

Dear readers,

Welcome to the first issue of the renewed EuCaNews, the Newsletter of EUROCARERS, the European Association for carers! Our initial aim for the Newsletter is that it becomes a useful and versatile tool to improve communication within our organisation. This is very much needed at a time in which its growth in terms of member associations requires more attention to ensure that information reaches all members in an effective, uncomplicated and quick way. If this experiment works out well, there is potential for the Newsletter to become a crucial means to increase the visibility of EUROCARERS and of its member associations to the outside world. This would in turn help to improve the recognition of carers across all European countries and societies.

Your feedback, comments and ideas for the Newsletter will be important to help us understand how this first attempt can be improved. We would be pleased to include contributions 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. So please do not hesitate to email them to us: we will use them to inform how we proceed with future editions of the Newsletter, together with suggestions from the Annual General Assembly in Dublin on 5th and 6th May.

Enjoy the reading and take care,

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Some introductory words from EUROCARERS President

Over the last year or so the membership of Eurocarers, the number of Member States involved and our profile at European level have increased markedly. This reflects the emerging recognition of the role and contribution of carers but also specifically efforts by Henk Bakkerode and colleagues. This growing engagement with Eurocarers has demanded greater efforts by us to communicate more effectively, particularly with our members. We have been grateful particularly to Frank Goodwin – and to SCA for their financial support – for building our new website as a key tool for information and exchange. Now, we welcome the re-launch of a newsletter for Eurocarers, thanks to Giovanni and Hilary. Please do let us know your views and please do feel encouraged to contribute your views and experiences. In this European Year of Volunteering we want to use the opportunity to highlight the valuable work of our members and member organisations.

Robert Anderson

News from the Executive Committee

MARK THE DATE: The EUROCARERS Annual General Meeting (AGM) will take place in Dublin on 5-6 May! Please pay attention to the following:

- The Executive Committee would like to draw attention to the fact that **two vacancies among its members will need to be filled in through election** at next AGM in Dublin. The candidates should preferably have specific skills in the field of **fundraising** and of **membership**, two areas which are fundamental to the future of Eurocarers. Candidates from Central and Eastern European countries are highly welcome, in order to ensure a more effective advocacy of the specific interests of carers organisations in this geographical area.
- Here some of the topics which will be discussed (from the programme to be circulated soon):
 - Focus on carers in Central and Eastern European Countries (two speakers);
 - opening address by Marian Harkin (Member of European Parliament) on “Working together for AN EU STRATEGY FOR CARERS”
 - Presentation of the IRISH STRATEGY FOR CARERS” (Enda Egan)
 - The role of ICT for caregivers (EU-officer Clara Centeno)
 - Long-term care across Europe (Jolanda Elferink)
 - Care givers quality of life and managing incontinence (Giovanni Lamura)
- Parallel workshops will be conducted on the above issues.

A more detailed and updated programme will be circulated soon. For more information please contact Frank Goodwin: info@eurocarers.org.

Eurocarers and its origins (from the EUROCARES website)

Eurocarers was officially established in Luxembourg in December 2006. The origin of Eurocarers 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 entire 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 Welfare¹, 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 established formally, which was achieved at the end of 2006, when Eurocarers was registered in Luxembourg under the number F 6854.

Since then the association has increased remarkably, especially in the last year, and includes now over 50 organisations and several individual associates from 24 European countries. Members of the current (2011-12) Executive are: Robert Anderson (President); Henk Bakkerode (Vice-President - Carers organisations), Giovanni Lamura (Vice-President -Research); Frank Goodwin (Secretary); Sebastian Fischer; Licia Boccaletti; Åke Fagerberg. The association can also count on the support of two advisers: Christine Marking and Marja Pijl. For more information on the members of the Executive: 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>.

Recent EU-level policy developments

by Christine Marking

In this section relevant developments at the European policy level are illustrated, distinguishing according to the institution from which they originate.

¹ NIZW was since reorganised and split up, and its work is now continued by Vilans and Movisie.

EUROPEAN COMMISSION

2011: European Year of Volunteering: The 2011 European year of Volunteering was officially launched by Justice Commissioner Viviane Redding on 2 December, and it aims pay tribute to the millions of Europeans who ‘contribute to make the world a better place’. The Commission estimates that 23 per cent of Europeans aged over 15 are volunteers, with sporting or outdoor leisure being the main areas of activity. Working for health, charitable or religious organisations is also widespread. However, there are huge variations between EU Member States as regards the level of voluntary activity. The budget earmarked for the year is €8 million. Link: <http://europa.eu/rapid/pressReleasesAction.do?reference=IP/09/862&format=HTML&aged=0&language=EN&guiLanguage=en> and <http://europa.eu/volunteering/>

Europe2020 flagship initiative: Commission launches Anti-Poverty platform: On 16 December, the Commission published a Communication entitled ‘Platform against Poverty and Social Exclusion’ to assist the 81 million Europeans threatened by poverty. This reaffirms traditional principles, such as the more efficient use of EU funds and the exchange of good practice and also introduces the concept of ‘social innovation’. According to the latter, innovative small-scale projects will be developed, tested and scientifically evaluated and, if positive, encouraged to be implemented at a wider level. In 2011, the Commission will also publish its White Paper on the future of pensions, with the aim to improve the effectiveness of social protection and social services. In 2012, the Commission will evaluate the implementation of the active inclusion national strategies. Link: <http://ec.europa.eu/social/main.jsp?langId=en&catId=961>

Commission holds Expert Workshops on Healthy Ageing: During October 2010, the Commission’s Directorate General for Health and Consumer Policy (DG SANCO) invited over 60 experts from across the EU to three one-day workshops which aimed to discuss, explore and create a common vision for healthy ageing in Europe. Each workshop addressed one of the three following themes: [adaptation of health systems to demographic change](#); [health innovations to keep people healthy and active](#); [consumers and active ageing](#). The conclusions of these workshops will feed into other initiatives currently being developed to address healthy and active ageing. Link: http://ec.europa.eu/health/ageing/docs/ev_20101011_reflections_en.pdf

Europe for Patients website launched: The Commission has launched a new multilingual Europe for Patients website, where updated factsheets, news, events, press releases and videos related to the Europe for Patients campaign can be found. The campaign includes 11 policy domains, i.e.: cross border health care; rare diseases; organ donation and transplantation; health workforce; patient safety; cancer; flu vaccination; childhood vaccination; use of antibiotics; mental health; Alzheimer and other dementia. Link: http://ec.europa.eu/health-eu/europe_for_patients/index_en.htm.

COUNCIL OF MINISTERS

Hungary sets its priority agenda: Hungary took over the EU Presidency from Belgium on 1 January 2011. Main Presidency themes are: growth, jobs and social inclusion; stronger Europe – building on the foundations and saving the future; a Union close to its citizens; enlarging responsibly and engaging globally. In the field of health, Hungary will focus on the ageing population, chronic diseases and eHealth, under the general heading of ‘Innovation and Solidarity in health care’. Current policy files to be addressed will be

cross-border healthcare, the pharmaceutical package, quality and safety of healthcare and Health professionals. On social issues, the Hungarian Presidency considers it a priority to "break taboos" and tackle the EU's demographic challenge, improve family policies, alleviate child poverty and achieve a breakthrough in the area of Roma inclusion. Link: http://www.mfa.gov.hu/kum/en/bal/european_union/eu_pres_2011/priorities.htm and Link: http://www.ehfg.org/fileadmin/ehfg/Website/Archiv/2010/Presentations/Plenary_1/Opening_Plenary_Szocska.pdf

SOCIAL AND HEALTH COUNCIL MEETING

2012 Year of Active Ageing: The Council of Ministers adopted a 'general approach' on a draft decision designating 2012 as the European Year of Active Ageing, pending the adoption of the European Parliament's opinion. The Year aims to increase awareness of the contribution of older people to society and by spreading innovative measures which could help to mobilise the full potential of the growing older population. Link: <http://register.consilium.europa.eu/pdf/en/10/st16/st16511.en10.pdf>

Fight against poverty and social exclusion: The Council of Ministers has adopted a declaration entitled "The European Year for Combating Poverty and Social Exclusion: Working together to fight poverty in 2010 and beyond", recalling the achievements of this Year and outlining the challenges ahead. The declaration argues for further development of the legacy of the European Year and calls upon the EU and its Member States to continue their work together in the fight against poverty. Link: <http://register.consilium.europa.eu/pdf/en/10/st16/st16435.en10.pdf>

Chronic diseases: The Council of Ministers also adopted conclusions on innovative approaches for chronic diseases in public health and healthcare systems, inviting the Member States to further develop patient-centred policies in the field of chronic diseases. The Member States and the Commission are called upon to start a 'reflection process', with a view to optimising the response to the challenge of chronic diseases, covering health promotion and prevention of chronic diseases, healthcare and comparative research on chronic diseases in Europe. The outcomes should be summarised in a paper by 2012. Link: <http://register.consilium.europa.eu/pdf/en/10/st16/st16559.en10.pdf>

EUROPEAN PARLIAMENT

Parliament agrees Citizen's Initiative: On 15 December 2010, MEPs gave the green light to the Citizens' Initiative, which will make it possible for one million citizens or more to demand new EU legislative acts. Member States will adapt their legislation by the end of this year to facilitate this. The agreed procedure is as follows: to start matters, a committee of at least seven citizens needs to approach the Commission to register the request for an initiative. It is the Commission that will determine its admissibility, basing itself on the EU Treaty. If the petition is admissible and collects at least one million signatures, its initiators will have the right to be received by the Commission and to take part in a public hearing. However, in accordance with the Treaty, the Commission will be the sole judge of the possibility of giving a legislative follow-up to a citizens' initiative. Link: <http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+TA+P7-TA-2010-0480+0+DOC+XML+V0//EN&language=EN#BKMD-16>

Contributions from our members

Future informal care

By Anita Peters - Senior project manager, researcher and consultant on informal care, MOVISIE, Netherlands

Since the economic crisis, the social debate has focused on financial cutbacks. We intend to press for discussions on the social consequences for the role of caregiver on the basis of the Trend Study into informal care in ‘Shrinking Families’. Policymakers have high expectations of the potential of informal carers to provide relief from the consequences of cost-cutting measures. But is this realistic when we consider the issues of an ageing population, increasing pressure on work participation, greater geographic distances and looser relationships between family members? We have observed a considerable increase in the number of stressed informal carers.

In this Trend study, MOVISIE has determined the issues that will face future caregivers for the elderly and where possible solutions could be sought and found. This will enable the supporting policy to respond accordingly and place expectations of its implementation in a true perspective.

The demand for informal care will increase because of population ageing. It is therefore self-evident that we should investigate whether there will be sufficient carers for the future. A study carried out by the Netherlands Institute for Social Research shows that supply and demand in informal care are expected to be in balance in 2030, despite the ageing population. Around this time, following a particularly rapid increase after 2020, the surge in population ageing will be approaching its peak. The principle explanation for this balance is that future pensioners will be less reliant on informal care because of their generally higher level of education. This will make them more independent and consequently less dependent on support from their environment. While their share in the population will increase by over 60 per cent, their demand on informal care will remain limited to an increase of 25 per cent.

The researchers have however included certain cautionary remarks regarding the generally reassuring results from their study into the future up to 2030. In the Trend Study into informal care in ‘Shrinking families’, we provide the issues of future caregivers with definite form by categorising them into partner care, child-parent care and care for other relatives and by determining what this means ‘behind the front door’. At this level, we see that caregivers are faced with considerable challenges, with increasing risks of stress.

The issues for caregivers are concentrated in the generation of fifty-year olds – the sandwich generation – who have to combine caring for their children with caring for their ageing parents. They will be under additional stress not only from this combination of care but also because of aspects such as having to travel greater distances, being required to work more frequently and for longer and help with voluntary work.

Among the older caregivers, the care will often be given to people in their home, usually their partner. They will therefore run an increased risk of stress and damage to their health, in particular if the care is for people with cognitive disorders such as dementia.

It has also been shown that traditional family compositions (mum, dad, children, in-laws, grandchildren) are to an increasing extent changing to new, modern family compositions that include stepchildren. Instead of a single set of parents and parents-in-law, there are now two sets, with the possible addition of stepbrothers and half-sisters, to whom you need to relate. Within the new complex family compositions it is no longer so self-evident who will perform the duty of informal care and to what degree. Informal care is care that is generally given by family members. We rely on familiar values and standards (Hochschild: feeling and framing rules) where caring for each other is concerned. However, family relations are changing. The members of these complex patchwork families will have to develop new rules together.

Government policy is based on the vision that citizens will take more responsibility for their own care and welfare. The principle here is that we should care more for each other. But do we feel it is a social responsibility to make informal care possible or do we simply accept the increasing gap between those with money and those without? In the future, an increasing number of the elderly will be sufficiently wealthy to purchase supplementary care from the “informal circuit” or commercial homecare agencies. As professional care becomes scarcer and labour market shortages increase, it becomes more inviting to look across the national borders. Countries such as Germany and Italy are already employing a lot of female economic migrants who are taking over household and care duties (Lutz, 2008, Parreñas, 2001). This development also appears to be increasing in the Netherlands, as witnessed by the offers on Marktplaats.nl, E-bay and other advertising websites from Filipino housekeepers and experienced but cheap Polish and Slovakian carers. At first sight, both parties appear to benefit. The elderly person receives tailor-made care and the foreign woman has work and income, which she can use to support members of her own family. However, both parties have to deal with language and cultural differences as well as their mutual dependence, which makes it easier for the care to go awry. In addition, to be able to provide care in the Netherlands, some of the women have to hand over the care of their own children in their home country to other people. Parreñas (2001) considers this form of economic migration *care drain*, which results in social disruption in the countries of origin. Do we simply accept that a large scale care drain is starting up within Europe, from central and eastern European countries to western Europe?

Alternatively, do we jointly invest in a sustainable policy, so that with the support of their friends and family, people can in fact count on good quality care in their own environment? To achieve this, we are thinking of making it easier to combine work and care tasks. Caring children in particular, both by blood and marriage, will benefit from this, as will caring partners if the pension age continues to increase. It is important that employers have pro-caregiver personnel policy, but the government also has an important role to play here. Government goals for work participation and the provision of informal care are inconsistent with each other. This tension can only be kept manageable by opting for a more equal division of work and care tasks amongst men and women. An additional practical focus must be the modification of conditions in statutory regulations, to ensure primary caregivers can benefit from them regardless of their degree of blood relationship.

Long distances are another important stumbling block for the modern caregiver. Possible ways of dealing with these distances include informal care accommodation and the use of social media. A third option to help lighten the load on the caregiver of the future is to better share the care, by drawing on the entire network of potential helpers and if necessary by reinforcing this network. New possibilities can also be created by the use of IT and telecare solutions. Each of the different types of solution has its benefits, but also disadvantages. One possible disadvantage that certainly deserves attention here is social safety. If the network of helpers is widened to include distant relations as well as old and new acquaintances, the situation becomes more complex. This makes it more difficult to assess the good, or not so good, intentions of those involved. Unfamiliar people will be visiting, possibly more frequently than the family caregivers, and establishing a bond. Little control is possible in the home environment and it is difficult to monitor the safety of the vulnerable elderly. This is also the case when using social media. Undesirable guests can easily penetrate the front door via the digital environment.

Many policymakers in Europe are faced with the challenge of an increasing demand for care but with decreasing funds to allocate to it. We can currently rely on a good, acceptable quality of care, certainly in western Europe. However, if financial stringency is the driving factor for policymakers, we feel that undesirable situations may prevail in which the infirm elderly become reliant on charity, whereby social isolation becomes the norm rather than the exception and all personal control is lost. The policymaker who does not take a broad social perspective when considering the precautionary and other measures required guaranteeing the quality of care in the home and keeping the load on the caregiver at an acceptable level will find they have cut their own fingers rather than the costs. We are therefore pressing for a broad social debate on the theme of informal care. We have proposed a number of topics for discussion in our Trend study which we will present and debate at the Spring Conference of Eurocarers in Dublin. In the meantime, if anyone would like further information or a copy of the final report, please e-mail to J.Elferink@movisie.nl.

N.d.R: Other countries face similar issues, as shown by the work undertaken elsewhere (see for instance the projections until 2050 by Linda Pickard and colleagues at the London School of Economics for informal carers). Here's the link <http://www2.lse.ac.uk/LSEHealthAndSocialCare/PSSRU/whosWho/pickard.aspx>.

The European Network of Intercultural Elderly Care (ENIEC)

By Marije Vermaas, Centre of Expertise for Informal Care, Netherlands

“Sarah was 56 years old when she had to flee her country because of war. Together with her daughter and husband she left her home country - Pakistani and heard that she might be welcome in the Netherlands. At the age of 71, she lost her husband. Sarah doesn't know the language and feels often lonely. Last year she noticed she is getting older – she is often tired and her health isn't as good as it used to be. Sarah has some questions about her health and would like to get some help, but she doesn't know where to ask for it. Last year she remembered many things from her childhood, but no one listens to her or

understands what she has left behind. The only person who takes care of her is her daughter.”

At the annual meeting at ENIEC we discuss cases like this. How may we provide care for everyone? What does this mean? How may we help informal carers to deal with this situation?

ENIEC is a non-profit membership association for enthusiastic professionals engaged in care for elderly migrants in Europe. ENIEC is an official network with the objective of creating an informal platform of exchanging ideas and experiences cross borders in today's Europe. The professional aim is to secure that European elderly with a foreign ethnic background can live in an environment of tolerance, intercultural understanding and respect for their needs and for their cultural background.

Through ENIEC, members develop new practises in care of elderly migrants, in their welfare in general and in the area of preventive initiatives. The migration history of European countries differs, which makes it interesting to compare the problems and solutions and learn from each others' experiences. Members learn to view their work from a more European perspective and teaches them the differences in culture, values, needs and tradition.

At present, members are professionals from The Netherlands, Germany, Belgium, Denmark, Sweden, Norway, Finland and Turkey. They are working at nursing homes, in home care, in day activities, in municipal administrations, universities, as advisors or consultants, etc. Members and the Board would like to include persons from other European countries in the network. Also, volunteers and others with a special interest in elderly migrants are welcome as members.

More information: www.eniec.eu

Update on the research project “Quality of life in caregivers of dependent people affected by incontinence in Europe”

By Sabrina Quattrini (INRCA, Italy) and Giovanni Lamura (INRCA, Italy and European Centre for Social Welfare Policy and Research, Vienna, Austria)

After a long preparation phase, in Spring 2010 EUROCARERS and SCA (a multinational company in the field of hygiene products) agreed to cooperate to carry out a qualitative survey (based on face-to-face interviews) on “Quality of life in caregivers of dependent older people affected by incontinence in Europe”. The study, funded by SCA and coordinated on behalf of Eurocarers by INRCA, is now coming to a conclusion. It has involved research teams and field studies in four countries, each representing a different macro-area of the European continent: Southern Europe (Italy, INRCA, Italian National Research Centre on Aging), Eastern Europe (Slovak Republic, Institute for Labour and Family Research), Scandinavia (Sweden, The National Competence Centre for Family Care) and Western Europe (The Netherlands, Vilans).

The aim of the study was to explore the experiences of adult partners and children in caring for dependent older persons aged 65 and over, living at home and suffering from urinary/and or faecal incontinence on a daily basis, in order to gain a better understanding of which measures and interventions might improve the current situation of caregivers. The data collection, concluded in January 2011, has involved between ten and 16 in-depth interviews per country. After the qualitative analysis the national reports have now been completed, and currently the final comparative report is being finalised. The final meeting among the project partners will take place on 8th – 9th March 2011 at INRCA in Ancona, where the final version of the comparative report will be discussed, and appropriate dissemination strategies agreed. The findings emerging from the study will be presented for the first time at the next EUROCARERS Annual General Meeting, to take place in Dublin at the beginning of May.

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