



**EUROCARERS**

EUROPEAN ASSOCIATION  
WORKING FOR CARERS

# 2017 ANNUAL REPORT





# EUROCARERS

EUROPEAN ASSOCIATION  
WORKING FOR CARERS



Eurocarers receives support  
from The European Union through the programme  
for Employment and Social Innovation (EASI  
Programme 2014-2017)

✉ 3, Rue Abbé Cuypers - 1040 Brussels - Belgium | ☎ 0032 (0)2 741 24 05 | 📧 info@eurocarers.org  
🌐 www.eurocarers.org | 📘 EuropeanAssociationWorkingForCarers | 🐦 @Eurocarers\_info

# TABLE OF CONTENTS

FOREWORDS	4
ABOUT US	6
PILLAR OF SOCIAL RIGHTS	8
Equal opportunities and access to the labour market	8
Education, training and lifelong learning	8
Gender equality	10
Equal opportunities	11
Active support to employment	12
Fair working conditions	13
Work-life balance	14
Social protection and inclusion	15
Social protection	15
Old age income and pensions	16
Health care	17
Inclusion of people with disabilities	19
Long-term care	20
WHO'S WHO	23
MEMBERS	24
HOW WE ARE FUNDED	26
SUPPORTING EUROCARERS	27

# FOREWORDS

Dear colleagues,

This is my last introduction to a Eurocarers Annual Report and I pleased to be able to reflect on another successful year.

We secured the Commission's approval not only for another 4 year framework partnership under the EaSI programme but also for six separate project proposals in which Eurocarers is a partner. Combined with our steadily expanding membership base and a growing list of sponsorship agreements we now have a sustainable foundation for the work of the organisation over the next few years.

Whilst elected representatives and officials in each of the EU institutions have traditionally engaged constructively with issues relating to informal carers, the publication of **the EU Pillar of Social Rights offers a potentially fertile new framework for our advocacy work.** The report prepared by the Secretariat setting out its implications for carers across Europe will, I believe, be extremely important in framing the work of our Policy Group for future years.

I am happy to report the success of our initiative to re-launch the Carer Interest Group in the European Parliament which led to pledges of support from 26 new MEPs from 10 countries. And that we have begun to engage with the European Network of Living Labs as a mechanism to promote innovative best practice in supporting family carers across Europe.

The final key strategic challenge we face is to enable the development of a network of strong national carer organisations across all of Europe. There are no short-cuts for this but I believe we are now on a promising path.

All of this does not happen without great effort and skill. The organisation owes a significant debt of gratitude to Stecy Yghemonos, our Executive Director, for his leadership, dedication and sheer hard work throughout the year. It's also important to acknowledge the unfailing effort, expertise and commitment of our other staff and of Christine Marking, who has been a key support for Eurocarers on a consultancy basis for many years.

I would also like to thank my colleagues on the Board for their enormous contribution over the past year: Elizabeth Hanson, Vice-President Research; Marja Tuomi, Vice President, Membership; Chloe Wright, Vice President, Policy; Ivar Paimre, Treasurer and our newest Directors Bruno Alves and Valentina Hlebec. Marja

retired from the Board during the year having been appointed Head of the Funding Centre for Social Welfare and Health Organisations in the Ministry of Social Affairs and Health of Finland. I'd also like to congratulate Elizabeth on her appointment as scientific advisor regarding carer support by the Swedish National Board of Health and Welfare in the course of 2017.

Last but not least, I want to acknowledge the work that you, our member organisations, do in supporting and affirming informal carers across Europe. As I always say without you none of this would be either possible or meaningful.



John Dunne  
President



Dear readers,

Last year, the unanimous endorsement of the EU Pillar of Social Rights by all EU member states brought a new - and long overdue - impetus to the idea of a social Europe committed towards better working and living conditions for all. **The Pillar includes 20 key principles to deliver new and more effective rights for citizens in light of challenges such as an ageing society, globalisation and digitalisation.** It is designed as a compass for a renewed process of convergence among Member States and is structured around three categories: Equal opportunities and access to the labour market, Fair working conditions and Social protection and inclusion. As such, it offers a revitalised environment for our work and the emergence of carer-friendly societies in Europe.

The principles that concern work-life balance for parents and people with caregiving responsibilities and access to affordable and good quality health and long-term care are of particular relevance for our message around a combination of support and emancipating policy measures to address carers' needs. The principles related to access to education, gender equality or equal opportunities – among others – are as important tools to make a difference in the daily life of carers across Europe. Yet, despite this hopeful development, a lot remains to be done at EU, national and regional level to ensure that the Pillar is properly implemented and not watered down or weakened in any way.

**The work of the Eurocarers network perfectly fits into the framework offered by the Pillar and actively contributes to its enactment.** To illustrate this, we have chosen to shape this edition of our annual report for the period 2017-2018 around the commonalities that exist between our core mission and the objectives of the Pillar. We hope that you will find it useful and interesting – enjoy your reading!



Stecy Yghemonos  
Executive Director



# ABOUT US

**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 66 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.

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.

We work 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.

Eurocarers' work is structured around activities aiming to collect and generate the evidence-base. This information is required to inform the policy developments needed for the emergence of a society that truly values and support the contribution of its carers, while giving them the opportunity to maintain or go back to a fully active and enriching life. Our initiatives in the fields of advocacy, networking, research and capacity building therefore aim to reinforce our now established positioning as a knowledge-brokering organisation specialising in the fields of care and caring. **One of Eurocarers key tools for policy change at EU and national level is the European Parliament Interest Group on Informal Carers** for which we hold the secretariat. Since its inception in 2007, the interest Group has focused on topical issues, closely following EU policy development and priorities, such as the Social Pillar, the Social Investment Package, Horizon 2020, the Social Protection Committee's report on long term care and social innovation.

Following a revitalisation process, in conjunction with the group's 10th Anniversary, we are glad to count on the active support of at least **31 MEPs from 11 countries**. During its meeting on the 11th April 2017, the Interest Group discussed the potential offered by the then proposed EU Pillar of Social Rights which is now at the core of our work.

Our renewed proposal for a **European Carers Strategy**, developed in collaboration with MEPs, will serve to contribute to the implementation of the Pillar by highlighting and connecting the dots between the policy areas that have a direct bearing on the daily life and opportunities of carers across Europe. Our Policy briefing on **"The relevance of EU policy development to carers and vice versa"** is already demonstrating that numerous existing policy instruments could be used to support and empower carers.



## European Parliament Informal Carers Interest Group

2007-2017



## The relevance of EU policy development to carers and vice versa

An overview



# EQUAL OPPORTUNITIES AND ACCESS TO THE LABOUR MARKET

1

## Education, training and lifelong learning

*Everyone has the right to quality and inclusive education, training and lifelong learning in order to maintain and acquire skills that enable them to participate fully in society and manage successfully transitions in the labour market.*



Young carers 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. This can have a negative impact on their health and well-being, education and ability to access employment, training or apprenticeship. So, supporting young carers is essential to achieve the EU objective of reducing the EU average early school leaving rate to less than 10% by 2020.



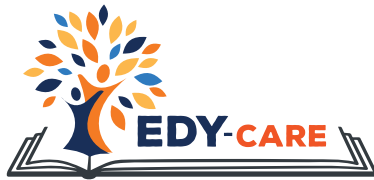
The 2nd International Young Carers Conference, entitled **“Every Child has the Right to...”**, held from the 29th to the 31st May 2017 in Malmö, Sweden was a great opportunity for relevant policy-makers, stakeholders, practitioners and researchers from across the world to meet and exchange experiences and learn from each other regarding the situation, specific challenges and needs of young carers. The event was co-hosted by Nka (Swedish Family Care Competence Centre), Linnaeus Univer-

sity, BarnsBeste (National Competence Network Norway), FORTE (Swedish Research Council for Health, Working Life and Welfare), the National Board of Health and Welfare in Sweden, the National Board of Social Services in Denmark, Region Skåne, Malmö City, Region Jönköping County and Eurocarers. The conference brought together more than 500 people from 26 countries, of which 100 were speakers.





The **Eurocarers Young Carers Working Group (EYCWG)**, which was launched in the margins of the International Conference consists of 21 young carers from 10 European countries (+ Australia) who – through our structure - have the opportunity to meet, learn from each other, be briefed, consulted and involved in policy dialogues about EU priorities that concern them. The goals of this working group are to build on the carers' movement, feed into Eurocarers' advocacy activities, and speak with one voice on behalf of young carers.



**EdyCare aims to empower teachers and other school staff** in upper secondary education to recognise adolescent young carers (16-19 years old) in classes and maximize their learning opportunities, while ensuring their social inclusion. The project partners will develop an assessment tool, a package of educational strategies, a handbook and a massive open online course (MOOC) for training teachers and school staff on the young carers phenomenon, their needs and preferences

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



Together with our Italian member organisation Anziani e non Solo, as well as CAR. ER. (Emilia Romagna Carers Association) and COMIP (Association of Children of Parents with Mental Illnesses) **Eurocarers signed a Memorandum of understanding with the Italian Ministry of Education.**



Our **Policy Paper on “Young Carers”** and the side event co-organised with the **European Social Network (ESN)** and **EuroHealthNet** during the Annual Convention for Inclusive Growth 2017 also allowed to emphasise and discuss the barriers and success factors that may impact on young people’s ability to fully participate in society.



**Me-We (Psychosocial Support for Promoting Mental Health and Well-being among adolescent Young Carers in Europe / Horizon 2020 / 2018-2021)** aims to mitigate the risk factor of being an adolescent young carer by empowering the young with improved resilience and enhanced social support (from family, schools, peers, services). The project aims to systematise knowledge on adolescent young carers, co-design, develop and test - together with adolescent young carers - a framework of effective and multicomponent psychosocial interventions for primary prevention, and to carry out wide knowledge translation actions for dissemination, awareness promotion and advocacy.

<http://me-we.eu>

2

## Gender equality

*Equality of treatment and opportunities between women and men must be ensured and fostered in all areas, including regarding participation in the labour market, terms and conditions of employment and career progression. Women and men have the right to equal pay for work of equal value.*



Informal carers are typically spouses, middle-aged daughters or daughters-in-law. In the EU, informal care is mostly provided by women aged 45 to 75. The unequal distribution of caring responsibilities between women and men over the lifecycle explains some structural features of the female employment.




Eurocarers actively collaborates to the work of the European Institute for Gender Equality (EIGE) and Civil Society Organisations to highlight the barrier to equality between women and men that informal care represents throughout Europe. **Our new Policy Paper on “the Gender dimension of informal care”** provides a comprehensive overview of the root causes and consequences of this and presents a few initiatives that could be taken in order to address the issue an empower carers.

3

## Equal opportunities

*Regardless of gender, racial or ethnic origin, religion or belief, disability, age or sexual orientation, everyone has the right to equal treatment and opportunities regarding employment, social protection, education, and access to goods and services available to the public. Equal opportunities of underrepresented groups shall be fostered.*




Carers should have equal opportunities in all spheres of life. Yet, it is far from being the case as their work is generally not recognised in relation to social protection, education and access to goods and services that are essential to their caregiving tasks. In many ways, the adverse impact of caregiving on carers themselves and the dependence on informal care could therefore be seen as a ground for discrimination.



The **CARE4DEM project** (Erasmus +, 2017-2020), which **focuses on Dementia carers**, aims to develop an innovative model of mutual aid groups through web-based tools combined with other type of interventions, in order to enhance carers' satisfaction with care and reduce burnout. Mutual aid groups are commonly associated with improved mental and social well-being, increased self-confidence, resilience and knowledge. They offer great opportunities for non-formal learning. The project also intends to expand the professional skills of mutual aid groups' facilitators by creating a network for mutual and peer learning across Europe.

[www.eurocarers.org/care4dem](http://www.eurocarers.org/care4dem)



Informal carers, and especially women, have been found to be at higher risk of poverty, reflecting a weaker attachment to the labour force and hence the accrual of lower pension entitlements.



The fight against poverty and social exclusion is at the heart of our activities. We contribute to the **Annual Conventions on Inclusive Growth** and were delighted to participate in **EAPN's 16th European Meeting of People experiencing Poverty on In-work poverty**, held in Brussels on the 9-10 November 2017.

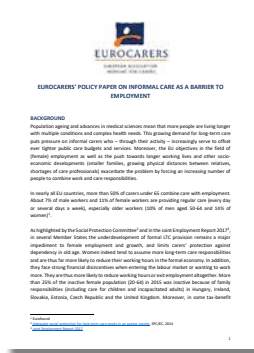
4

## Active support to employment

*Everyone has the right to timely and tailored assistance to improve employment or self-employment prospects. Young people have the right to continued education, apprenticeship, traineeship or a job offer of good standing within 4 months of becoming unemployed or leaving education. People unemployed have the right to personalised, continuous and consistent support. The long-term unemployed have the right to an in-depth individual assessment at the latest at 18 months of unemployment.*



Many carers have to perform a difficult balancing act and may be compelled to reduce their working hours or eventually give up paid employment, thereby reducing their income and pension entitlements.



The Eurocarers Policy Paper on “Informal care as a barrier to employment” highlights the impact of informal care on carers’ capacity to access the labour market and maintain an active and flourishing professional life. The document also suggests measures that could be implemented to address the problem at EU, national and regional level.



TRaining and recognition of informal Carers' sKills

TRACK is an Erasmus+ project aimed to at develop and test a training programme for informal carers. The programme is proposed in a flexible ‘blended’ mode (mixing online and face to face sessions) and includes mentoring for informal carers. A method to assess the skills acquired by informal carers on the job was also developed as part of the project.

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



# FAIR WORKING CONDITIONS

5

## Secure and adaptable employment

*Regardless of the type and duration of the employment relationship, workers have the right to fair and equal treatment regarding working conditions, access to social protection and training. The transition towards open-ended forms of employment shall be fostered.*

6

## Wages

*Workers have the right to fair wages that provide for a decent standard of living. Adequate minimum wages shall be ensured, in a way that provide for the satisfaction of the needs of the worker and his/her family in the light of national economic and social conditions, whilst safeguarding access to employment and incentives to seek work. In-work poverty shall be prevented. All wages shall be set in a transparent and predictable way according to national practices and respecting the autonomy of the social partners.*

7

## Information about employment conditions and protection in case of dismissals

*Workers have the right to be informed in writing at the start of employment about their rights and obligations resulting from the employment relationship, including on probation period. Prior to any dismissal, workers have the right to be informed of the reasons and be granted a reasonable period of notice. They have the right to access to effective and impartial dispute resolution and, in case of unjustified dismissal, a right to redress, including adequate compensation.*

8

## Social dialogue and involvement of workers

*The social partners shall be consulted on the design and implementation of economic, employment and social policies according to national practices. They shall be encouraged to negotiate and conclude collective agreements in matters relevant to them, while respecting their autonomy and the right to collective action. Where appropriate, agreements concluded between the social partners shall be implemented at the level of the Union and its Member States.*

*Workers or their representatives have the right to be informed and consulted in good time on matters relevant to them, in particular on the transfer, restructuring and merger of undertakings and on collective redundancies.*

*Support for increased capacity of social partners to promote social dialogue shall be encouraged.*

9

## Work-life balance

*Parents and people with caring responsibilities have the right to suitable leave, flexible working arrangements and access to care services. Women and men shall have equal access to special leaves of absence in order to fulfil their caring responsibilities and be encouraged to use them in a balanced way.*



Striking work-life balance for people with caregiving responsibilities for dependent relatives largely depends on the interplay between a broader set of social and employment policies. Policies that aim to assist working carers should include appropriate long-term care services to support dependent people and their families, income support and other “flexicurity” measures for carers, rights and regulations in the employment field as well as practical measures that can be implemented by employers at company level.

Eurocarers has actively contributed to the development, promotion and ongoing discussion around the **EC Proposal for a directive on work-life balance for parents and carers**. Building on our existing Policy Paper entitled “Reconciling work and care: the need to support informal carers” (2016) and on the extensive work and expertise of our member organisations, we have keenly advocated for the inclusion of an annual paid carer’s leave and the provision of flexible working conditions for working carers in the EC proposal. Among other things, our activities on this topic have led us to **meet with representatives of the cabinets of Vice-President Timmermans, Vice-President Dombrovskis, Commissioner Thyssen and Commissioner Jourova**. We have also contributed to **numerous events across the EU**, including the Joint Hearing on Work-Life balance organised by the EMPL/FEMM committees at the European Parliament. Finally, we have collaborated with fellow NGOs to make our joint message heard.

### RECONCILING WORK AND CARE: THE NEED TO SUPPORT INFORMAL CARERS

Eurocarers has actively contributed to the development, promotion and ongoing discussion around the EC Proposal for a **directive on work-life balance for parents and carers**. Building on our existing Policy Paper entitled “**Reconciling work and care: the need to support informal carers**” (2016) and on the **extensive work and expertise of our member organisations**, we have keenly advocated for the inclusion of an annual paid carer’s leave and the provision of flexible working conditions for working carers in the EC proposal.

### JOINT PUBLIC HEARING

COMMITTEE ON EMPLOYMENT AND  
SOCIAL AFFAIRS  
COMMITTEE ON WOMEN'S RIGHTS AND  
GENDER EQUALITY



Among other things, our activities on this topic have led us to meet with representatives of the cabinets of Vice-President Timmermans, Vice-President Dombrovskis, Commissioner Thyssen and Commissioner Jourova. **We have also contributed to numerous events across the EU, including the Joint Hearing on Work-Life balance organised by the EMPL/FEMM committees at the European Parliament**. Finally, we have collaborated with fellow NGOs to make our joint message heard.

10

### Healthy, safe and well-adapted work environment and data protection

*Workers have the right to a high level of protection of their health and safety at work. Workers have the right to a working environment adapted to their professional needs and which enables them to prolong their participation in the labour market. Workers have the right to have their personal data protected in the employment context.*



# SOCIAL PROTECTION AND INCLUSION

12

## Social protection

*Regardless of the type and duration of their employment relationship, workers, and, under comparable conditions, the self-employed, have the right to adequate social protection.*

11

### Childcare and support to children

*Children have the right to affordable early childhood education and care of good quality.*

*Children have the right to protection from poverty.*

*Children from disadvantaged backgrounds have the right to specific measures to enhance equal opportunities.*



Providing assistance with the (Instrumental) Activities of Daily Living, even if not paid, can be hard work and must still meet the basic standards of paid labour. It must therefore meet health and safety standards, build on adequate training, support, respite and partnerships with relevant paid sectors and not be penalised in terms of social security. Measures to support carers can include the provision of a direct carer allowance or cash benefits to the care user, taxation and fiscal incentives. Considering the time spent caring in the calculation of pension credit can also help prevent old-age poverty and the (gender) pension gap that most carers experience.

Eurocarers continuously advocates for the recognition of informal care as an important contribution to be nurtured and performed in the best conditions possible. Our contribution to the S&D Group Workshop on the Coordination of Social Security Systems in Europe, held in October 2017 at the European Parliament is one of the numerous opportunities used by our network to make that point.

13

### Unemployment benefits

*The unemployed have the right to adequate activation support from public employment services to (re)integrate in the labour market and adequate unemployment benefits of reasonable duration, in line with their contributions and national eligibility rules. Such benefits shall not constitute a disincentive for a quick return to employment.*

14

### Minimum income

*Everyone lacking sufficient resources has the right to adequate minimum income benefits ensuring a life in dignity at all stages of life, and effective access to enabling goods and services. For those who can work, minimum income benefits should be combined with incentives to (re)integrate into the labour market.*

15

## Old age income and pensions

*Workers and the self-employed in retirement have the right to a pension commensurate to their contributions and ensuring an adequate income. Women and men shall have equal opportunities to acquire pension rights.*

*Everyone in old age has the right to resources that ensure living in dignity.*

*Considering the time spent caring in the calculation of pension credit should also be envisaged in order to prevent old-age poverty and the (gender) pension gap that most carers experience.*



Obligations to look after elderly relatives can cause poverty when informal carers reach pensionable age, unless arrangements have been made to help them to reconcile work and care responsibilities and to build up pension rights. Research shows that single women with care responsibilities incur a greater risk of old-age poverty. Intensive carers tend to have lower income than non-intensive carers. In addition to the loss of income (both current and future, if pension rights accrual is also affected), family carers may be exposed to a heavy workload and social isolation.

The risks attached to the provision of unsupported caregiving activities for carers themselves are well documented. Everyone in the EU has been, is, will be or will need a carer. This is the reason why we use a life course perspective in all of our activities, to capture the diversity of challenges facing younger and older carers and to adopt a preventative approach to their needs.



16

## Health care

*Everyone has the right to timely access to affordable, preventive and curative health care of good quality.*



Informal carers can be under considerable stress and most have received no training in caring for a dependent person. The prevalence of mental health problems among informal carers is 20% higher than among non-carers, and particularly high for people who provide very intensive care. Adverse effects on physical health are also well documented, as carers are less likely than others to meet their own health needs. This can result in harmful habits and lifestyles (smoking, inadequate food or sleep habits) and failure to take preventive health measures (such as medical consultations).

Eurocarers' activities in the field of health aim to drive the development of a more favourable environment for carers, both in the prevention of mental and physical health issues and in the recognition of carers as reliable 'partners in care' by social and health care professionals.

Prevention and the perspective of informal care as a social determinant of health were reflected in our position paper on 'Non-communicable diseases and informal care', which serves to raise awareness about the health impact of informal care.

Although our network aims to be the voice for informal carers irrespective of the particular age or health need of the person they care for, we have initiated ad-hoc partnerships on diseases of particular relevance to carers. **The White Paper on Cancer Carers** (developed in collaboration with the European Cancer Patient Coalition - ECPC) **presents EU and national policy-makers with recommendations for a robust policy framework supporting cancer carers.** The challenges faced by the latter are very illustrative of those faced by carers generally.



This initiative was followed up by a **'Policy Roadmap on addressing Metastatic Breast Cancer (MBC)'**. Limited awareness of MBC's distinctiveness from early breast cancer, remains an issue which affects access to quality treatment and support services and prevents urgently needed improvements in patient outcomes. Besides an opportunity to contribute to an important campaign, the roadmap also allowed us to investigate how we can help meet the needs of a more specific group of carers (breast cancer carers), a majority of whom are men and who often face more particular challenges. The policy roadmap is intended as a practical document that showcases policy actions that can be taken to close these gaps across Europe. It was developed by a multi-disciplinary Working Group of stakeholders, including healthcare professionals, patient advocates and informal carers' advocates, policy makers, academics, industry representatives and healthcare payers.



Through our participation in the **WHO Primary Health Care Advisory Group to the Regional Director for Europe (PHCAG)**, created in 2016, we advocate for people-centred care systems that recognise and support carers. Primary Care has a key role to play in this process by acknowledging carers, treating them as partners in care, giving them a choice about which tasks to take upon themselves, enquiring about their health and wellbeing or providing them with the information they need. The PHCAG functions as a source of expert advice and advocacy to champion Primary Health Care.



The **ENHANCE (EuropeAN curriculum for family and Community nurse / Erasmus +, 2018-2020) Project** seeks to target the existing mismatch between the skills currently offered by nurses working in Primary Health Care (PHC) and those actually demanded by both public health care institutions and private service providers when applying innovative healthcare models centred on PHC. Currently no standardised EU-wide Professional Profile has been defined for family and community nurses taking into account WHO and EU recommendations. The competence-based professional profile will be the baseline for the definition of a European, innovative, learning outcome-oriented modular VET Curriculum for nurses.

[www.enhance-fcn.eu](http://www.enhance-fcn.eu)

Eurocarers has also co-signed calls for action on **Health Equity, mental health** and **Patient Safety** with various EU umbrella organisations.

17

## Inclusion of people with disabilities

*People with disabilities have the right to income support that ensures living in dignity, services that enable them to participate in the labour market and in society, and a work environment adapted to their needs.*



The 2006 Convention on the Rights of Persons with Disabilities (CRPD) was ratified by the EU in December 2010. The CRPD contains an extensive list of rights for persons with disabilities, aimed at securing equality in the enjoyment of their rights, as well as imposing a range of obligations on the state to undertake positive measures.

Importantly for the Eurocarers network, Article 16 of the CRPD states that: Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse.

**On the 6th December, Eurocarers took part in the conference of the “After Us” Law put in place in Italy in 2016.** The law focuses on the “independent life project” of people with severe disabilities. For the first time, responsible institutions are required to collaborate with families and, most importantly, with the people with a disability themselves to plan for their future once their carers will no longer be alive or able to provide care. Eurocarers’ participation to the conference – facilitated by C’entro Association, one of our local member organisations - served to highlight the good practices that already exist in other parts of the EU regarding the assistance and life projects of persons with a disability, from individual domiciliary initiatives to co-housing models.

via Riva di Reno 57, Bologna

## Un “dopo di noi” sostenibile

Esperienze italiane ed europee

14.30 *Saluti*  
S.E. Mons. **Matteo Zuppi**, Arcivescovo di Bologna

14.40 *Introduce* **Giovanni Zonin**, Scuola Centrale Formazione  
*Moderata* **Carla Landuzzi**, Fondazione IPSSER

**Stato dell’arte della Legge 112/2016 in Emilia Romagna**

14.45 *Attori, Strategie e Priorità del Piano Regionale di Attuazione della Legge “Dopo di noi”*  
**Luigi Mazza** - Sviluppo delle Politiche Socio-Sanitarie per i disabili, Dir. Gen. Cura della Persona, Salute e Welfare, Regione Emilia Romagna

15.15 *Progetti innovativi e accesso ai fondi regionali dedicati attraverso la Legge 112/2016*  
**Pietro Stefanini**, Fondazione Trustee, Parma

Question Time

**Prospettive nazionali ed europee**

16.15 *Stato dell’arte della Legge “Dopo di noi” nella Regione*

18

## Long-term care

*Everyone has the right to affordable long-term care services of good quality, in particular homecare and community-based services.*



The precondition for a 'carer-friendly society' and for good work-life balance for people with caregiving responsibilities is the availability of high quality, affordable and accessible formal long-term care services. There is indeed a clear correlation between labour force participation rates and the extent of access to long-term care services. When these services are provided, the intensity of informal care provision is visibly reduced and reconciliation issues are not so pressing. Investment in services should therefore be regarded as a priority. In the short run, it will nevertheless be difficult to meet the growing care needs of an ageing population without the contribution of carers.

Deinstitutionalisation and home care have been consensual policy objectives of many European governments. However, this does not automatically result in positive outcomes for carers since it often means shifting responsibility from the formal sector to the family. The expansion in home care services has not always matched the increase in care needs. The main reason why at-home care costs less than residential care is precisely because part of the work is shifted to the family as non-paid work. More resolute investments in home care services are therefore needed and the contribution of carers – when chosen and adequate - should be formalised and supported.

The overview table developed by Eurocarers on the situation of carers in Europe as well as the support measures available to them highlighted the great diversity of approaches that exist across Europe. It also underlined the gaps that still need to be bridged, including in 'carer-friendly' countries, and it emphasised the lack of relevant and consistent definitions and identification mechanisms across EU member states.

Our Regional Seminar 2017 co-organised in Porto on the 9th May with our colleagues from 'Cuidadores Portugal' focused on the specific needs of carers and on the features of care systems in the Mediterranean region. The event brought together representatives from seven countries and gave a chance to present and discuss the potential offered by the EU Pillar of Social Rights to support carers through support and empowering measures (e.g. work-life balance, investment in long-term care, etc.)



The 'Caring for carers' event, co-hosted by Eurocarers and EPIONI, and held in Athens on the 19th September gave a chance to promote the newly-established Greek Association of Carers (EPIONI) – a member of our network – and bring together stakeholders and decision-makers to shed light on the need to address the challenges facing carers in the context of an ageing Europe and a country with a weak social, health and long-term care system and a female employment rate below the EU average.

**Eurocarers has also played an active role in supporting policy developments at national level.** In October 2017, we accompanied the Italian Senate's intention to examine a law proposal aiming to address the needs of informal carers in the country. At the same time, Eurocarers actively advocated for the inclusion of a broad definition of informal care, as commonly used at European level, in the proposal. On 27 November 2017, the Senate's Budget Commission unanimously approved an amendment establishing the "Fund to support the caring role of informal carers" at the Ministry of Labour and Social Policies. The contents of this Amendment are in full harmony with Eurocarers' recommendations. The Fund represents a major step forward in the Italian legal framework and an important result for the more than 3 million carers in Italy.



The DARE (Domiciliary Assistance REvisited through Integrated Services) project is a two-year initiative (2017-2019), funded by the European Commission through the Erasmus+ programme. **DARE aims to support innovation in the provision of home care services, by ensuring an integrated approach in their delivery and – therefore – the development and reinforcement of transversal competences among care staffs.** Effective home care assistance cannot happen without the direct involvement of health and social professionals themselves, which is the reason why the activities organised in the framework of the project all seek to bring them together around the same table. The implementation of the project consists in a series of study visits allowing the exchange of best practices on integrated services for home assistance.



Carers require access to information and training to provide safe and adequate care. The **cancer carer toolkit** developed by Eurocarers builds on the expertise of our member organisations, the daily needs of cancer carers as identified through desk research and interviews, our ongoing dialogues with cancer organisations and specialist. **The toolkit consists in an online repository of practical information hosted on the Eurocarers website and aiming to offer carers with information and advice about caregiving.** This valuable and practical source of information seeks to address different aspects of the carer's experience, including Coping with caregiving; Communicating with the care recipient and healthcare professionals; Maintaining a good level of well-being; Maintaining work-life balance and informing your employer; etc. The toolkit also includes information on the needs of breast cancer carers, who often face more specific challenges and therefore require more particular support.



Assistive technology (AT) can be a key tool for enabling older people to live independently. However, the design of AT devices is often poor, undermining the end-user acceptance. Building on the most advanced technology, **the project aims to produce an innovative assistive technology, that will achieve a better integration of sensors into fabrics and textiles,** allowing designers to create products for older people that are not only functional but also more desirable and appealing as well as being lighter and more comfortable.

Eurocarers is also a member of the Advisory Board in the following projects:

- **The Network on quality and cost-effectiveness in long-term care and dependency prevention** (DG EMPL, 2015-2018), which is coordinated by London School of Economics, 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 of care systems.
- **Measuring social protection for older people with long-term care needs:** as part of the follow-up to the Staff Working Document in the Social Investment Package on Long-Term Care and the Joint Report on Adequate Social Protection for Long-term care in Ageing Societies, the EC is working with the OECD to build a methodology for cross-country comparisons of social protection against the costs of long-term care dependency. The OECD's previous work on long-term care allowed to collect information about the types of collective support that people in different countries receive when facing long-term care needs. This project seeks to complement that by taking a theoretical, bottom-up approach to understanding who is entitled to what public support for long-term care in EU and OECD countries.
- **SPRINT** is a three-year research project coordinated by the London School of Economics which **seeks to elucidate how long-term care can be located within the concept of social investment.** It conducts research with a view to define the "social" character and impact of long-term care schemes and to propose a set of tools, guidelines and policy recommendations that will support successful implementation of investment in Long-Term Care ([www.sprint-project.eu](http://www.sprint-project.eu)).
- **The Sustainable Care Research Programme (2017-2021)**, which is coordinated by the University of Sheffield, aims to explore how care arrangements, currently 'in crisis' in parts of the UK, can be made sustainable and deliver wellbeing outcomes; and support policy/practice actors and scholars to conceptualise sustainability in care as an issue of rights, values, ethics and justice, as well as of resource distribution. The overarching objective is to advance understanding of sources of economic and social sustainability in care, especially how wellbeing outcomes can be achieved for care users, their carers and paid care workers.

19

#### Housing and assistance for the homeless

- a. Access to social housing or housing assistance of good quality shall be provided for those in need.*
- b. Vulnerable people have the right to appropriate assistance and protection against forced eviction.*
- c. Adequate shelter and services shall be provided to the homeless in order to promote their social inclusion.*

20

#### Access to essential services

*Everyone has the right to access essential services of good quality, including water, sanitation, energy, transport, financial services and digital communications. Support for access to such services shall be available for those in need.*

# WHO'S WHO

## The EUROCARERS Executive Committee

<i>President</i>	<b>John Dunne</b> Family Carers Ireland - Ireland
<i>Vice-President Research organisations</i>	<b>Elizabeth Hanson</b> Swedish National Family Care Competence Centre
<i>Vice-President Carers organisations</i>	<b>Marja Tuomi</b> Central Association of Carers in Finland
<i>Treasurer</i>	<b>Ivar Paimre</b> Estonian Carers
<i>Executive member</i>	<b>Chloe Wright</b> Carers UK
<i>Executive member</i>	<b>Bruno Alves</b> Cuidadores Portugal
<i>Adviser</i>	<b>Valentina Hlebec</b> University of Ljubljana - Faculty of Social Sciences
<i>Consultant</i>	<b>Christine Marking</b> Marking Public Affairs

## The EUROCARERS Secretariat

<i>Executive Director</i>	<b>Stecy Yghemonos</b>
<i>Administration and Finance Officer</i>	<b>Riika Lempiäinen</b>
<i>Senior Communication Officer</i>	<b>Olivier Jacqmain</b>
<i>Policy Officer</i>	<b>Claire Champeix</b>
<i>Senior Project Officer</i>	<b>Mariana Vicente</b>
<i>Project Officer</i>	<b>Francesca Centola</b>

# MEMBERS

## Associate Members

European Centre for Social Welfare Policy and Research	Austria
Aidants proches Bruxelles	Belgium
Institut Recherche Santé et Société, Université Catholique de Louvain	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
Organisations for Carers Network Finland	Finland
The Central Association of Carers in Finland	Finland
Association Française des aidants	France
La compagnie des aidants	France
Centre for Quality in Care	Germany
wir pflegen e.V.	Germany
Greek Association of Alzheimer's Disease & Related Disorders	Greece
Institute of Mental Health Semmelweis University	Hungary
Care Alliance Ireland	Ireland
Family Carers Ireland	Ireland
Anziani e non solo società cooperativa	Italy
Istituto Nazionale di Riposo e Cura per Anziani V.E.II(INRCA) Dipartimento Ricerche Gerontologiche	Italy
SOS Malta - Solidarity Overseas Development Malta	Malta
department of Sociology, Faculty of Social Sciences, VU University Amsterdam	Netherlands
MOVISIE, Centre of Expertise for Informal Care	Netherlands

VILANS	Netherlands
Pårørendealliansen (Norwegian National Alliance for Carers)	Norway
European Care Foundation	Poland
Cuidadores Portugal	Portugal
Anton Trstenjak Institute of gerontology and intergenerational relations	Slovenia
University of Ljubljana. Faculty of Social Sciences	Slovenia
CEAFA: Confederacion Espanola de Familiares de Enfermos de Alzheimer y otras Dementias	Spain
Anhörigas Riksförbund (AHR), carers Sweden	Sweden
The Swedish Family Care Competence Centre	Sweden
Carers Federation	UK
Carers UK	UK
CIRCLE (Centre for International Research on Care, Labour and Equalities), University of Sheffield	UK
The Open University Faculty of Health and Social Care	UK
Carers Trust	UK
The Coalition of Carers in Scotland	UK- Scotland
VOCAL - Voice of Carers Across Lothian	UK- Scotland



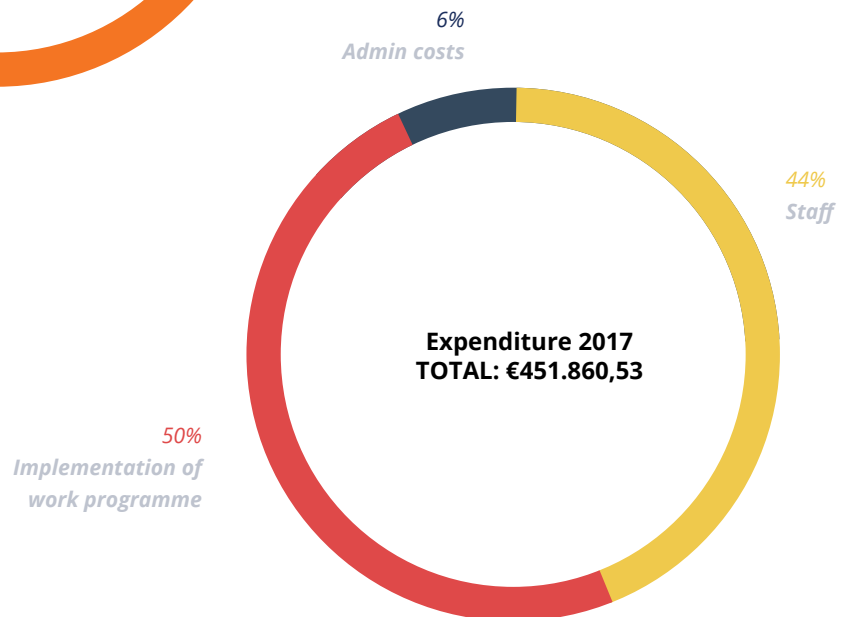
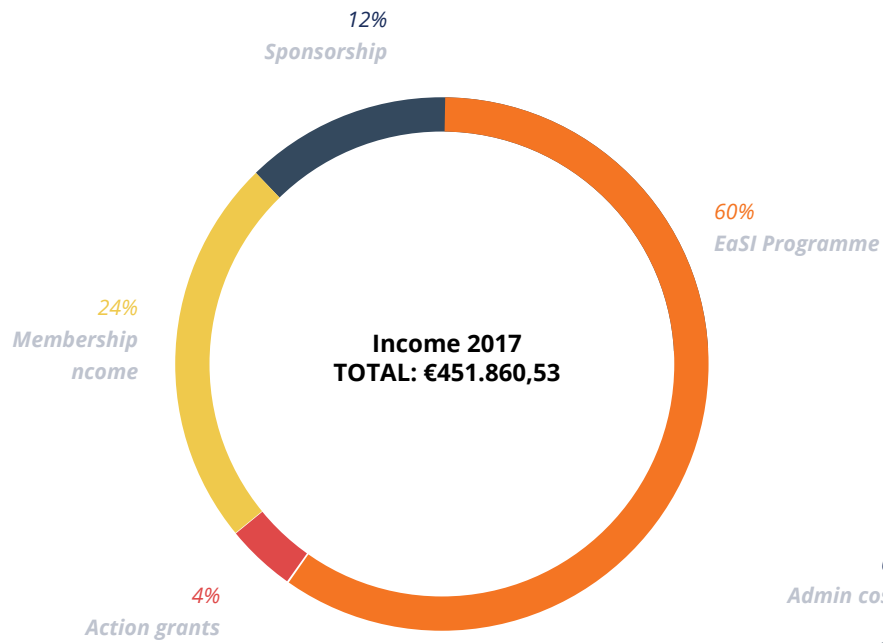
## Associate Members

Austrian Carers Organisation	Austria
Kurt Debaere, Howest, University of applied sciences, research cluster: Kennispunt Mantelzorg	Belgium
Samana	Belgium
Universiteit Antwerpen - Centre for Longevity Research (CELLO)	Belgium
Aidants proches	Belgium
Jeunes Aidants proches	Belgium
Alzheimer Bulgaria (Civil Association "Alzheimer-Bulgaria")	Bulgaria
DaneAge	Denmark
Athens Association of Alzheimer's Disease and Related Disorders	Greece
EPIONI	Greece
University of Bologna	Italy
Associazione C'ENTRO	Italy
RBS Center fir Altersfroen asbl	Luxembourg
Mezzo, Landelijke Vereniging voor Mantelzorgers en Vrijwilligerszorg. Dutch Association for Carers and Voluntary Help	Netherlands
The Netherlands Institute for Social Research (SCP)	Netherlands
Slovenian Federation of Pensioners' Organisations - Zveza Drustev Upokojencev Slovenije (ZDUS)	Slovenia
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
Dr. Henk Bakkerode	Netherlands
Marja Pijl	Netherlands
Dr. Jolanta Perek Bialas	Poland
Professor Piotr Bledowski	Poland
Cuidadores Familiares	Spain
Martha Mackay	Spain
Daniel Phelps	UK
Saul Becker	UK

# HOW WE ARE FUNDED



# 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 Admin and Finance Officer, Ms. Riika Lempiäinen, in our Brussels secretariat at [rl@eurocarers.org](mailto:rl@eurocarers.org).



# EUROCARERS

EUROPEAN ASSOCIATION  
WORKING FOR CARERS



Eurocarers receives support  
from The European Union through the programme  
for Employment and Social Innovation (EASI  
Programme 2014-2017)

✉ 3, Rue Abbé Cuypers - 1040 Brussels - Belgium | ☎ 0032 (0)2 741 24 05 | 📧 [info@eurocarers.org](mailto:info@eurocarers.org)  
🌐 [www.eurocarers.org](http://www.eurocarers.org) | 📘 [EuropeanAssociationWorkingForCarers](https://www.facebook.com/EuropeanAssociationWorkingForCarers) | 🐦 [@Eurocarers\\_info](https://twitter.com/Eurocarers_info)