



ENABLING CARERS TO CARE

**An EU Strategy to support
and empower informal carers**

The 10 steps towards carer-friendly societies across Europe



**EURO
CARERS**

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INTRODUCTION

Demographic ageing in Europe gives rise to a growing incidence of age-related conditions, an increasing demand for care and a serious sustainability test for our social and health-care systems. According to research, **informal carers provide over 80% of all care in Europe**, with **women providing approximately two-thirds of care** mainly as daughters (in law) and wives/partners. Estimates suggest that the **economic value of unpaid informal care** in the EU - as a percentage of the overall cost of formal Long-Term Care provision - ranges from 50 to 90 %. While it is clear that carers will be essential to meet the challenges posed by ageing societies, **free choice and personal autonomy** should remain at the core of any initiative focusing on them.

This Strategy aims to define **10 core Steps identified by the Eurocarers network to implement a carer-friendly policy environment seeking to recognise, support and empower informal carers across Europe in a comprehensive and coherent manner**. It is designed to help policy makers (as well as all other stakeholders who can improve the lives of carers, in partnership with them, and who can influence the support provided to carers) acting at EU, national and regional level to consolidate existing but sometimes tokenistic approaches and to yield **new evidence-informed initiatives in favour of carers' rights**. The Steps listed in this document are closely interconnected and should therefore be approached as part of a whole

They are in line with a vision of care which:

- Adopts individuals', carers', families' and communities' perspectives as **participants** in, and **beneficiaries** of, trusted care systems organised around their needs and preferences¹;
- Respects people's **right to choose freely whether they want to be a carer**, and to what extent they want to be involved in caring;
- **Recognises and values carers** as equal partners in care;
- **Supports and empowers carers** to manage their caring responsibilities with confidence and in good health and to have a life of their own outside of caring; and
- Seeks to **prevent situation where carers are disadvantaged, or discriminated against**, by virtue of being a carer.

STEP 1

Define and acknowledge Carers

Informal carers are vital, both to the care of people with long-term conditions and disabilities in the community and to the economy of EU countries. Yet, decision makers largely fail to meet their needs due to the use of narrow-focused definitions of informal care or the absence of such definitions in the legislation.

What should be done

- ➔ **Public authorities at International/EU, National and regional level should seek to agree on a clear and wide-ranging definition of informal care, along the lines of the definition used by Eurocarers**

Eurocarers definition of an INFORMAL CARER:

- ☑ A carer is a person who provides usually unpaid care to someone with a long-term illness, disability or other long-lasting health or care need, outside a professional or formal framework.

- ➔ **This broad definition should serve to drive the implementation of more systematic and proactive approaches to consolidate and flesh out carers' existing legal rights and to set out principles for carer support now and in the future.**

STEP 2

Identify your Carers

Despite a growing momentum around care and caring, carers still form a largely invisible and undervalued workforce in many EU member states. When carers are identified early and properly supported, they are better able to continue in their caring roles and maintain a healthy lifestyle.

What should be done

- ➔ **Public authorities and stakeholders should seek to raise awareness about informal care and to collect data about the number, typology, needs and preferences of carers through national census, surveys and self identification tools.**
- ➔ **Care professionals are in the forefront of carers' support and measures should be put in place to inform them about informal care and to train them to identify, support and cooperate with carers.**

STEP 3

Assess the needs of your Carers

Carers should have access to an assessment of the measures that might help make their life easier. This will allow to develop a personalised set of support measures which, in turn, can help support change. Carers organisations have a vital role to play in this process by engaging carers in co-designing these assessment tools and by supporting the dissemination and uptake process.

What should be done

- ➔ Public authorities should take steps to develop and – when already in existence - improve the uptake and quality of carers assessments tools in order to personalise support plans to the actual needs of carers (based on how caring affects the carer's life, including for example, physical, mental and emotional needs, and whether the carer is able or willing to carry on caring).
- ➔ Public authorities should seek to identify, nurture, support and involve organisations representing carers in the design of assessment tools.

STEP 4

Support multisectoral partnerships for integrated and community-based care services

Integrating care, services and supporting activities means that the design and delivery of care is made in a more effective manner, so that users receive a continuum of preventive, curative, rehabilitative and support interventions throughout the life course which are suited to their needs over time and are seamlessly available across different levels and areas of health and social systems. Carers should be central to the planning, shaping and delivery of services for the people with care needs and in relation to support for themselves. In this context, informal carers should be approached as partners in care.

What should be done



Partnerships of relevant actors, including informal carers, should be established in order to ensure that care services respond to the needs of the community effectively and in a personalised and holistic manner.

STEP 5

Facilitate carers' access to information and advice about care, caring and care-life balance

Carers often need to take on caregiving responsibilities without warning or planning. Most of them do not realise that they are carers and, when they do, they often struggle to access basic information about what it means to be a carer, benefits and entitlements, support services, employment, carers' breaks, training opportunities or the potential consequences for them and the cared-for person.

What should be done



Measures should be taken to develop one-stop shops for carers to access information about care, caring and the support measures at their disposal to provide quality care while maintaining a productive and healthy life. ICT-based solutions and peer support initiatives offer great potential in this respect and should therefore be encouraged and supported.

STEP 6

Pay attention to carers' health and prevent negative health outcomes

Carers frequently suffer poor physical and mental health outcomes as a result of their caregiving activities, when not adequately supported. Early identification and support along with specific preventive measures are therefore essential to maintain carers' health and wellbeing, prevent negative health outcomes and to avoid creating a vicious circle where carers themselves become unwell and in need of care.

What should be done

- ➔ **Care professionals should be informed about the health risks of informal care on carers themselves and health checks should be organised more systematically to assess Carers' health and wellbeing.**
- ➔ **Health promotion, counselling and training offer great potential to prevent negative health outcomes among informal carers. Tailor-made resource on issues relating to physical/mental health and caring should be produced and actively promoted.**
- ➔ **Access to emotional support through carers' centres, condition-specific organisations or through General Practitioners – or other primary care professionals – should be supported.**

STEP 7

Give Carers a break

Respite care is often perceived as the most important and common form of support to alleviate caregiving burden and stress. Respite care can provide carers a break from usual caring duties for a short period or a longer time. Without respite, carers may face serious health and social risks due to the stress associated with continuous caregiving, and may also have little time for essential personal and social needs or feel isolated.

What should be done

- ➔ Policies ensuring ease of access to respite, for example via financial support to pay for such breaks, geographical proximity and sufficient availability of respite services should be developed.
- ➔ Local authorities should actively provide, and support access to short breaks, which can be delivered in partnership with the voluntary sector and including respite within the home and elsewhere.

STEP 8

Provide Carers with access to training and recognise their skills

Carer training promotes carer confidence and enables carers to provide better quality care for longer and in better conditions for themselves and the person they care for. The preventive aspects of well-trained and well-supported informal carers in avoiding or delaying hospital admission and long-term institutional care are well documented. Recognising, developing and validating the numerous – sometimes very technical - skills gained by informal carers while performing their caregiving tasks also offers great potential to improve the quality of life of carers and their caree, but also to contribute to the sustainability of our care systems and to the EU (female) employment objectives.

What should be done

- ➔ Investments in carer training should be made in order to strengthen carers' skills, improve the quality of the care they provide, maximise their opportunities to maintain an active professional life and exercise their acquired talents beyond their caregiving stretch. The expertise developed by carer organisations in the topic as well as the potential offered by ICT-based solutions are huge and should be further explored.
- ➔ The possibility and added value of a certification process to apply to the competences developed by carers in the framework of their caregiving activities should be explored in order to value their skills and facilitate their adherence, (re-)entry in the labour market.

STEP 9

Prevent Carers' poverty and allow them to maintain an active professional/educational life

Taking on a caring role should not mean that people have to face financial hardship and social exclusion or give up work or education to care. Carers who want and are able to study or work should be enabled to do so, and should not be discriminated against. They should be supported at school/university and in the workplace to maintain their employment status. Carers should also have access to lifelong learning opportunities, further and higher education and skills development in ways which take account of their caring responsibilities. This is essential to avoid poverty and social exclusion and it is particularly important in the light of the gender pay and pension gap in Europe and the EU objectives in the fields of education, employment and growth.

What should be done

- ➔ Investments in carer training should be made in order to strengthen carers' skills, improve the quality of the care they provide, maximise their opportunities to maintain an active professional life and exercise their acquired talents beyond their caregiving stretch. The expertise developed by carer organisations in the topic as well as the potential offered by ICT-based solutions are significant and should be further explored.
- ➔ Financial support to carers – through care allowances or cash benefits that can be passed on to them - should be further developed and regulated. The level of financial support should be adequate enough to prevent carers from falling into poverty.
- ➔ Carer-friendly employment practices (e.g. flexible working hours, part-time work, care leave, care brokerage, mental health in the workplace, etc.) should be actively encouraged and promoted. All relevant stakeholders (workers, employers, social partners and public authorities) should be involved in shaping and implementing these legislative and practical measures.
- ➔ Young carers should be identified as early as possible (via improved vigilance and screening tools of professionals), their needs should be addressed and the needs of the whole family should be assessed. This requires good joint working between adult and children's services. The educational sector should also be made aware of the impact of informal care on (young) carers' ability to achieve educational attainment.

STEP 10

Adopt the Carers' perspective in all relevant policies

The success of initiatives aiming to address the needs and preference of carers largely depends on the interplay between a broad set of health and social policies. Yet, there is a clear need for better strategic planning and collaborative working between a wide range of services to ensure the effective delivery of co-ordinated support measures that meet the multidimensional needs of carers.

What should be done

- ➔ **Public authorities and stakeholders should ensure that this happens by supporting the implementation and achievement of the objectives defined in this document and by considering the carers' perspective in all policy developments that could potentially impact their daily life.**
- ➔ **Civil Society Organisations are invited to use the present document to emphasise the consequences of public policies on the daily life of carers and to improve the accountability of policy-makers for the impacts of their decision at all levels of policy-making.**

***LET'S MAKE
CARER-FRIENDLY
SOCIETIES
A REALITY***



