

ANNUAL REPORT 2018

**Heading towards a revitalised
environment for our work and
the promotion of carer-friendly
societies in Europe**



**EURO
CARERS**
European Association Working for Carers



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Forewords

I am privileged to introduce the Eurocarers Annual Report for 2018, which provides a rich 'smorgasbord' of our main collaborative activities and achievements during the year.

2018 heralded new strategic opportunities for our advocacy work thanks to the momentum created by the united endorsement of the EU Pillar of Social Rights by all EU member states in November 2017. Closely followed on its heels, an updated Eurocarers' EU Strategy on Carers was launched at the European Parliament, which set out a rights-based approach of 10 core steps for implementing a carer-friendly policy environment. I am delighted to report that the Strategy has already had synergy effects as a growing number of Eurocarers' member organisations have embarked on adapting the strategy to suit their national and/or regional policy contexts, as part of their organisation's core advocacy work.

The Spring meeting of the Carer Interest Group in the European Parliament focused on the situation of young carers for the very first time. I'd like to express my thanks to our founding MEP member Marian Harkin for all her valuable work with the Interest Group over the years.

Eurocarers is an increasingly visible and respected organisation – indeed, we were invited to more than 200 events during 2018. Our membership continues to steadily increase and our 2018 EaSI annual report was positively evaluated by the Commission. We are also a partner in 7 different EU action grants and we now boast a new and improved website.

These successes are not possible without the dynamic leadership and dedication of Stecy Yghemonos, our Executive Director, together with the skills and commitment of our staff: Riika Lempiäinen, Francesca Centola, Claire Champeix, Nadia Kamel and Olivier Jacqmain. Thank you to each and every one of you. I also appreciate the support and joint efforts of the Board over the past year: Sari Tervonen, Vice President Membership; Ivar Paimre, Treasurer and Directors Chloe Wright, Valentina Hlebec, Anita Vatland and Bruno Alves. Further, I value Christine Marking's continued support of Eurocarers.

Finally, my bouquet of thanks is directed to you, our member organisations, for all the invaluable work you do to recognise, support and empower informal carers across Europe!



Elizabeth Hanson
President

Dear Readers,

I am pleased to present you with the 2018 annual report of Eurocarers, which provides a brief overview of the scope and diversity of the activities carried out by our network over the year in favour and on behalf of informal carers across Europe. Our mission is to achieve greater recognition and support for all carers, irrespective of their age or the particular care need of the person they are caring for, and I am happy to say that, year-on-year, we continue to make good progress, as illustrated below.

Much has happened in the last few months regarding the carers' agenda at international, EU and – to some extent – national and regional level. The unanimous endorsement of the EU Pillar of Social Rights by all EU member states at the end of 2017 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. The Pillar clearly offers a revitalised environment for our work and the promotion of carer-friendly societies in Europe.

The principles that concern work-life balance for parents and carers and access to affordable and good quality health and long-term care are of particular relevance to our message around the need for a combination of support and emancipating measures to address carers' needs. The principles related that access to education, gender equality or equal opportunities are as important tools to make a difference in the daily life of European carers. All of these aspects have therefore been at the core of our work in 2018 and will likely remain so in the years to come. We achieved much in 2018, but a lot of course remains to be done at EU, national and regional level to achieve our goals and to ensure that the important role played by carers is recognised and supported as it should. On behalf of the Secretariat, I would like to thank all colleagues for their participation and support to our activities to date. We very much look forward to working with you again in the future!

We achieved much in 2018, but a lot of course remains to be done at EU, national and regional level to achieve our goals

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 64 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 level. An overview of our membership is available on our website: www.eurocarers.org/membership.

Eurocarers is designed as a platform for collaboration, support, exchange, awareness-raising and policy change. Our collective efforts seek to ensure that the existing and growing care needs of an ageing European population are addressed in a universal and equitable way and that the essential contribution of unpaid/informal carers in the provision of care is valued and recognised as central to the sustainability of health and long-term care systems, and supported to prevent the negative impact of care on carers themselves. We believe that carers' know-how and needs are worth listening to and 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.

THE MISSION OF THE EUROCARERS NETWORK

is therefore to act as a voice for informal carers by:

- Documenting and raising awareness about the significant contribution made by carers to health and social care systems and the economy as a whole, the impact of caring on carers' ability to maximise their life prospects and maintain an active and productive life, as well as the need to address the daily challenges facing carers across Europe;
- Contribute to evidence-based policy development at national as well as European level that take account of carers, i.e. promote their social inclusion, the development of support services, enable them to remain active in paid employment and maintain a social life; and
- Promote mutual learning and an exchange of good practice and innovation throughout the EU.

Policy environment

The efforts of the Eurocarers network aim to inform, maintain and expand the momentum around informal care – and its impact on carers themselves – in as many relevant policy areas as possible. In 2018, Eurocarers has continued to be involved in policy dialogues related to the social inclusion of informal carers, their access to employment, the gender dimension of care, young carers or the development of people-centred and community-based long-term care services (and the role of carers therein).

EU Pillar of Social Rights

The EU Pillar of Social Rights was announced by the European Commission back in September 2015, presented in March 2016 and finally proclaimed (i.e. endorsed) by the European Parliament, the Council of the European Union (i.e. member states) and the European Commission on the 17th November 2017, at the Social Summit for Fair Jobs and Growth in Gothenburg, Sweden. It is widely seen by the civil society as a laudable attempt by the Commission to bring the social dimension of the union back on the EU policy agenda.

The Pillar recognises the need to act proactively in order to reinforce social cohesion within the EU. It takes a holistic point of view, choosing to address all challenges at once. It values adequate social protection as a productive factor, and social convergence as a necessity. In that context, the fact that more cohesive countries perform better in difficult times is considered as clearly demonstrated. Finally, the Pillar contains a number of positive proposals, some of which were put forward by civil society organisations themselves (including Eurocarers).

Although uncertainties remain as to what extent the Pillar will enable to pave the way for a truly social Europe), the initiative has undeniably generated a unique political momentum in favour of a more cohesive Europe built on a social acquis. Eurocarers is committed to using the principles contained in the Pillar to contribute to the implementation of the EU objectives in a manner that acknowledges and respects the situation and added value of carers across Europe.

The **Face-to-face meeting of the Eurocarers Policy Working Group**, held on the 25th June 2018 in Brussels, was therefore fully dedicated to the potential added value of the 20 principles contained in the Pillar for the daily life of carers. The meeting served to inform the development of our policy brief on the topic as well as our proposal for an EU Strategy on carers. It also provided an opportunity to discuss the learnings of the ESPN report “Long-term care challenges in Europe” with its author, Ms. Slavina Spasova.

Work-life balance for parents and carers

Population ageing and advances in medical sciences mean that more people are living longer with multiple conditions and complex health needs. This growing demand for long-term care puts pressure on informal carers who – through their activity – offset ever tighter public care budgets and services. Moreover, the EU objectives in the field of (female) employment, the push towards longer working lives and other socio-economic developments (smaller families, growing physical distances between relatives, shortages of care professionals) exacerbate the problem by forcing an increasing number of people to combine work and care responsibilities.

Against this backdrop, the debate about policies and practices that support the reconciliation of caregiving responsibilities with paid employment has gained ground and has been at the core of our activities in the last few years. It is therefore no surprise that one of the first initiatives accompanying the launch of the Pillar of Social Rights concerned an ambitious and comprehensive proposal on “Work-Life balance for parents and carers”, which nicely reflected most of Eurocarers’ pleas for a life-cycle and transversal approach, and contained many of the elements we call for. Following a long and complex campaign in support of the proposal and despite a pretty adverse reaction from employers, we are delighted to report that our advocacy, communication and networking activities have finally proved fruitful and that the Directive was approved by the Council and European Parliament at the beginning of 2019. The Directive introduces the concept of “carers’ leave for workers caring for relatives in need of care or support due to serious medical reasons” at EU level. As a result, carers across Europe will now be able to benefit from a leave of 5 working days per year. The Directive also extends the right to request flexible working arrangements to working carers, which is also one of the key needs of working carers. Having said that, it will be important for our network to keep an eye on the implementation of the

CURRENT EU LAW



No minimum standards for carers at EU level (except “force majeure” allowing to take some time off for imperative and unexpected family reasons)



Right to request reduced and flexible working hours upon return from parental leave.

Right to request part-time work for all workers.

IMPACT OF THE NEW DIRECTIVE

All workers will have the right to 5 working days of carer's leave per year

All working parents with children up to at least 8 years old and all carers will have the right to request the following flexible working arrangements:

1. reduced working hours
2. flexible working hours
3. flexibility on the place of work

Directive, in particular the questions related to the definition of informal care and the financial compensation attached to the leave, which remain at the discretion of member states. EU member states have three years to transpose these new rights into their national laws

EP Interest Group on Informal Carers

The **European Parliament's Interest Group on Informal Carers** remains one of Eurocarers' main instruments for policy change at EU and national level. The role of the Interest Group is to monitor and analyse EU policy development for its impact on carers and to propose and advocate concrete action in order to improve the day-to-day situation for Europe's many carers, working in close partnership with relevant stakeholders. The Group currently brings together 31 MEPs from 11 countries interested in care and caring.

Two meetings of the EP Interest Group were held in 2018. The first meeting took place on the 6th March 2018 in Brussels on the topic of Young Carers. The event brought together more than 40 participants from 13 countries and allowed to reflect with key policy makers and stakeholders (including young carers themselves) on ways to overcome young carers' general invisibility in EU policies. The meeting allowed to establish new links with EC services and shed light on the work of the Eurocarers Young Carers Working Group as well as on Eurocarers ongoing research projects on the topic (i.e. Me-We and Edy-Care, see Research section below).

Eurocarers has since initiated a successful collaboration with the European Network of Ombudspersons for Children and presented the Me-We project at their annual conference. As a result, the ENOC statement on child mental health – adopted at the ENOC General Assembly on the 21st September - includes a clear reference to young carers (a recommendation to develop support programmes for young carers to enable them to better enhance and protect their mental health). Another success concerns our advocacy work around and contribution to the EP Report on "Care Services in the EU for Improved Gender Equality" which calls on the Commission and Member States to undertake research and initiate policy action as regards young carers' needs.

The second meeting of the Interest Group took place on the 21st November 2019 in Brussels and brought together 32 participants from 12 countries. This meeting aimed to explore EU efforts in the fields of long-term care and work-life balance for parents and carers, which are two key components of our call for a 'carer-friendly policy environment', and to connect the dots between these policy agendas. The success of initiatives aiming to address the needs and preferences of carers indeed largely depends on the relationship between a broad set of policies in the social, health and employment fields. Yet, policy developments of relevance to car-



ers are often designed and implemented in a fragmented manner and therefore do not always result in real improvements in carer support.

The Interest Group meeting was used by Eurocarers to re-introduced the idea of an **EU Strategy to Support and Empower Carers across Europe**. The document aims to define the 10 Steps that are required to implement a carer-friendly policy environment seeking to recognise, support and empower informal carers across Europe in a comprehensive and coherent manner.

The launch was also accompanied by a press release which was largely disseminated, including through the social media. The Strategy and its accompanying explanatory document, which were developed in collaboration with MEPs, will form the backbone of our future advocacy and communication activities at international and national level. The Strategy is also the starting point of an in-country advocacy campaign as it will serve to develop country profiles as well as specific messages to support our member organisations' policy work across Europe. The Strategy will contribute to the implementation of the EU Pillar of Social Rights 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.

Eurocarers' proposed 10 steps towards carer-friendly societies in Europe

STEP 1	<i>Define and acknowledge Carers</i>
STEP 2	<i>Identify your Carers</i>
STEP 3	<i>Assess the needs of your Carers</i>
STEP 4	<i>Support multisectoral care partnerships for integrated and community-based care services</i>
STEP 5	<i>Facilitate Carers' access to information and advice about care, caring and care-life balance</i>

Since the opening of our secretariat five years ago and thanks to the partnership agreement renewed with the European Commission (DG EMPL) in 2018 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 to inform EU and national policy developments on how recognising and supporting the contribution of carers can benefit European society. Our positioning as a credible knowledge broker has allowed us to play a part in relevant policy debates with the EU institutions (European Parliament, European Commission, Committee of the Regions and European Economic and Social Committee) and a huge variety of stakeholders (WHO, OECD, Civil Society Organisations, the Industry); as well as through a series of advocacy activities and tools, which – in 2018 - included **2 Policy briefings, 9 position papers and Joint statements/Calls for action, and 5 press releases** (see details below).

STEP 6	<i>Pay attention to Carers' health and prevent negative health outcomes</i>
STEP 7	<i>Give Carers a break</i>
STEP 8	<i>Provide Carers with access to training and recognise their skills</i>
STEP 9	<i>Prevent Carers' poverty and allow them to maintain an active professional/educational life</i>
STEP 10	<i>Adopt the Carers' perspective in all relevant policies</i>

Capacity Building

Eurocarers continuously seeks to strengthen its members' understanding of the EU/national policy environment in which they work as well as of the opportunities and challenges that they entail. Our annual programme of activities, therefore includes a series of 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 5 capacity-building events.



An in-country **Study Visit on the topic of “Carers, human rights and associative discrimination”** was co-organised with Anziani e Non Solo and the Department of Law of Modena University (Italy) on the 5-6 June 2018, in Modena. Associative discrimination comes about when someone is treated unfavourably on the basis of another person's protected characteristic. In relation to carers, it is probably best understood where a disadvantage can be expressed in the following simple statement: 'but for my relationship with a dependent person, this would not have happened.'

The Study Visit benefited from the expertise of external guests, including Pr. Luke Clements (from The School of Law at the University of Leeds), representatives from the School of Law at the University of Modena, colleagues from the Regional Carers Association in Italy (who shared their experience about the development of the regional and national law on carers) and an Italian Senator.

Our Study Visits provide an opportunity for Eurocarers members to learn from each other, take stock of our network's knowledge and good practices and lay the ground for future common initiatives at policy and/or practice level. Participating members played an active role as they presented and exchanged on their organisation's work and/or views on the topic or the legal environment for work in their country/region. The visit brought together 20 participants from 9 countries.

Eurocarers also organised **Knowledge-exchange Workshops** as part of its AGM 2018, on the 25th and 26th June in Brussels. These focused on three topics selected by member organisations themselves., which included:

- The potential offered by the European Social Fund (ESF);

- Collecting statistics about carers in Europe; and
- Developing an EU-wide communication campaign

The workshops allowed to build on members' experience and interest and to define common approaches and strategies for the network's activities in 2018 and beyond.

As it is now customary, the programme of the AGM 2018 also included a discussion with members on Eurocarers' annual **Analysis of the EU Semester background documents** (Country reports, National Reform Programmes, Country Specific Recommendations) and the relevant entry points they include.

Finally, Eurocarers also develops ad-hoc policy briefings in order 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 2018 focused on:

- "Informal care, poverty and social exclusion"; and
- "The European Structural and Investment Funds: a state of play"

The **Overview Table on the Number of carers and existing support measures across the EU**, developed by Eurocarers was updated in 2018, based on desk research, a continuous data collection and consultation with/through member organisations. The table aims to:

- Highlight the great diversity of approaches that exist across Europe when it comes to recognizing, identifying and supporting carers (when such measures exist);
- Keep track of the progress made in the development of carer-friendly policies;
- Underline the gaps that still need to be bridged, including in 'carer-friendly' countries;
- Emphasise the lack of relevant and consistent definitions and identification mechanisms across EU member states.

Position papers and calls for action

In 2018, Eurocarers also co-developed and disseminated a series of position papers and joint calls for action on:

- Improving patient empowerment and self-management of care in mental health;
- Raccolta segnalazioni di Giovanni Caregiver / Signature of an MoU with the Italian Ministry of Education;
- The need for a multi-Stakeholder Digital Health Roadmap to support Integrated Care;
- Europe's health deserves the EU's attention: Investing in chronic disease prevention and management
- The United Nations Global Compact on Migration as a Key Opportunity to Recognise Rights of Migrant Domestic and Care Workers + Working Paper entitled 'Shared concerns and joint recommendations on migrant domestic and care work';
- ECCO's Essential Requirements for Quality Cancer Care;
- Eurocarers' contribution to the public consultation on integration of long-term unemployed into the labour market;
- An EU Strategy to support and empower informal carers (and explanatory note); and
- A sustainable approach to depression: moving from words to actions.

Networking

In addition, in 2018, Eurocarers also played an active role in more than 200 events focusing on topics of relevance to our network's 'natural' policy entry points (e.g. European Semester for economic governance, Social Open Method of Coordination, Annual Convention on Inclusive Growth, EU Pillar of Social Rights, European Innovative Partnership on Active and Healthy Ageing, etc.) as well as new links in other agendas related to health and long-term care, disability, youth, gender equality, ICT and equal opportunities. This allowed us to connect the dots between relevant policies, inform them and contribute to a "care in all policies" (carer-friendly) approach.

Action at national and regional level

While the EU level is key to provide a platform for information and exchange to Eurocarers members and supporters and to inform the much-needed co-ordination efforts initiated by the European Commission and Parliament in the fields of care and caring, most of the policy areas that affect the daily life of carers across Europe are ultimately managed at national or regional level. Consequently, Eurocarers also co-hosted or contributed to **4 high-level policy in-country dialogues** in order to ensure that our messaging is not only used in EU policy contexts but is also integrated in national, regional and local policy dialogues on the daily needs of carers, their support and empowerment, and the implementation of the EU Pillar of Social Rights and Social Investment Package.

The in-country events held in 2018 included:

- The very First Conference on Informal Care in Slovenia, held in Ljubljana on the 8th May 2018. The event was co-organised by the Anton Trstenjak Institute of gerontology and intergenerational relations, the Slovenian Ministry of Health and Eurocarers. The conference brought together more than 350 participants from across the country with a programme that included interventions from three ministries (Ministry of Health; Ministry of Labour, Family, Social Affairs and Equal Opportunities; and Ministry of Environment and Spatial Planning) and from the University of Ljubljana.
- The Caring for Carers conference on Young Carers in a Changing World, held at the office of the European Parliament in Athens, Greece on the 28th September 2018. The event, which brought together around 50 participants, aimed to shed light about the daily challenges facing the carers of people with a chronic disease or disability - and ways of addressing them - with the participation of healthcare professionals, psychologists, social workers and lawyers, who give answers to a wide range of medical, legal, educational and employment issues of interest to the public. The event was organised under the auspices of the Ministry of Health in Greece, the World Federation for Mental Health, the Hellenic Psychiatric Association, the European Brain Council and Eurocarers.
- Our contribution to the Hearing on carers at the Italian Senate, held on the 22nd-26th October 2018 in Rome, Italy; and
- The participation of a Eurocarers delegation to the meeting of the Scottish Carers Parliament 2018 on the 24th October 2018 in Edinburgh, Scotland.



Communication

The **Eurocarers website** (www.eurocarers.org) remains 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. A new version of the website was developed in 2018. It provides a more user-friendly information hub on care, carers and caring to our targeted audiences (i.e. policy-makers, stakeholders, carers and the media).

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. 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.

In 2018, Eurocarers has produced and disseminated **5 press releases**, focusing on:

- “Every child has the right to...” - A reality check for young carers;
- World Mental Health Day 2018: Let’s work together to promote good mental health for Young Carers!;
- A national protocol to support young carers in schools;
- International Women’s day 2018 - Eurocarers drew the attention to its publication (released at the end of 2017) on “The gender dimension of informal care”; and
- European Parliament Informal Carers Interest Group calls for action to support young carers.

Our Research Work

The mission of Eurocarers is to document the situation and needs of informal carers and contribute to evidence-based policy developments that take account of carers. Developing a strong knowledge base is critical to inform policy in all areas affecting carers, especially in health, care, education, employment, social protection, transport and housing. It also informs evidence-based practice concerning support services for carers and dependent persons. Research is therefore one of the central areas in which our network is engaged.



The need for research and knowledge exchange drives the work of the **Eurocarers Research Working Group**, which currently brings together 39 expert organisations (mainly universities & research institutes) from 20 countries. The Working Group meets on a regular basis 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 care and caring in the EU. Two Eurocarers Research Working Group meetings were held in 2018 and allowed members to share and discuss the learnings of their work in the fields of care and caring. The meetings also offered the opportunity to exchange on the development of good quality indicators of long-term care and informal care.



The Eurocarers network is involved in various research and implementation projects aiming to help us formulate credible and applicable policy recommendations for the recognition of carers and carers' needs.

Young Carers

Eurocarers is currently involved in two research projects on the topic of young carers, thanks to the support of the EU, through the Horizon 2020 and Erasmus+ programmes respectively.

Me-We (Psychosocial Support for Promoting Mental Health and Well-being among adolescent Young Carers in Europe / 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 specific objectives of the project are 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.





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 to help teachers and school staff to identify young carers; develop a package of educational strategies, didactical approaches and organisational adjustments to help schools to facilitate young carers, produce a handbook providing guidelines and recommendations on how teachers and school staff can work at best with young carers; and develop a massive open online course (MOOC) for training teachers and school staff on the young carers phenomenon, their needs and preferences.

Besides these important research activities, Eurocarers can also rely on the contribution of its very vibrant **Young Carers Working Group (EYCWG)**, which aims to build on the carers' movement, feed into Eurocarers' advocacy activities, and speak with one voice on behalf of young carers. Through our programme of activities, the group provides young carers with an opportunity to meet, learn from each other, be briefed, consulted and involved in policy dialogues about EU priorities that concern them.

Two face-to-face meetings of the EYCWG were held in 2018. The first one took place in the margins of the EP interest Group Meeting in Brussels on the 6th March and gave a chance to update young carers about the Legal framework and political environment for work and to discuss the way the EYCWG could position itself and communicate, including in the light of the upcoming EU elections. The second meeting was held on the 25-26 June 2018 - in the margins of Eurocarers' AGM - and gave a chance to build on our first discussion, finetune the EYCWG's communication strategy and analyse the potential offered by principles 1, 4, 11 and 18 of the EU Pillar of Social Rights (Education, training and lifelong learning; Active support to employment; Childcare and support to children; and Long-term care). The EYCWG meetings brought together 19 young carers from 10 countries.

ICT based solutions for care

Eurocarers recognises that ICT Tools can greatly benefit the social integration of carers, provide them with social, emotional and peer support, facilitate their participation in aspects of life outside the home and thus improve carers' quality of life. Our network is therefore involved in research and innovation projects aiming to develop new technology-enabled solutions in favour of carers and care recipients.

The **CARE4DEM** project, which focuses on Dementia carers, aims to develop a new and innovative model of mutual aid groups which promotes carers' involvement by introducing web-based tools and integrating it with other type of interventions, in order to enhance caregivers' satisfaction with care and reduce burnout. Mutual aid groups are commonly associated with several benefits, including mental and social well-being, by increasing self-confidence, resilience and knowledge. They are a powerful opportunity for non-formal learning, as they help carers cope with difficulties, by sharing of experiences, interaction with peers, building connection and affectivity. The project also intends to expand the professional development of mutual aid groups' facilitators by creating a network for mutual and peer learning across Europe.



The **MATUROLIFE** project integrates creative artists and fashion designers into the research team to facilitate design-driven innovation. The project builds on existing technological advances in materials which have produced a highly innovative selective metallisation process that utilises nanotechnology, electrochemistry and materials science to encapsulate fibres in textiles with metal and thereby provide conductivity and electronic connectivity. In this way, better integration of electronics and sensors into fabrics and textiles will be possible. This will give the fashion designers and artists the tools to produce assistive technology for older people that is not only functional but is more desirable and appealing as well as being lighter and more comfortable.



Carers as partners in care

Integrating care, services and supporting activities means that the design and delivery of care is made in a more effective manner, so that users receive a continuum of preventive, curative, rehabilitative, and support interventions throughout the life course which are suited to their needs over time and are seamlessly available across different levels and areas of health and social systems. Carers are central to the planning, shaping and delivery of services for the people with care needs and in relation to support for themselves. When approached by other actors of the care pathway (i.e. care professionals) as equal partners in the delivery of care, Carers enable people with illnesses or disabilities to remain at home and in their own communities safely, independently and with dignity. Multidisciplinary approaches, including carers' involvement and perspective, should therefore be supported in order to implement the principles of integrated people-centred care. Eurocarers is involved in various projects aiming to contribute to this aim.



The **ENhANCE** (European curriculum for family and community nurse) 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 standardized 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.

The value of informal care in Europe

In the last few years, a growing number of academic and non-academic publications focusing on the impact of demographic ageing, the future of health and long-term care, access to employment and education, work-life balance or gender equality – among others – have emphasized the great contribution of informal carers to the sustainability and efficiency of care systems and the economy as a whole as well as the obstacles generated by informal care in the pursuit of more inclusive and caring European societies. These publications have called for a better recognition of carers' essential role, added value and challenges. Nevertheless, despite a very positive political momentum at international, EU, national and local level around the topic of care and caring, the lack of comprehensive and consistent data regarding the **economic value of informal care in Europe** often remains a major barrier to convince decision-makers that resolute action is needed to support carers.

Different methods are used to assess the value of non-market commodities and have been applied to informal care. This report aims to review them and identify their strengths and weaknesses. It describes the key principles underpinning the existing valuation methods of informal care and presents the theoretical and practical issues that they entail. The report also makes recommendations on the use of these methods.

Long-term care

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.

Eurocarers is therefore also involved in projects exploring various models of formal long-term care, which take into consideration the needs and preferences of informal carers both as co-providers of care and as secondary users.



The **DARE** project (which stands for Domiciliary Assistance REvisited through Integrated Services) 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.



Our living environments have a tremendous impact on our health. Ensuring their suitability of people's homes throughout their lives to permit persons to age in place is one of the most effective approaches to respond to Europe's ageing demographics. Given the future demographic changes, and the resulting increased reliance on support from informal carers in providing long-term care, smart solutions to adapting the home and the immediate environment to the needs and desires of senior persons and their informal carers will be one of the ways to make society more age- and carer-friendly. The 2-year **Homes4Life** project, which is funded under the Horizon 2020 programme) will contribute to the development of a European certification scheme for ageing in place ready for widespread adoption by a dedicated community of lead users. The scheme will be based on a holistic life-course approach and will help develop better living environments integrating construction and digital solutions where this is beneficial.

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

- **Cost effectiveness and quality in long-term care** (CEQUA) network (DG EMPL, 2015-2018). The overall objective of the CEQUA Network, which is coordinated by the Personal Social Services Research Unit at the London School of Economics, is 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 inter country long-term care policy learning between EU countries. (www.cequa.org)
- **SPRINT** (Social Protection Innovative Investment in Long-Term Care, 2016-2018)), which is a three-year research project funded under the Horizon 2020 programme and coordinated by the London School of Economics and 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 LTC (www.sprint-project.eu).
- **Sustainable Care: connecting people and systems** (2017-2021): The Sustainable Care Research Programme, which is coordinated by the University of Sheffield, will 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. Our 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 families / carers and paid care workers. (<http://circle.group.shef.ac.uk/sustainable-care>)



Who's who

The Eurocarers Executive Committee



Chairperson

Elizabeth Hanson

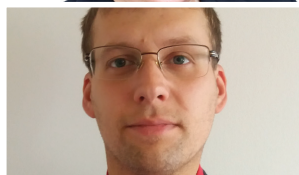
Swedish National Family
Care Competence Centre



Vice-Chairperson
Membership

Sari Tervonen

Central Association of
Carers in Finland



Treasurer

Ivar Paimre

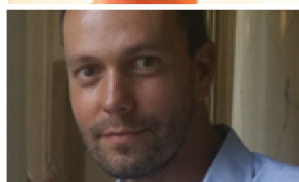
Estonian Carers



Executive member

Chloe Wright

Carers UK



Executive member

Bruno Alves

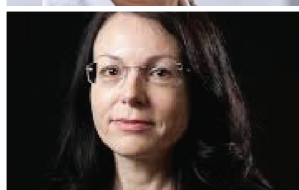
Cuidadores Portugal



Executive member

Anita Vatland

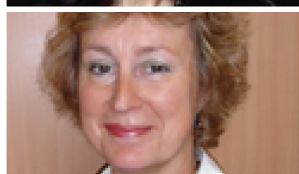
Carers Norway



Adviser

Valentina Hlebec

University of Ljubljana -
Faculty of Social Sciences



Consultant

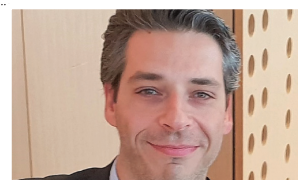
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Marking Public Affairs

The Eurocarers Secretariat

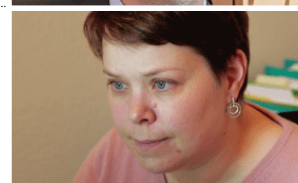
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Stecy Yghemonos



Administrative and
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Riika Lempiäinen



Communication
Officer

Olivier Jacqmain



Policy Officer

Claire Champeix



Project Officer

Nadia Kamel

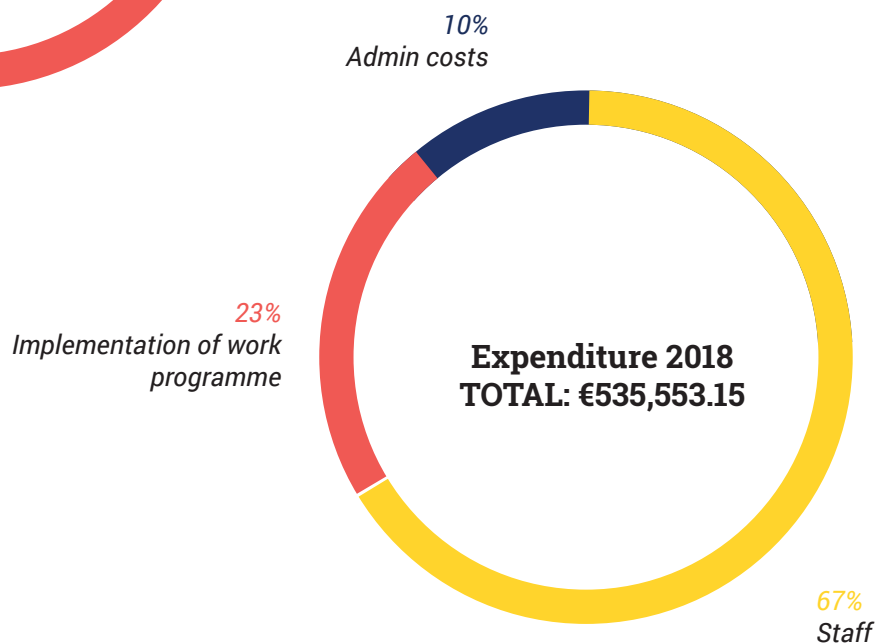
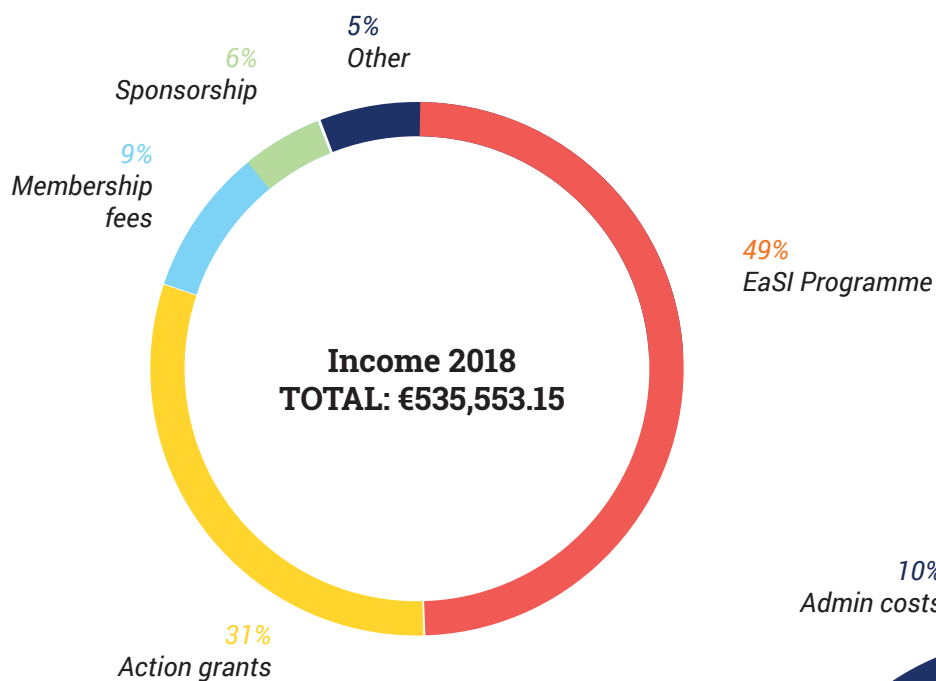


Project Officer

Francesca Centola



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 private 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 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.

Our members

Full members

European Centre for Social Welfare Policy and Research	Austria
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 (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
Cuidadores Portugal	Portugal
Anton Trstenjak Institute of gerontology and intergenerational relations	Slovenia
University of Ljubljana. Faculty of Social Sciences	Slovenia
CEAFA: Confederación Española 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
Carers Trust	UK
The Coalition of Carers in Scotland	UK
VOCAL - Voice of Carers Across Lothian	UK

Associate Members

Austrian Carers Organisation	Austria
Samana	Belgium
University of Antwerp - Centre for Longevity Research (CELLO)	Belgium
Howest, University of applied sciences	Belgium
Aidants Proches	Belgium
Aidants Proches Bruxelles	Belgium
Jeunes Aidants Proches	Belgium
Alzheimer Bulgaria	Bulgaria
DaneAge	Denmark
Athens Association of Alzheimer's Disease and Related Disorders	Greece
EPIONI	Greece
Associazione C'ENTRO	Italy
University of Bologna	Italy
RBS Center fir Altersfroen asbl	Luxembourg
The Netherlands Institute for Social Research (SCP)	Netherlands
Mezzo, Dutch Association for Carers and Voluntary Help	Netherlands
Slovenian Federation of Pensioners' Organisations (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
Maria Jesús Luzan (Cuidadores Familiares)	Spain
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Daniel Phelps	UK
Saul Becker	UK
The Open University Faculty of Health and Social Care	UK

*The European
voice for
informal carers*



www.eurocarers.org