



# Who are 'informal carers'?

**Informal** carers are **unpaid** carers, **family members or friends**, who support a partner, relative or child with a frailty, disability, long-term condition, mental health issue or addiction.

Informal carers are **providers of care** but have very **few rights to receiving support**.

*“There is nothing informal about the care I provide for my husband.*

*Every day, I do everything a nurse would do, if my husband was in hospital!”*

Anna (67) cares for her husband who had a stroke in 2017

# Who cares in Europe?

- 80% of long-term care in Europe is provided by informal carers<sup>1</sup>
- 10% up to 25% of the total adult population in Europe are estimated to care <sup>1</sup>
- 22% of carers are 65 or over, and approx. 60% of unpaid carers are women

Unpaid carers = the pillars of every care system!

*An estimated  
75 - 150 million  
people in Europe  
provide unpaid  
care!*

<sup>1</sup> Informal Care in Europe.  
European Commission, 2018

# Still unequal Partners in Care

Although carers are the largest group of care providers, they often experience **inequality and discrimination**. They are at the **margins of society** and feel excluded.

Unpaid carers must become central to all policy, care and service planning to protect their health and wellbeing and harness their economic contribution.

*“When Covid-19 came, all support stopped overnight.*

*I was on my own and still have to provide everything we lost.”*

Martin (72) cares for his wife (68) who has several long-term conditions

# The main challenges unpaid carers face:

- Lack of information, advice and training
- Lack of practical support
- Lack of time and lack of sleep
- Social isolation
- Lack of regular breaks from caring
- Lack of emotional and therapeutic support to manage changing relationships
- Lack of income and financial support

*“I care 24/7.  
Day and night.*

*My mother’s dementia  
means, she has lost all  
sense of time!”*

Helga (58) cares for her mother (84)  
who has dementia

# From Recognition to Rights

Like the paid workforce, unpaid carers need an entitlement and right for training, breaks from caring, support with the caring role and financial support.

And they need a choice of services in their community to support them.

*“I don’t need praise and warm words for what I do for my wife.*

*I need someone to come and help me. And I need some time to myself.”*

Filip (58) cares for his wife who has Multiple Sclerosis

# From Recognition to Rights

In some countries, carers are now better recognized, but still have few legal rights.

**National and regional carer strategies and carer legislation** as frameworks for improving carer support.

Developed with carers and their organisations, and with all planning partners

*“Carers are recognised and valued as equal partners in care and involved in decision making relating to their caring role.”*

Scotland Carers Strategy 2022-25

# A mixed care economy

We require more investment in unpaid carers, care staff and in home-based care services.

This must include flexible care budgets to allow families to plan and broker care solutions tailored to their circumstances and cultural requirements

*Scotland invested an additional £95 million in carer support from 2018 to 2023.*

*Scotland published a review of its social care system in 2021!*

Carers (Scotland) Act 2016 and  
Independent Review of Adult Social  
Care 2022



# Preventing carer poverty

Carers require a better work-care balance

- Extended rights to care leave – up to 36 months
- Salary replacement benefits – up to 36 months
- Flexible personal budgets
- Pension credits for financial security in old age
- Care costs fully met by care systems

*“No person should be financially worse off for providing care to a relative or friend.”*

Key principle to guide all social care and family planning

# Carer Representation

To achieve better recognition and rights, unpaid carers need a strong voice and lobby.

- Prioritise developing advocacy organisations
- Supported by good research and policy
- Working closely with older people and other civil society organisation
- in all nations, regions and local communities

*“Carer-led advocacy organisations are 21<sup>st</sup> century trade unions of the unpaid workforce.”*

Sebastian Fischer, working since 1994 for carer advocacy

# Advocacy organisations in Scotland and Germany

These organisations are **carer-led**  
and **policy focused**. Some also  
provide direct support to carers.  
Please contact them, if you wish  
to develop a carer organisation  
in your country or region.

[www.carernet.org](http://www.carernet.org)

[www.vocal.org.uk](http://www.vocal.org.uk)

[www.wir-pflegen.net](http://www.wir-pflegen.net)



# Carer Advocacy in Europe

## Eurocarers

Our network currently brings together 76 carer organisations and relevant research and development organisations from 26 countries. Join us!



**EURO  
CARERS**

European Association **Working for Carers**

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

# Future Directions

- 20 principles of the **European Pillar of Social Rights**
- The publication of the **European Care Strategy** this autumn
- The **Declaration of this Joint Forum of Civil Society and Scientific Research**

Thank you for your attention!

