their work with family carers. Basically, professionals need to see family carers as co-workers, with expert knowledge of the patient or resident, sometimes also as exhausted informal carers who are in need of care themselves, but also as relatives who may have known each other for a lifetime. The latter is especially important in the case of, for instance, dementia or other cognitive impairments. In this way, we will hopefully be able to change the perspective on family carers and enhance their valuable contribution to the quality of life of their nearest and dearest, both at home and in residential care.

For more information please contact Jolanda Elfenrink: [J.Elferink@movisie.nl](mailto:J.Elferink@movisie.nl).

## **Impressions of a carer at the Global Forum on Incontinence on 8-9 April 2014**

**By Carolyn Akintola (The Carers Association, Ireland)**

*Below you find a report prepared by Carolyn after her attendance of this Global Forum on Incontinence (GFI), organised last April by SCA in Madrid*

Well, there's no doubt about it: our Frank Goodwin can deliver a girl a glamorous gig!... He asked me as a family carer to speak at a conference in Madrid... Thing is, the topic of the conference was The Global Forum on Incontinence! Anyway, as this is a subject that affects many carers in our caring role, it's an important if somewhat un-glamorous subject, and it's a subject I have an interest in... So, I jumped at the chance! So early on the Monday morning, I caught the 6.25 flight to Madrid, and two and a half hours later, I landed to a very warm and sunny morning in Madrid... I registered as a delegate/speaker, and then had a lovely lunch... We had a fantastic 'getting to know you' dinner that evening, and a good night's sleep set me up for a wonderful two day conference beginning the next morning...

Our moderators were Dr Ian Milsom, a gynaecologist from Sweden, and Dr Adrian Wagg, Professor of Healthy Aging from Alberta, Canada. Among the subjects discussed on the first morning were the burden of incontinence, and its financial, medical and emotional aspects. I was particularly interested to hear Family Carers mentioned. A speaker made crystal clear that care is NOT free: there is a cost, whether financial, or otherwise to a family carer when they take on the role of caring. Particular difficulties and costs arise when there are continence issues: there was also a very interesting discussion around incontinence needing to be a health and social priority, and the demographic challenge of an aging

population and the impact of incontinence. Following a coffee, there was a plenary session looking at incontinence in the medical landscape, and then Adrian Wagg delivered a speech on incontinence in older people (VERY interesting!). There are so many complexities in older people with this condition including many medical conditions. It was stated that incontinence in older people can be a pretty accurate indicator of future frailty, and requirement for Nursing Home care. There was then a presentation on awareness of incontinence among the general public, and policy makers. Suffice to say, the awareness is not great: mind you, it's probably not an issue any of us want to really face up to...

After lunch, there were three people who have incontinence and myself involved in a panel discussion of the issue. We discussed the physical, and emotional issues involved, we were the people 'at the coal face', so to speak... I got to mention the lack of training for carers, the physical difficulties in moving a very dependent person to deal with product changes, the lack of places to change an adult with incontinence when we're out and about, and the emotional issues surrounding the dignity of the cared for person...

The last session on that first day of the conference covered such issues as the importance of having an Optimal Continence Service Specification. I believe this to be a great idea: everybody, no matter their age, gender, geographical location, or medical status deserves a really good continence care service. Unfortunately, wherever you are in Europe, there appears to be a type of 'Postcode lottery': some areas provide a great service, others still have a long way to go!

We went out for a lovely dinner in a local restaurant that night, and I had a great chat with lots of people who have a professional interest in the issue. Many of them mentioned things I had said in my speech, so that was gratifying... was nice to see that the policy makers, nurses, doctors, etc. were interested in hearing a carer's perspective...

The next morning there was a very interesting presentation from Diane Gove around care guidelines for people who have dementia and incontinence. It was great to hear someone discussing the particular challenges surrounding this particular group, it re-established my eternal respect for caregivers, either professional or family who care for people who have dementia, they are an incredibly special group of people!

After coffee we broke into groups and discussed some of the issues surrounding barriers to having really good continence care, and well trained healthcare professionals, particularly nurses, in this particular field. Perceived barriers included the low priorities policy makers seem to attach to the issue, the difficulty of getting good training in the issue, the lack of a 'professional qualification' in the field. Some nurses felt that if there wasn't a certificate, and perhaps a monetary reward at the end, there was little incentive to pursue the training. I pointed out that I saw two barriers here in Ireland, one being image (it's not the most glamorous of specialities...), and the second being the present recruitment embargo in healthcare settings in Ireland: hospital wards, and community health facilities just can't let precious nurses off to training, they're not permitted to replace them!

I have to say that this was the most interesting conference I've ever been at: a subject that affects a lot of carers, and isn't really to be spoken about 'in polite company'. I always joke

that you're REALLY a carer to an older, frail person if you can discuss pee and poop, over lunch!

I'd also like to mention the conference organisers who did a fantastic job: I'm a wheelchair user who also has a severe nut allergy. They couldn't have done a better job of looking after me, a lovely, totally accessible hotel room, consideration to access when choosing venues, and provision of the greatest wheelchair accessible taxi service ever: Joshua (this was his name) was retained to attend to all of my transport needs, was knowledgeable, very caring, and really witty, I couldn't possibly tell you some of the things we discussed (I'd have to kill you if I did!), but there was some serious laughter in that cab!

Oliver at the hotel was also a gem, he took such good care of me: due to the allergy, I couldn't safely eat from the buffet, so he made sure I was always well fed and the fruit platters I had instead of biscuits at coffee time were fab! SCA did a wonderful job of organising everything. They made it look SO easy when I know that there was months of work involved. Nieves was a rock, always making sure I was looked after and could access everything: thank you all! I think the next of these forums takes place in two years time, and I'd encourage anybody who gets a chance to attend... I only hope I get the opportunity!

For more information about the GFI please click here:

<http://www.gfiforum.com/Documents/Madrid-2014/Conference%20Summary%20Report%205th%20GFI.pdf>

## **A new Employers' Kite Mark to improve support to working carers in Scotland**

**By Sebastian Fischer (Vocal, Voice of Carers across Lothian, Scotland)**

During the last **National Carers Week** in the UK (9-15 June 2014), the Scottish government, Carers Scotland and other carer organisations launched a new **Employers' Kite Mark** ("Quality Mark"), in order to improve the support to working carers in this area. The so called "Carer Positive kitemark" is awarded to employers in Scotland who have a working environment where carers are valued and supported, thus recognising the importance of retaining experienced members of staff, reducing absence, and cutting down on avoidable recruitment costs.

More information can be found on the new website: <http://www.carerpositive.org>.

## **The third edition of the Scottish Carers Parliament on 8 October 2014**

**By Sebastian Fischer (Vocal – Voice of Carers across Lothian, Scotland)**

The Scottish Carers Parliament is going to be held again on Wednesday 8 October 2014 in Edinburgh. This will be the third annual event. The Parliament is organised by Carers Scotland on behalf of the Scottish Government and in partnership with the national carer



organisations, for carers from all across Scotland. It aims to give carers and young carers in Scotland a real opportunity to express their opinions, and to have these opinions heard by senior politicians, human rights officials, fellow campaigners and third sector organisations in order to affect positive change.

Last year's event focused on a debate between the need for new rights, or better enforcement of existing rights. The event was attended by carers and young carers, First Minister Alex Salmond, MSP Michael Mathieson, Minister for Public Health and Caroline Waters, Vice Chair of the Equality and Human Rights Commission along with representatives from various third sector organisations.

Carers Scotland is inviting to this event delegations from another four to five national carers organisations from European countries, as a good opportunity to exchange views and experiences and to plan some joint priorities within the new Eurocarers Progress programme.

For more information please contact Sebastian Fischer at VOCAL - Voice of Carers Across Lothian, e-mail: [sfischer@vocal.org.uk](mailto:sfischer@vocal.org.uk); website: [www.vocal.org.uk](http://www.vocal.org.uk)

## RESEARCH ON THE MOVE

### **“Imprisoned carers”: the findings of a PhD study on prisoners’ experience of healthcare in England**

**By Julia Dawn Tabreham**

This thesis – whose full title is: “Prisoners’ experience of healthcare in England: Post-transfer to National Health Service responsibility - A Case Study” - is concerned with the transfer of prison healthcare to National Health Service (NHS) responsibility, and investigates whether equitable provision has been achieved for prison-based patients. Among the different findings emerging from this interesting study, some indicate that, despite considerable policy focus and activity, the lack of integrated service commissioning means that equitable provision for this prisoner population has not been consistently experienced by imprisoned patients. In its absence, prisoners have themselves adopted the role of carer for the sick and frail amongst their prison communities. These individuals report that they undertake these caring roles unsupported by the NHS and/or the Prison Service, whilst at considerable risk to both themselves and the person for whom they care. To achieve equitable provision for English prisoners, this thesis suggests the development of a prison multi-agency health and social care integrated service commissioning plan, which recognises the needs of imprisoned carers as highlighted in this investigation.

### **A new book on volunteering in older age in Europe**

**By Giovanni Lamura (INRCA, Italy)**

Carers’ organisations are mainly based on the volunteer work of the numerous carers – many of whom are in the older age group – who provide an invaluable amount of time and energy to carry out the organisations’ initiatives. Though not focused on carers’ organisations only, a recent publication edited by Principi A., Jensen P. H. and Lamura G. with the title *Active Ageing: Voluntary Work by Older People in Europe* (published by the Policy Press), analyses for the first time at European level the patterns and factors affecting volunteering among older people, by comparing data collected in eight European countries representing different kinds of welfare regimes. This study highlights the interactions facilitating or hindering older people’s inclusion in voluntary work, and helps formulate policy suggestions for an integrated strategy by policy makers and practitioners in the third sector as well as voluntary organisations. For more information: <http://www.policypress.co.uk/display.asp?ISBN=9781447307204&> (and for a 50 per cent discount on its nominal price, contact [a.principi@inrca.it](mailto:a.principi@inrca.it)).

## IN BRIEF

**The "European Semester":** this is a cycle of economic and fiscal policy coordination within the EU. Its focus is on the six-month period from the beginning of each year, during which the Member States align their budgetary and economic policies with the objectives and rules agreed at EU level. This way the Semester aims to: ensure sound public finances; foster economic growth; and prevent macroeconomic imbalances in the EU. The semester process is important in the relationship between member nations and the EU institutions. Our national governments are supposed to consult with stakeholders (this meaning also "us" as national carers organisations!), to formulate their submission in the Semester cycle. To learn about the Semester process and the key dates in the annual cycle, please see the "Explanation of Semester" (<http://www.consilium.europa.eu/special-reports/european-semester>) or "2014 European Semester: Country-specific recommendations" ([http://ec.europa.eu/europe2020/pdf/csr2014/eccom2014\\_en.pdf](http://ec.europa.eu/europe2020/pdf/csr2014/eccom2014_en.pdf)).

**Carers in the press:** Two recent articles in the Irish Times (Dublin, Ireland) have reported relevant information concerning the condition of carers in the Irish society. In the first one ("Majority of carers experience cuts in support": <http://www.irishtimes.com/news/social-affairs/majority-of-carers-have-experienced-cuts-in-supports-1.1826067>), the findings emerging from a recent survey carried out by Care Alliance Ireland are summarised, according to which about 80 per cent of Irish carers have experienced cuts to home care packages within the past three years. The survey also highlighted that in the same period 77 per cent of respondents had been affected by cuts to respite services, and 70 per cent by cuts to home help.

A second article ("Elder abuse linked to depressed carers": <http://www.irishtimes.com/life-and-style/health-family/elder-abuse-linked-to-depressed-carers-1.1826121>) focuses on the findings emerging from another significant study (*Family Carers of Older People: Results of a National Survey of Stress, Conflict and Coping*), carried out by the National Centre for the Protection of Older People (NCPPOP) by the University College Dublin (UCD), according to which 44 per cent of carers are at risk of clinical depression, a condition which is associated with potentially harmful carer behaviour. The survey, which reached a sample of 2,311 family carers in Ireland who are in receipt of a carer's allowance, also found that a higher number of hours of care per week and a longer period of caring time are likely to lead carers in potentially abusive behaviour towards the cared-for person.

**The spring edition of "Exchange", Care Alliance Ireland Newsletter...:** The Spring 2014 edition of our Newsletter, Care Alliance Ireland Exchange, is now available to download. Issues covered in this edition include: Care Alliance Ireland Fully Compliant with the Governance Code; New Partner for the 8<sup>th</sup> National Carers Week; Carers Guide and Emergency Card Launched in West Cork; Report questions the efficacy of Home Visits. The Newsletter also includes all our regular pieces on Members News, National and International News, Policy and Practice Publications, Practical Resources, International News, Policy Developments and a Member Profile. To download the Newsletter [click here](#).

**... and that from the Carers Association, Ireland:** Please download here the latest issue from April 2014 of *Take Care*, the Newsletter of The Carers Association: [http://www.carersireland.com/emailtemplates/2014\\_04/newsletter.htm](http://www.carersireland.com/emailtemplates/2014_04/newsletter.htm).

## About EUROCARERS

*EUROCARERS was officially established in Luxembourg in December 2006. Its origin lies in two European networks: Carmen, a network on integrated care and Eurofamcare, a research network on carers of older persons. In the Carmen project researchers, practitioners and policy makers, among them representatives of the carers' movement, found each other and came to the conclusion that it was time for carers to be heard at European level. The Eurofamcare network - consisting of researchers who mapped the situation of carers of older persons and the policy measures developed for this category in the EU and who did quantitative research on the support of carers of older persons in six countries - also diagnosed a strong need for carers to make themselves heard in Europe.*

*Representatives of the two networks and other interested persons met in Maastricht in 2004 on the initiative of NIZW, the Dutch Institute of Care and Welfare (later reorganised into the two organisations Vilans and Movisie), to discuss the feasibility of establishing a European organisation and decided to go ahead with this task. Christine Marking had written a preparatory paper which helped those who met in Maastricht in formulating decisions about some crucial issues. An interim board was established consisting of: Brigid Barron, President; Patrick Michielsseune, Treasurer; Marja Pijl, Secretary; and the following other members: Judy Triantafillou, Isobel Anderson, Hanneli Döhner, Caroline Glendinning and Henk Nies. Several working groups were formed. Geraldine Visser and Nicoline Tamsma made a report of the meeting. Several meetings took place in the following months and some activities were already developed before EUROCARERS was formally registered in Luxembourg at the end of 2006.*

*Since then the association has increased remarkably, especially in the last year, and includes now over 60 organisations and several individual associates from all European Member States. Members of the current (2014-15) Executive Committee are: John Dunne (President), Hanneli Döhner (Vice President Carers Associations), Elizabeth Hanson (Vice President Research), Marijke Steenbergen (Treasurer), Licia Boccaletti, Helle Lepik and Marja Tuomi. In addition, the Executive is supported by four advisers, Christine Marking, Frank Goodwin, Giovanni Lamura and Katherine Wilson. For more information on the members of the Executive Committee: [http://www.eurocarers.org/about\\_executive.php](http://www.eurocarers.org/about_executive.php).*

*For more information on the aims and guiding principles of EUROCARERS please go to the link: <http://www.eurocarers.org/about.php>.*

### **EUROCARERS key contacts:**

EUROCARERS, 23 Ranelagh Road, Dublin 6, Ireland

Phone: 00 353 861294296

Email: [eurocarers@gmail.com](mailto:eurocarers@gmail.com)

Website: [www.eurocarers.org](http://www.eurocarers.org)

EUROCARERS is an NGO & non-profit organisation registered in Luxembourg in 2006 (registration no. F6854).

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