

European Carers Day – 6 October 2024

Elevating informal carers as equal partners in Europe's care systems

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Across Europe, millions of people provide unpaid care for family members, friends or neighbours with chronic illnesses, disabilities or age-related conditions. These individuals, known as "informal carers", offer essential support to those in need. The importance of informal care is not only rooted in solidarity — a value that should be upheld as a public good in our ageing society — but also in its estimated economic value, which far exceeds the budgets dedicated by Member States to professional long-term care. Informal carers are the backbone of European care systems. However, despite their critical role, informal carers are often overlooked in policy discussions and service delivery models, treated more as a silent and exploitable workforce rather than as equal partners in the caregiving process.

In recent years, especially in the aftermath of the pandemic, the lack of consideration for informal carers has drawn the attention of EU decision makers. In September 2022, the European Commission introduced the **European Care Strategy**¹ to ensure quality, affordable and accessible care services across the EU and improve the situation for both care receivers and those who care for them, whether professionally or informally.

The Strategy calls on Member States to establish clear procedures to identify informal carers and provide them with essential support. This includes fostering collaboration between informal carers and long-term care workers, helping carers access training, counselling, healthcare, psychological support and respite care. Additionally, it calls for adequate financial support, ensuring that these measures do not discourage participation in the labour market.

In response, Eurocarers, the European organisation advocating for informal carers, is launching its fifth European Carers Day campaign on the 6th October 2024, under the theme "Informal Carers ARE Partners in Care". The campaign aims to raise awareness of the vital role informal carers play in the care system and promote their inclusion in care-related decision-making processes. This year's theme emphasises the importance of moving beyond mere recognition to genuinely include carers as equal partners in care.

What does it mean for informal carers to be partners in care?

Recognising informal carers as partners in care involves acknowledging their unique insights into the needs of those they support, derived from their deep understanding of the care recipient's

¹ **Europäische Strategie für Pflege und Betreuung:** https://ec.europa.eu/commission/presscorner/detail/de/ip_22_5169
und <https://eur-lex.europa.eu/legal-content/DE/TXT/?uri=CELEX%3A52022DC0440>



condition and preferences. This intimate knowledge often provides a continuity of care that professional workers may not always be able to achieve.

Involving carers as partners integrates their expertise into care decisions, making them integral members of the care team rather than merely supporters. This collaborative approach replaces a hierarchical model with one in which carers actively participate in planning and decision-making, sharing responsibility with health and social care professionals to enhance the overall quality of care. A successful partnership relies on mutual respect and open communication, where both professionals and carers recognise each other's contributions — professionals provide clinical expertise while carers offer vital personal insights.

To facilitate this recognition, several guiding principles should be established. First and foremost, carers must be formally acknowledged within care systems. A broad and inclusive definition of informal care and carers should serve as the foundation for any actions aimed at consolidating their rights and establishing key principles for carer support now and in the future. This recognition involves affirming their essential role in the care process and ensuring that their contributions are valued by both care professionals and policymakers alike. Furthermore, recognition should extend to social and employment policies that support carers in their dual roles.

Secondly, it is crucial that carers are actively involved in decision-making processes regarding the care of their loved ones. Care professionals should consult with carers and take their input into account when developing care plans, treatments and services. Their insights can significantly enhance the quality of care by ensuring it is personalised and tailored to the specific needs of the care recipient.

Thirdly, carers should have access to adequate resources and training that enable them to fulfil their roles effectively as partners in care. This could include educational programmes on caregiving tasks, psychological support and services such as respite care to prevent burnout. Financial support should also be made available to help carers maintain their well-being while caring for others.

Finally, it is vital for European States to ensure that labour laws provide flexibility, such as offering paid carers' leave, flexible working hours or part-time opportunities. Such flexibility allows carers to continue contributing to the workforce while managing their caregiving responsibilities. Yet, balancing caregiving with employment remains a significant challenge for many informal carers.

Examples of support measures across Europe

The effectiveness of initiatives aimed at recognising informal carers as partners depends on cohesive policies across social, health and employment sectors. Several European countries have introduced measures to support informal carers actively.

Scotland has been a pioneer in this regard. The Health and Social Care Partnerships (HSCPs) integrate health and social care services across local authorities and NHS boards, ensuring that informal carers are involved in decision-making. This inclusion enhances care quality by considering carers' insights and needs. Another key initiative is the Carers Parliament, which provides a platform for informal carers to share their experiences and recommendations directly



with policymakers. This collaborative model improves care outcomes and reinforces the importance of informal carers as vital members of the care team.

The Scottish model has inspired Finland, which established the Finnish Carers' Parliament (Omaishoitoparlamentti) in 2016 to facilitate carers' involvement in policy discussions. Finland's National Care Plan also focuses on supporting informal carers through improved services and financial assistance, alongside Care Support Services that offer respite care options.

Sweden is well-known for its extensive support for informal carers. The country provides carers with access to training, counselling and peer support groups. Importantly, Swedish municipalities are legally required to assess the needs of informal carers, ensuring they receive essential services. Most recently, Sweden launched its first-ever National Carer Strategy (Nationell anhörigstrategi) to assist municipalities and regions in strengthening the carer perspective in care and support, aiming to make assistance for carers more personalised and equitable across the country. The foundation of this strategy is that carers' efforts and involvement should always be based on voluntariness.

In the **Netherlands**, the Social Support Act (Wet Maatschappelijke Ondersteuning, 2015) mandates municipalities to support informal care, enabling carers to fulfil their caregiving tasks while supporting the care recipient. The Act includes provisions for carer support, such as short-term institutional stays for care recipients, providing respite for carers. The "Strong Together for Informal Care" initiative, launched nationwide in 2020, aims to improve access to support services for carers, recognising their vital role in care planning and decision-making.

As one of the fastest-ageing countries in Europe, with a care system heavily reliant on unpaid care, **Germany** cannot afford to neglect the needs of informal carers or delay reforms that provide adequate support and recognition for them as integral partners in the care system. While informal carers receive some rights and benefits, such as financial support and respite care, they are not fully recognised as equal partners in care. The current framework acknowledges their crucial role but often focuses on support rather than integrating them into decision-making processes.

For true recognition as partners in care, a more collaborative approach is needed, involving carers in planning and decision-making alongside professionals. Although progress has been made through carer leave policies and social security measures, the concept of treating informal carers as equal partners is still developing in Germany. Increased emphasis on co-decision-making and valuing their unique insights is essential for genuine partnership recognition.

Why partnership matters: A holistic approach to care

Recognising informal carers as partners is not only fair but essential. As health and social care systems confront increasing pressures from ageing populations and workforce shortages, informal carers play a crucial role in sustaining these systems. Their insights lead to more personalised care and better outcomes.

The theme of the fifth European Carers Day, "Informal Carers ARE Partners in Care", highlights a necessary paradigm shift across Europe. Acknowledging informal carers as equal partners is



about more than just expressing gratitude - it's about ensuring they are actively involved, supported and treated as vital contributors to our care system.

By adopting this collaborative approach, health and social care systems throughout the EU can provide more comprehensive, person-centred care while safeguarding the well-being of the carers themselves. As countries implement and enhance measures to support informal carers, we hope this shift will lead to stronger, more resilient care systems that can meet the needs of Europe's ageing population.

This European Carers Day, let's commit to recognising and supporting informal carers — not merely as contributors to care but as true partners!

