

A FAIR DEAL FOR CARERS

Principles for employing informal carers

Eurocarers' Position Paper



Acknowledgments

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Contact: cc@eurocarers.org



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Executive summary

As the demand for care continues to rise across Europe, the role of informal carers has become increasingly vital. Informal carers are individuals – i.e. relatives, friends and neighbours – who provide unpaid care and support to individuals with health conditions, disabilities or age-related needs. Despite their essential contributions, informal carers often receive little recognition or support.

The formalisation of informal care through employment frameworks is a critical step in improving the quality of care, safeguarding carers' rights, and enhancing the well-being of both carers and the individuals they support. However, the success of such initiatives relies on a principled, rights-based and balanced approach addressing multiples and sometimes conflicting needs

Based on extensive dialogue, consultation, a thorough appraisal of opportunities and risks, and an analysis of existing contractual employment schemes, Eurocarers has identified **ten guiding principles essential to ensuring a 'fair deal' for carers**. This position paper presents these principles to guide the design and implementation of contractual employment schemes for informal carers. The principles aim to protect the rights and dignity of all parties involved while fostering a fair, inclusive and sustainable care system.

Principle 1

A Fair Financial Deal for Carers

Carers employed under these schemes must receive fair compensation that reflects the level of their responsibilities, aligned with public sector pay rates and always above the national minimum wage or living wage.

Principle 2

Universal Employment Rights

All contractual employment schemes must adhere to universal employment rights and comply with relevant employment legislation, ensuring fairness and protection for carers in formalised roles.

Principle 3

Choice and Self-directed Support

Employment schemes must embed the principles of choice, independent living and self-directed support. Both carers and care recipients should have the ability to define the nature and quality of their care arrangements.

Principle 4

Improved Personal Outcomes

These schemes should be designed to achieve improved personal outcomes for both carers and the individuals they support. They must never result in the deterioration of caring relationships or the quality of care provided.

Principle 5

Continuing Access to Formal Care Support

Contractual employment must complement, not replace, existing care services. Carers and care recipients must continue to have access to formal care services, along with free independent emotional and therapeutic support for carers.

Principle 6

Income Protection for the Person Requiring Care

The financial support and benefits of the care recipient must be safeguarded. No scheme should involve withdrawing financial support from the care recipient to pay the carer, as this would undermine the individual's rights and self-determination.

Principle 7

The Choice to Employ Relatives

Care recipients who receive personal budgets should have the option to employ relatives, including close family members, when this is the most suitable arrangement. Safeguards must be in place to ensure transparency and compliance with employment laws.

Principle 8

Promoting Male Engagement in Caring Roles

Employment initiatives must actively encourage male participation in caregiving roles to help reduce gender inequalities. These schemes should address traditional gender stereotypes, provide support and training, and foster an inclusive environment for all genders.

Principle 9

(Re-)Entering the Wider Employment Market

Contractual employment schemes should provide carers with opportunities for career development and include strategies for transitioning into wider employment markets beyond the care sector.

Principle 10

Partnerships and Participation

Employment schemes for informal carers must adopt a partnership approach, involving the full participation of all stakeholders. Carers' representative organisations must be recognised as equal partners at the centre of all negotiations.

In conclusion, the formalisation of informal care must be approached with careful consideration of the rights and needs of carers and care recipients alike. The ten principles above provide a robust framework for ensuring that such initiatives enhance the quality of care, support carers' livelihoods and promote fairness, inclusivity and long-term sustainability in the care system.

Introduction: Formalising informal care and involving carers in policy design

Setting the Scene

Well over 80% of care across all European countries is provided by informal carers¹ – relatives, partners, children, neighbours and friends – often with little or no formal support. As the need for long-term care grows, the provision of care for older people, adults and children with disabilities, chronic conditions or mental impairments is increasingly recognised as a societal responsibility. However, even greater responsibility will be shifted onto families if European countries fail to address pressing challenges such as demographic trends, ageing populations, the rising prevalence of chronic conditions, increasing demand for care, a shrinking workforce and significant structural issues in the care sector.

In response to the acute shortfall in long-term care provision, the European Union introduced the European Care Strategy in 2022, providing Member States with a foundational tool to enhance the accessibility, affordability and quality of long-term care. The strategy emphasises the importance of recognising and supporting informal carers, reflecting the growing aware-

ness of their crucial role in care systems and the ongoing demands from the carers' movement for equitable support as partners in care.

Notably, the European Commission calls on Member States to “*combat gender stereotypes and promote a more equal sharing of care responsibilities between women and men*” and to “*design support measures for informal carers, such as counselling, psychological support, respite care and/or adequate financial support, which do not deter labour market participation, alongside policies to formalise informal care*”².

Faced with growing shortages in the care workforce, European countries are increasingly recognising the vital role of informal carers. In this context, the ‘formalisation’ of informal care, through contractual employment for the care services provided by informal carers, is gaining traction. This approach aims to provide informal carers with a support framework and increased financial security while respecting “*the preference of the vast majority in all EU countries to maintain ‘independent living’ in their own or family homes for as long as possible.*”³

The successful integration of contractual employment into informal care arrangements can be a significant component of the necessary paradigm shift in our care systems to secure positive outcomes for all stakeholders. However, if such formalisation is not embedded within a comprehensive framework **grounded in carers' rights and choices**, it carries significant risks.

This position paper seeks **to enhance understanding of the complex issues at stake**, including the potential benefits and risks of moving towards the formalisation of informal care. It provides an in-depth exploration of the challenges that make this process a delicate balancing act, followed by **a review of the strengths and weaknesses of existing schemes**. Finally, the paper **offers 10 guiding principles** to underpin the design and the implementation of such policy.

By drawing on the unique expertise of its member organisations regarding existing measures and the challenges facing informal carers, Eurocarers aims to contribute to improving long-term care systems for the benefit of informal carers, care recipients and professional care staff alike.

Aims and objectives

Eurocarers has long advocated for an EU initiative focused on informal carers. Many of our recommendations have been integrated into the European Care Strategy and we are committed to contributing to its effective and sustainable implementation across European nations.

To achieve successful reforms, it is essential to establish a comprehensive vision for a **'Fair Deal' for Carers**, who provide over 80% of all care throughout Europe. This vision should prioritise participation and co-design with all stakeholders to ensure sustainable improvements for vulnerable individuals and the informal carers who support them.

This position paper summarises the views and interests of informal carers regarding the provision of legal status and recognition. It aims to provide guidance for all involved stakeholders, including national, regional and local governments, health and care services providers, and employers and their organisations.

Organisations working with and for informal carers, should be recognised as knowledgeable, solution-focused experts and vital partners in the design of long-term care reforms and measures that shape carers' employment and support.

We hope that the mutual learning activities⁴ introduced by the European Care Strategy will encourage Member States to ensure the **meaningful participation of carers' organisations** in the design and implementation of relevant policy reforms.

A 'living document'

The content of this document was developed through a series of consultations held between May 2023 and September 2024, led by the Eurocarers Policy Working Group. The Eurocarers network will continue to monitor future developments and will update this Policy Paper to reflect evolving practices and policies.

'Formalising' informal care: a delicate balancing act

Beyond the lack of political will and investment that contribute to the shortcomings of current measures, Eurocarers has identified several **challenges that make the design of contractual arrangements for informal care particularly complex**. This practice is still relatively recent, implemented only in a limited geographical scope and rarely evaluated. As a result, there is a lack of evidence on effective strategies for both carers and care recipients. However, based on our knowledge and experience, it is evident that successfully formalising the contributions of informal carers requires addressing the following challenges, which can only be overcome through a participative process involving all relevant stakeholders.

Safeguarding the relationship between the informal carer and the person receiving care

Direct employment by the person receiving care in the UK

In Scotland, informal carers can be employed as Personal Assistants for those requiring care, using a personal budget. However, this option is rarely used and is seen as a last resort in specific cases. Although this provision has been recently expanded, it is still not widely adopted and is primarily considered in areas with limited services or where cultural needs are unmet. Some carers appreciate this option, while others express concerns about potential strains on the carer-care recipient relationship arising from direct employment. Carer organisations are initiating discussions on this possibility. **In England**, a family member can choose to be self-employed as an alternative to becoming the direct employee of the relative in need of care using local authority payments.

In the context of a contract, the financial security offered to the carer can provide much-needed stability. However, it may also introduce strains into the personal relationship between the carer and the person receiving care. This shift can create complexities, as financial dynamics might alter the nature of their interaction, potentially leading to feelings of obligation or dependency. Such changes can exacerbate existing challenges, making it more difficult for both parties to maintain a healthy and balanced relationship.

To mitigate these risks, it is crucial to provide personalised support and counselling. This can help both the carer and the care recipient navigate the emotional and practical implications of a formalised arrangement. Additionally, it is essential to present this contractual arrangement as just one option among various available choices. Currently, many systems do not adequately promote alternative care arrangements, limiting the flexibility needed to accommodate individual circumstances and preferences. By broadening the range of options, individuals can make more informed decisions that best suit their unique needs, thereby preserving the integrity of their personal relationships.

Direct employment of a relative as Personal Assistant: insights from the Disability Movement

In countries where support is provided through a Personal Budget, direct employment of a relative as a carer already exists within the disability sector. This budget allows individuals with disabilities to pay for formal care services or hire a Personal Assistant, who may also be a relative. Such schemes empower people with disabilities by offering choices and enabling them to maintain control over their care, in line with the principles of the Independent Living movement. This model allows them to select a person who fits their lifestyle or specific needs (e.g. for travel or sport) and access one-on-one support when required, such as at work or at home.

While assuming the role of employer, which may present challenges in complying with all legal requirements, they can also receive support in managing these obligations.

Individuals with disabilities who can rely on a Personal Assistant are less likely to end up in large residential settings, which are often the least preferred option. For instance, this right is established in the Netherlands, England and Nordic countries, and is allocated at discretion in Ireland.

Although individuals with disabilities should have the freedom to choose the care arrangement that best suits their needs and lifestyle, concerns arise that hiring a family member may compromise their autonomy. This concern is particularly relevant when hiring a relative becomes the default choice due to difficulties in recruiting personal assistants. However, no data currently exists on the proportion of Personal Budget beneficiaries opting to hire a family member, nor is there evidence regarding the impact of such arrangements.

Ensuring easy access and navigation within long-term care systems while providing sufficient schemes to address all situations

To effectively support informal carers, it is crucial to provide a variety of financial support options that cater to diverse situations and preferences. However, these systems must remain clear and accessible to users; overly complex frameworks can lead to confusion, reduced self-awareness and low uptake of available resources.

For example, in **the Netherlands**, various income compensation sources exist for informal carers, ranging from token payments to the use of the care recipient's Personal Budget, tax reductions, double child benefits and carer support integrated into healthcare insurance schemes. Therefore, it is essential to offer guidance to informal carers navigating these options⁵.

Moreover, Member States must ensure that much-needed investments in financial support for informal carers are accompanied by a thorough review of existing schemes. This review should focus on delivering integrated support centred around the actual needs of users, moving away from a fragmented institutional approach and unnecessary bureaucracy.

Flexibility at the risk of role confusion

Any care arrangement involving informal carers must allow for flexibility. However, this flexibility can complicate the clear contractual definition of their responsibilities. At the same time, our ageing societies increasingly depend on individuals to care for one another, whether explicitly or implicitly. While fostering values such as volunteering

and solidarity is essential, it is equally important to strike the right balance of responsibilities between public authorities and individuals. This balance should be a central element of the policy dialogue surrounding long-term care reforms and needs to be clearly articulated.

Current trends in the Netherlands towards a shared commitment to care

A series of developments in the Netherlands are challenging the boundaries between informal, volunteer and formal care, leading to new ways of combining public and private care provision.

- Parents of children with special needs can jointly organise services, which are publicly funded, while remaining ultimately responsible for their management;
- In a recent report⁶, the Council for Public Health and Society (RVS) advocates for a shift towards a more 'hybrid' care system across the country, allowing for various mixed forms of paid, unpaid, organised, non-organised and voluntary care. This includes supporting volunteering within formal residential care settings. In this context, Vilans, a knowledge organisation focused on care and a Eurocarers member, provides informal carers with clear and accessible information on the laws and regulations that apply to different care providers, what informal carers are permitted to do, who is liable and how healthcare organisations can effectively initiate conversations about transferring care tasks.
- Commercial organisations offering informal carers support are emerging, providing assistance from laypeople to informal carers;
- An increasing number of individuals are organising themselves into 'caring communities', where residents actively look out for each other's well-being, fostering a supportive and caring environment. These initiatives, which emphasise living together, caring together and supporting each other, are represented by the network organisation 'The Netherlands Takes Care of Each Other' (Nederland Zorgt Voor Elkaar)⁷.

The risk of losing priority on investing in formal services and retaining care professionals

Carers' organisations generally do not emphasise the formalisation of informal care as a primary focus. Instead, they advocate for increased investment in formal long-term care services to address the pressing needs of both carers and care recipients. This sentiment is prevalent in most European countries, including Belgium, Italy, Ireland, Germany and Bulgaria, where the lack of adequate care services is blatant.

Too many families struggle to find adequate support for their loved ones, which can lead to increased stress and burden on informal carers. Therefore, while informal care plays a vital role in the overall care landscape, it cannot be viewed as a substitute for the need for robust, formalised care services. Instead, the contractual employment of informal carers should be seen as a complementary solution that can enhance the overall care system.

By acknowledging the vital contributions of informal carers, such a framework would enable these individuals to receive appropriate recognition and support, thereby improving their well-being. However, it is essential to prioritise the development of formal services, which can provide a safety net and ensure that all individuals receive the care they need. This dual approach would create a more integrated and sustainable care system, benefiting both carers and those they care for.

Informal care is work... but can it become employment?

Providing care is undoubtedly work – a reality that is often overlooked but fundamentally clear. Even when arising from personal choice and offering a sense of fulfilment, caregiving encompasses a wide range of physical, intellectual, organisational, operational and planning tasks. The demands associated with these responsibilities lead to a substantial investment of the carer's time and energy, firmly aligning with the international community's definition of work⁸.

However, it is crucial to recognise that informal care cannot be reduced to, or treated in the same way as, ordinary work. The nature of informal care is inherently multidimensional; the same individual providing informal care may be viewed as a worker, a service provider, a personal assistant or even as a vulnerable person at risk... These multiple realities or identities can hardly be encapsulated under the label of 'employment'. Many carers feel that this designation does not fully encompass their experiences or the essence of informal care. Therefore, it is important to think thoroughly about the terminology used when designing schemes allowing to formalise informal care, and to consider alternative wording instead of employment (such as 'Care agreement' or 'Memorandum of Understanding' for instance).

Furthermore, many informal carers express resistance to the notion of formal contracts, often preferring to provide informal care 'out of love' rather than under a contractual obligation. Even if employment schemes were widely available to informal carers, it is likely that only a fraction would take up this opportunity. This highlights the need for a nuanced understanding of informal care that respects the choices of carers while acknowledging the essential work

Current approaches to formalising informal care

Are there any 'good practices' for employing carers that could serve as a model? While some European countries have established schemes that provide informal carers with contractual safeguards, financial compensation, training and support, these initiatives often fall short of delivering fair and sustainable arrangements.

The following section examines the common strengths and weaknesses of formalisation schemes currently in place in 11 EU countries (Austria, Belgium, Bulgaria, Czech Republic, Denmark, Finland, Ireland, Italy, the Netherlands, Norway and Slovakia). Additionally, we explore an employment scheme for carers developed by home care services in Switzerland, as well as the status of Personal Assistants employed by individuals with disabilities, many of whom are informal carers.

Existing arrangements that come closest to providing legal employment status are detailed in the accompanying boxes.

How existing contractual employment schemes meet the pressing needs of informal carers:

Carer Identification

One positive outcome of these schemes is the increased identification of informal carers by public authorities. As governments and policymakers implement contractual employment frameworks, the visibility of informal carers is significantly enhanced. This visibility is crucial for several reasons. Firstly, it allows public authorities to recognise the invaluable contributions of informal carers to the overall healthcare and social support systems. By acknowledging their role, governments can better appreciate the impact that informal care has on the lives of individuals who rely on these services and on the formal care systems that might otherwise be overwhelmed without such support.

Furthermore, the development of these frameworks generates vital data that improves the understanding of the prevalence of informal care across various demographics. Such data collection is essential for informed policymaking, as it sheds light on the number of informal carers, the types of care they provide and the challenges they face. This understanding can help public authorities tailor their policies to better meet the needs of informal carers and the people they care for. For instance, identifying trends in the types of care provided can inform the allocation of resources, ensuring that support services are designed to address specific gaps in care provision.

Moreover, increased visibility can lead to greater advocacy for informal carers' rights and needs. As more informal carers are recognised in public policies, there is a greater opportunity for them to receive the support and resources necessary to sustain their caregiving roles. This recognition can also lead to the development of targeted training programmes, financial support options and respite services that enhance the well-being of informal carers, ultimately improving the quality of care received by care recipients.

Financial Support

The provision of financial support acknowledges the critical role of informal carers and offers much-needed economic compensation, especially for those facing poverty. Recognising that informal carers often provide essential services that significantly relieve the strain on formal care systems, financial support acts as a vital lifeline.

Informal carers frequently grapple with the difficult task of balancing their caregiving responsibilities with their own employment needs. This dual burden can lead to significant financial strain, as they may have to reduce working hours or even leave paid employment altogether to meet the demands of caregiving. The added economic pressures from caring for

older individuals, children or adults with chronic illnesses or disabilities can exacerbate this situation, resulting in a cycle of financial insecurity that is difficult to escape.

By providing financial support through contractual employment schemes, policymakers not only recognise the indispensable contributions of informal carers but also help alleviate some of the economic burdens they face. This support enables carers to focus on their caregiving roles without the constant worry of financial instability, allowing them to dedicate more time and energy to those they care for. Additionally, financial compensation helps promote a sense of value and legitimacy in the work that informal carers do.

Formalisation of Care Arrangements

In some instances, contractual employment schemes help to clarify caregiving roles and boundaries, even within families. This clarity is essential in fostering a more structured approach to care provision, which can prevent misunderstandings and conflicts that may arise when family dynamics are involved in caregiving arrangements. For example, **in Denmark**, the responsibility for informal care – along with the associated benefits – can be shared among different family members. This shared responsibility not only enhances the quality of care provided but also encourages collaboration and communication among family members.

By establishing clear roles and expectations through contractual agreements, family members can delineate who is responsible for specific caregiving tasks. This framework helps to ensure that everyone involved understands their obligations and the support available to them, thus promoting a more harmonious caregiving environment. When family members are aware of their roles, they are less likely to experience feelings of resentment or frustration that can arise from unacknowledged or unequal caregiving burdens.

Moreover, shared responsibility can alleviate the stress often placed on a single carer, distributing the demands of care more evenly among family members. This collaborative approach can lead to improved carer well-being, as individuals may feel less isolated in their caregiving responsibilities. By having structured arrangements in place, informal carers can better support one another, allowing for breaks and self-care without compromising the quality of care for the individual receiving support.

Ensuring Accessible Care for All

'Formalised' care arrangements provide concrete compensation for the lack of long-term care services, particularly in remote rural areas or among groups with specific linguistic and cultural needs. In Scotland and England for instance, the possibility of hiring carers as Personal Assistants for the person needing care is considered in such circumstances.

Employing Informal Carers by Home Care Services: Real Life Experiences from Switzerland (*)

The rationale for measures aimed at formalising informal care in Switzerland focuses on ensuring adequate care for all amid increasing demand due to an ageing population and chronic conditions. In Switzerland, employing informal carers through licenced home care services has been a practice since several decades, with the Federal Court addressing the issue in 2006. The policy context and conditions for employing family members as carers have significantly evolved through various reforms of social security legislation in recent decades. Currently, informal carers can be employed through home care services for the care they provide, but this is limited to specific hands-on care tasks. Salaries are funded partly by the health insurance of the home care client, municipalities and the client's financial contribution. However, everyday tasks such as household chores

and accompanying care recipients to medical appointments fall outside the list of eligible activities. The tasks that can be performed under these employment contracts are precisely defined by law and confirmed through a personal needs assessment conducted by registered nurses from the client's home care service.

This employment opportunity is available to spouses, parents, adult children of older individuals and young adult carers. People over the age of 65 are also eligible, although the employment of neighbours and friends remains a topic of debate.

While a certain level of educational attainment is a prerequisite for employment as informal carers, there was little recognition of the skills acquired through informal caring experience until 2024. Currently, the criteria, content and pedagogical approach of a dedicated training course are being designed to acknowledge the carer's expertise and skills.

The interaction between formal and informal carers necessitates capacity building and stakeholders need to adapt alongside medical advancements and the increasing complexity of care tasks. Municipalities, responsible for providing long-term care and supporting informal carers, must develop innovative multistakeholder financing models.

Employing informal carers by licenced home care services remains a relatively novel approach that challenges traditional roles and social representations. This model is currently a topic of public debate within political agendas and the media, often overshadowed by concerns about rising societal costs, despite the fact that the public has benefited from decades of unpaid care provided by family members.

While this model may not suit all situations, it offers alternative arrangements to the consumer-driven employer model. It requires further research

and adaptation but already provides informal carers with financial support and recognises their role within the care team, presenting a much-needed option within a care policy mix aimed at delivering quality care.

(): Information from a presentation by PD Dr. Iren Bischofberger, senior lecturer at the Institute of Nursing Science at the University of Vienna, Senior Researcher at ETH Zurich, TransdisciplinarityLab and president, rethinking care (Switzerland).*

However, these schemes fall short of providing sustainable and fair solutions

Insufficient Financial Remuneration

The level of financial compensation for informal carers remains inadequate. These carers should not face financial penalties for providing care to parents, partners, children, relatives or friends, nor should they be at risk of poverty, which is often the case today and perpetuates gender inequalities.

In all examined instances, the financial remuneration allocated to carers was insufficient to adequately compensate them for their caregiving responsibilities. This shortfall is evident even in the Nordic countries, which are renowned for their generous welfare systems. For example, **in Sweden**, the lack of a formal national agreement results in municipalities employing informal carers under varying financial conditions across the country.

'Towards a Participation Income for Family Carers' Research, Ireland

In Ireland, there is a growing consensus that the Carer's Allowance, established in 1990, fails to recognise, value, reward or redistribute family-based care work between families and the state, society and the market, as well as between women and men. This concern was highlighted by a recent study from Family Carers Ireland⁹. The study recommends reforming the allowance to provide income support that genuinely acknowledges the economic and social value of caregiving, enabling carers to maintain a connection to the paid labour force.

The research underpinning this transformative proposal examined the challenges informal carers face in accessing the Carer's Allowance and in providing care while receiving this benefit. Currently, the Irish income support system – largely composed of means-tested social assistance payments, labour market-dependent social insurance payments and occasional age-related universal payments – does not include mechanisms to value care work outside the paid labour market.

Merely adjusting the existing Carer's Allowance means test would not suffice to recognise the economic and social value of care or support carers in remaining connected to the workforce. Instead, the report proposes a fundamental transformation of the Carer's Allowance into a non-means-tested Informal Carer's Income Support as a form of Participation Income. While reforming the Carer's Allowance is essential for addressing carers' needs, a significant concern remains: the underinvestment in and inadequacy of services. Therefore, parallel investment in comprehensive services is crucial.

A zero-sum game for families

In some cases, providing a salary to the informal carer leads to the withdrawal of benefits for either the carer or the care recipient. Consequently, this can compromise the carer/care recipient relationship, as a single beneficiary of public support must be chosen, resulting in minimal financial improvement for the household.

This situation is evident in a pilot programme implemented in Burgenland, **Austria**, since 2019, where informal carers can be employed by local authorities. However, this arrangement often results in individuals needing care losing their care allowances¹⁰.

Lack of employment rights

A prevalent issue in many existing schemes is the denial of fundamental employment rights for informal carers. Although these individuals are often classified as 'employees' within contractual frameworks, they frequently lack access to essential rights typically afforded to formal workers. This includes crucial benefits such as health insurance, protections against excessive working hours, entitlement to annual leave and the opportunity to participate in decision-making processes related to their roles.

This lack of rights is particularly concerning given that informal carers constitute a vital segment of the broader care workforce. As highlighted in the European Care Strategy, these carers play an essential role alongside formal care workers in delivering essential support and services. By failing to extend proper employment rights to informal carers, we undermine not only their well-being and job satisfaction but also the quality of care provided to those in need.

The absence of these protections can lead to burnout and financial insecurity for carers, who may already be juggling multiple responsibilities. It also perpetuates a hierarchical system within the care sector, where informal carers are treated as secondary contributors, despite their significant contributions to caregiving.

Risk of Intersectional Discrimination

Current schemes often disproportionately attract the most vulnerable women, who frequently encounter intersectional discrimination based on factors such as gender, socioeconomic status and ethnicity. These women are often in precarious positions, with caregiving responsibilities compounding their existing challenges. The absence of clear pathways to re-enter the labour market after a period dedicated to caregiving further exacerbates their situation, increasing the risk of long-term exclusion from employment opportunities. For example, this is an active concern in **Denmark** and in **Sweden**.

In Denmark, municipalities have the authority to employ informal carers directly. To be recognised as a potential carer under this scheme, individuals often need to demonstrate that they are providing full-time care or that their informal care significantly reduces the need for care home placement. This approach allows for flexibility in care arrangements and aims to support families while acknowledging the contributions of informal carers.

However, many informal carers face significant barriers when trying to transition back into the labour market. The lack of support structures and retraining programmes means that once they step away from formal employment to provide care, they struggle to reintegrate into the workforce. This not only impacts their financial independence but also reinforces gender inequalities within the labour market, as women are often the primary carers.

Lack of a comprehensive support for informal care

Too often, financial support for informal carers is offered as a stand-alone measure, which limits its effectiveness. Many carers find themselves unable to access adequate support services that could alleviate the negative impact of their caregiving responsibilities. **In Finland**, for example, while there is a legal right to respite care for carers, this right is not effectively enforced due to a lack of sufficient facilities. As a result, carers may struggle to take breaks from their responsibilities, leading to increased stress and burnout.

The absence of accessible respite options undermines the financial support provided, as it fails to address the holistic needs of carers. This situation highlights the need for a more integrated approach that combines financial assistance with robust support services, ensuring that carers receive comprehensive help that enhances their well-being and allows them to maintain their caregiving roles effectively.

Lack of recognition of informal carers as partners in care

Overall, carers' organisations frequently lack an integrated care approach that encompasses both the individuals in need of support and the informal carers themselves. Even when receiving financial support, informal carers are often not acknowledged as equal partners alongside formal care workers within the long-term care system. This exclusion extends to the policy-making process, where they are commonly left out of consultations prior to the formulation or implementation of relevant policies. As a result, the perspectives and needs of informal carers are often overlooked, undermining efforts to create a cohesive and effective care system that values their contributions.

Formal employment in the Nordic countries: a possibility, with limitations

In Denmark, informal carers receive financial support through two main schemes:

- Compensation for loss of income: This scheme provides financial security to those who leave their jobs to take on caregiving responsibilities, such as caring for children with disabilities or providing end-of-life care. However, it is important to note that this scheme does not grant any associated rights to the carers.
- Formal employment by public authorities: carers can also be employed on a part-time or full-time basis at salaries near minimum wage.

In Norway, informal carers can be contracted by local authorities for the care they provide. However, a legal review conducted by Carers' Norway has highlighted significant loopholes:

- Absence of insurance coverage: Carers may find themselves personally liable for medical injuries and they often lack insurance for injuries sustained during caregiving activities.
- Impact on social benefits: Carers receiving social benefits risk losing these supports if they accept contracts for caregiving.
- Insufficient support for reintegration: There is a lack of adequate support plans to help carers reintegrate into paid work, employment or education once their caregiving contracts end.

In 2025, a new 'care agreement' (rather than a 'care contract') will be introduced to regulate the respective commitments of public authorities and carers, which will include some financial compensation for the latter.

In Sweden, while informal carers can be contracted by municipalities, the processes, practices and treatment vary widely across the 21 regions and 290 municipalities. Additionally, the Swedish Carers Association (Carers Sweden) is not currently involved in policy discussions related to these arrangements.

Designing Fair Care Arrangements: Key Principles

Policies supporting informal carers fairly and sustainably can only be designed through participative processes involving carers themselves. The principles listed below are intended to guide a structured dialogue between public authorities and carers' representatives prior to designing new care arrangements. They derive from the long-standing experiences of Eurocarers' member organisations, a rights-based approach and evidence from a growing body of research reports and experience in the field.

We believe that any just and sustainable policy reform concerning informal carers should be underpinned by a common ethical framework based on recognition of and respect for them, and a shared vision of respective responsibilities in care. Naturally, expectations regarding the role of the State vary depending on countries and cultural areas, and policies need to be adapted to specific contexts locally. However, long-term care is ultimately a fundamental responsibility of the State that is shared with – but should not be predominantly devolved to – the population.

The priority is therefore to invest in the development of high-quality, affordable and accessible care formal care services rather than shifting the responsibility of care to the family. In addition to providing formal services, public authorities must ensure a framework is in place to support people to care for others. They must ensure our ageing societies become more

care- and carer-friendly, involving all stakeholders' responsibility including employers'. Within this framework, informal care contracts should only be an additional possibility.

Principles

In light of the above, the formalisation of informal care via employment frameworks should be governed by the following ten principles. Each principle builds a comprehensive framework to ensure that the formalisation of informal care through contractual employment schemes is equitable, effective and sustainable, benefiting both carers and the individuals they support.

Principle 1

A Fair Financial Deal for Carers

Carers must be fairly compensated for the demanding and essential work they do. Remuneration should reflect the level of responsibility involved, be in line with public sector pay scales and never fall below the national minimum wage or living wage. Fair pay not only recognises the value of caregiving but also ensures carers are not financially disadvantaged for providing care. This is particularly crucial in maintaining the dignity and motivation of carers.

Principle 2

Universal Employment Rights

Carers employed through these schemes must enjoy the same employment rights as any other worker. This includes the right to fair wages, access to sick leave, holiday pay, pension contributions, information and training, protection under health and safety regulations,

reasonable working hours, insurance and protection from excessive liability. Adhering to existing employment legislation ensures that carers are treated with respect and are provided with the protections they deserve in their dual role as both worker and carer.

Principle 3

Choice and Self-directed Support

At the heart of any contractual employment scheme should be the principle of choice, allowing both the person needing care and the carer to have control over their care arrangements. Self-directed support ensures that care is tailored to individual needs, supporting independent living and personal preferences. Carers and those they care for should have the flexibility to determine what works best for them, from the type of care provided to how it's delivered, ensuring that care arrangements are not imposed but rather co-designed to meet personal goals. In no case should it be the subject of pressure or obligation towards the carer.

Principle 4

Improved Personal Outcomes

The ultimate aim of contractual employment schemes must be to improve the well-being of both carers and care recipients. These schemes should aim to enhance the quality of life, providing tangible benefits such as better financial security for carers and improved care outcomes for individuals. Importantly, they should avoid exacerbating any tensions in the caregiving relationship. Success should be measured not just by financial or quantitative outcomes, but by the personal and relational improvements achieved.

Principle 5

Continuing Access to Formal Care Support

Contractual employment schemes should complement, not replace, formal care services. It is essential that carers and those they care for continue to have access to professional services like respite care, nursing support or emotional and therapeutic services. Providing informal carers with employment opportunities should enhance their ability to care rather than shift the full responsibility of care onto them, which would ultimately undermine the quality of care provided.

Principle 6

Income Protection for the Person Requiring Care

The financial security of the person receiving care must be safeguarded at all costs. Contractual employment schemes run by local authorities or third parties should never divert the personal income or benefits of the care recipient to fund the carer's wage. Doing so would undermine the individual's financial independence, which is essential to their autonomy and self-determination. It is critical that any such schemes protect the financial well-being of both the carer and the person receiving care, ensuring that neither party is placed at risk. Maintaining separate and secure financial arrangements is fundamental to upholding the rights and dignity of the person in need of care.

Principle 7

The Choice to Employ Relatives

For some individuals, employing a family member as a carer is the best option, given the trust, familiarity and comfort it provides. Personal budgets should allow for this flexibility, empowering those with care needs to employ close relatives if they choose. However, this arrangement must adhere to employment regulations to prevent exploitation and ensure that all parties are protected under standard employment laws.

Principle 8

Promoting Male Engagement in Caring Roles

Historically, caregiving has been seen as a predominantly female role, leading to gender imbalances in both unpaid and paid care work. Contractual employment initiatives should actively challenge these stereotypes by encouraging greater male participation. This could include targeted outreach, training programmes and awareness campaigns that highlight the importance of caregiving and its value for all genders. By creating an inclusive and supportive environment for male carers, such initiatives can help to promote gender equality and a more balanced distribution of care responsibilities within families.

Principle 9

(Re-)Entering the Wider Employment Market

While caregiving may be a full-time role for some, many carers will eventually want or need to move into other employment. Contractual employment schemes should offer support for career development, allowing carers to gain new skills, qualifications and work experience. Exit strategies should be built into these employment schemes, providing a pathway for carers to transition into the broader job market when they want, enabling them to re-establish themselves in new career opportunities beyond the care sector.

Principle 10

Partnerships and Participation

Employment schemes for informal carers must adopt a partnership approach, involving the full participation of all stakeholders. Carers' representative organisations must be recognised as equal partners at the centre of all negotiations.

Conclusions

The evolving recognition of informal care as a societal issue is a significant step forward. However, the lack of meaningful involvement of carers in shaping the policies that affect them remains a considerable shortcoming. Informal carers, who are essential to long-term care systems, are often not included in structured dialogue, contradicting the principles of social dialogue and worker involvement outlined in principle 8 of the EU Pillar of Social Rights¹¹. This absence of recognition, coupled with the challenges of caring for a loved one, adversely impacts the health and well-being of informal carers, leading to frustration and mistrust towards policymakers. Such a situation poses not only a public health concern but also threatens the inclusivity of our democratic systems.

Carers are more than just providers of care; they are key partners in the care system alongside all care professionals. Therefore, it is essential for them to be involved in the design and implementation of policies through innovative participatory methods¹². While the contractualisation of informal care holds promise, its outcomes – whether positive or negative – will largely depend on the values and methods that underpin it. Consequently, any move to formalise informal care should be part of broader care system reforms that prioritise people and respect the intrinsic value of caregiving.

Importantly, formalising informal care should not be viewed as a cost-saving solution. It requires significant investment in support services for both carers and the individuals they care for. Providing psychological support, counselling, training, respite care and integrated formal care services alongside informal care is crucial to ensure that carers are not overburdened. Without addressing the broader challenges of long-term care, healthcare integration and public awareness, any contractual scheme will fail to achieve its intended goals.

Furthermore, financial support for informal carers must reflect the true costs of caring, including the time involved and additional expenses, such as housing, medication and mobility needs.

Based on the Eurocarers network's experience, several key elements are essential for the success and sustainability of contractualised informal care. First, caregiving must remain a choice, not an obligation, with alternative options to informal care available. Formalised care arrangements should ensure a decent standard of living for both carers and care recipients, while safeguarding the personal relationship between them.

It is also important to distinguish informal carers from professional carers, as the emotional bond with the care recipient sets their role apart. Some carers may prefer to remain outside formal contracts, and their choice should be respected and supported equally.

Clear communication of available options is crucial to ensure that carers are fully informed about the choices and support systems in place. Additionally, greater efforts are needed to raise awareness about informal carers, promote understanding of their situation, and address the isolation and discrimination they often face.

Eurocarers remains fully committed to contributing to evidence-based policy and support measures addressing these challenges and ensuring that the European Care Strategy is making a difference for carers across Europe.

Endnotes

1. Study on exploring the incidence and costs of informal long-term care in the E; European Commission, 2021.
2. European Commission, Communication on the European Care Strategy, 2022, pp. 17-18. The document highlights that “policies to formalise informal care, for example by service contracts with public authorities, can benefit informal carers and their dependents and help recognise and value better caregiving.”
3. As highlighted in the 2014 Report jointly prepared by the Social Protection Committee and the European Commission “Adequate social protection for long-term care needs in an ageing society”.
4. The COUNCIL RECOMMENDATION on access to affordable high-quality long-term care foresee that “The Commission will work jointly with the long-term care coordinators, the Social Protection Committee and the Employment Committee, as well as all other relevant stakeholders, to facilitate mutual learning, share experiences and follow up on Member State actions taken to implement this recommendation”.
5. The carers’ organisation MantelzorgNL provides detailed information on a dedicated webpage (in Dutch): <https://www.mantelzorg.nl/onderwerpen/geldzaken>
6. Anders leven en zorgen Naar een gelijkwaardig samenspel tussen naasten, vrijwilligers en beroepskrachten, Raad voor Volksgezondheid en Samenleving (RVS), 2022.
7. See for more information: <https://www.nlzve.nl/default.aspx>
8. ‘Any activity performed by persons of any sex and age to produce goods or to provide services for use by others or for own use’, definition adopted by 19th International Conference of Labour Statisticians in 2013
9. Towards a Participation Income for Family Carers, Family Carers Ireland and Maynooth University (2023)
10. This study explores a new form of income support for Irish informal carers (family carers). The report outlines a practical reform plan, detailing various steps over the next seven years, which includes governance aspects and cost estimations. It recommends establishing an Implementation Group composed of representatives from public administration, family carers and individuals needing additional care, along with clear mechanisms for benchmarking and indexing. Additionally, a Navigational Operations Group is suggested to improve the processes for applying for and proving eligibility for carers’ payments, adhering to co-production principles to facilitate practical changes in communication, training and eligibility reviews. See: <https://www.familycarers.ie/media/3113/towards-a-participation-income-for-family-carers.pdf>
11. Land Burgenland and FH Burgenland. 2019. Zukunftsplan Pflege Bedarfs- und Entwicklungsplanung 2018–2030. Available from: https://www.burgenland.at/fileadmin/user_upload/Bilder/Aktuelle_Meldungen/2019/Maerz/Zukunftsplan_Pflege_21_Massnahmen_fuer_die_Pflege_der_Zukunft.pdf.
12. See the 20 principles of the European Social Pillar [here](#).
13. For a concrete example of a successful local participatory approach, have a look at the [InCARE project](#).



12, Avenue de Broqueville - 1150 Brussels - Belgium | info@eurocarers.org
www.eurocarers.org | [f EuropeanAssociationWorkingForCarers](https://www.facebook.com/EuropeanAssociationWorkingForCarers) | [t @Eurocarers_info](https://twitter.com/Eurocarers_info)