

ANNUAL REPORT

2023



**Celebrating our collective
journey in advocacy and
support for informal
carers across Europe**

Contents

FOREWORD	3
ABOUT US	5
POLICY ENVIRONMENT	6
Eurocarers' instruments for Policy change	8
Capacity Building	13
COMMUNICATION	16
European Carers Day	16
OUR RESEARCH WORK	19
Research working group	19
Young Carers	20
Carers as partners in care	20
Long-term care	24
WHO'S WHO	26
The Eurocarers Executive Committee	26
The Eurocarers Secretariat	27
HOW WE ARE FUNDED	28
OUR MEMBERS	29



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Foreword

Dear Friends of Eurocarers,

We are thrilled to unveil the annual report of our organisation, a comprehensive reflection of our collective efforts and achievements throughout the past few months. With each passing year, the acknowledgment of the vital role played by informal carers in Europe's caregiving landscape deepens. Likewise, our dedication to strengthening and empowering carers grows, as evidenced by the activities outlined in this report.

Throughout the ups and downs of 2023, our organisation stood firm in our mission to advocate for the rights and well-being of carers across the continent. From engaging with policymakers to connecting with communities at the grassroots level, our efforts spanned a wide range of initiatives aimed at amplifying the voices of those who selflessly care for their loved ones.

Recognising that enduring policies and support measures demand evidence-based foundations, our network remains committed to research, capacity-building, advocacy and policy influence, all extensively covered in this report. Whether conducting rigorous policy analysis or facilitating hands-on workshops, each of our initiative is driven by our overarching goal of advancing the interests of informal carers and nurturing an environment of support and recognition.

Our activities in 2023 were guided by the EU Care Strategy, launched in 2022, which provided renewed purpose and relevance to our work. With the Strategy as our guiding compass, our organisation played a pivotal role in implementing and monitoring its objectives, catalysing positive change in care and caring. Notable initiatives, such as our study visit on collaboration between care professionals and informal carers or the exploration of employment models for informal carers led by our Policy Working Group, exemplify this transformative journey.

As we reflect on the accomplishments of the past year, let us reaffirm our collective commitment to advocating for the rights and well-being of informal carers across Europe. Together, let us continue to uphold and acknowledge their invaluable contributions in every corner of our continent.

Warm regards,

Steyc Yghemonos - Executive Director



Foreword

As organisations supporting carers, our mission is to bring about positive changes in the lives of carers and their families. For quite some time, we have underscored the challenges faced by informal carers and advocated for decision-makers to acknowledge the critical role of informal care as the foundation of long-term care.

Should we change the narrative? This does not mean neglecting to discuss the negative health effects, financial problems and isolation experienced by carers. Nor does it mean placing additional care responsibilities on the shoulders of informal carers. However, given the significant challenges posed by population ageing in Western societies, we cannot ignore the need to safeguard informal care.

The new narrative entails discussing the broader context. The key to developing comprehensive care systems, addressing issues such as care quality, the sufficiency of professional care and state budget deficits, is within our reach. We must make suitable investments in informal care, as it is significantly more cost-effective than alternative care options.

Caring is often perceived as a personal, family matter confined within the home. However, care is inherently universal and political. Informal care impacts everyone and is a significant societal issue with far-reaching implications. It influences all aspects of politics, not only within the social and healthcare sectors but increasingly in areas related to the working lives of carers. To address these complexities, we require comprehensive informal care strategies that encompass both family and community-based approaches at the local, national and European levels. While the European Care Strategy was a positive step forward, it was too fragmented, offering kind words about informal care without substantial concrete actions to enhance the lives or status of carers.

There are always options in policies and practices. Public finances should not be solely calculated based on GDP, which, I would like to stress, is not value-free. Social values such as care and well-being are paramount. Comprehensive care is a fundamental element in establishing a humane, safe and functional society, where companies contribute added value for society and people, rather than the other way around.

It is undeniable that each of us has or will have a caring role at some point in our lives. We have all needed care at certain times, and many of us will require it in the future.

I would like to express my gratitude to all member organisations, Board members, the Executive Director and the Secretariat for their cooperation during my five-year presidency. I have gained valuable insights and knowledge and have done my best to contribute. I remain committed to working with all of you to create more carer-friendly societies, advocate for adequate funding of comprehensive care systems, and elevate informal care to the position it deserves!

Sari Tervonen - President



About us

Eurocarers is the European network representing informal carers and their organisations, regardless of the specific age or health needs of the individuals they support. Our network comprises 75 carers' organisations and relevant research and development institutions across 26 countries, forming a distinctive alliance that empowers evidence-based advocacy. These organisations operate at international, national, and regional levels. An overview of our membership is available on our website:



[Eurocarers membership](#)

At Eurocarers, we define a 'carer' as an individual who provides unpaid care to someone with a chronic illness, disability or other enduring health or care needs, outside of a professional or formal framework. We actively collaborate with partners to promote widespread acceptance and adoption of this definition among all stakeholders.

Our network is established as a platform dedicated to fostering collaboration, providing support, facilitating exchange, raising awareness and driving policy change. Our collective efforts are aimed at ensuring that the evolving care needs of an ageing European population are met in a manner that is universal and fair, 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 firmly 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 Eurocarers network aims to represent informal carers by:



Documenting and raising awareness about carers' substantial contributions to health, social care systems and the economy, alongside the impact of caregiving on carers' ability to pursue life prospects and sustain an active, productive life. This involves addressing the daily challenges faced by carers across Europe;



Contributing to evidence-based policy development at both national and European levels, ensuring that policies acknowledge and support carers. This includes promoting their social inclusion, developing support services, facilitating their participation in paid employment and maintaining a social life; and



Facilitate mutual learning and the exchange of best practices and innovations across the EU.

Policy environment

The European Union faces a significant challenge in adequately supporting its ageing and vulnerable populations. This challenge is expected to become more pressing as the proportion of people aged 65 and over, particularly those aged 80 and above requiring increased health and care services, is projected to rise steeply. Member States, while holding primary responsibility for long-term care (LTC) provision, collectively grapple with common issues such as rising demand, a shrinking pool of available professional and informal carers, ensuring quality, financial constraints and the negative impact of informal caregiving on carers' well-being. Hence, there is an urgent need for greater alignment among Member States to address the complex issues associated with ageing societies.

As social protection systems undergo modernisation, informal carers find themselves under growing pressure, raising concerns about the sustainability of care provision as demand exceeds supply. Informal care is often viewed solely as a cost-containment measure, disregarding its profound implications for carers unless measures are taken to identify, acknowledge, support and empower them. The European Commission has underscored the importance of integrated approaches to social service provision, advocating for comprehensive policies that acknowledge and support carers' invaluable contribution to society while offering them viable alternatives to informal caregiving.

Despite their pivotal role in care provision and their broader impact on the economy and society, carers' interests are frequently neglected. Various policy areas, including health, social services, education, employment, social security, technology, research, transportation and housing, should incorporate the perspective and concerns of carers. However, these considerations are often overlooked or inadequately addressed.

Over the last decade, there has been significant evolution in the EU policy landscape concerning informal carers. When our Secretariat was established in Brussels in 2014, EU Member States paid limited attention to Long-term Care (LTC) and informal care, and were hesitant to collaborate on the topic due to institutional constraints. Consequently, we partnered with the European Commission and stakeholders to advocate for coordinated action.

The endorsement of the **European Pillar of Social Rights** in November 2017 marked a turning point, providing renewed focus on social cohesion across the EU. This framework emphasised the importance of social protection and convergence, outlining 20 key

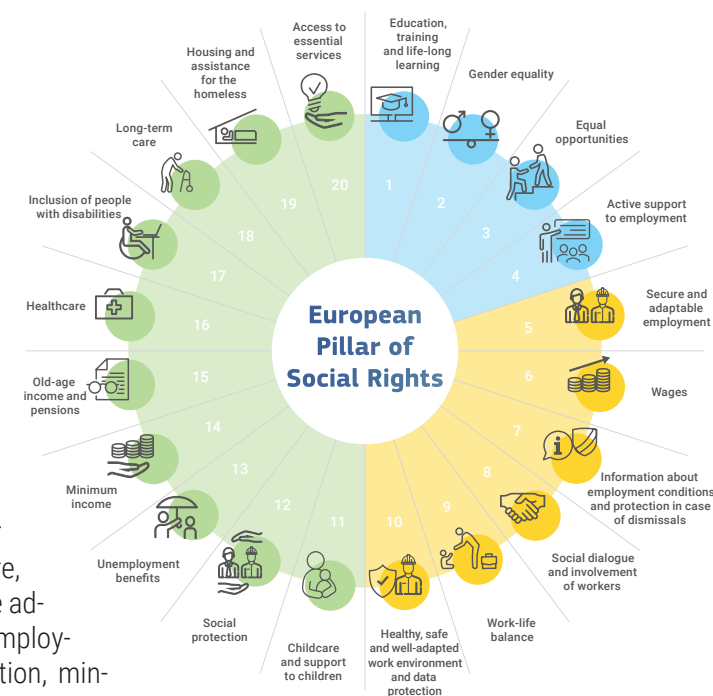
principles essential for fair labour markets and social protection systems. Subsequently, the Action Plan aimed to operationalise the Pillar and support Member States.

While Article 18 of the Pillar addressed long-term care, other sections, such as those addressing gender equality, employment support, social protection, minimum income and healthcare, presented additional opportunities for our advocacy efforts.

Together with the proposal for a European Social Pillar, the EC introduced legislative proposals aligned with Principle 9 on Work/Life balance, aimed at enabling better work-life balance and promoting gender equality in caregiving responsibilities. These proposals were the result of public consultations and aimed to address gaps left by previous initiatives.

The Communication titled "An initiative to support Work-Life Balance for Working Parents and Carers" encompasses both a directive proposal from the Commission and non-legislative measures.

The **EU Directive on work-life balance for parents and carers**, endorsed in 2019, introduced measures aimed at supporting carers. These measures include the introduction of carers' leave, permitting workers caring for seriously ill or dependent relatives to take up to 5 days per year. Additionally, it grants the right to request flexible working arrangements, such as reduced hours, flexible schedules, and remote work.



Policy environment

On 15th September 2021, EC President Ursula von der Leyen announced a significant milestone: the proposal of a new **European Care Strategy** as part of the Commission's Work Programme. This strategy aims to address the needs of both carers and care recipients, covering childcare to long-term care, and ensuring access to quality and sustainable care services throughout life. Importantly, the Strategy is an integral part of the European Pillar of Social Rights' implementation plan.

The Strategy outlines recommendations for Member States to support informal carers by facilitating cooperation with care professionals, providing access to training, counselling, healthcare, psychological support, respite care, and ensuring adequate financial support.

To address the integration of informal carers into the care framework as equal partners, our **Eurocarers Policy Working Group (EPWG)** initiated a reflection process to investigate appropriate employment models for carers. A virtual meeting held on the 9th November 2023 aimed to discuss and establish a consensus on principles governing the employment of informal carers.

The meeting aimed to achieve specific objectives:

- ➔ **Assessing Contracting Practices:** This involved examining global contracting practices to understand their pros and cons.
- ➔ **Enhancing Carer Choice:** Another goal was to expand carers' options through different contractual arrangements, fostering collaboration between informal and formal carers, and improving care quality.
- ➔ **Establishing Practical Criteria:** The objective was to set standards and guidelines for contracting unpaid informal carers, ensuring alignment with specific criteria to enhance caregiving effectiveness.

The meeting facilitated in-depth discussions and collaborative decision-making within the Eurocarers Policy Working Group, focusing on addressing challenges and opportunities associated with contracting practices for informal carers, with the aim of enhancing care quality through strategic principles and practical criteria. 23 member organisations from 17 countries participated in the event.



Adhering to our principle of “nothing about carers without carers,” the **Eurocarers Young Carers Working Group (EYCWG)** convened in Berlin, Germany, on the 26th May 2023. The purpose of this meeting, attended by 15 participants from 8 countries, was to actively involve young carers in our initiatives concerning the implementation of the EU Care Strategy, our European Carers Day campaign for 2023 and the strategic planning for the International Young Carers Conference in 2024.

The meeting commenced with an overview of available EU policy instruments, providing members with insights for personal and advocacy purposes within their respective countries. Additionally, updates on Eurocarers' ongoing research projects were shared and discussed with EYCWG members.

The event also served as a platform for fostering discussions and collaboration among young carers. Key discussion points included the necessity for more frequent interactions of the group, the importance of highlighting the positive aspects of being a young carer and the potential for recognising and validating skills acquired through informal caregiving. Furthermore, participants discussed existing school and university policies supporting young carers, and explored strategies for identifying young carers in schools who may not be fully aware of their status.

Eurocarers' instruments for Policy change

Our secretariat is committed to fostering evidence-based dialogues that connect carers, academics, and policymakers. We aim to inform EU and national policy developments by illustrating how recognising and supporting carers can benefit European societies. Leveraging our reputation as a trusted source of information on care and caring in Europe, we actively engage in policy debates with EU institutions and various stakeholders, including the WHO, OECD, civil society organisations and the private sector. In 2023, our advocacy efforts included publishing 2 new policy briefings and issuing 8 position papers and consultation responses.

Creating a policy environment supportive of carers depends on integrating policies and practices across social, health and employment sectors. Eurocarers actively participates in outreach events, policy dialogues, scientific conferences and exhibitions at both EU and national levels to achieve this. These **networking activities** enable us to build partnerships, foster cross-sectoral collaboration and communicate the opportunities and challenges presented by EU and national policy instruments to a diverse audience.

In 2023, Eurocarers made significant contributions to events such as the Congress of the European Society for Medical Oncology, 1st EU Continence Health Summit, AIM Expert Talk on the quality of non-residential long-term care, Domestic & home care EU Congress, OECD's Unlocking Social Dialogue for Long-Term Care webinar and the WHO International Day of Care and Support webinar. These engagements strengthen our influence, facilitate connections and promote a "care in all policies" approach.

During the reported period, two new **Policy Briefings** were added to our 'why carers count' series:

What lies ahead for mental health in the EU?

August 2023

Mental health poses a significant challenge for the EU, impacting individual well-being and society as a whole. This briefing explores the opportunities presented by the new EU initiative on mental health, announced by President von der Leyen in her September 2022 State of the Union Address. Specifically, it examines how the initiative addresses the needs of informal carers.



[What lies ahead for Mental Health in the EU?](#)

Eurocarers' instruments for Policy change

How to activate the EU Semester to support ambitious care policies?

November 2023

Despite the significant contributions of informal carers to society and the challenges they face, they are often overlooked in policy analyses. This briefing highlights the urgent need for transformative change in our systems, requiring Member States to commit to long-anticipated reforms. Our analysis of the European Semester emphasises the recurring theme of the need to value and organise care, especially informal care. Drawing on a comprehensive review of Country Reports, Country Specific Recommendations and information from Eurocarers' members, this briefing provides insights on activating the EU Semester to support ambitious care policies.



[How to activate the EU Semester to support ambitious care policies?](#)

Furthermore, our team conducted an extensive review of the policy landscape concerning care and caregiving throughout Europe. This effort included revising our online **Overview Table on the Number of carers and existing support measures across the EU.**

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%	✗	✗	✗	✗	✗	✗	✗	✗	✗
CY	60.372	5,20%	187.954	21%	✗	✗	✗	✗	✓	✗	✗	✗	✗
CZ	485.300	4,60%	2.141.871	20,00%	✗	✗	✗	✗	✗	✗	✓	✓	✗
DE	5.554.920	6,80%	15.810.476	19%	✓	✗	✗	✓	✓	✓	✓	✓	✓
DK	863.816	15,20%	1.313.555	22%	✗	✗	✗	✓	✓	✓	✓	✓	✓
EE	176.210	13,40%	210.764	15,80%	✗	✗	✗	✓	✗	✓	✗	✗	✗
EL	724.940	6,70%	3.148.764	29,50%	✓	✗	✗	✗	✗	✗	✗	✓	✗
ES	5.340.600	11,50%	10.901.700	23,00%	✗	✗	✗	✗	✓	✓	✓	✓	✗
FI	657.600	12,00%	968.745	17,50%	✓	✗	✗	✓	✓	✓	✓	✓	✗
FR	9.383.550	14,10%	10.148.502	15,00%	✓	✗	✗	✓	✓	✓	✓	✓	✗
HR	280.000	6,40%	1.595.945	38,10%	✗	✗	✗	✗	✗	✗	✗	✗	✗

[Number of carers and existing support measures across the EU](#)

Additionally, we updated our series of 28 country profiles to reflect the latest policies and practices relevant to our work.

[Country profiles](#)

These tools are intended to provide a comprehensive understanding of the diverse policy environment within the EU regarding crucial aspects of care provision and support for carers. They also offer an opportunity to evaluate the progress made over time and assess the level of carer-friendliness in each country. Additionally, they contribute to the work of our member organisations at national and regional levels, inform the narrative of our European Carers Day campaign and enrich the discussions during our capacity-building and coordination activities, such as working group meetings, knowledge-sharing seminars and our Annual General Meeting.

Eurocarers' instruments for Policy change

In 2023, Eurocarers also (co-)developed and disseminated new **position papers and consultation responses** in order to inform international and national policy developments, including on:

- 📄 **The EU comprehensive approach to mental health**
(February 2023);
- 📄 **The EC call for evidence on the 2023 Strategic Foresight Report**
(March 2023);
- 📄 **The Physical and Mental Health Implications of Informal Caregiving**
(June 2023);
- 📄 **Caring for Loved Ones at the End of Life**
(September 2023);
- 📄 **A White Paper on bladder cancer to leverage legislative opportunities for better support of patients and carers in Europe**
(September 2023);
- 📄 **A lifetime of Caring – Who cares?**
(October 2023);
- 📄 **A joint call to action on UN Day of care and support**
(October 2023); and
- 📄 **Our network's EU election manifesto**
(November 2023)

The **European Parliament's Interest Group on Informal Carers** serves as a crucial tool for Eurocarers to influence policy change at both EU and national levels. The group's role includes monitoring and analysing EU policy developments affecting carers, proposing concrete actions, and advocating for improvements in collaboration with relevant stakeholders. Currently, the group comprises 28 MEPs interested in care and caring, representing 11 countries and 5 EU political groups (S&D, EPP, Renew, GUE/NGL, and the Greens). A virtual meeting of the Interest Group was held on the 28th of November 2023.

Over the past decade, it has become evident that meeting the needs of older individuals with increasingly complex care requirements, while respecting their preference for living in the community, presents a significant challenge across the European Union. Although the European Commission responded positively to calls for action from the EP and relevant stakeholders by introducing a European Care Strategy, there remains an unresolved need for more specific measures to ensure proper implementation across all Member States.

Therefore, the objective of the EP Interest Group meeting was to draw attention to a pivotal theme at the intersection of social and long-term care policies: "Addressing care poverty: how inequalities hinder older people from accessing the support they need." The concept of care poverty integrates insights from feminist social policy research, gerontological research, and studies on poverty and social disparities. Professor Teppo Kröger from the University of Jyväskylä, Finland, who recently published an influential book on the topic, delivered a keynote address during the meeting.

Care poverty occurs when older individuals require care and support but do not receive sufficient assistance, highlighting instances where individual care needs surpass the available help from both formal and informal channels. Professor Kröger's work offers fresh insights into long-term care policies. Representatives from the European Commission (DG EMPL) and organisations dedicated to addressing care provision and poverty were also invited to share their perspectives and articulate their priorities concerning inequalities in care.

The event aimed to establish a clear message for future EU-level work on long-term care and carers and contribute to setting the agenda for the next parliamentary term. The meeting brought together 43 participants, including Members of the European Parliament (MEPs), EU officials, MEP assistants, academics, representatives from civil society organizations and informal carers. The diverse group of attendees provided varied perspectives and expertise on the challenges surrounding care poverty and how inequalities impact older individuals' ability to access necessary support.



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 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 2023, five knowledge-sharing sessions were held, covering diverse topics.

The initial session, styled as a World Café, delved into strategies to empower carers. This entailed discussions on three main themes: “Establishing new carers’ organisations across Europe and expanding our network”, “Strengthening carer evidence through collecting and generating compelling data”, and “Guiding the development of new or improved carer policies”. These discussions were informed by the momentum generated by our community and the recent launch of an EU Care Strategy.

The subsequent session, known as a Research Tour de Table, aimed to assess ongoing research activities and priorities within our network, offering insights into the current research landscape related to caregiving.

The final session was a workshop dedicated to planning our communication strategy for European Carers Day 2023, with a specific focus on the theme “Work, Life, and Care – Trade-offs or Synergies?” This workshop aimed to strategise how we could effectively communicate and engage with our audience on this important day, considering the intricate dynamics between work, life and caregiving responsibilities.

Study Visit

Eurocarers’ study visits offer a platform to spotlight particular entry points present in both EU and national agendas. They enable interested member organisations to share their perspectives, experiences, and expertise, including insights from existing successful or promising practices, concerning these policy opportunities.

In 2023, our Visit, themed “From competition to collaboration: The interface between informal and formal carers”, occurred in Glasgow, Scotland, on the 2nd and 3rd of October. This event, in collaboration with the Universities of Strathclyde and Dundee, drew 31 participants from 13 countries. Attendees included representatives from carers’ organisations, universities, research institutes, care professionals and informal carers. The aim was to facilitate knowledge exchange and peer learning, focusing on fostering collaboration between informal and formal carers while addressing obstacles in delivering high-quality support.

In addition to promoting exchange and learning, the visit contributed to an ongoing research study by both universities, examining factors enhancing collaboration between informal and formal carers. Common concerns regarding increased responsibilities on informal carers were discussed, aiming to explore sustainable care options through various forms of evidence.

Participants were tasked with presenting a 3-minute thesis on a specific concept related to research or experience from their country regarding the interface between formal and informal carers, serving as the stimulus for discussions. Following country presentations, small groups engaged in discussions and exploration of common concepts, generating conceptual questions guided by criteria such as relevance to everyone, importance, relatability to experiences and potential for differing opinions. The six emerging questions focused on the interaction and collaboration between informal carers and care professionals, addressing issues such as facilitating new initiatives, defining equality in partnerships, addressing cultural influences on caregiving choices, integrating relationships into policy, identifying expertise and considering trade-offs in care system inclusion.

Capacity Building

Action at national and regional level

Promising progress has been evident across Member States, as a result of our collaboration with EU institutions and relevant stakeholders. In recent years, initiatives such as the EU Directive on work-life balance for parents and carers, alongside the EU Care Strategy, have inspired an increasing number of countries to adopt (some of) the measures required to address the needs of informal carers and mitigate the adverse effects of caregiving on their social inclusion and employment opportunities. Eurocarers remains committed to supporting and monitoring these advancements closely. Additionally, we are dedicated to nurturing and advocating for further progress in all European countries, particularly as our members and partners often play active roles in shaping and implementing these initiatives.


In-country policy dialogues on situation and needs of carers

To facilitate this process, the Eurocarers Secretariat collaborates annually with member organisations to co-host national or regional events. These events aim to engage decision-makers from the health and social sectors in dialogue regarding the challenges faced by carers and strategies to support them. The discussions are grounded in the principles outlined in the European Pillar of Social Rights and EU Semester/Recovery and Resilience Facility.

These “in-country policy events” serve two main objectives:


1. **Raise awareness about the needs and circumstances of carers**, fostering the development of new national or regional initiatives on care and caregiving, aligning with the proposed EU Strategy on carers’ 10 steps.
2. **Enhance alignment between EU objectives**, particularly the principles of the European Pillar of Social Rights and the European Semester, and national or regional policy agendas. This alignment aims to promote integrated and multidimensional approaches to care and caring.

In 2023, Eurocarers co-organised/contributed to six in-country policy dialogues on the situation and needs of carers as well as on possible solutions to address them, including:


-  A face-to-face event on carers research organised in Oslo, Norway on the 16th March 2023. The event was organised in collaboration with the Norwegian National Alliance for Carers (Pårørendealliansen), the Network for Carers Research and NHO Geneo. It brought together 120 participants to discuss ongoing challenges in the care sector, present the current status of research and analytical work, and highlight knowledge gaps. The objective was to inspire researchers, organisations, professional communities, businesses and government officials by identifying valuable collaborative partners and acquiring more insights into the role of informal carers across different societal domains. The event benefited from the participation of Ms. Ingvild Kjerkol, Minister for Health and Care.



[More information](#)

-  A hybrid conference entitled ‘Mainstreaming Care in the European Year of Skills 2023: Strategies and measures to strengthen informal and formal care’, held from Berlin, Germany on the 26th May 2023 in the margins of Eurocarers AGM. The conference convened 56 participants from 21 countries. The aim of the event was to gain insights into recent European policy developments relevant to informal carers, including initiatives outlined or implemented by the German government, the Swedish Carers Strategy and supportive measures in Scotland.

Capacity Building

 The 7th Caring for Carers Conference took place in Athens on the 16th June 2023 and was organised by Epioni, the Greek Carers Network. The conference was held in collaboration with the Region of Attica, the Hellenic Psychiatric Association, the Hellenic Brain Council, Eurocarers and EUFAMI. The conference addressed carer policy and recognition with contributions from Mr. Stelios Kypouropoulos (MEP) and other key figures.




[More information](#)

 The implementation of our European campaign “European Carers Day” included, among other things, a symposium organised in Athens by our colleagues at Epioni on the 6th October. This event brought together around thirty participants, including healthcare professionals, academics and NGOs, to discuss the necessary measures to support carers in Greece, a country that continues lag behind in these matters.



[More information](#)

 A policy event titled “The Next Chapter: Making Carers’ Rights a Reality” took place at Edinburgh City Chambers in Scotland on the 4th October 2023. Moderated by Derek Feeley, Chair of the Independent Review of Adult Social Care, the event was organised by the Coalition of Carers in Scotland and VOCAL – Voice of Carers Across Lothian, both of which are members of Eurocarers. This event reviewed carer policy developments and explored collaborative practices. A delegation of Eurocarers representatives from Brussels, Finland, Slovenia and Sweden actively contributed to the event.



[More information](#)

 The Swedish Carers Days conference, held in Karlstad on the 25th October 2023, centred around the theme of “Unlimited Kinship.” This event explored both tangible and intangible boundaries, addressing intersections between localities and regions, intercultural limits and scenarios where individuals, as family members or close relatives, may need to extend their boundaries for mutual convenience. Eurocarers contributed to the dialogue by presenting an intervention on the prevailing policy landscape supporting informal carers at both Swedish and European levels, aligning with the Swedish and European Care Strategy objectives.



[More information](#)

Communication

European Carers Day

Our fourth **European Carers Day (ECD)** campaign was held on (and around) the 6th October 2023. The campaign forms part of our general communication strategy (“European Carers Awareness campaign”). It is implemented in close collaboration with our member organisations and it aims to coordinate/nurture national awareness-raising efforts on the Carers’ issues under a pan-European structure. The specific objectives the European Carers Day campaign are to:



health and equal opportunities policies at the EU level and national strategies supporting carers are enacted at the member state level. This will build on our uninterrupted call for more investment in formal care and on the 10 steps of our EU Carers Strategy ‘Enabling Carers to Care’.

ECD is therefore a continuous effort with peak activity revolving around the 6th October of each year and specific themes selected by our network on a yearly basis. The theme selected for this edition of the campaign was “Work, Life, and Care – Trade-offs or Synergies?”.

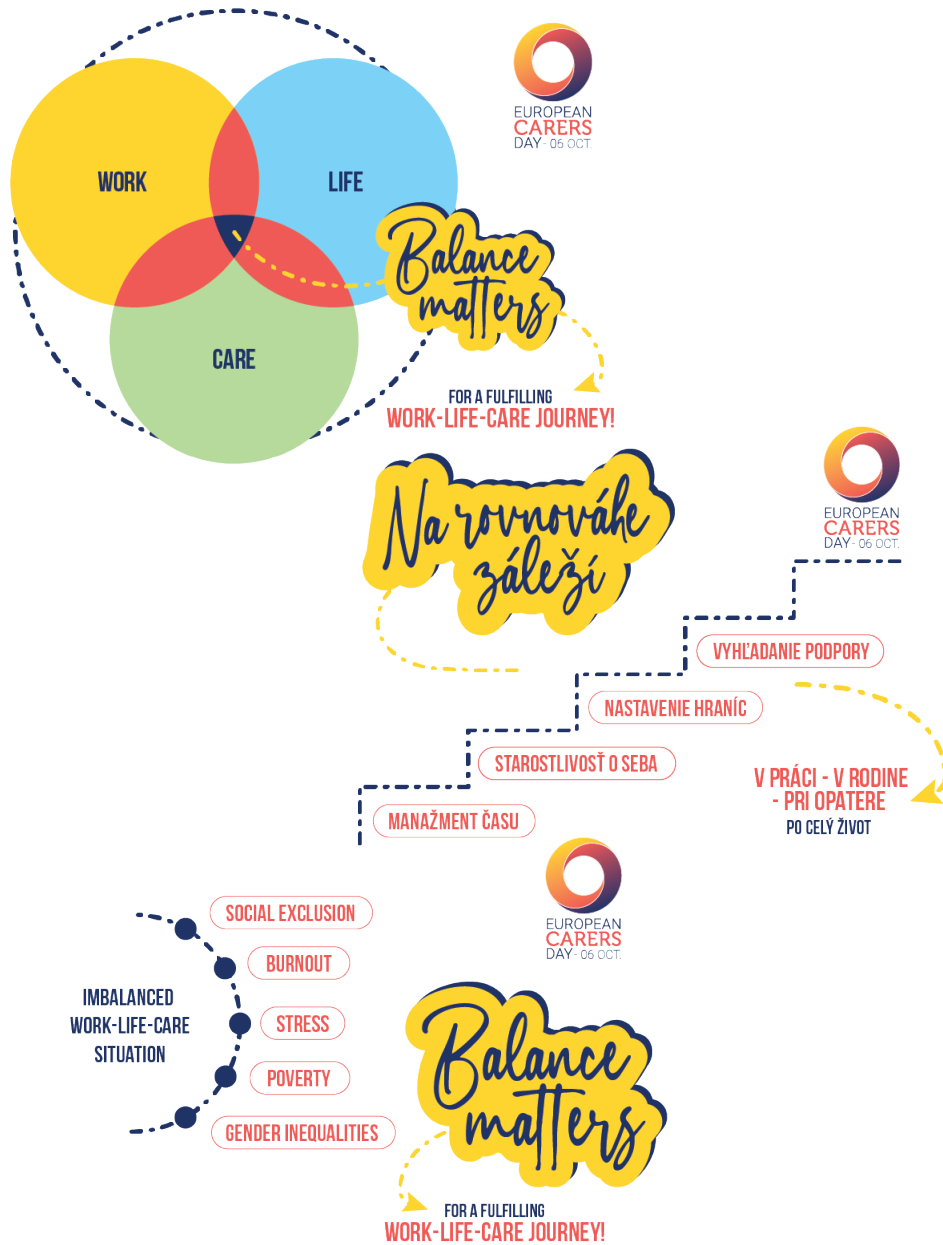
- 1. Foster a feeling of community** among carers organisations rooted in internal unity, communality of vision and a clear direction to inspire action;
- 2. Raise public awareness about carers’ role in society:** a wider-reaching European campaign will have the ambition to inspire local, regional, national and European action, therefore creating a grassroots movement supporting caregivers; and
- 3. Achieve policy change:** by directing common efforts towards policymakers across the European Union, the campaign will ultimately contribute to ensuring that the needs of carers are mainstreamed into social, employment,

The primary aim was to spotlight the widespread issue of unbalanced caregiving responsibilities, highlighting the disparities among individuals. Through close collaboration with our member organisations, the Eurocarers Secretariat curated a comprehensive communication toolkit, comprising key messages, posters, social media content, visuals, infographics and joint statements.

The campaign placed particular emphasis on multilingualism by translating PR materials into 14 languages, promoting inclusivity across diverse linguistic communities. A new addition this year was the introduction of a podcast series, featuring both curated and original content, which garnered significant interest and will remain a focal point in future campaigns.



Communication



Communication

The impact of the campaign extended beyond our immediate network, resonating through strategically tailored press releases disseminated at both EU and national levels. Original press releases were distributed by Eurocarers to nearly 1000 recipients, including press contacts and MEPs. What sets this campaign apart is its adaptability; our member organisations seamlessly integrate campaign tools, tailoring messages to local needs and translating visual materials for their audiences, thus amplifying our messages across Europe.

Moreover, the Eurocarers website attracted over 5,000 visitors in October alone, reaching its peak on European Carers Day itself. The ripple effect of the campaign reached far and wide, with numerous sister organisations and partners enthusiastically joining the cause. Esteemed MEPs such as Sirpa Pietikainen, Isabel Carvalhais, Marisa Matias, Frances Fitzgerald, Deirdre Clune, and Sean Kelly, as well as influential stakeholders like the EPP Group, Irish Minister Humphreys, German Senator Dr. Czyborra, WHO Europe, Eurofound, and others, lent their support to the campaign.

Additionally, various European-funded projects, whether affiliated with Eurocarers or not, amplified the campaign's reach. Notably, media outlets, governmental bodies and advocacy groups also amplified our message, reinforcing the collaborative spirit that defines Eurocarers' initiatives. The success of the 2023 ECD campaign lies not only in its numerical achievements but also in the collective voice it fostered, resonating through corridors of power, policy and public awareness alike.



Our Research Work

Research Working Group

The **Eurocarers Research Working Group** is committed to informing evidence-based practice and contributing to the broader research agenda at the EU level in the fields of care, carers and caregiving. The group's face-to-face meeting in 2023 was held in Ancona, Italy, on the 30th November and 1st December, co-hosted by our colleagues from the National Institute of Health and Sciences on Ageing (INRCA), whose significant contributions ensured the success of the event.



Given the complexity of care and caring, it is essential to implement diverse policy initiatives and practical support measures across various sectors. Over the years, the collective efforts of our network have expanded the avenues through which Eurocarers communicates its message. Exciting developments, such as the comprehensive EU Care Strategy launched in 2022 and our ongoing dialogues with the EC, the EP, as well as with esteemed bodies like the WHO and the OECD, signify significant progress in our journey.

However, it remains our duty to meticulously document every facet of carers' lives deserving attention and, more importantly, to propose solutions that bolster care systems while acknowledging the invaluable contributions of carers. Sustainable policymaking

necessitates a bedrock of evidence, underscoring the vital importance of the work undertaken by our Research Working Group.

In 2023, our Group engaged in fruitful discussions on our ongoing research, identified remaining gaps, explored the potential impacts of Artificial Intelligence in our sector, deliberated on the criteria employed by public authorities to support carers and outlined the scope of a future online information/training platform in collaboration with the WHO and the EC. As always, the event provided an opportunity to foster synergies among members, an equally essential aspect of our collective efforts. A total of 29 participants from 24 organisations representing 19 countries attended the event.



[More information](#)

Besides the work of our dedicated Research Working Group, the Eurocarers network is actively involved in research projects seeking to document various aspects of care and caring, thanks to the support of the EU via its funding programmes.

Our Research Work

Integrated Care

Integrated care is a concept that involves bringing together different elements of care (such as health services, social services and support services) to ensure they function as a coherent whole. It aims to provide seamless, coordinated and continuous care across different settings, with the goal of improving the overall outcomes and experiences of individuals, especially those with complex health and social needs. Integrated care emphasises a person-centred approach, focusing on the needs and preferences of individuals and their families while promoting collaboration among health and social care providers.



Evaluation of an integrated patient-centred biopsychosocial and behavioral collaborative CARE Pathway for the management of multi-morbid aged patients

ESCAPE is a 5 year-long research and innovation project funded through the Horizon 2020 programme. It has an interdisciplinary team who are developing a holistic, patient-centred intervention. Using digital health technologies, ESCAPE is in a process of creating integrated and personalised treatment plans for elderly patients with multiple health conditions to investigate improvements to their health-related quality of life.

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.

The latest project milestone achieved is the successfully screening of over 3500 patients for potential participation. Out of these, 200+ patients have been randomised to the trial, marking a pivotal moment in the project's journey. ESCAPE aims to randomise 300 patients across our five trial countries: Germany, Denmark, Italy, Hungary and Lithuania.



[More information on ESCAPE](#)



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 multi-stakeholder cooperation, evidence-based decision-making, capacity building, and skills transfer. The project emphasizes empowering local stakeholders, communities, care users, and their families to shape LTC services.

InCare reflects the aspirations and needs of older people with functional or cognitive impairment and their carers, highlighting the role of local communities and service providers in shaping care service delivery with national policy-level support.

The project concluded in October 2023 with a successful dissemination conference in Vienna, where its positive outcomes were discussed.

Publications outlining the participatory method and project results in each pilot country (Spain, Austria, North Macedonia) are available on the project website: <https://incare.euro.centre.org>. This material aims to inspire and support long-term care system reforms, enhancing accessibility, quality, and affordability of care within the European Long-Term Care Strategy framework.



[More information on InCARE](#)

Our Research Work



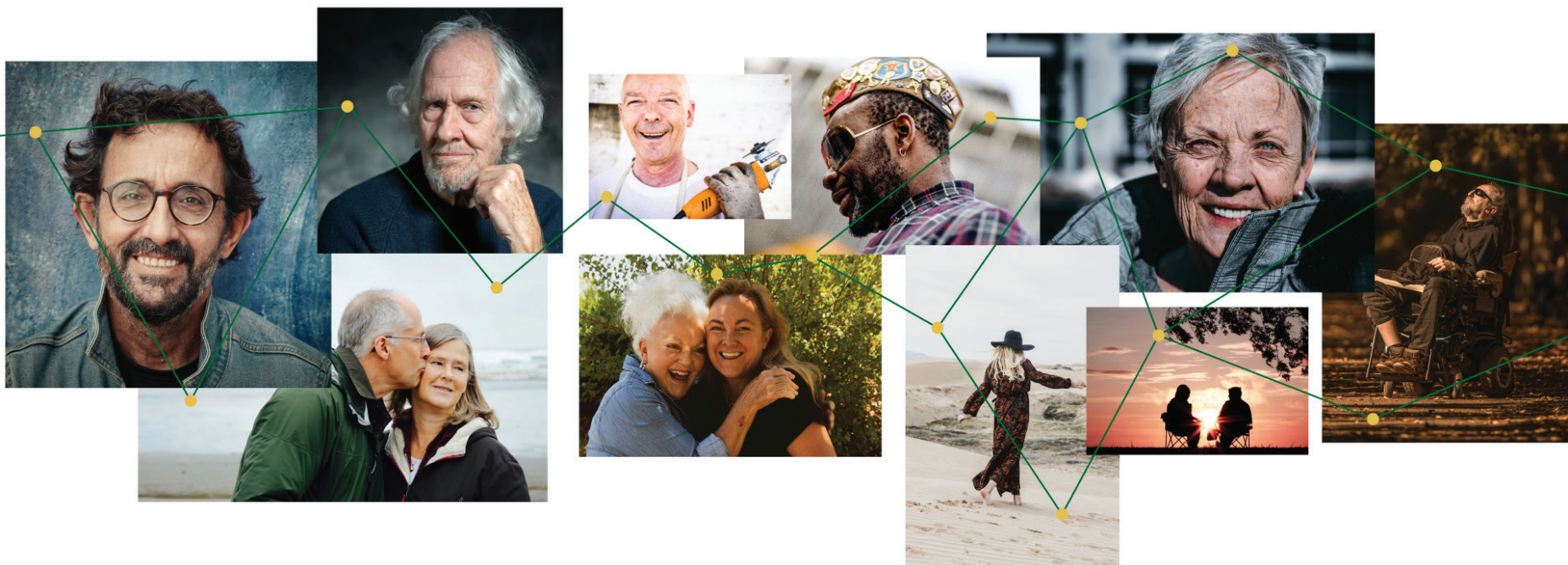
LAUREL - Actionable policies for adopting high-quality integrated long-term care

Laurel aims to gather valuable insights into regional differences of integrated long-term care provision in Europe. Long-term care services are intended for people who depend on help with daily living activities and who may also need permanent nursing care. There is currently a growing demand all over Europe for the necessary tools and resources to meet the needs for long-term care. However, budget restrictions, lack of qualified staff and shortcomings in the quality of services are creating a troubling scenario that needs to be addressed. Laurel aims to find answers to these problems by identifying the best innovative solutions in integrated long-term care services in the 27 EU countries.

These innovative solutions will focus on person-centred care and take into account territorial inequalities and gender aspects. The main outcome will be a white paper with actionable policy recommendations for policy makers, along with training tools for those delivering care.



[More information on Laurel](#)



Our Research Work

Better equipped care workforce

A better equipped care workforce signifies a transformative shift towards enhanced quality, accessibility and sustainability in care provision. It encompasses comprehensive training and upskilling initiatives to empower carers with the knowledge, skills and resources needed to deliver person-centred care effectively. This includes investing in specialised training programmes, promoting continuous professional development and fostering interdisciplinary collaboration among care actors. Moreover, it involves improved working conditions and adequate support systems to ensure the well-being and retention of carers. By prioritising the development and support of the care workforce, Europe can foster a resilient and responsive care system that meets the diverse needs of individuals and communities, ultimately enhancing the overall quality of care delivery.



WELL CARE - Investing in the mental health and wellbeing of informal carers and long-term care workers through the identification, evaluation, and promotion of good practices across Europe

Providing care for someone can be mentally draining for both informal carers and professional long-term care (LTC) workers. They risk compromising their mental health and well-being over time. How can we safeguard their health and resilience?

To address this pressing challenge, the WELL CARE project aims to enhance support for LTC workers and informal carers, focusing on improving their resilience and mental well-being. We will identify, refine, and implement innovative solutions to address the dynamics of care partnerships. This includes exploring best practices that improve mental health and tackling occupational risks like heavy workloads, stressful conditions, and exposure to infectious agents, as well as non-occupational risks such as gender, age, migration background, socio-economic status, and the quality of care partnerships. Prioritising LTC integration can help mitigate risks for carers. The WELL CARE project will model and promote innovative solutions, including prototypes, focusing on five EU countries: Germany, Italy, Netherlands, Slovenia, and Sweden.

The project was prepared in 2023 and officially launched in January 2024.



[More information on WELL CARE](#)



Eldicare 2.0 - Re-defining skills in a post-COVID European Silver Economy

Eldicare 2.0 is the continuation of the previous project 'Eldicare: Matching Skills in a growing European Silver Economy'. The project aims to update the occupational profiles and competencies in the elderly caregiving sector, by providing a long-term strategy to tackle skill gaps and anticipate future skill needs on the labour market. It will do so by strengthening the cooperation among sectoral partners in elderly care and educational providers in healthcare, bringing together a consortium of 17 organisations. The main outcomes will be a set of up-to-date occupational skills profiles for elderly care and the design of modular competence-based training curricula for the reskilling and upskilling of elderly care practitioners (based on the new occupational profiles).

Eldicare 2.0 started in July 2023. During the first six months of the project, consortium members were involved in a variety of activities to ensure sound management and coordination – including setting up project management processes, financial reporting, and quality assurance. The main communication activities concerned the launch of the project website and social media channels, where the consortium posts regular updates on the activities that are undertaken. The bulk of the research activities started in November 2023, with a desk review of the available evidence on skill needs for elderly caregivers post COVID-19.



[More information on Eldicare 2.0](#)

Our Research Work



SOUND - Training Social and health care professionals in music-based therapeutic interventions to support older people with Dementia

SOUND is a 30-month ERASMUS+ co-funded project. Its objective is to develop a comprehensive curriculum and training program for dementia social and healthcare professionals, as well as informal carers. This program will equip them with competencies, techniques, and tools to effectively engage older people with dementia (OPD) in passive and active music-making activities. Additionally, the project aims to create a music-based non-pharmacological intervention tailored specifically for OPD, with the goal of improving their behaviour, mood, cognitive functions, and overall quality of life. Care professionals will be trained in the SOUND approach and will deliver the intervention as part of this project, providing an opportunity to assess its effectiveness.

The project is in its final stage and it has already achieved most of its objectives, namely:

- It developed a training module for dementia care professionals on the use of music-based activities and Virtual Music Circle. It designed and implemented a methodology for assessing the learning outcomes and the impact of the methodology on the professionals' work-related stress management, self-efficacy and sense of frustration;
- It carried out a series of music-based non-pharmacological therapeutic interventions addressed to OPD;
- It created a Virtual Music Circle. i.e. an interactive e-learning platform through which care professionals, OPD and their informal carers can easily meet and make music together whenever they want;
- A series of micro-consultancies for informal carers were carried out to present and explain the use of the SOUND method and the Virtual Music Circle.

The project will end with a Europe-wide dementia awareness raising campaign based on the music performances delivered during the SOUND implementation phases which will take place on June 19th 2024.



[More information on Sound](#)

Our Research Work

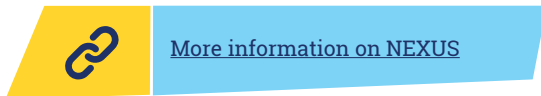
Young carers



NEXUS - connecting research, policy and practices to support young carers

NEXUS is a 3-year ERASMUS+ co-funded project which started at the beginning of 2023. The project objectives is to strengthen the links between policy, research and practice both in the youth as well as in the welfare sector by raising awareness on the importance of end-users' involvement in research and policy development among youth and young carers' support workers by upskilling them to that end and by promoting their work. The project also to support active citizenship, sense of initiative and entrepreneurship of young people and, in particular, of young carers.

NEXUS project is in a process of designing a multi-language training program about the core-competencies needed by youth workers to contribute to research and policy around young carers, together with a guide for its replication by other providers. It will also develop an open online educational resource (OER) for youth workers across Europe to acquire the skills they need to engage in evidence-based policy development. Another project result will be policy recommendations to meaningfully engage with youth workers, young carers, service providers, researchers and policy makers in the format of a national and European workshop.



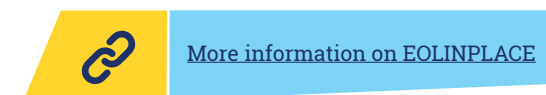
End-of-life care

The role of informal carers in end-of-life and palliative care can be complex and challenging. Informal carers may experience a range of emotional and physical stressors, including grief, anxiety and fatigue. However, they can also provide valuable support to patients and their families, helping to improve quality of life and ensure that patients receive care that is aligned with their wishes and values.

EOLINPLACE













EOLinPLACE - Choice of where we die: a classification reform to discern diversity in individual end of life pathways.

Respecting preferences for place of death is important. The first step is to classify the dying places (home, hospital, among others) in a way that is meaningful for individuals. In this context, the EU-funded EOLinPLACE project will create a solid base for the first international classification tool to map preferred and actual places towards death. We will conduct a mixed-methods study in four countries covering existing target variation (Portugal, Netherlands, Uganda, USA) 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.



Who's who

The Eurocarers Executive Committee

	President	Sari Tervonen	Central Association of Carers in Finland		Executive member	Iveta Zdilova	Chamber of caregivers of Slovakia
	Vice President Research	Henk Nies	Vilans		Advisor to the Board	Georgia Casanova	National Institute of Health and Science on Aging (Italy)
	Treasurer	Anita Vatland	Norwegian alliance for informal Carers		Advisor to the Board	John Dunne	Family Carers Ireland
	Executive member	Bruno Alves	Cuidadores Portugal		Advisor to the Board	Elizabeth Hanson	Swedish National Family Care Competence Centre
	Executive member	Sebastian Fischer	VOCAL – Voice of Carers Across Lothian		Advisor to the Board	Emily Holzhausen	Carers UK
	Executive member	Andreas Hoff	Zittau/Görlitz University of Applied Sciences		External advisor	Christine Marking	Marking Public Affairs

Who's who

The Eurocarers Secretariat



Executive Director

Stecy Yghemonos



Administrative and
Financial Officer

Jenny Nekrilova



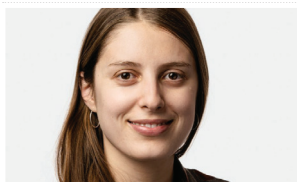
Project Officer

Svetlana Atanasova



Policy Officer

Claire Champeix



Project Officer

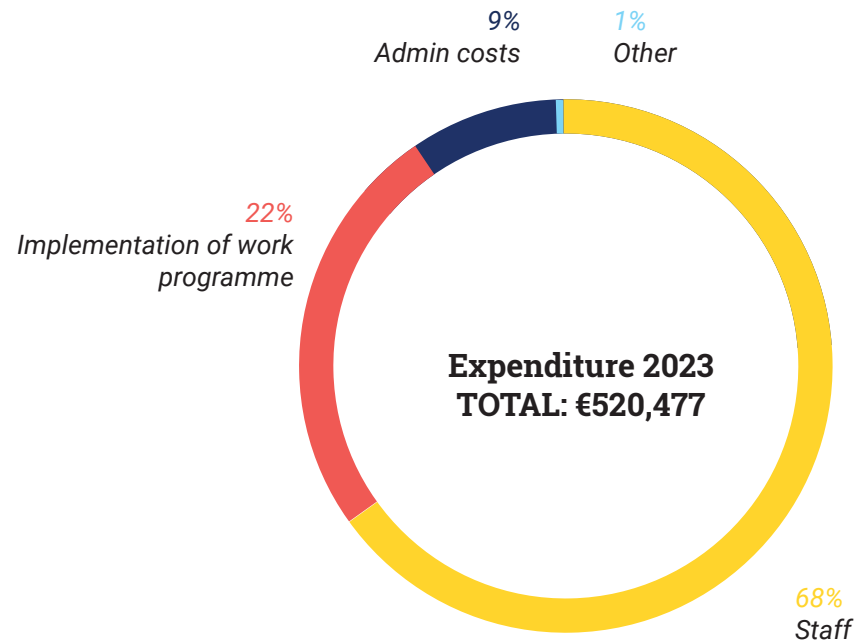
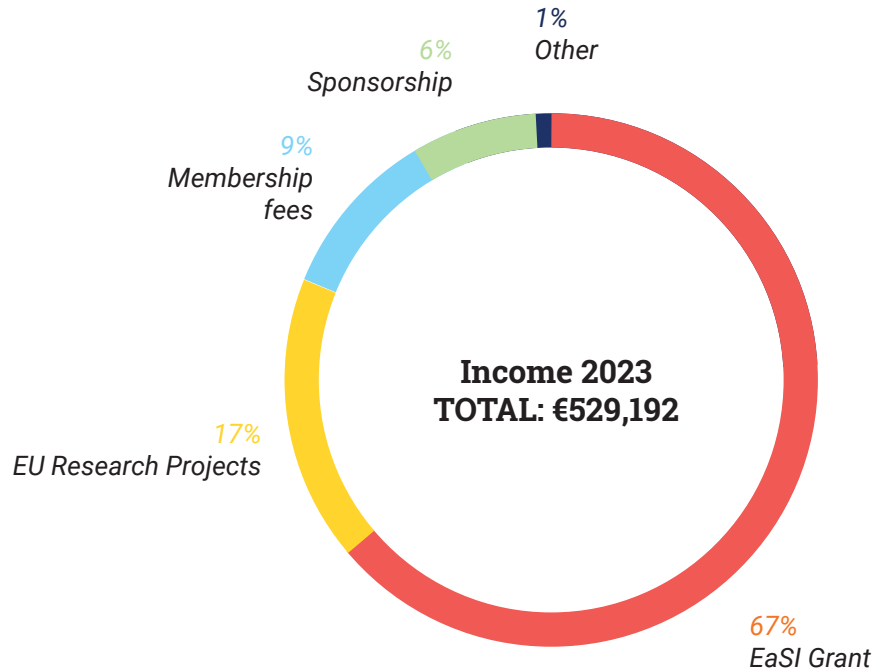
Giulia Lanfredi



Senior
Communication
Officer

Olivier Jacqmain

How we are funded



Our members

Full members

European Centre for Social Welfare Policy and Research	Austria	NTNU - Centre for Care Research	Norway
HOGENT Departement Gezondheidszorg	Belgium	ANCI - Associação Nacional de Cuidadores Informais	Portugal
Magenta - KU Leuven	Belgium	Cuidadores Portugal, Bruno Alves	Portugal
Steunpunt Mantelzorg	Belgium	DGASPC-S1 General Directorate of Social Work and Child Protection	Romania
Diaconia of the Evangelical Church of Czech Brethren	Czech Republic	Chamber of Caregivers of Slovakia	Slovakia
Carers Denmark	Denmark	Anton Trstenjak Institute	Slovenia
Organisations for Carers Network Finland, Jonna Skand	Finland	University of Ljubljana	Slovenia
The Central Association of Carers Finland	Finland	ACUFADE	Spain
Association Française des aidants	France	Carers Sweden	Sweden
Federation Nationale des Aidants et Accueillants Familiales	France	Swedish Family Care Competence Centre	Sweden
Jeunes aidants ensemble (JADE)	France	Careum Stiftung	Switzerland
wir pflegen e.V.	Germany	Carers Trust	UK
Zentrum für Qualität in der Pflege	Germany	Carers UK	UK
Greek Carers Network EPIONI	Greece	CIRCLE (Centre for International Research on Care, Labour and Equalities), University of Sheffield	UK
Institute of Mental Health Semmelweis University	Hungary	University of Birmingham	UK
Care Alliance Ireland	Ireland	The Coalition of Carers in Scotland	UK/Scotland
Family Carers Ireland	Ireland	VOCAL - Voice of Carers Across Lothian	UK/Scotland
Anziani e Non Solo società cooperativa sociale	Italy		
Istituto Nazionale di Riposo e Cura per Anziani (INRCA)	Italy		
MOVISIE, Centre of Expertise for Informal Care	Netherlands		
Vilans	Netherlands		
VU University Amsterdam	Netherlands		
Norwegian National Alliance for informal Carers	Norway		

Our members

Associate members

Austrian Carers Organisation	Austria
Aidants Proches Bruxelles	Belgium
Aidants proches Wallonie asbl	Belgium
Jeunes Aidants proches Bruxelles	Belgium
Samana	Belgium
Alzheimer Bulgaria Association	Bulgaria
Alfa Human Service	Czech Republic
Daneage	Denmark
La Compagnie des Aidants	France
Métropole Aidante	France
Proches Aidants France - Francis Chirol	France
AlliPa - Allianz pflegende Angehörige e.V.	Germany
GAT- Institut für Gesundheit, Altern und Technik	Germany
Greek Association of Alzheimer's Disease & Related Disorders	Greece
Associazione C'ENTRO	Italy
Associazione de Banfield - ONLUS ODV	Italy
CARER ETS	Italy
Community Development Institute	Macedonia
Mantelzorg NL	Netherlands
The Netherlands Institute for Social Research (SCP)	Netherlands
Longevidade Digital	Portugal
Slovenian Federation of Pensioners' Organisations (ZDUS)	Slovenia

Grupo SSI	Spain
Pro Aidants	Switzerland

Observer Members

Myra Lewinter, University of Copenhagen Department of Sociology	Denmark
Dr. Henk Bakkerode	Netherlands
Marja Pijl	Netherlands
Dr. Jolanta Perek Bialas	Poland
Simona Hvalic Touzery	Slovenia
Martha Mackay	Spain
Geraldine Boyle	UK
Jitka Vseteckova	UK
Saul Becker	UK