

ANNUAL REPORT

2022

**Acknowledging the central
role played by informal carers
across Europe through the
implementation of the
EU Care Strategy**

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Foreword

Dear friends and colleagues,

Caring for someone you love is the most precious time of all. It is with this simple and yet powerful message that EC President Von der Leyen introduced the idea of an EU Care Strategy, back in September 2021. The launch of the Strategy, a year later, is the culmination of more than a decade of our network's work and impact. Its ambition is to support men and women in finding the best care and the best life balance for them. More concretely, it is a long-awaited call on all Member States to work towards the same goals on both formal and informal care.

The existence of an EU Strategy on Care can be seen as an achievement in itself. Not too long ago, care was exclusively treated as a national prerogative while the EU policy narrative regularly presented formal and informal care as two mutually exclusive forms of care. We have come a long way and it is now common for EU policy makers to emphasise the "large economic and societal value of informal care" or to refer to informal carers as the "backbone of care systems". The COVID-19 pandemic of course explains - at least in part - this change of mindset but as they say, it takes a crisis to solve a crisis...

What matters to us is that the Strategy finally acknowledges the importance of both professional and informal care, in adequate measures: While improving the provision of formal care remains the main answer to reducing pressure on informal carers, measures are needed to support those who decide to care for family members or friends. More importantly, it invites Member States to establish clear procedures to identify carers and to support them. The Strategy therefore holds great potential for the next steps of our mission and it positions our organisation as a natural observatory for its implementation.

This new milestone in the history of our movement is the direct result of our network's untiring efforts and dedication throughout the years – we are very lucky to collaborate with and learn from such a committed group of advocates and researchers. The leadership of the EC should also be applauded: formulating such a comprehensive plan is no easy feat. Finally, I also want to thank the

members of the EP Interest Group on Informal Carers for their pioneering role on behalf of carers. 2022 marked the group's 15th Anniversary and the EU Care Strategy was the perfect token of its success.

Eurocarers can now rely on a sustainable and well-defined platform on which to roll out its activities in the years to come. We are more eager than ever to inform and monitor the implementation of the EU Care Strategy across Europe, and even beyond.

Steyc Yghemonos - Executive Director



Foreword

The Eurocarers network comprise 75 NGOs and research organisations, all of whom share the common objective of advancing the cause of informal carers. Our Network is committed not only to facilitating the efforts of our members, but also to supporting the establishment of new NGOs in countries where there is little or no civil society movement focused on family care. Our goal is to strengthen our presence and influence across the entire continent, so that informal care becomes a significant factor in policy-making at the local, national and European levels.

The primary objective of Eurocarers is to improve the welfare of informal carers. We are dedicated to working with carers of all ages, regardless of the needs of the care recipients. However, we recognise that a one-size-fits-all approach is not appropriate, and that support and aid for carers must be customised to their individual needs.

Our policy work is grounded in research and facts. While there are significant challenges across all European countries when it comes to the rights and status of informal carers, there are also promising examples of legislation and support measures. Despite differences between societies and social systems, our network facilitates the sharing of knowledge and best practices among our members.

Informal carers should not be taken for granted. While it is typical for political leaders to mention them in their speeches and call upon them to solve care challenges in ageing societies, we must recognise that these carers are an essential part of our care ecosystem. As such, we must work collaboratively with informal carers to tackle the challenges they face in a fair and reasonable manner, with appropriate resources and support. We believe that informal care should be viewed as a social investment, and that it should be seen as a partnership between informal and formal care systems.

We are grateful to our members for their invaluable contributions to our network, and we are especially thankful to our Board members, who bring a wealth of expertise to our organisation. Finally, we extend our sincerest thanks to the

funders who have supported our network and made our work possible. Last but by no means least, on behalf of the Board, I would like to express our gratitude to our Executive Director and the entire Secretariat, who consistently work in an innovative and effective manner producing excellent results for our network.

Sari Tervonen - President



About us

Eurocarers is the European network representing informal carers and their organisations, irrespective of the particular age or health needs of the person for whom they care. Our network brings together 75 carers' organisations as well as relevant research & development organisations in 26 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:

EUROCARERS MEMBERSHIP

Eurocarers recognises unpaid/informal carers as equal partners in care. 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, recognised as central to the sustainability of health and long-term care systems, and supported to prevent the negative impact of caring on carers themselves. We believe that carers 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.

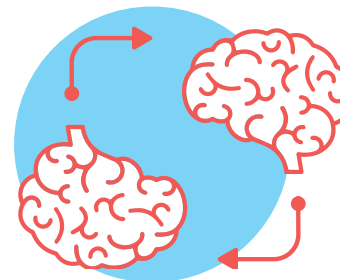
The mission of the Eurocarers network is therefore to act as a voice for informal carers by:



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;



Contributing 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



Promoting mutual learning and an exchange of good practice and innovation throughout the EU.

Policy environment

Europe's overall increase in life expectancy and ageing demographics are accompanied by a growing prevalence of chronic conditions, a growing demand for care and a severe challenge when it comes to the adequacy and sustainability of our care systems. This is exacerbated by structural problems in the long-term care (LTC) sector, as well as by the need for new skills due to new care patterns and the rise of new technologies. These challenges concern all European countries.

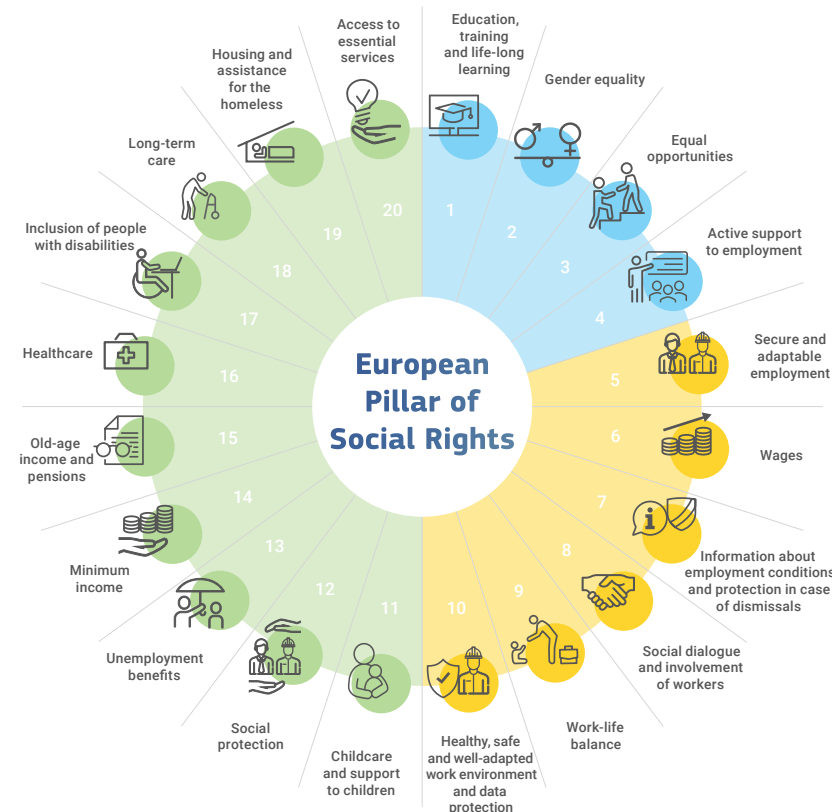
Research nevertheless shows that informal carers provide the bulk of all care in Europe today, with women providing the lion's share as daughters (in law) and wives/partners. The estimated economic value of this unpaid care is gigantic and the role played by informal carers in the provision of care in Europe therefore cannot be overstated, ignored or replaced altogether.

However, the negative impact of caregiving on carers' social and professional life is well documented: being a carer can be a determinant of negative health outcomes, a barrier to education and employment, and a driver of discrimination, social exclusion and poverty - even more so when people have limited choice in their caring roles or when no adequate support is available.

Moreover, the COVID-19 pandemic has amplified the amount and intensity of informal care provided across Europe and policy responses to the crisis (e.g. confinement measures and the reallocation of care services to patients with urgent needs) have worsened carers' isolation and deprived them from many of the tools at their disposal to maintain an acceptable social-work-care balance.

Recognition of the crucial contribution made by carers to care systems, society and the economy is on the increase at international, EU and national levels. Many recent policy developments indeed refer to carers, the impact of informal care on people's social and professional life and the importance of addressing carers' needs.

Most of the 20 principles of the **European Pillar of Social Rights (EPSR)** can be used to explore and address the many facets of informal care, for both



European society and carers themselves. The EPSR - and its Action Plan - thus offer a revitalised environment for our work and a great opportunity to promote our proposal for a comprehensive EU approach towards Care and Caring that would serve to connect the dots between existing policy initiatives of relevance to carers and identify remaining gaps. The EPSR principles on access to health and Long-Term Care and on work-life balance for parents and carers naturally remain at the core of our activities. But the principles dedicated to inclusive education, gender equality or equal opportunities are equally important to make the case for carers in Europe.

As shown in this report, Eurocarers' activities in 2022 have continued to highlight the potential added value of a coordinated EU approach towards Long-Term Care (and informal care), supported by good and comparable data on care and caring in Europe. We are proud to report that this has led to a number of positive developments at all levels of governance in the last few months.

Policy environment

At EU level, the main token of our fruitful input – and collaboration with DG EMPL - lies in the **EU Care Strategy** which reflects almost all of the elements contained in our message. The Strategy holds great potential for the next steps of our work, for various reasons.

Firstly, it recognises that professional and informal care go hand in hand and that the latter should supplement the former, not the other way round: While improving the provision of formal care remains the main answer to reducing pressure on informal carers, measures are needed to support those who decide to care for family members or friends, thus mitigating the negative consequences of care responsibilities .

Secondly, it calls on Member States to establish clear procedures to identify informal carers and to support them, including via training, counselling, health-care, psychological support, respite care and adequate financial support.

Thirdly, it urges Member States to foster better collaboration between care professionals and informal carers, thereby supporting the shift towards community-based care and the recognition of informal carers as equal partners in care.

While a potential game changer for our movement, the EU Care Strategy is only the last addition to the long list of EU policy initiatives informed by our activities in the last few years: the Green paper on ageing, the Work-Life Balance directive, the Social Protection Committee's Long-Term Care report 2021, the Ageing Report, the EU Gender Equality Strategy and the EU Beating Cancer Plan all call for a better recognition and support of informal carers.

Care and caring have also gained prominence in the context of economic governance. Long-Term Care continues to appear in Country Reports and Country-Specific Recommendations, as part of the European Semester even though the transposition of ambitions has yet to materialise in Recovery and Resilience plans.

At international level, WHO Europe, the United Nations Economic Commission for Europe (UNECE) and the OECD have also increased their attention to long-term care and informal care over the last few months. There again, we were able to develop constructive and long-lasting collaborations and inform developments. This demonstrates the usefulness of our work in the context of global and cross-government coordination efforts. It also shows that our message allows to frame EU initiatives in the context of international ambitions, such as the achievement of SDGs (in particular goal 5.4).

Finally, our message has also informed national/regional developments across EU Member States and neighbouring countries, such as Belgium, Germany, Ireland, Italy, Slovenia, Spain, Sweden, UK, etc.

This favourable policy backdrop should not be taken for granted as a lot remains to be done to harmoniously implement the principles of the Pillar and our vision of a care(r)-friendly society.



Eurocarers' instruments for Policy change

The mission of our secretariat is to lead and support evidence-based dialogues aiming 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 societies. Our positioning as a respected source of information regarding care and caring in Europe has allowed us to play a part in relevant policy debates with the EU institutions and a broad variety of stakeholders (WHO, OECD, Civil Society Organisations, private sector); as well as through a series of advocacy activities and tools, which – in 2022 - included 2 new Policy briefings as well as 7 position papers and Consultation responses (see details below).

The development of a care(r)-friendly policy environment largely depends on the relationship between a broad set of policies and practices in the social, health and employment sectors (among others). It is therefore important for Eurocarers to organise and take part in outreach events, policy dialogues, scientific conferences, exhibitions, etc. at EU and national level. These **networking activities** allow us to build synergies, foster cross-sectoral cooperation and convey our message on the opportunities and challenges offered by EU (and national) policy instruments to a large audience. In 2022, Eurocarers played an active role in more than 100 events focusing on our 'natural' entry points in the policy agenda (e.g. EU Semester/Recovery and Resilience Facility, EU Pillar of Social Rights, SPC, etc.) as well as on (mental) health, disability, youth, gender equality, ICT and equal opportunities. As always, this gave us a chance to reinforce our sphere of influence, connect the dots and contribute to a "care in all policies" approach.

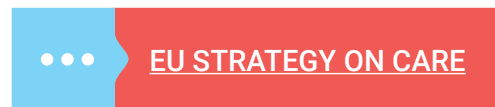
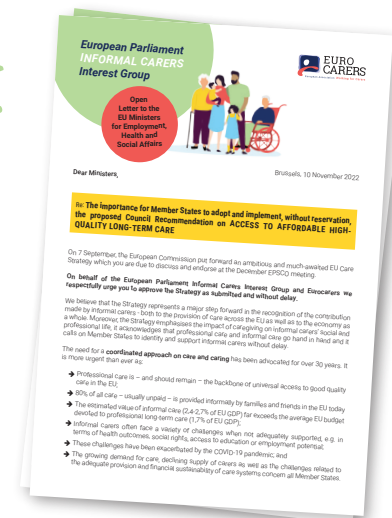
Two **Policy Briefings** were developed by our network in 2022:

THE EU STRATEGY ON CARE - A NEW PARADIGM FOR CARERS ACROSS EUROPE?

March 2022

The declared ambition of the long-awaited EU Care Strategy is to address both carers and care recipients, from childcare to long-term care, and to guarantee access to good-quality and sustainable care services for all throughout the life course by setting a framework for policy reforms. Importantly for our network, the Strategy covers the provision of both formal and informal care in Europe and is an integral part of the European Pillar of Social Rights' implementation plan.

Against this backdrop, our first briefing of the year aimed to underline the reasons why Eurocarers welcomes the EC approach, which reflects the vision that we have been advocating for the last 15 years: care is a multifaceted sector that should be rooted in human rights, choice and dignity for both care users and their informal carers. Good quality care cannot be achieved without considering care recipients and their carers as equal partners in care. As for integrated care, it does call for a comprehensive delivery of quality care services across the life-course, designed to prevent, manage and overcome risks in accordance with the multi-dimensional needs of the population/individual and delivered by a coordinated multidisciplinary team of providers working across settings and levels of care.



Eurocarers' instruments for Policy change

EUROCARERS' ASSESSMENT OF THE EU SEMESTER PACKAGE

December 2022

Our second briefing presented the results of our annual analysis of the EU Semester package. As usual, our objective was to support carers and research organisations as they use EU instruments to inform relevant policy developments in their respective countries. While considering the objectives of the European Care Strategy, our briefing aimed to offer guidance on how to navigate the seemingly-complex process of the EU Semester, provide pointers for improvement as well as advice on how to get involved in the coordination process.



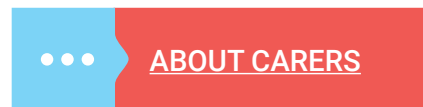
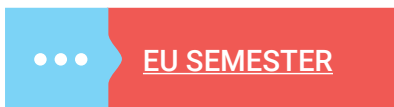
NUMBER OF CARERS AND EXISTING MEASURES

Our package of monitoring documents on carer-friendly policy environments across the EU was updated based on our continuous desk research, research projects and networking activities. The package – which includes an **Overview Table on the Number of carers and existing support measures across the EU** as well as **28 Country Profiles** - allows our community as well as all interested stakeholders to keep track of recent advances made at international, national and regional level with regard to our overall mission.

EURO CARERS	OFFICIAL NUMBER		UNOFFICIAL NUMBER		1 - Legal recognition of carers	2 - Identification	3 - Needs Assessment	SUPPORT TO CARE			9 - SOCIAL INCLUSION / PROTECTION		
	Number of carers	% of population with caring responsibilities	Number of carers	% of population with caring responsibilities				5 - Access to information	7 - Respite care	8 - Training	Financial compensation (direct or indirect)	Carers' leave	Pension credits
AT	700.083	8,10%	1.519.940	17,00%	✓	✘	✘	✘	✓	✓	✓	✓	✓
BE	1.307.320	11,60%	2.597.515	22,50%	✓	✓	✘	✘	✓	✓	✓	✓	✓
BG	437.858	6,10%	2.070.622	29,90%	✘	✘	✘	✘	✘	✘	✘	✘	✘
CH	600.000	7,00%	1.047.168	10,80%	✘	✘	✘	✘	✘	✘	✘	✘	✘

Besides its role as an advocacy and awareness-raising tool, the package also serves to guide and support our activities around the objectives of the Europe 2020 Strategy, the principles of the European Pillar of Social Rights and the EU Care. The country profiles also feed into the work of our member organisations at national and regional level, the narrative developed around our European Carers Day campaign and the discussions held during our capacity-building and coordination activities.

The table and country profiles are accessible via our website



Eurocarers' instruments for Policy change

POSITION PAPERS & CONSULTATION RESPONSES

In 2022, Eurocarers also (co-)developed and disseminated seven new **position papers and consultation responses** in order to inform international and national policy developments, including:

- **Joint recommendations for the European Care Strategy regarding migrant care providers and service users, developed in collaboration with colleagues from 16 organisations** (March 2022);
- Our response to the **EU open consultation on Minimum Income** (April 2022);
- Our response to the European Health Parliament HP7 **Policy Recommendations on the Wellbeing of Healthcare Workers “Recover, Reinvest, Reinvent: Creating a resilient European Health Union”** (May 2022);
- The **“Caregiving impacts on informal carers’ health and well-being – a gender perspective”** paper, developed with WHO Europe (June 2022);
- The **joint statement on the European Care Strategy**, published with the European Federation of Public Service Unions (September 2022);
- Our explainer on the links between **‘Informal care, poverty and social exclusion’** (October 2022); and
- Our new paper on **“The human rights dimension of informal care - towards a positive EU obligation to support informal carers?”** (December 2022).

EUROPEAN PARLIAMENT'S INTEREST GROUP ON INFORMAL CARERS

The **European Parliament's Interest Group on Informal Carers** is one of Eurocarers' main instruments to contribute to policy change at EU and national level. The role of the Interest Group is indeed 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 28 MEPs interested in care and caring from 11 countries and 5 EU political groups (S&D, EPP, Renew, GUE/NGL and the Greens). Two meetings of the Interest Group were convened in 2022.

The first meeting took place on the 20th April and focused on the topic: **“Informal Care and Corporate Social responsibility – a natural fit”**. The event allowed to:

- Make the business case for employers paying attention to carers, which is important considering that many of the entitlements listed in the WLB Directive are to be provided by employers on an ad hoc and voluntary basis;
- Explore the potential of the concept and practice of Corporate Social Responsibility and what companies can do to support and enable carers to care;
- Be informed of practical examples of carers and CSR; and
- Reflect on the implementation of the Work/life balance Directive across EU Member States, based on Eurocarers analysis of its strengths and shortcomings.

Eurocarers' instruments for Policy change

The second meeting of the EP Interest Group took place on the 12th October, on the topic **“An EU Care Strategy – looking ahead at its merits for carers”**. The meeting served to highlight the wide acknowledgement of the Strategy as a positive EU initiative to foster and inform future developments at national/regional level. More importantly, it also gave an opportunity to reflect on the elements required to support its successful implementation, with contributions from various current and former MEPs, Ms. Katarina Ivankovic Knezevic, Director of the Social Rights and Inclusion Directorate at DG EMPL, as well as civil society representatives from across Europe.

Following this second meeting, an Open Letter was sent to urge the EU Ministers for Employment, Health and Social Affairs to adopt the EC proposal on a Council Recommendation as submitted and without delay.

Building on the conclusions of both working groups' discussions in previous years and given the need to align priorities in order to maximise impact, the annual face-to-face meetings of our **Policy and Research Working Groups** were held jointly in Ljubljana, Slovenia, on the 8-9 September 2022. The meeting was used to hold a dialogue with Eurocarers' member organisations on ways to efficiently support the design and implementation of the (then upcoming) EU Care Strategy while providing the evidence base required to convince decision makers to adopt a holistic approach in their support of carers.

More specifically, the meeting was structured around sessions on:

- The core elements of the **EU Care Strategy**;
- The **definition of monitoring indicators** to accompany the implementation of EU/national care(r) strategies, based on the example of the national Swedish Carer Strategy;
- A **Policy 'tour de table'** which focused on the Finnish Family Caregiver Act, Social policies and measures targeted at carers in France, the Norwegian Informal care strategy and surveys, the international congress on informal carers in Tenerife, Spain, the Irish Nursing Home support Scheme Act and the outcomes of the UNECE Ministerial Conference on the Madrid Plan of Action on Ageing (MIPAA); and
- A **Research 'Tour de table'**, which shed light on the DETCAREMIX study and Informal care in Slovenia (Ljubljana University), Morbidity among Finnish family caregivers (Folkhälsan Research Centre), the potential of virtual reality in care (Pro Aidants Switzerland), Good practices in support of dementia carers (Greek association of Alzheimer Disease), the Kaleidoscope project to Guide Family Carers Back to Employment (Care Alliance Ireland), and the British Centre for Care (Centre for International Research on Care, Labour and Equalities, Sheffield University).



RESEARCH AND POLICY WORKING GROUPS

Eurocarers' instruments for Policy change

At the occasion of this joint meeting of our working groups, our local member organisation (Anton Trstenjak Institute) organised a press conference involving representatives of our Secretariat and network in order to discuss the launch and added value of the EU Care Strategy, the strengths and limitations of the Slovenian LTC Act (December 2021) and the enduring weaknesses of Slovenia's care system. The press conference brought together representatives of the national press agency (STA - Slovenian press agency), Delo (the most-read newspaper in the country), Večer (online and printed) and Nova24.

Nothing about young carers without young carers! This was the main ambition behind the creation of the Eurocarers Young Carers Working Group (EYCWG), in May 2017. By then, young carers had remained in the blind spot of policy makers for way too long and it was high time to give them the attention and respect they so rightly deserve. With this in mind, the aim of the working group is to combine efforts and resources, to make young carers' voices heard and to infuse policies and practices with an impact on their daily life with their first-hand experience. As it stands, the group benefits from the involvement of more than 30 young carers, young adult carers or former young carers from 11 countries.

The 6th annual meeting of our Young Carers Working Group took place in the margins of our AGM 2022 in Porto, Portugal, on the 2nd June. The main objectives of our meeting were to:

- ➔ Take stock of the policy environment of interest to young carers, in particular following the International Young Carers Conference held in 2021;
- ➔ Discuss the expected impact of recent policy developments, including the EU Care Strategy;

- ➔ Hear the perspective of young carers as regards the activities planned in the context of European Carers Day 2022; and
- ➔ Brainstorm on the next steps of the group's collective journey, aspirations and goals.



Capacity Building

KNOWLEDGE-SHARING SEMINARS

Our “knowledge-sharing seminars” serve to generate an exchange of views and good practices among our members and partners in the areas of policy, research and communication. The themes of these events directly proceed from our members’ interest and needs and is therefore selected by our network. They usually relate to existing EU priorities and decision-making mechanisms, such as the EU Semester process, the EU Pillar of Social Rights or any other tool potentially useful to help our members in their own advocacy work at national and local level. Our seminars (or webinars) traditionally take place in the margins of our Annual General Meeting. The co-operative implementation of the EU Social Pillar and our proposed European Strategy on Carers; measures to facilitate the transposition of the Strategy at national and regional level; our collective activities to document the needs and situation of carers across Europe as well as our work to monitor the transposition of the Work-Life Balance Directive (among others) all form part of these discussions.

In 2022, our knowledge-sharing seminars explored:

- Our **European Carers Day campaign 2022**, on the theme of ‘Equality and fairness in informal care’. The campaign gave an opportunity to call for a better (re)distribution of caregiving responsibilities between individuals and the state as well as between women and men;
- A **selection of good practices and activities targeted at young carers** including the Me-We and Together projects as well as the ‘Jovens Cuidadores’ project by Cuidadores Portugal and Vila Nova de Gaia;



- Ongoing **policy developments** of relevance to our mission (and remaining stumbling blocks) from across Europe.

Capacity Building

NATIONAL AND REGIONAL DEVELOPMENTS

While the competence for the design and implementation of policies with an impact on the daily life of informal carers mainly lies at national level, it is very clear that an EU-level coordination process greatly helps to foster an exchange of information and good practices, encourage collaborations, monitor progress and complement national efforts. The idea is of course not to put the exact same support measures in place across the continent but to encourage all European countries to work towards the same objectives on both formal and informal care.

We are glad to report that the visibility and understanding of caregiving continue to improve in a growing number of countries and our network's support to national efforts, our contribution to national or regional policy dialogues and our awareness-raising activities are seen as contributing factors by relevant stakeholders. Considering the recent and long-awaited launch of an EU Strategy on Care, an important milestone for our movement, the Eurocarers network will only redouble its efforts to inform and report on existing and future developments across the continent.

In-country policy dialogues regarding the situation and needs of carers



Every year, our programme of activities includes national/regional policy dialogues that seek to facilitate the transposition of our ambitions – as well as the now well-defined EU objectives - in the areas of care and caring. These events are organised in close collaboration with our local member organisations and they aim to trigger a dialogue with the policy-makers, academics and civil society organisations that shape the portfolio of policies and support measures targeted at informal/unpaid carers. In this context, the EU tools and instruments at our disposal (e.g. EU Pillar of Social Rights, EU Semester/Recovery and

Resilience Facility, EU Care Strategy, etc.) are used to create win-win outcomes for all stakeholders (and carers in particular) .


Our policy dialogues aim to:


1. Raise awareness on the situation and needs of carers and contribute to the development of new national/regional initiatives on care and caring, in accordance with the 10 steps of our proposed EU Strategy on carers, and
2. Contribute to better synergies between EU objectives (in particular, the principles of the European Pillar of Social Rights and the European Semester) and national/regional policy agendas around integrated and multidimensional approaches to care and caring.


In 2022, Eurocarers co-organised/contributed to five in-country events, including:

-  The conference **“How can local authorities support informal carers?”** (Comment les pouvoirs locaux peuvent soutenir les aidants proches?), organised with Aidants Proches Belgique and held in Brussels on the 4th October 2022.
-  Since 2020, Aidants Proches Belgique – a member of our network - has been collaborating with several of the 19 Brussels ‘communes’ on the **development and provision of support measures targeted at informal carers** by local administrations and territories. These efforts form part of the ‘Bruxelles Région Aidante’ initiative, which seeks to strengthen the care sector in Brussels. This conference, held against the backdrop of European Carers Day and the Belgian Carers Week, shed light on the existing rights of carers in Belgium and the carer-friendly practices put in place in three specific communes in Brussels (i.e. Uccle, Woluwé Saint Lambert and Woluwé Saint Pierre). The event also gave a chance to assess these measures in dialogue with local officials.

Capacity Building

 **“Gender, equality and care – care should be shared and fair”**, was the theme of a hybrid conference, held in/from Sweden on the 6th October 2022, which is both Swedish and European Carers Day. The event was co-organised with the Swedish Family Care Competence Centre (Nka) and focused on the unequal gender distribution of caregiving responsibilities. It was moderated by the journalist, writer, and television host Mark Leven-good and allowed to discuss the root causes (and potential solutions) to the unequal distribution of caregiving responsibilities between women and men, based on a new study and data from Nka and Linnaeus University’s population study from 2018.

 The policy dialogue **“Carers and depression”**, organised with EPIONI in a hybrid format from Athens – Greece on the 7th October 2022 focused on the mental health of informal carers and, in particular, on the prevalence and impact of depression resulting from the provision of informal care. The event was held in association with mental health organisations from Greece and was structured as a knowledge-sharing session targeted at policy makers and professionals who provide answers to the many issues of interest to informal carers. The conference was organised under the auspices of the Office of the European Parliament in Greece, the Region of Attica, the Municipality of Vari-Voula-Vouliagmeni and the Hellenic Psychiatric Association.

 The **first international Congress on Care** (Primer Congreso Internacional sobre Cuidados), organised by the local association of carers ACUFADE, was held at the University of La Laguna in Tenerife, Spain on the 3-5 November 2022. The event brought together 1500 professionals and practitioners of the care sector from various countries, a real prowess that confirms the growing interest in the topic and demonstrates the fruitful international teamwork around the Congress. The event provided a nice space to build international bridges on the topic of the future care and caring. The initiative was inspired by the collaboration initiated by ACUFADE and Eurocarers (as observer) with the Vice-Ministry for Equality and Diversity of the

Government of the Canary Islands, in the context of the implementation of the Spanish government’s Co-responsibility Plan (Plan Corresponsables). The Plan is a new public policy under the Ministry of Equality’s Secretary of State for Equality and against Gender Violence, which aims to initiate the path towards guaranteeing care as a right in Spain from the perspective of equality between women and men.

 The **“Informal carers in times of crisis”** policy dialogue was organised by our colleagues at Carers Sweden on the 9-10 November, as part of the 2022 edition of Sweden’s Carers days. The event, held online and broadcast from Varberg, focused on “informal carers in times of crisis”, a theme that can be interpreted in several ways. The discussion was moderated by the journalist and presenter Lisa Syrén who has been an ambassador for Carers Sweden since 2021. The event not only alluded to the pandemic but also served to discuss the impact of the war in Ukraine on our economy. This, in turn, also affects relatives, who may already be struggling financially as a result of their caregiving responsibilities. In this context, the recent launch of the national Swedish Carers’ Strategy, a by-product of the EU Care Strategy, was presented as a great success both for the European carers’ movement and for all carers in Sweden.

Communication

basis. The theme selected for this third European Carers Day campaign, was “(Gender) Equality and fairness in caregiving”.



Our network’s choice for this year’s topic was driven by various reasons:

- The much-needed discussion around gender inequalities is intrinsically linked to questions that concern the future of care and caring in Europe. A majority of informal carers (59%) across the EU are women, more than 80% of long-term care professionals are women and women are also more prone to experiencing long-term limitations in their activities due to health problems;
- Not only do women outnumber men in the care sector, care is also provided in gendered ways. First of all, women provide more hours of care/week than men (17 hours/week for women, compared to 14 hours for men). Secondly, women provide more demanding and intensive forms of daily caring than men, such as bathing and dressing, continence care and walking, and with relatively complex tasks including dressing changes, assistance with medical equipment and the administration of multiple prescription medication. Men’s contribution, on the other hand, is much more likely to be concentrated in care management or household maintenance, shopping or transportation;
- The institutional framework around our labour market and social protection system contributes to the longevity of the traditional/archaic “male breadwinner/female carer” model, according to which men are engaged in productive work and are the main earner in the family while women are confined to domestic and generally undervalued tasks, especially caregiving. In our modern welfare states, the needs and rights related to caregiving activities have been shaped accordingly, therefore perpetuating a form of gendered citizenship which needs to be challenged;
- Finally, more could be done to encourage men to take on caregiving responsibilities, by promoting a positive image of care and care provided by male carers.

Communication

As always, the Eurocarers Secretariat developed a communication toolkit in consultation with our member organisations, for circulation and use by our network and partners. The toolkit consisted in posters, social media posts, visuals, statements, etc. available in 10 languages. Besides the wide dissemination of our PR material, ECD 2022 was also celebrated by many of our sister organisations and partners (including various MEPs, the EPP Group, Heather Humphreys – the Irish Minister for Rural and Community Development and for Social Protection, Eurofound, Carers Worldwide, AGE Platform Europe, Inclusion Europe, the European Brain Council, the Women’s Brain project, Digestive Cancers Europe, VdK – the Social Welfare Association in Germany, the World Bladder Cancer Coalition, the Parliament Magazine, Merck Healthcare, Northern Ireland’s Disability and Carers Group, SIOPE Europe, and more).

As in previous years, Eurocarers has also contributed to various podcasts regarding care and caring in Europe. In 2022, these included:

- [A podcast episode providing the “European Perspective on Working Carers”](#), recorded in the framework of the Carewell research project carried out by University College Dublin in partnership with our member organisation ‘Family Carers Ireland’; and
- [A podcast episode on “the European Care Strategy”](#) as part of the CARE MATTERS series produced by the Centre for Care to discuss crucial issues in social care and to provide accessible evidence on care to inform changes.

The redistribution of care responsibilities is crucial to achieve gender equality



In ganz Europa werden bis zu 80 % der Care-Arbeit von betreuenden Angehörigen erbracht



Our Research Work

RESEARCH WORKING GROUP

The mission of the Eurocarers Research Working Group is to inform evidence-based practice and contribute to the wider EU-level research agenda in the areas of care, carers and caring. In 2022, the aim of the Group's meeting (held on the 8-9 September in Ljubljana, Slovenia) was to exchange on members' ongoing research work and future priorities, as well as on the evidence base (data and good practices) required to support the successful implementation of the EU Care Strategy across Member States.

When it comes to our **contribution to research projects in 2022**, it includes:

Prevalence of informal care in Europe

In 2022, Eurocarers coordinated the development and implementation of the EIGE Survey of Gender Gaps in Unpaid Care, Individual and Social Activities (EIGE/2021/OPER/10). The objective of this survey was to collect data from all EU Member States to understand different uses of time in such activities by women and men aged 16+ in their diversity as well as the factors that hinder or help their participation. Moreover, the study aimed to inform possible policy responses based on our data collection and analysis.

The survey was conducted over the summer 2022 and a total of more than 60,000 respondents were interviewed. It produced the following results regarding the prevalence of informal care:

Around 20% of respondents reported being involved in the provision of informal long-term care, with minimal gender differences at EU-level (with exceptions in BG, EE, HR, LT, LV, RO, SK). Approximately 60% of carers reported providing informal care at least 4 days a week. On average, 29% of female and male carers in the EU reported providing more than 22 hours of informal long-term care per week. Interestingly, male carers reported a more time-intensive provision of care in a majority of countries (16).

When it comes to the reliance on external support, male carers were much more likely than female carers to receive additional unpaid help when providing informal long-term care. Across nearly all countries, female carers were more likely to be the sole informal carer.

On average, about 20% of carers reported that the person for whom they provided care had unmet needs. Unaffordability, long-waiting lists and failure to meet eligibility criteria were among the most commonly-reported reasons for these unmet care needs.

This study nicely complemented our core mission and proved particularly informative for our advocacy activities around the EU Care Strategy and the update of our above-mentioned monitoring tools. As stated in the EU Care Strategy itself, it is expected that the survey will serve to collect data regularly, develop indicators and carry out analyses on the gender care gap, the gender pay gap, and the use of time in paid and unpaid work, individual and social activities by women and men with care responsibilities and on work arrangements throughout their working life.

Our Research Work

YOUNG CARERS

The Erasmus+ **TOGETHER project** (2020-2022) aimed to support social inclusion and engagement of young carers in Germany, Italy, Greece and UK by helping young carers and professionals to adopt a



whole family approach, where members of the household (including the care recipient) are encouraged to communicate openly about the illness and caring; the condition of the care recipient is explained clearly to the younger family members; and professionals are equipped to provide adults and children with the tools to set, plan for, and achieve their goals together.

The project officially came to an end in March 2022 and the following results are freely available in four languages on the project website:

- The **Together Database**, containing national and international resources on the topic of young carers;
- A set of ad hoc **resources addressed to young carers**, family members and practitioners to promote identification and communication;
- The **Together workshop model for young carers** and family members on emotions, needs and communication about the impact of caring responsibilities;
- The **Together e-learning programme**, both online and printable, for practitioners to increase their knowledge on the topic, guide them in the use of resources and in the implementation and evaluation based on the Together whole family model.

CARERS AS PARTNERS IN CARE

The effective design and delivery of care involve integrating care services and supporting activities to ensure that users receive a continuum of preventive, curative, rehabilitative and support interventions throughout their lives, based on their actual needs. These interventions should be applied seamlessly across different levels and areas of health and social systems. Informal carers play a vital role in planning, shaping and delivering services to people with care needs, as well as in supporting themselves. When care professionals treat informal carers as equal partners in care delivery, they help people with long-term care needs stay at home and in their communities safely, independently, and with dignity for a longer time. Eurocarers is therefore involved in multiple projects aimed at informing the design and implementation of integrated care.



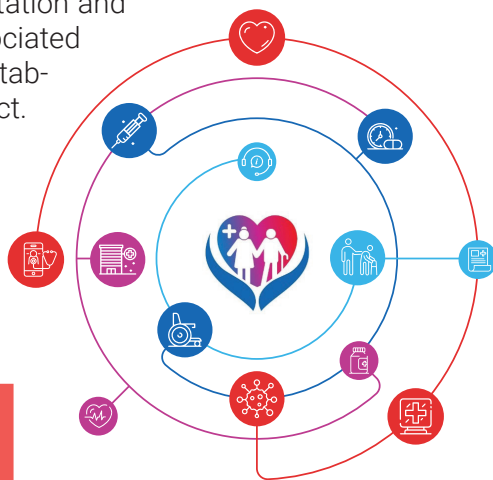
TOGETHER PROJECT

Our Research Work

ESCAPE (Evaluation of an integrated patient-centred biopsychosocial and behavioral collaborative CARE Pathway for the management of multi-morbid aged patients) is a 5 year-long project funded through the Horizon 2020 programme. ESCAPE builds on a combination of Wagner's chronic care concept and the collaborative care tradition in a model of blended collaborative care (BCC), using proactive communication with patients and health care providers in order to simultaneously support patients and care providers in a sustainable effort to tackle multiple physical and mental health problems. The project aims to extend the BCC framework for addressing the multiple medical and psychosocial needs of elderly multimorbid patients and their formal and informal carers in order to improve their QoL and medical disease outcomes.



In 2022, a range of tools and resources were developed in order to ensure the project's visibility. The consortium's dissemination activities resulted in the publication of 18 articles in magazines and newspapers as well as in the presentation of the project at five international academic conferences. ESCAPE's Knowledge Management methodology, which aims to ensure the long-term exploitation of the project outputs, was defined and the first round of knowledge outputs was collected. The Exploitation and IPR Management Committee and associated Publication Sub-Committee were established to support ESCAPE's overall impact.



SOUND is an Erasmus+ funded project which aims to develop a training curriculum of active and passive music-making activities targeted at social and healthcare professionals and informal carers involved in dementia care. The project also aims to produce an original music-based nonpharmacological intervention to improve the behaviour, mood and quality of life of older people with dementia and delay further cognitive decline for as long as possible.



The SOUND educational programme will seek to address different needs:

- ➔ Those of dementia care professionals, who look for more effective methods and techniques for dealing with dementia patients,
- ➔ Those of informal carers, who need to keep on training and acquiring new competences for better managing their loved ones in everyday life, and
- ➔ Those of older people with dementia who must be listened and understood, should be able to communicate through a universal language, need to maintain their residual cognitive capabilities and seek to improve their quality of life.

SOUND's target audience includes

1. **Partner organisations:** Management structures, Professors and teachers, Students' community, Associated members and Communication departments;
2. **External stakeholders:** care professionals, informal carers, People living with dementia, other relevant professionals (musicians and artists) willing to hear/learn about the intervention, field experts or practitioners, decision-makers at local, regional, national and European level, press and media, and the general public.



Our Research Work

InCare - Supporting INclusive development of community-based long-term CARE services through multi-stakeholder participatory approaches InCARE aims to promote participatory, innovative and integrated approaches to long-term care policy and service development by focusing on aspects that are instrumental for system sustainability and innovation capacity: multi-stakeholder cooperation, evidence-based decision-making, capacity building and skills transfer. The project focuses on the development of a coherent and coordinated approach to the development of national care policies and services, with a focus on empowering local stakeholders, communities, care users and their families to contribute to and shape the development of LTC services.



InCare builds on the idea that social innovation in LTC should reflect the aspirations and needs of older people with functional or cognitive impairment and their carers, while emphasizing the role of local communities and service providers to shape care service delivery in innovative ways, facilitated by national policy-level support for adapting, adopting and enhancing these initiatives.

The activities of the InCare project are implemented in close collaboration with care users, care providers and policy-makers in Spain, Austria and North Macedonia. In that context, the survey on attitudes, experiences and expectations on long-term care, carried out between September 2021 and February 2022, has already contributed to the evidence-base required to design a coordinated approach towards long-term care policy and services rooted in social innovation and participatory decision-making processes. The survey was modelled after the Special Eurobarometer 283/ Wave 67.3 conducted in 2007 and it is the first data collection effort attempting to evaluate how the views of Europeans on long-term care are evolving over time. The InCARE survey allowed to collect 2,373 responses from 26 EU countries, thereby gathering quantitative and qualitative data. While this remains a modest sample in terms of size and representativeness compared with the above-mentioned Eurobarometer (28,000 responses), it does shed light on significant changes in the attitudes, expectations and experience of Europeans concerning LTC, with an overwhelming support for an increased role of the

State in the organisation, provision and financing of LTC as well as a demand to see the burden of care shifted away from families and individuals.

Considering this, Eurocarers conducted an additional study in order to disaggregate and cross-reference the data at our disposal, explore the below research questions and formulate policy recommendations. Our research questions focused on:

- ➔ Getting to know informal carers better: What are the profiles of people providing regular care to a next of kin in Europe? Can specific informal care contexts be defined as riskier for informal carers and the person they are caring for?
- ➔ Impact of the caregiving experience on attitudes and expectations regarding LTC: According to the survey outcomes, women tend to have a marked preference for formal care. Does this reflect gender differences in attitudes towards LTC generally or is this related to the fact that women - having experienced informal care more frequently and intensely than men - see the challenges attached to it more clearly? What is the relationship between being a (former) informal carer and attitudes and expectations about (long term) care?
- ➔ Access to services: Adequate support to carers entails access to affordable and qualitative formal care services, likely to ease the burden if adequately combined with informal care. Our dataset provides a snapshot of Europeans' perception of care accessibility, affordability and quality. At a time when the carers' movement deplores the dismantling of various support services following the COVID-19 crisis, what is the state of play of informal carers' access to essential services?

The results of our small-scale study give good insights into carers' experience regarding access, affordability, and quality of care services. [These can be accessed here.](#)



Our Research Work

Giving Care – Empowering (In)formal care-givers by developing technical, soft and digital skills



The main objective of the Giving Care project is to empower formal & informal carers as well as personal assistants & other health professionals by supporting their technical, soft & digital skills in order to respond to the gap in the Higher Education Institutions (HEIs) provision. This takes place via the design and implementation of an innovative Continuous Education Programme (CEP) and related materials/resources, based on independent modules. Giving Care seeks to offer a Guide for Personal Carers & Assistants as well as health professionals to enhance their professional development and their daily activities (e.g. Good Practices for Caring; How to take care of who cares; and selection of storytelling videos based on real cases with visual examples of care practices). Moreover, the project also aims to develop and promote a professional occupational profile for personal carers and assistants fostering their social & professional recognition, and providing them with the support & tools they need to take care of themselves & others.



Stay Safe - Preventing and responding to sexual violence against women with disabilities



The Stay Safe project aims to raise awareness and educate women with disabilities on how to respond to sexual harassment (both online and offline) and violent incidents, developing a training model which will apply the gender-based behavioural approach and will be based on creative drama techniques and gaming elements. Moreover, applying creative drama methodologies, it intends to train professionals working in the disability field on how to recognize the risks of sexual harassment to which women with mental disabilities are exposed to and how to support them.

The project, which concluded in 2021, carried out an analysis of the different forms of sexual harassment and sexual violence against women with disabilities that exist in participating countries (Italy, Greece, Spain, Portugal and Lithuania). Moreover, it produced a training manual targeted at social, health and GBV professionals and seeking to help them recognise and contrast sexual violence against women with disabilities; an online course for professionals working with women with psycho-social disabilities; a training programme for women with psycho-social disabilities; as well as various awareness-raising resources.



WOMEN WITH PSYCHO-SOCIAL DISABILITIES HAVE THE HIGHEST RISK TO BE VICTIM OF VIOLENCE



WOMEN WITH DISABILITIES ARE LESS LIKELY TO DISCLOSE VIOLENCE OR SEEK HELP



WOMEN WITH DISABILITIES ARE OFTEN UNAWARE THEY ARE BEING ABUSED



GIVING CARE PROJECT



STAY SAFE PROJECT

Our Research Work

LONG-TERM CARE

To establish carer-friendly societies and promote work-life balance for those with caregiving responsibilities, it is crucial to prevent frailty and dependency while ensuring that professional long-term care services are universally available and of high quality. These elements are essential in reducing the reliance on informal care and enabling carers to balance their caregiving responsibilities with a fulfilling social and professional life. Priority should be given to investing in prevention and care services.

As part of this effort, Eurocarers is also engaged in projects that investigate care models that account for the needs and preferences of informal carers, both as co-providers of care and as secondary users.



The **Centre for Care** is a collaboration between the Universities of Sheffield, Birmingham, Kent and Oxford, the London School of Hygiene & Tropical Medicine, the Office for National Statistics, and three leading charities: Carers UK, the National Children's Bureau and the Social Care Institute for Excellence. The Centre was awarded Economic and Social Research Council (ESRC) funding in 2021 to explore and collect evidence in the following research areas:

- ➔ Care as a Complex, Adaptive Ecosystem;
- ➔ Digital Care: roles, risks, realities and rewards;
- ➔ Care Data Infrastructure;
- ➔ Care Trajectories and Constraints;
- ➔ Inequalities in Care; and
- ➔ Care Workforce Change.

The Centre can rely on a long list of organisations in the care sector, people with direct experience of care as well as international academic partners in order to co-produce research on care and caring. Eurocarers is a member of the Centre's international Advisory Board.



Our Research Work

EOLinPLACE (2022-2027):

Respecting people's preferences regarding the place of death is important. To do this, the first step is to classify dying places (home, hospital, among others) in a way that is meaningful for individuals. In this context, the EU-funded EOLinPLACE project (Choice of where we die: a classification reform to discern diversity in individual end of life pathways) seeks to create a solid base for the first international classification tool to map preferred vs. actual places of death. The project will conduct a mixed-methods study in four countries covering existing target variation to explore nuances and commonalities in people's end of life pathways. The findings will provide new insights into how to care for the dying.

EOLINPLACE



EOLINPLACE

Who's who

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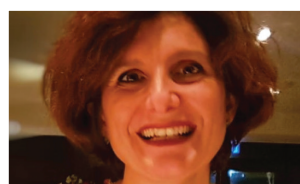
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Riika Lempiäinen



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Policy Officer

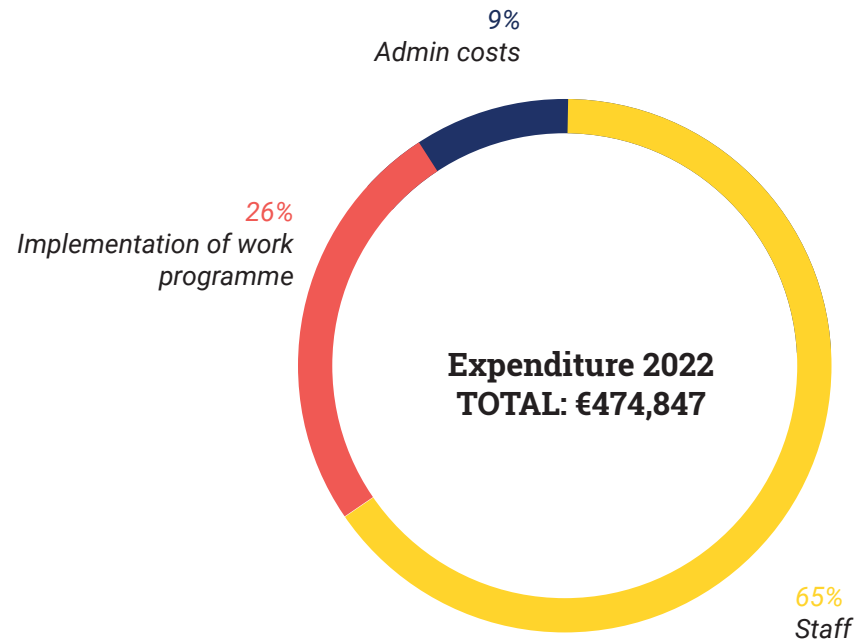
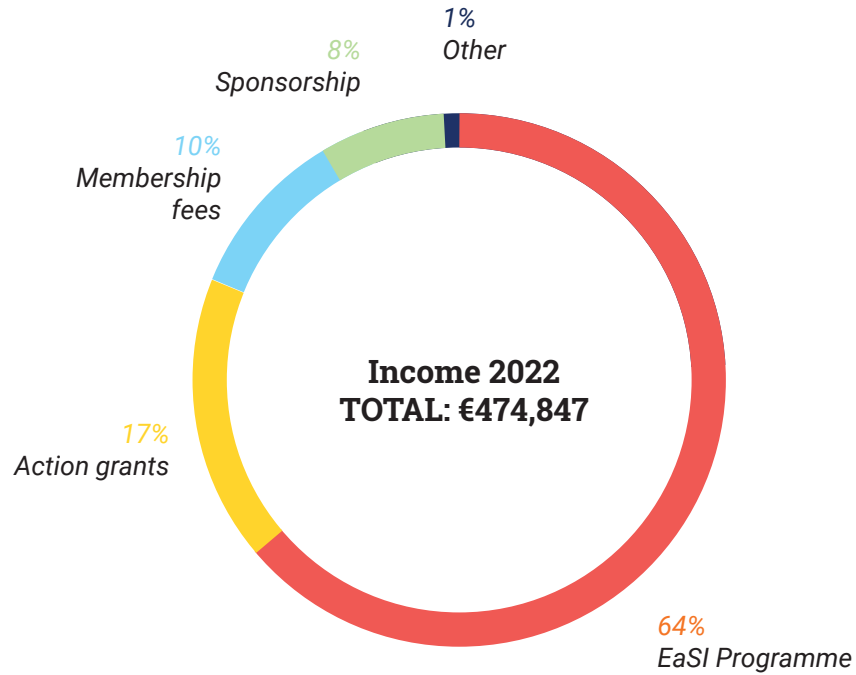
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Project Officer

Svetlana Atanasova

How we are funded



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University College Ghent, Department of Education, Health care and Social work	Belgium	ANCI - Associação Nacional de Cuidadores Informais	Portugal
Diaconia of the Evangelical Church of Czech Brethren	Czech Republic	Cuidadores Portugal	Portugal
Carers Denmark	Denmark	DGASPC-S1 General Directorate of Social Work and Child Protection, District 1	Romania
Organisations for Carers Network Finland	Finland	Chamber of Caregivers of Slovakia	Slovakia
The Central Association of Carers in Finland	Finland	Anton Trstenjak Institute of gerontology and intergenerational relations	Slovenia
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Federation Nationale des Aidants et Accueillants Familiales	France	ACUFADE	Spain
Jeunes aidants ensemble Association Nationale Fr	France	CEAFA: Confederación Española de Familiares de Enfermos de Alzheimer y otras Demencias	Spain
Centre for Quality in Care	Germany	Anhörigas Riksförbund (AHR), Carers Sweden	Sweden
wir pflegen e.V.	Germany	The Swedish Family Care Competence Centre	Sweden
EPIONI	Greece	Careum Stiftung	Switzerland
Institute of Mental Health Semmelweis University	Hungary	Carers UK	UK
Care Alliance Ireland	Ireland	CIRCLE (Centre for International Research on Care, Labour and Equalities), University of Sheffield	UK
Family Carers Ireland	Ireland	Carers Trust	UK
Anziani e non solo società cooperativa	Italy	The Coalition of Carers in Scotland	UK- Scotland
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VILANS	Netherlands		

Our members

Associate members

Aidants proches Bruxelles	Belgium
Samana	Belgium
Aidants proches asbl	Belgium
Jeunes Aidants proches Bruxelles	Belgium
Alzheimer Bulgaria (Civil Association "Alzheimer-Bulgaria")	Bulgaria
DaneAge	Denmark
La compagnie des aidants	France
Métropole Aidante	France
AlliPa - Allianz pflegende Angehörige – Interessengemeinschaft und Selbsthilfe e.V.	Germany
GAT - Institute für Gesundheit, Altern und Technik, Hochschule Zittau, Görlitz	Germany
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Associazione de Banfield (ONLUS ODV)	Italy
Carer ETS	Italy
Associazione C'ENTRO	Italy
GERO Center fir Altersfroen asbl	Luxembourg
Community Development Institut Macedonia	Macedonia
Mantelzorg NL	Netherlands
The Netherlands Institute for Social Research (SCP)	Netherlands
Zveza Drustev Upokojencev Slovenije (ZDUS - Slovenian Federation of Pensioners' Organisations)	Slovenia

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