



EUROCARERS

EUROPEAN ASSOCIATION
WORKING FOR CARERS

ANNUAL REPORT

Eurocarers is the European network **working with and for informal carers and their organisations**, with the aim to **advance their interests**, irrespective of the particular age or health need of the person they are caring for.

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2017





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FOREWORD

This report covers another busy and productive year which included the celebration of our organisation's 10th anniversary.

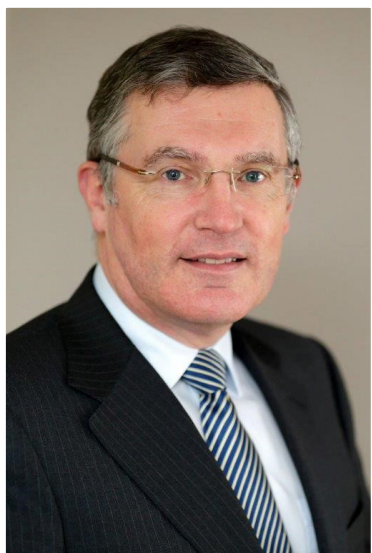
We marked this milestone with a particularly comprehensive programme of activities during our AGM held in Brussels in June. The General Assembly adopted a series of changes to the statutes and internal rules based on the new membership policy approved the year before; it also endorsed the EaSI action plan to be submitted to the EC in respect of 2017 and saw the inaugural meeting of a new Policy working group to complement the Research working group established in 2015.

We continued to work closely with the European Commission and Parliament throughout the year. There is no question that without access to the EaSI support we would be unable to deliver the range of services we currently offer to support and affirm informal carers across Europe. But it is also important to acknowledge the willingness of elected representatives and officials in each of the EU institutions to engage with issues relating to informal carers, based on genuine appreciation of their relevance to the long-term sustainability of Europe's economic and social fabric.

I would like to thank my colleagues on the Board for the energy and expertise they have brought to our work over the past year and, in particular, to acknowledge the work of Elizabeth Hanson, Vice-President Research; Marja Tuomi, Vice President Membership; Chloe Wright, Vice President Policy; and Ivar Paimre, Treasurer. I would also like to pay a special tribute to Hanneli Döhner who retired from the Board having completed two consecutive mandates on the Board and to Marijke Steenbergen who unfortunately had to step down for personal reasons.

I would also like to thank Stecy Yghemonos, our Executive Director, for his leadership, dedication and sheer hard work throughout the year. And to acknowledge the unfailing effort, expertise and commitment of our staff – Francesca Centola and Claire Champeix. Finally, I would like to thank Christine Mar-king who has been a key support for Eurocarers on a consultancy basis for many years.

Last but not least, I would like to thank our member organisations for the work they do in supporting and affirming informal carers across Europe. As I always say, without them none of this would be either possible or meaningful.



JOHN DUNNE
President

Dear Readers,

It is with great pleasure that I present you with this report, which highlights the wealth of Eurocarers' activities and achievements in 2016–2017. Our mission is to achieve greater recognition and support for all carers across Europe and I am glad to say that – only two years after introducing our new network structure – we are going from strength to strength. This past year has indeed been one of growth and commitment.

Ever since our network was set up in 2006, we have facilitated effective exchange and cooperation among carers, academics, relevant stakeholders and responsible authorities in Member States. The partnership agreement signed with the European Commission in 2014 is a prominent lever in Eurocarers' strategic and operational planning. It has allowed us to more dynamically liaise with EU institutions and proactively contribute to the development of social protection systems that truly recognise and value the role of carers.

Throughout these 10 years we have learned that the success of our mission depends on the interplay between a broader set of social, health and employment policies. This requires the involvement of various sectors and a mix of policy measures that address the many facets of caregiving in Europe. I am pleased to say that our work in the last year has resulted in further successful multi-sectoral collaboration and synergies.

First and foremost, this report reflects the dedication as well as the individual and collective achievements of our member organisations. The output of their efforts has been incredibly rich and diverse. On behalf of the Secretariat, I would like to thank them all for their participation and support to our activities in the last year. We look forward to further exploring new and exciting ways of investing in carer-friendly societies in 2017– 2018 and beyond.



STECY YGHEMONOS
Executive Director

WHO WE ARE

Eurocarers is the European network representing informal carers and their organisations, irrespective of the particular age or health need of the person they are caring for. Our network brings together 65 carers' organisations as well as relevant research & development organisations from 25 countries – a combination that enables evidence-based advocacy. These organisations are active at international, national and regional levels. For a membership overview: <http://www.eurocarers.org/membership>.

Eurocarers was established to advance the issue of informal care at both national and EU levels by:

- Carrying out and supporting research on issues that concern carers in order to help build the evidence for sound advocacy, communication and – ultimately – policy development;
- Advocating the interests of carers with a focus on their health, pensions and social security, social inclusion and employment. As part of this activity, Eurocarers holds the secretariat for the European Parliament's Interest Group on Carers;
- Encouraging and facilitating the development of representative and sustainable carers' organisations in all EU states;
- Promoting the development of inclusive and patient-centred care systems, which fully recognise the role, contribution and added value of carers.

WHAT WE STRIVE FOR

Europe's demographic ageing gives rise to a growing prevalence of age-related diseases, a growing demand for care and a serious sustainability challenge for our social and health care systems. Against this backdrop, community care has become a prominent EU priority in the last few years and the shift towards home-based care is seen as a practical measure to contain the costs of services while also seconding widespread preferences among the elderly for being cared for in their own home.

Informal carers across the EU currently provide over 80% of all care, with women providing approximately two thirds of care mainly as daughters (in law) and wives/partners. Even in countries with a well-developed supply of formal long-term care, using narrow definitions of informal carers, their number is estimated to be at least twice as big as the formal care workforce. Advances in medicine also mean that carers find themselves having to deliver more and more sophisticated levels of care, with very little training and minimal support. Caring can have – if not adequately supported – many challenging consequences for the (physical and mental) health and well-being of carers, their capacity to balance paid work with care responsibilities, their financial situation, their social integration as well as their access to employment and education.

We strongly believe that people should have the right to choose freely whether they want to be a carer, and to what extent they want to be involved in caring; people needing care should have the right to choose

who they wish to be their carers but this right only becomes truly valid once the carer has freely chosen to be a carer. Carers should not be socially and economically penalised as a result of their caregiving activities. Measures designed to identify and support them should therefore aim to recognise them and their vital role in society; provide them with the essential information and counselling they need; give them access to allowances that offset the costs they face and truly value their contribution; develop flexible working arrangements and care leave schemes to allow them to maintain an active life; and improve the provision of equitable, accessible and good quality formal care services to ensure carers can rely on professional alternatives to informal care.

Eurocarers works for a future in which caring is recognised and valued, and in which unpaid carers do not face poverty, social exclusion or discrimination. The network aspires to be the leading authority on carers and their contribution to the sustainability of health and long-term care systems across the EU.

The role of carers is more crucial than ever due to demographic changes and challenges to formal health and social care services throughout Europe. Eurocarers aims to:

- Raise awareness of the significant contribution made by carers to health and social care systems and the economy as a whole, and of the need to safeguard this contribution; and
- Ensure that EU and national policies take account of carers, i.e. promote social inclusion of carers, the development of support services for carers, enable them to remain active in paid employment and maintain a social life.

OUR MISSION

DATA COLLECTION AND PRODUCTION

- Evidence
- Share good practices among Member States
- Recommendations

➡ IMPLEMENT / DOCUMENT



ADVOCACY

- Partnerships
- Solidarity and economic argument
- Inform policy makers
- Communication (newsletters, websites)

➡ RAISE AWARENESS

EUROCARERS' 10 KEY PRINCIPLES

Eurocarers has adopted ten key principles which serve to frame our action and strengthen the position of carers. Our network strives for the implementation of these principles in all policy areas relevant to carers and at the same time uses them as guidance for its own actions.

1 Recognition

Carers should be recognised for the central role they play in community care, and this recognition should be reflected in all policies having effect on carers.

2 Social inclusion

Carers have a right to a social life.

3 Equality of opportunity

Carers should have equal opportunities in all spheres of life.

4 Choice

People should have the right to choose freely whether they want to be a carer, and to what extent they want to be involved in caring; people needing care should have the right to choose who they wish to be their carers.

5 Information

Carers should have easy access to the information, guidance, advocacy, advice and training they desire – fitting to the stage of their carer's career.

6 Support

Carers need financial, practical and emotional support in their role as carers as well as access to needed formal care that is available and affordable.

7 Time off

Carers should have the opportunity of taking time off. Therefore, adequate relief i.e. respite care arrangements, acceptable both to the carer and the cared for person, must be readily available and tailored to carers' needs.

8 Compatibility of care and employment

Carers should have the possibility to combine caring with paid employment. This presupposes labour market policies that allow for caring activities as well as formal care available during working hours.

9 Health promotion and projection

Carers' own health care needs should be recognised.

10 Financial security

Carers should be covered by social security schemes such as income replacement benefits, accident insurance and old age pensions, in order to avoid impoverishment as a consequence of caring.

THE SITUATION OF CARERS IN THE EU

By 2060, 155 million Europeans – 30% of the total European population – will be aged 65 and older. According to conservative estimates, 30% of these people (~45 million) will have at least one disability that disrupts activities of daily living. The need is even greater for Europeans aged 80+, for whom long-term care is expected to triple by 2060.

There are currently more than 100 million carers in Europe, a largely underestimated figure given the (self-)recognition problem of carers. These carers provide 80% of care across the EU. A typical carer is a woman between 45 and 75 years of age. Estimates suggest that the economic value of unpaid informal care as a percentage of the overall cost of long-term care in EU Member States ranges from 50 % to 90 %.

42% of non-working carers are in the lowest income quartile, almost twice the proportion for non-carers.

WHAT DO CARERS NEED?

In 2011, a Eurobarometer survey identified the most useful things that governments could do to help informal carer (in order of preference).

These measures include:


- Provide financial remuneration for carers;
- Facilitate flexible working hours;
- Allow leave from work for care reasons;
- Give pension credits for care time;
- Provide a right to part-time work;
- Provide training;
- Fund respite care during caregiver holidays.

To be successful, policies targeted at the wellbeing and social inclusion of the carer should take into account the interplay between a broad set of social, employment and care policies: these issues cannot be separated from each other!

100,000,000+
CARERS in 

42% of
non-working
CARERS



By 2060
30% of 
>65 y.o.

NUMBER OF CARERS AND EXISTING SUPPORT MEASURES ACROSS THE EU

Country	Official number		Unofficial number		Formal recognition of carers	Financial remuneration		Leave to care		Pension credits for care time	Flexible working arrangements	Counseling	Respite care	Training	Self-help groups
						Care Allowance (direct)	Attendance Allowance (indirect)	For dependent relatives	For terminally ill relatives						
AT	290.000	3,50%	837.116	9,80%	✓	✗	✓	✓	✓	✓	—	✓	✓	✓	✗
BE	420.000	4%	1.358.830	12,10%	✓	✗	✓ Regional and local level	✓	✓	✗	—	✓ Regional and local level	✓ Regional and local level	✓ Regional and local level	✗
BG	N/A	N/A	N/A	N/A	✗	✗	✓	✓	✗	✗	—	✗	✓	✓	✗
HR	N/A	N/A	N/A	N/A	—	—	—	—	—	—	—	✗	✓	✗	✗
CY	N/A	N/A	N/A	N/A	✗	✗	✗	✓	✗	✗	—	✗	✗	✗	✗
CZ	281.000	2,70%	1.263.600	12%	✗	✗	✓	✓	✗	✓	✓	✓	✓ Regional and local level	✓	✓
DE	3.256.000	4%	8.907.800	11%	✓	✓	✗	✓	✗	✓	—	✗	✓	✓	✗
DK	20.000	0,40%	524.799	9,30%	✓	✓ local level	✗	✓	✓	✓	—	✓	✓	✓	✓ local level
EE	N/A	N/A	N/A	N/A	✗	✓ local level	✗	✓	✗	✗	—	✓	✓	✓	✓ local level
FI	N/A	N/A	350.000	6,30%	✓	✓ local level	✗	✓ local level	✗	✓	✓ local level	✓	✓ local level	✓ local level	✓ local level
FR	2.102.000	3,30%	7.115.500	10,70%	✓	✗	✓ regional level	✓	✓	✗	✓ local level	✓	✓ local level	✓	✓ local level
EL	273.000	2,50%	947.430	8,70%	✗	✗	✓	✓	✗	✗	—	✓ local level	✓	✓ local level	✗
HU	N/A	N/A	N/A	N/A	✗	✓	✗	✓	✗	✗	—	✗	✓	✗	✗
IE	187.000	4,10%	674.082	14,60%	✓	✓	✗	✓	✗	✓	✓	✓ local level	✓ Regional and local level	✓ local level	✓ local level

Country	Official number		Unofficial number		Formal recognition of carers	Financial remuneration		Leave to care		Pension credits for care time	Flexible working arrangements	Counseling	Respite care	Training	Self-help groups
						Care Allowance (direct)	Attendance Allowance (indirect)	For dependent relatives	For terminally ill relatives						
IT	4.035.000	7,00%	9.847.980	16,20%	✓	✗	✓	✓	✗	✓	✓ Regional level	✓ Regional and local level	✓	✓	✓ Regional and local level
LV	N/A	N/A	N/A	N/A	✗	✗	✗	✗	✗	✗	—	✓	✓	✓	✓
LT	N/A	N/A	N/A	N/A	✗	✗	✓	✓	✗	✓	—	✗	✗	✓	✗
LU	4.752	1,00%	N/A	N/A	✓	✗	✓	✓	✓	✓	✓ local level	✓	✓	✓	✓
MT	N/A	N/A	N/A	N/A	✗	✗	✓	✓	✓	✓	✓ local level	✗	✓	✗	✗
NL	3.500.000	21,30%	1.923.180	11,40%	✓	✓ local level	✓	✓ local level	✗	✗	✓ local level	✓ local level	✓	✓ local level	✓ local level
PL	1.214.000	3,20%	3.915.030	10,30%	✗	✗	✓	✓	✗	✗	—	✗	✗	✗	✗
PT	N/A	N/A	N/A	N/A	✗	✗	✓ Regional level	✓	✗	✗	—	✗	✓	✓	✓ local level
RO	N/A	N/A	N/A	N/A	✗	✗	✓	✓	✗	✗	—	✗	✗	✓	✗
SK	58.000	1,10%	N/A	N/A	✗	✓	✓	✓	✗	✗	—	✗	✓	✗	✗
SI	N/A	N/A	N/A	N/A	✗	✗	✗	✓	✗	✓	—	✗	✗	✗	✓ local level
ES	427.000	0,9%	7.155.810	15,3%	✗	✗	✓	✓	✗	✗	—	✓	✓	✓	✓ local level
SE	200.000	2,2%	750.240	8%	✓	✓	✓	✗	✓	✗	—	✓	✓	✗	✓
CH	N/A	N/A	1.047.168	10,8%	—	—	—	—	—	—	—	—	—	—	—
UK	5.550.000	8,9%	9.820.720	15,2%	✓	✓ local level	✓	✓ local level	✗	✓	✓ local level	✓ Regional and local level	✓	✓ local level	✓ local level

POLICY CONTEXT

The Eurocarers network thrives to maintain and increase the momentum around the important role and added value of informal carers in the development of quality, people-centred, community-based care systems. From a carer's perspective, this calls for a comprehensive and multidisciplinary set of policies that not only recognise and support the contribution of carers to society but also provide them with alternative and emancipating options to informal caregiving. This combination only will allow to meet the societal and economic needs of an ageing society while preserving the choice, rights and best interest of people with caregiving responsibilities. Yet, despite the obvious importance of carers' contribution – both to care supply as well as to the economy and society as a whole – their interests are still rarely considered in policies that impact them in a consistent and across-the-board manner: health, social, education, employment, social security, transport and housing policies, all come into play in different ways. In 2016, Eurocarers enthusiastically engaged in the development of key new policy developments that bear great potential for carer.

EC Proposal for an EU Pillar of Social Rights



The pillar of social rights is designed as a self-standing reference document, of a legal nature, setting out key principles and values shared at EU level. The Pillar sets out a number of key principles and rights to support fair and well-functioning labour markets and welfare systems. These are structured around three main categories: Equal opportunities and access to labour market, Fair working conditions, Social protection and inclusion. If approved by the two co-legislators – the European Parliament and Council of the EU, it could serve as a framework to screen employment and social performance in the light of changing work patterns and societies. The Pillar will also be used as a compass for a renewed process of convergence towards better working and living conditions among member states.

This initiative builds on the 'trickle-down' theory, according to which social progress will derive from growth and jobs. It recognises the need to act proactively in order to reinforce social cohesion within the EU. In addition, it takes a holistic point of view, addressing all challenges simultaneously, rather than addressing them one by one and adding up new ad hoc tools. Adequate social protection is approached as a productive factor, and social convergence as a necessity for the stability of the euro area. The fact that more cohesive countries perform better in difficult times is seen as clearly demonstrated. Finally, the Pillar contains a number of positive proposals, some of which were put forward by civil society organisations – including Eurocarers.

The Pillar includes an ambitious and comprehensive proposal on "Work-Life balance for working parents and carers", which nicely reflects most of Eurocarers pleas for a life-cycle and transversal approach, and contains many of the elements we call for. This new

proposal builds on previously existing rights and strengthens them. The combined legislative and non-legislative measures set up a modern policy framework that seeks to:

1. Increase female participation in the labour market and reduce the gender gap, including pay and pension gaps;
2. Give workers more opportunities and choice to balance their professional and care responsibilities by updating and modernising the current legal and policy framework, with particular attention to the role of men;
3. Support Member States' modern family policies including to address demographic and societal challenges;
4. Address shortcomings in care services facilities and eliminate economic disincentives to work for second earners.

The Pillar introduces – among others – new rights to carers' leave (5 days of leave paid at sick pay level per year per worker to take care of seriously ill or dependent relatives) as well as a call on member states to credit family-related leave periods in the pension system; to support innovative working arrangements such as family leaves and flexible working arrangements; to develop the provision of accessible, affordable and quality childcare, out-of-school and long-term care services; and to address economic disincentives for second earners.

The Pillar creates a unique political momentum in favour of a more cohesive Europe built on a strong social protection. As such, it also provides Eurocarers with a new natural framework for our research and policy work in 2017 and beyond.

Our Advocacy work

Since its opening in 2014 and thanks to the partnership agreement signed with the European Commission (DG EMPL) in the framework of the EU Programme for Employment and Social Innovation (EaSI), our secretariat leads evidence-based work to build bridges between carers, academics and policy makers and inform EU and national policy processes on how recognising and supporting the contribution of carers can benefit European society. This has allowed us to play a part in relevant policy debates with the EU institutions and a huge variety of stakeholders (WHO, OECD, Civil Society Organisations, the Industry); as well as through a series of tailor-made advocacy and networking activities, which include 9 policy briefings, 2 consultation responses, 4 joint calls for action, 1 editorial in a scientific journal, 2 articles in the national media and 8 press releases (underlining our position) developed by Eurocarers in 2016.

All of our advocacy activities build on the work of the Eurocarers Policy Working Group (EPWG), which provides members and the secretariat with a platform to align priorities and exchange ideas, expertise and best practices on strategies to advance the cause of carers. The kick-off meeting of the EPWG was held in Brussels, the margins of the AGM 2016.

European Parliament's Interest Group on carers



Since 2009, Eurocarers acts as the secretariat of the European Parliament's Interest group on Carers. The interest group is a parliamentary forum for debate and discussion of European policy development in relation to carers. It serves to assess the impact of individual policy initiatives on the lives and interest of carers and initiate EU level policy actions. The Interest Group brings 18 MEPs from different countries and political parties. It meets three times a year on average and is currently chaired by:

- Marian Harkin (ALDE – IRL);
- Heinz Becker (PPE – A);
- Jean Lambert (Greens-UK);
- Sirpa Pietikainen (PPE – FL).

The meetings of the Interest Group held during the period covered by this report allowed to inform participants (including MEPs) about the links between the following topics (and related EU initiatives) and the situation of carers in Europe:

- Experiences of family carers for people with a severe mental illness, Joint Meeting of the European Parliament Interest Group on Carers and the Interest Group on Mental Health, Well-being and Brain Disorders – 12 January 2016;
- The need for an EU initiative to facilitate work/life balance – 15 June 2016.

Eurocarers has also facilitated a series of bilateral policy dialogues between some of its national member organisations and their respective MEPs from different political groups in order to raise awareness, create new opportunities and ensure our EU work is echoed at national and regional level. Over the reported period, these

have allowed our Italian members to meet with Mr. Brando Benifei (S&D), Ms. Laura Agea (EFDD), Ms. Elly Schlein (S&D) as well as the assistant of Ms. Patrizia Toia (S&D). Various bilateral meetings were also held (face to face and through conference calls) between our Portuguese member organisation, Cuidadores Portugal and Ms. Marisa Matias (GUE/NGL). Ms. Marian Harkin (ALDE) also held various meetings with our Irish member organisations (and carers) in Ireland and in the margins of Eurocarers events. Finally, links were also facilitated between Ms. Kostadinka Kuneva (GUE/NGL) and one of our Greek member organisations – KINAPSI – following the release of Ms. Kuneva's report on women domestic workers and carers in the EU.

In addition to these events, our secretariat holds a continuous dialogue with the European Parliament and the members of the Interest Group in order to explore new ways of conveying the voice of carers at EU level.

Policy briefings

Eurocarers' policy briefings seek to inform its members and partners about policy developments that could generate new challenges and/or opportunities for carers across Europe. These publications bring together relevant facts and figures that may assist policy makers at the EU or the national level, funders and carers' organisations, as well as health and social care providers at all policy levels. In doing so, they serve as effective advocacy tools to align priorities, identify entry points in the EU agenda(s) and convey the reality of carers at EU level.

The policy briefings developed by Eurocarers in 2016 include:

- The relevance of EU policy development to carers and vice versa: an overview;
- The European Pillar of Social Rights;
- Why addressing the needs of informal carers is a crucial issue for Europe;
- Towards community-based people-centred integrated care: the role of informal care;
- Information and Communication Technology (ICT) for carers;
- Informal carers' skills and training – a tool for recognition and empowerment;
- The impact of caregiving on informal carers' mental and physical health;
- What do informal carers need? Towards a fair and rights-based deal; and
- Reconciling work and caring responsibilities: the need to support informal carers.

Consultation responses

Our efforts to inform policy developments that have an impact on the life of carers across Europe naturally lead us to respond to relevant consultations by the European Commission. This year, our consultation responses focused on

- The proposal for a European Pillar of Social Rights; and

- Possible action to address the challenges of work-life balance faced by working parents and caregivers.

Networking

Networking is an important element in our advocacy strategy as it allows us to identify synergies, learn from others, exchange ideas and spread our messaging as far and wide as we can. As part of our activities in 2016, the Eurocarers team has attended and played an active role in more than 130 events. These gave a chance to liaise with European and national policy makers and stakeholders to define further opportunities for evidence-based input and to give prominence to the carer's perspective in relevant policy dossiers. These events also gave a chance to build synergies and disseminate information about significant EU and national developments.



On the 31st March 2016, Eurocarers took part in a conference organised by Anziani e non solo and CARER Emilia Romagna at the Italian Parliament in Rome. The event 'Riconoscimento di ruolo e valorizzazione del caregiver familiare' gave an opportunity to present the interesting developments regarding carers that have recently taken place in the country. In January and March 2016, two bills were submitted to the Italian

Parliament (respectively to the Chamber (with link to <http://www.caregiverfamiliare.it/wp-content/uploads/pdl-Cargiver-On.Patriarca.pdf>) and to the Senate (with link to <http://www.caregiverfamiliare.it/wp-content/uploads/Disegno-di-legge-Sen-AngioniDDL-2266.pdf>) to recognise the role of carers and support them. These texts – if approved – will translate at national level a reality that currently only exists in the Emilia Romagna Region. The texts indeed mirror the Regional Law (L.R.2/14 – with link to http://www.caregiverfamiliare.it/wp-content/themes/thunderbolt/docs/DL_25-3-14-n87.pdf) for the recognition and support of informal carers approved in March 2014 (now in its implementation phase). For the first time in Italy, carers are recognised by law as an informal element and a resource of an integrated care system and they are provided with measures supporting them in their carer role. The Emilia Romagna's law – which is the result of a process of active citizenship (with an important role played by the associations Anziani e non solo and Carer) – has triggered further legislation at Regional and national level. Eurocarers and the other participants in the event welcomed these developments and called on policy makers to follow the good example of the Emilia Romagna Region.



On the 2-4 May 2016, Eurocarers was invited to contribute to the WHO consultation on people-centred integrated health care delivery held in Copenhagen, Denmark. The WHO Framework on Integrated, People-Centred Health Services, approved by the World Health Assembly at the end of June 2016 calls for a fundamental

shift in the way health services are funded, managed and delivered. The People-centred care approach to care considers individuals', carers', families' and communities' perspectives as participants in, and beneficiaries of, trusted health systems that respond to their needs and preferences in humane and holistic ways. As such, it provides a natural environment for our messaging and work.



On the 25–26 August 2016, Eurocarers was honoured to contribute to first ever Carers Parliament meeting in Helsinki. The event was organised to mark the 25th anniversary of the Central Association of Carers in Finland, based on the model of the annual Carers Parliament's meetings held in Scotland since 2012. Some 170 delegates representing local carer associations from all over Finland as well as 50 guests attended the Parliament's meeting in Helsinki. Speakers included the former Speaker of the Finnish Parliament and the Minister of Family Affairs and Social Services together with ministry officials, who responded to the questions raised by carers.



Eurocarers also actively contributed to the 15th European Meeting of People Experiencing Poverty held in Brussels on the 15th and 16th November 2016. The meeting was organised by the European Anti-Poverty Network (EAPN) with the support of the European Commission, the Slovakian presidency of the Council of the European Union, and the EAPN Fund. The event gave an opportunity to reflect and highlight the correlation between informal care, social exclusion and poverty. More broadly, the meeting served to bring forward the views and perspectives of people experiencing poverty from different European countries on what is meaningful participation and how it can be achieved. It also provided a chance to debate how the EC proposal for a European Pillar of Social Rights can enhance participation at national and European level.



On the 25th November 2016, Eurocarers took part in an International Conference "Support of Carers in the Czech Republic and Abroad: From Theory to Practice" organised by the Diaconia of the Evangelical Church of Czech Brethren in the Czech Chamber of Deputies in Prague. The event brought together leading experts, including representatives of the Ministry of Labour and Social affairs as well as various Eurocarers member organisations to discuss ways of strengthening support to carers in the Czech Republic. The Conference was chaired by the Czech Member of Parliament, actress and long-term carer Mrs. Táňa Fischerová.



In December 2016, Commissioner Oettinger invited all stakeholders to work together with the European Commission in the development of a blueprint; a living document containing a 'shared vision' on how innovation enabled by a Digital Single Market can transform health and care provision and contribute to the European Silver Economy. Recognising that a shared vision is essential to mobilise investment and guarantee the commitment of all actors to a digital transformation of health and care for the ageing society, a number of industrial players, regional authorities, professional organisations and multi-stakeholder platforms accepted the invitation from the Commissioner and started the work. As a result, three representatives officially handed over the Blueprint on Digital Transformation of Health and Care for the Ageing Society to the Commissioner at the second European Summit on Innovation for Active and Healthy Ageing (5–8 December 2016): Regional Health Minister Encarna Guillen (Murcia, Spain), Christian Reinaudo (President of AGFA Gevaert) and John Dunne (President Eurocarers).

In addition to the above-mentioned events, Eurocarers has established a number of contacts with EU and international networks active in fields relevant to the work of informal carers. Eurocarers is also an associate member of the Social Platform. Regular coordination meetings, exchanges of information, ideas and good practices therefore take place in order to align priorities and maximise the impact of our work.

COMMUNICATION

Our communication tools aim to complement our advocacy and networking activities by raising awareness and providing background information about the situation of carers in Europe, the work of our members and partners and the aims of our network.

Website

The Eurocarers website – www.eurocarers.org – is our central communication tool. It serves as a repository of key communication and advocacy material as well as practical information and good practices for carers and those who support the recognition of their important role and added value. In 2016, the following developments have been brought to the website.

- A tailor-made section has been added to provide access to information about the TRACK project, in which Eurocarers has been involved since September 2015. This new webpage is used to disseminate the project deliverables, including publications and material targeted at informal carers. As of June 2017, the online training pathway – and related material –



designed to support informal carers who provide care to a person affected by dementia, which is currently being developed through the project, will also be available via this section of the Eurocarers website.

- A new 'Repository' of research and good practices has been added to our website in order to give people access to the wealth of evidence collected and generated by Eurocarers' member organisations. Through this new tool, our aim is to facilitate the exchange of knowledge among member organisations; promote our members' intelligence among a wider audience; and strengthen the role of Eurocarers as an EU knowledge broker on issues related to informal care. Our objective is also to progressively convert our website into a key source of information on and for informal carers throughout Europe.

The Eurocarers website still hosts the Informcare platform, which offers carers – as well as care professionals and employers in a selection of countries – with information and advice about caregiving activities as well as useful contacts and interactive tools to communicate with peers, exchange experiences and provide mutual support in their own national language. Finally, the Eurocarers website also provides access to an online directory of successful or promising examples of ICT-based solutions targeted at informal carers (CARICT).

Newsletter

Our bi-monthly newsletter aims to present members and partners with first-hand information about relevant policy developments, research



initiatives and outcomes as well as funding and networking opportunities. It also provides readers with updates about the successes and challenges of fellow members. Its structure builds around five key sections: EU Policy developments, Research in action, Events and calls for proposals, news from the network and Opinions. The Eurocarers newsletter is an exclusive information service to the members and partners of our network. Five editions of our newsletter were disseminated in 2016.

Press releases and calls for action

In 2016, Eurocarers has produced 8 press releases, including:

- "Young carers across the EU must receive specific attention" – February 2016;
- Empowering people with incontinence and their carers to live independent and dignified lives at home and in the community – April 2016;
- Launch of Joint Call for Action to scale up Integrated Care in Europe – June 2016;
- Eurocarers takes part in a press Conference in

CAPACITY BUILDING

the Italian Parliament on a bill on recognition of carers – June 2016;

- Joint Statement by Eurocarers and other networks on “Creating labour market conditions favourable for work–life balance” – September 2016;
- Eurocarers welcomes the call for investment in care services in the Annual Growth Survey 2017 – November 2016;
- Better Policy for metastatic cancer patients: Make it Happen – November 2016; and
- Recognition and valorisation of informal carers – Italian members of the Eurocarers network meet their MEPs – December 2016.

Our network also developed and disseminated 4 joint calls for action on:

1. The need for EU action on LTC with special focus on integrated care (with AGE Platform Europe, Alzheimer Europe, EASPD, EFSI, EPR, Eurodiaconia, Inclusion Europe and Pour la solidarité);
2. EU Initiatives and Progress on Chronic Diseases (with ENSP, EPHA, the smoke free partnership, Eurocare, UEG and UEMS);
3. The need to strengthen Work–Life balance opportunities for Europe’s families (with ELISAN, ENIL, ENSA, EWL, Eurochild, IFSBH and Make Mothers Matter); and
4. Call for Action “United towards Integrated Care” (with COCIR, ECCF, EPF, ESTRO, UEHP, UEMO and the VOKA health community).

In September 2016, Eurocarers published an article in «Hommes et libertés», the monthly magazine issued by La Ligue des droits de l’Homme, which focused especially on informal carers. Eurocarers’ article presented the work of our organisation. In November 2016, Eurocarers published an article in “Welfare oggi”, a bimonthly magazine specialised in welfare policies and services. The article – through a comparative analysis of policies across Europe – aimed to demonstrate the need to recognise and support the vital contribution of carers to our societies. Finally, Stecy Yghemonos (Executive Director of Eurocarers) was also invited to write an editorial for the ‘Primary Health Care Research & Development journal’, which is entitled ‘The importance of informal carers for primary health care’ (published in October 2016).

As part of our annual programme of activities, Eurocarers organises peer training and capacity building sessions based on the expertise of our members and identified interests. These capacity–building events gather small groups of members and partners either through face–to–face meetings or online. They seek to encourage the exchange of good and promising practices between members in line with the EU priorities in order to actively contribute to the implementation of the EU2020 objectives through the European Semester process, the European Innovation Partnership on Active and Health Ageing and any other relevant instruments. Over the reported period, Eurocarers organised 7 capacity–building events.

Two in–country study visits were co–organised with national members in the first quarter of 2016 in order to provide Eurocarers members (and, on an ad–hoc basis, partners) with opportunities to:

- Discuss recent EU and national policy developments, promising research outcomes and good practices with regards to a specific topic of relevance to the work of Eurocarers;
- Hold a peer review with fellow member organisations and exchange on successful managerial policies and procedures.

Our very first study visit looked into the challenges faced by young carers. Young carers across Europe carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult. Although there are no precise figures about how many young carers there are across Europe today, data suggests that about 7–8% of children in Europe will have caregiving responsibilities. These are children who are largely invisible to public authorities, social policy and interventions

from health and social care services. Statistics show that young people with a sick family member tend to have more mental health problems and more adverse outcomes in behavioural, psychosocial, and academic adjustment than their counterparts without a chronically ill family member. Addressing this topic is therefore very timely and relevant in the light of the European Commission's initiatives on children and young people. The visit took place in Hamburg, Germany and was kindly hosted by our German member *wir pflegen* on the 18th and 19th February 2016.

Our second study visit focused on the issue of working carers. Research has already shown some of the negative impact of high intensity caring over time on working carers' physical and mental health and well-being and their ability to stay in paid work; many carers reduce their working hours or leave the workplace altogether – thereby reducing their income and pension entitlements. Addressing the issues of working carers is therefore not only important to alleviate carers' burden, it also makes economic sense. This event was hosted by Carers UK and gave a chance to discuss good practices and innovative approaches to engage and coordinate with employers in order to support and improve

the sometimes difficult situation of working carers. The event took place in London on the 3rd and 4th March 2016.

Participating members played an active role as they presented and exchanged on their activities in the light of these topics. This has proved to increase the sense of ownership, interest and contribution in the EU decision-making process and encourage participants to put their work into perspective.

Eurocarers also organised capacity-building activities in the margins of its AGM, on the 13th and 14th June 2016, including:

- An interactive session 'Testing of Active and Assisted Living projects' – co-organised with the Central Management Unit of the Ambient Assisted Living (AAL) programme – where Eurocarers members were invited to test and provide feedback on a number of AAL solutions in the field of care, social inclusion and mobility. The session was an opportunity to hear about the potential offered by this programme and have a direct say about ongoing projects which can have an impact on the situation of carers across the EU. The event marked the

beginning of the 10th Anniversary celebration of the Eurocarers network and was followed by a reception where Ms. Ruth Paserman, Deputy Head of Commissioner Marianne Thyssen's Cabinet (DG Employment, Social Affairs, Skills and Labour Mobility, European Commission) and Ms. Marian Harkin (ALDE), MEP and Co-Chair of the European Parliament Interest Group on Carers conveyed their messages and comments on the day;

- A workshop on 'Supporting young carers in Europe' gave an opportunity to hold an interactive dialogue with four young carers from Italy, Scotland, Sweden and the Netherlands about their specific needs and the daily challenges they face. The key topics addressed during the workshop included ways of making the voices of Young Carers (YC) and Young Adult Carers (YAC) heard at EU level and pathways for their empowerment in a movement to achieve Young Carers-friendly policies and practices across Europe. The event also served to pave the way for the International Young Carers Conference held in Malmö, Sweden on the 28–31 May 2017;



OUR RESEARCH WORK

- Two briefing seminars on the opportunities and challenges arising from the European Semester 2016 and the Horizon 2020 annual work programme.

On the 7th November 2016, Eurocarers also co-hosted a one day seminar with Care Alliance Ireland entitled “Supporting the Delivery of High Quality Family Carer Training”, which took place on Monday 7th November 2016 in Dublin, Ireland. The event, which focused on best practice in the sphere of Family Carer training, brought together fourteen organisations across Ireland and Europe. These presented their experience in providing and planning for such training, with input from those supporting Family Carers in diverse sectors such as dementia care, mental health, intellectual disability, autism and palliative care.

The vast majority of help, care and support of older and/or disabled people and people with long-term conditions in Europe is carried out by family members (especially spouses and adult children) and by neighbours and friends. However, the fundamental role played by these ‘informal’ carers is still not widely recognised in all Member States, even though recent EU policy on long-term care acknowledges that it is crucial that carers are valued and fully supported in their role, particularly in view of key societal challenges – ageing demographic trends and fiscal constraints. Research is therefore extremely important and urgently needed to build a comprehensive, up-to-date picture of carers’ situation at pan-European and national level. This knowledge base will be critical in informing policy in all areas affecting carers, especially in health, care, education, employment, social protection, transport and housing. It will also inform evidence-based practice concerning support services for carers and dependent persons.

This need for research and knowledge exchange drives the work of the Eurocarers Research Working Group, which consists of a selected group of expert member organisations led by Eurocarers Vice-President, Elizabeth Hanson. The Working Group meets on a regular basis (4 times in 2016) to share and discuss the state of the art in research and good practices that are relevant to our collective work. The Group also explores new emerging opportunities for research work in the area of carers, care and caring in the EU.



The Eurocarers network is involved in various research and implementation projects aiming to collect and generate the evidence-base required to formulate concrete and realistic policy recommendations for the recognition of carers and carers’ needs.



TRAIning and recognition of informal Carers' sKills

Track – Focusing on training as a means of support and social (re)integration for informal carers

Eurocarers is a partner in the TRACK project (TRAIning and Recognition of Carers’ sKills), funded through the Erasmus+ EU programme for the period 2015–2017. The TRACK project primarily aims to develop a custom-made online training programme to support the many informal carers who deal with the specific difficulties attached to dementia care without any adequate support. The objective of the project is also to help informal carers from disadvantaged groups to access the labour market through the recognition, development and certification of the skills they have acquired on the job – against the backdrop of a care skills shortage.

The consortium brings together various stakeholders from four countries: La Compagnie des Aidants (Carers’ organisation, France) – a member of the Eurocarers network, IPERIA l’Institut (training provider, France), WBS (training provider, Germany), WIAB (research institute, Austria),

Diputación de Jaén (local authority, Spain).

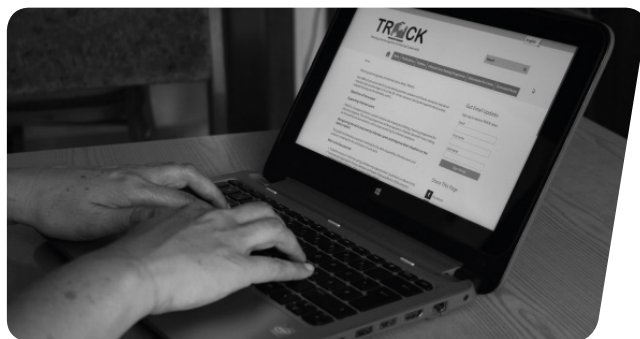
As foreseen, three main outcomes are expected by the end of the project and will be made available on the TRACK section of the Eurocarers website.

The baseline study coordinated by Eurocarers and published in March 2016 highlights:

- An overview of available support services and learning opportunities across Europe for informal carers;
- Some hints regarding the most efficient approaches to delivering training to informal carers;
- The challenges to be addressed to make relevant training accessible to all informal carers.

The study was based on a literature review, a survey as well as a series of interviews with key stakeholders across Europe and beyond.

Building on the findings of this study, as well as on the feedback collected during focus groups organised in three pilot countries (France, Spain and Germany), a blended training programme is being developed. The following principles underpin the methodology of the programme:



- Mentoring between informal carers and professional care workers;
- Modular structure and micro-learning (to ensure a comprehensive and time flexible training path);
- Self-evaluation activities at the end of each learning module.

The training programme will take about 20 hours spread over 6 weeks in total, out of which about 4 hours will be delivered through e-learning. It will be available in four languages (English, French, Spanish and German) free of charge. The programme was tested by sixty informal carers in France, Spain and Germany and an evaluation will be performed to further improve and develop the course.

Besides the training pathway, a feasibility study was also developed to explore the potential and added value of a certification process to validate the skills acquired through the TRACK training programme. This study was built via a desk analysis of the legislation in place regarding the recognition of informal and non-formal competences at EU level and in the partner countries, as well as through interviews with experts and workshops held in France, Germany and Spain. Based on the information gathered, a roadmap was developed to guide the uptake and integration of the programme in the countries covered by the consortium and at EU level.

The TRACK final conference hosted by Eurocarers on the 21st June 2017 in Brussels will give the opportunity to present and discuss the project's outcomes with practitioners and decision makers.

Contribution to other research projects

Eurocarers is also represented on the Advisory board of several relevant broader projects which focus on the development of innovative solutions for the development of sustainable and patient-centred social, health and long-term care systems. These include:

- The Network on quality and cost-effectiveness in Long-Term Care and dependency prevention, coordinated by the London School of Economics, which aims to support the long-term care policy-making process across the EU by identifying evidence about key strategies for reducing the need for care and for improving the efficiency with which care systems meet needs of users and carers. A key overarching objective of the Network will be to maximise long-term care policy learning between EU countries;
- The project 'Measuring social protection for older people with Long-Term Care needs', coordinated by the OECD and DG EMPL, which focuses on the description and analysis of existing integrated care models for patients with multiple chronic health problems;
- The Silver Economy Awards (SEED), coordinated by AGE platform Europe, which aims to set up the first European-level awards scheme to reward innovative and creative digital supported solutions that demonstrate a significant impact on the improvement of the quality of life of the ageing population; support the creation of age-friendly environments across Europe; create a pan-European movement that acknowledges and exploits the opportunities brought about by demographic

change and innovation; and mobilise different actors and economic sectors;





- The Joint Programme Initiative «More Years, Better Lives – The Potential and Challenges of Demographic Change», which seeks to enhance coordination and collaboration between European and national research programmes related to demographic change. Areas affected by demographic change cover a wide range of research fields and policy topics ranging from health to social welfare, education and learning, work and productivity to housing, urban and rural development and mobility. The JPI therefore follows a transnational, multi-disciplinary approach bringing together various disciplines.




OUR NETWORK

The Eurocarers network brings together 65 member organisations from 25 European countries. Collaborations have also been established with leading carers' organisations in Australia and the US. The way we operate our network is described on our website www.eurocarers.org. There you can access our membership and partnership criteria, our legal statutes, our ethical guidelines and other documents about how we work.

An important component is that all members meet each year to decide our work programme and hold our office and governance processes to account. All full members have an equal vote and can elect our Board of Directors. Our Annual General Meeting 2016 was held on the 13–15 June in Brussels, Belgium. It marked the celebration of the 10th Anniversary of the Eurocarers network.

The Eurocarers Board of Directors

President	John Dunne	Carers Association – Ireland	
Vice-President Research organisations	Elizabeth Hanson	Swedish National Family Care Competence Centre	
Vice-President Carers organisations	Marja Tuomi	Central Association of Carers in Finland	
Treasurer	Marijke Steenberg	MOVISIE, Netherlands centre for social development	

Executive member	Chloe Wright	Carers UK	
Executive member	Ivar Paimre	Estonian Carers	
Consultant	Christine Marking	Marking Public Affairs	

The Eurocarers Secretariat



Claire Champeix
Policy Officer

Francesca Centola
Network Co-ordinator

Stecy Yghemonos
Executive Director

OUR PARTNERS



Based in Stockholm, **Svenska Cellulosa Aktiebolaget (SCA)** is one of the world's largest companies in personal care with a large portfolio of personal care, tissue and forest products distributed in about 100 countries. SCA is considered a reference in sustainability and has been named one of the world's most ethical companies. With more than 50 years of experience in continence care SCA develops solutions and products that help improve dignity and the quality of people's lives. SCA pays specific attention to both patients and their carers and strives to build the understanding that well organised and professional continence care leads to substantial benefits for individuals as well as society as a whole.

SCA has well-established experience in continence care (with the brand TENA) and offers a full range of absorbent products, services and solutions that are tailored to the needs of individuals, their families (carers) and healthcare professionals. SCA places

individualised care at the core of its approach, with TENA solutions for care homes; SCA improves and documents residents' well-being, working atmosphere, budget and environmental footprint. SCA offers an integrated approach that consists of innovative products, best practice care routines, tools, training and expert support. Through effective and efficient partnerships, care homes are helped to find, implement and sustain quantifiable improvements within continence and personal hygiene care.

Global Forum on Incontinence (GFI)

SCA is organising every second year the Global Forum on Incontinence (GFI). The GFI is a platform for education and debate around continence care. The aim is to improve the health and social care provisions for incontinence, giving patients and caregivers a better quality of life. GFI demonstrate the impact of incontinence on the individual and their caregivers and on society as a whole. Continence care is approached from a holistic perspective. The ambition is to present and discuss both prevention, cure and care options and organization and management aspects.

Optimum Continence Service Specification (OCSS)

For people living at home with incontinence, SCA has initiated the development of a new care pathway on how to best organize the care. The result of this work which was executed with a panel of health and social care experts has been published and is called the Optimum Continence Service Specification. The OCSS can function as a benchmark for countries who want to improve the organization of care for people

with incontinence and their caregivers.

Given the number of our common interests and objectives and SCA's continuous support to Eurocarers' vision and work, we are delighted to report that the collaboration agreement established with SCA a few years ago was renewed for the period 2016–2017. Our collaboration includes the promotion of principles that we consider essential for patient-focused, sustainable and affordable systems for quality incontinence care.

More information about our collaboration with SCA and messaging on incontinence is available on our website: <http://www.eurocarers.org/Incontinence>



Eurocarers signed a partnership agreement with National Alliance for Caregiving and International Alliance of Carer Organizations (IACO) in 2015.

Incorporated in 2012, IACO serves as an umbrella organization that provides cohesive direction, facilitates information sharing, and actively advocates for carers at an international level. IACO provides research, awareness and education regarding family carers on a global scale. By bringing visibility and an understanding of the growing numbers of carers worldwide, IACO facilitates international collaboration by bringing together countries from around the globe that advocate for family carers.

The National Alliance for Caregiving serves as secretariat for IACO.



Eurocarers signed a partnership agreement with Carers Australia in 2016.

Carers Australia is the national peak body representing Australia's carers, advocating on behalf of Australia's carers to influence policies and services at a national level. It works collaboratively with partners and its member organisations, the Network of state and territory Carers Associations, to deliver a range of essential national carer services.



Eurocarers also signed a Memorandum of Understanding with the European Patients' Forum (EPF) in 2015. EPF is an umbrella organisation that works with patients' groups in public health and

health advocacy across Europe. EPF's members represent specific chronic disease groups at EU level or are national coalitions of patients.

EPF helps to empower patients' organisations through educational seminars, policy initiatives and projects. They coordinate best practice exchanges between patient organisations at European and national levels. Their programmes also help to strengthen their organisational and advocacy capacity.

EPF's six core strategic goals include:

1. Health Literacy
2. Healthcare access and quality
3. Patient's involvement
4. Patient's Empowerment
5. Sustainable Patient's Organisations
6. Non-Discrimination



In 2016, Eurocarers signed a partnership agreement with the European Forum for Primary Care (EFPC). EFPC aims to improve the health of the population by promoting strong Primary Care.

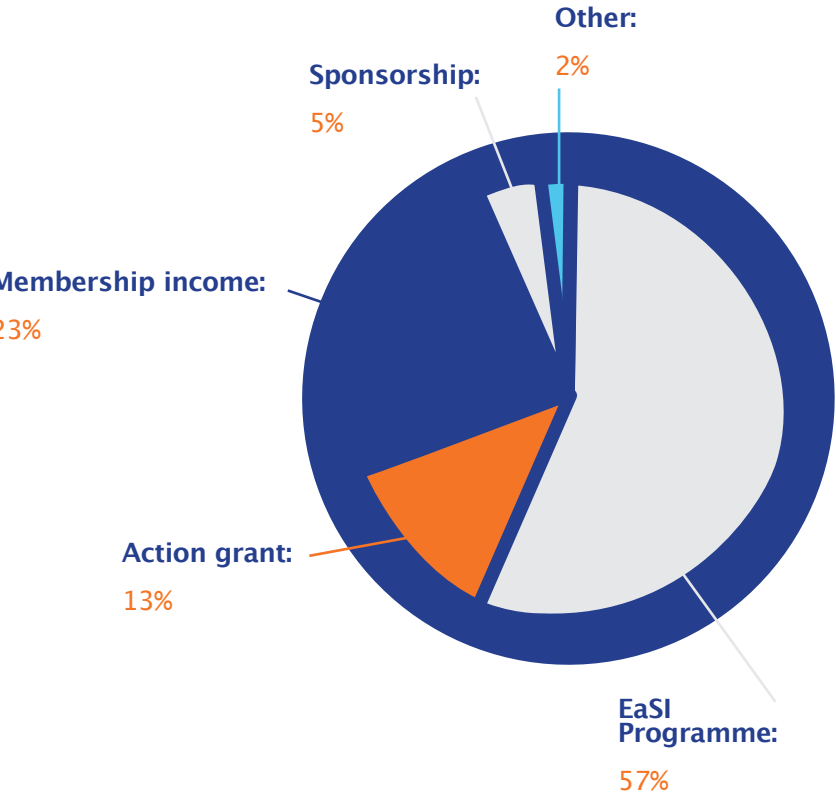
Strong primary care (PC) produces better health outcomes against lower costs. By promoting

strong PC the population's health can be improved. Nevertheless, this requires appropriate conditions at the health care system level as well as in actual practice to make PC providers able and willing to take responsibility for the health of the population under their care. The majority of health complaints of the people are dealt with through self-care and primary care, delivered in the local community. Addressing the needs of individuals in the context of their families and communities is one of the key features of primary care.

HOW WE ARE FUNDED

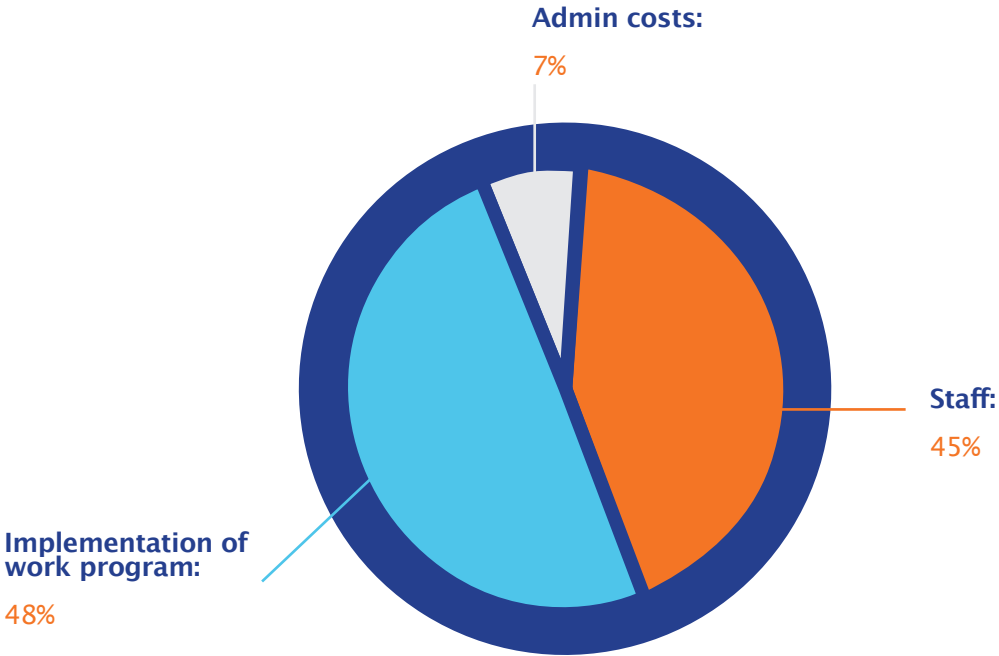
Income 2016

TOTAL: €474,535.06



Expenditure 2016

TOTAL: €474,535.06



SUPPORTING EUROCARERS

As a member

You can participate in policy-influencing activities on behalf of carers:

- by advocating their needs in the development of European policies, programmes and funding arrangements in areas that truly matter to carers;
- by formulating evidence-based input in policy development to influence European policy debates;
- by participating in EU-funded research projects, which help to shape carers-friendly policies.

You will have access to Information and capacity building:

- Through the Eurocarers network, members exchange information and experience and engage in initiatives of mutual interest;
- Eurocarers provides regular information on relevant developments and helps its members to be better informed, through its capacity-building events, newsletter, website and helpdesk services;
- Eurocarers provides opportunities for networking across boundaries.

You can help to strengthen the voice of carers at national and European level

Carers and their issues are rising up the European policy agenda, due to continuous representation, actively supported by the European Parliament's Interest Group on carers. While progress has been made, recognition of carers' issues needs to be both increased and consolidated and your organisation is needed to amplify the voice of carers!

As a partner

Eurocarers recognise that there are common interests between Eurocarers and some companies, to address the needs of carers and cared for persons and safeguard their interests in receiving good quality products and services. Ethics are first and foremost about respecting all members and continually building on trustworthiness. Eurocarers has therefore developed ethical guidelines to govern our relationships with the business sector and ensure the best interests of our members. The basis of sound and equal partnership is recognition of mutual rights and responsibilities. Eurocarers will always protect and safeguard its independence and reputation.

Interested parties can join the Eurocarers network of external partners as a Bronze, Silver or Gold partner against a fixed donation which varies according to the type of stakeholder and partnership category they decide to join. Alternatively, partners can also propose a specific issue or initiative around goods, services and environments of relevance to informal carers and on which they would like to work with Eurocarers.

If you want to receive more information about these partnership options, please do not hesitate to contact our Network Coordinator, Ms. Francesca Centola, in our Brussels secretariat at fc@eurocarers.org.

OUR MEMBERS

Full Members

European Centre for Social Welfare Policy and Research	Austria
Institut Recherche Santé et Société, Université Catholique de Louvain	Belgium
Aidants proches Bruxelles	Belgium
University College Ghent, Department of Education, Health care and Social work	Belgium
Diaconia of the Evangelical Church of Czech Brethren	Czech Republic
Carers Denmark	Denmark
NGO Estonian Carers	Estonia
The Central Association of Carers in Finland	Finland
Organisations for Carers Network Finland	Finland
La compagnie des aidants	France
Association Française des aidants	France
Centre for Quality in Care	Germany
wir pflegen e.V.	Germany
Institute of Mental Health Semmelweis University	Hungary
Family Carers Ireland	Ireland
Care Alliance Ireland	Ireland
Istituto Nazionale di Riposo e Cura per Anziani V.E.II(INRCA) Dipartimento Ricerche Gerontologiche	Italy
Anziani e non solo società cooperativa	Italy
SOS Malta – Solidarity Overseas Development Malta	Malta
VILANS	Netherlands
MOVISIE, Centre of Expertise for Informal Care	Netherlands
Department of Sociology, Faculty of Social Sciences, VU University Amsterdam	Netherlands
European Care Foundation	Poland
Cuidadores Portugal	Portugal
University of Ljubljana. Faculty of Social Sciences	Slovenia
Anton Trstenjak Institute of gerontology and intergenerational relations	Slovenia
CEAFA: Confederacion Espanola de Familiares de Enfermos de Alzheimer y otras Dementias	Spain
The Swedish Family Care Competence Centre	Sweden
Anhörigas Riksförbund (AHR), Carers Sweden	Sweden
The Open University Faculty of Health and Social Care	UK
Carers UK	UK
CIRCLE (Centre for International Research on Care, Labour and Equalities), University of Sheffield	UK
Carers Federation	UK
Carers Trust	UK
The Coalition of Carers in Scotland	UK
VOCAL – Voice of Carers Across Lothian	UK

Associate Members

Austrian Carers Organisation	Austria
Universiteit Antwerpen – Centre for Longevity Research (CELLO)	Belgium
Howest, University of applied sciences, research cluster: Kennispunt Mantelzorg	Belgium
Aidants proches	Belgium
Jeunes Aidants proches	Belgium
Samana	Belgium
Alzheimer Bulgaria (Civil Association "Alzheimer-Bulgaria")	Bulgaria
DaneAge	Denmark
Athens Association of Alzheimer's Disease and Related Disorders	Greece
Epioni – Greek Carers Network	Greece
Greek Association of Alzheimer's Disease & Related Disorders	Greece
Associazione C'ENTRO	Italy
RBS Center fir Altersfroen asbl	Luxembourg
The Netherlands Institute for Social Research (SCP)	Netherlands
Mezzo, Landelijke Vereniging voor Mantelzorgers en Vrijwilligerszorg. Dutch Association for Carers and Voluntary Help	Netherlands
Pårørendealliansen (Norwegian National Alliance for Carers)	Norway
Club of large families	Slovakia
Slovenian Federation of Pensioners' Organisations – Zveza Drustev Upokojencev Slovenije (ZDUS)	Slovenia
Cuidadores Familiares	Spain
Careum Stiftung	Switzerland

Observer Members

Myra Lewinter, University of Copenhagen Department of Sociology	Denmark
Tiina Auitio, Laadun Puolesta 4Q KY Company	Finland
Hanneli Döhner	Germany
Henk Bakkerode	Netherlands
Marja Pijl	Netherlands
Jolanta Perek Bialas	Poland
Piotr Bledowski	Poland
Martha Mackay	Spain
Saul Becker	UK
Daniel Phelps	UK

