

**Informal care,
poverty and
social exclusion**

Support to informal carers as a key component of policies aimed at combatting poverty and strengthening social cohesion.

Introduction

Europe's overall increase in life expectancy and ageing demographics are accompanied by a growing prevalence of chronic conditions and a booming demand for care in all age groups. As a result, public expenditure on long-term care (LTC) in European countries is projected to almost double by 2070 according to the European Commission¹. These projections nevertheless fail to consider the costs borne by care recipients themselves and their informal carers, or the value of the informal care on which many countries continue to rely for the provision of care. Besides, it is unclear whether the expected increase in public expenditure will suffice to meet the needs of older people, or protect them from the risk of catastrophic expenditures arising from meeting those same needs.

This sustainability challenge is aggravated by the many structural problems facing the European care sector, e.g. staff shortages, poor working conditions and job quality and inadequate skills. Against this backdrop, the development of community and home-based care has become a key EU policy priority in the last few years and is seen as a practical measure to contain the costs of services while supporting widespread preferences among (older) people².

All of this raises important questions regarding the principles of universality and equity of access to care and the responsibilities of individuals vs. the collective when it comes to the provision of long-term care. This position paper aims to highlight the association between poverty, social exclusion and informal care. It also seeks to provide pointers on where action is required to break that association.

"It is high time that States, human rights advocates and development actors recognized the importance of unpaid care work and its impact on poverty, inequality and human rights."

UN Special Rapporteur on extreme poverty and human rights, 68th session of the General Assembly (2013)

Persisting poverty and social exclusion in the EU: the importance of informal care

The European social model is often considered the best in the world. It is rooted in the principles of social justice and solidarity, and its primary aim is to foster both economic and social progress on an equal basis. Accordingly, social protection and access to employment are governments' primary instruments to fight poverty and social exclusion. Combating poverty and social exclusion is also one of the specific social policy goals of the EU and its Member States, even though social inclusion is to be achieved solely on the basis of non-legislative cooperation – the so-called open method of coordination³ – or via incentive measures and legal protection for potential victims, in accordance with the Treaty.

In spite of this, one in five people – i.e. 21.1% of the EU population or more than 92.4 million Europeans – were at risk of poverty or social exclusion⁴ in 2021 according to Eurostat. There are many sociological, structural and political factors to explain these worrying trends. In the last 15 years alone, an unprecedented combination of events has impacted European economies, including the 2008 financial/banking crisis, the Greek Debt Crisis, the Brexit Vote, the COVID-19 Pandemic and the war in Ukraine. Still, this casts a dark cloud on the efficacy of our social model and makes it critical to identify the reasons why millions of people continue to slip through the social protection safety net and fall into poverty and social exclusion.

Some of these have already been well documented. Research highlights the relationship between poverty and the probability of needing care as well as the connexion between the provision of informal care to a dependent relative (due to age, a disability or other long-lasting care needs) and informal carers' risk of poverty⁵ and social exclusion.

Firstly, there is substantial evidence that unfavourable socio-economic circumstances are strongly related to high morbidity and mortality, that socio-economic differences in health persist into old age, and

Who are the carers?

that health status is one of the strongest predictors of the use of both formal and informal care. As a result, it can be argued that **poverty is a driver of long-term care needs**.

Secondly, given the still limited public expenditure devoted to long-term care (LTC) in Europe, **care users and their informal carers may assume a significant share of LTC costs**. Out-of-pocket costs (the share of the total LTC costs that is left for care users to pay, after public support) may be very high when compared to disposable incomes, especially for home care beneficiaries with severe needs⁶. Consequently, without social protection, a majority of older people would be pushed into poverty due to out-of-pocket payments and even with social protection, many people with long-term care needs are at risk of poverty⁷.

Thirdly, **informal carers face opportunity costs due to the time spent on the provision of unpaid care**. Caring for an elderly or disabled person is different than caring for a child. It consists in an indefinite commitment, usually characterized by a growing level of responsibility and less ready access to support/respite services than is normally the case in the childcare sector. Many carers therefore have to perform a difficult balancing act between their social, professional and caregiving activities and some may have no choice but to reduce their working hours or leave the labour market altogether.

Finally, **informal carers run the risk of becoming patients themselves**. The strain and responsibility associated with informal caregiving indeed presents all the features of a chronic stress experience: it creates a physical and psychological tension over extended periods of time, it is accompanied by high levels of unpredictability and uncontrollability, it requires high levels of vigilance, and it has the capacity to create secondary stress in multiple life domains.

As identified in the last European Quality of Life Survey 2016, care, “for many societies in Europe, there is a growing gap between the need for long-term care and the availability of formal care provision”, and people may fulfil care responsibilities across the life cycle.

12% of the survey’s respondents said that they were involved in caring at least weekly for someone aged 75 or over (10% of men and 14% of women).

Involvement in care is also frequent in **people of working age**: 73% of men caring for someone who is disabled or infirm are in employment, compared to 58% of women.

Women still provide most of the care, whether for their own children, grandchildren or for relatives, friends and neighbours with a disability or infirmity. When it comes to providing care on a daily basis, twice as many women as men do so (Eurofund, 2017)

The association between socioeconomic deprivation and long-term care needs

Poverty, social exclusion and health are closely interrelated concepts. The material, behavioural and psychosocial factors that affect health outcomes are central to this relationship because they underpin the mechanisms leading from socioeconomic deprivation to ill health.

Poverty refers to a lack of the resources required to maintain an acceptable standard of living. It is commonly defined and measured by means of a monetary approach, which identifies it as a shortfall of consumption (or income) from a defined poverty line. The European Commission defines the poverty rate as the ratio of the number of people living below a threshold of 60% of median national income⁸.

Social exclusion is not just economic. It is a broader concept which relates poverty to unfavourable living conditions and it describes a situation where people do not have equal access to the opportunities and services that allow them to lead a decent life. This includes not being able to give input and have their voice heard on the rules of the society in which they live⁹.

Finally, health is defined by the World Health Organisation as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”¹⁰.

This conception is much more holistic than the purely medical model of health as it also stresses people’s personal and social resources and their ability to make choices in life, realise their aspirations, satisfy their needs and cope with their environment.

Poverty can be a cause of social exclusion, as income-poor people may become excluded due to a lack of resources or due to stigma. Low-income households appear to be much more frequently disadvantaged in non-monetary terms than the rest of the population¹¹. In turn, social exclusion can lead to poverty. People who are discriminated on the basis of their disability, ethnicity, gender or age may not get the opportunity to engage in economic activities and, consequently, may fall into income poverty¹².

In addition to genetics and lifestyles, people’s health is determined by a wide range of personal, social, economic and environmental factors (e.g. income and social status; employment and working conditions; education; physical environments; social support networks; personal behaviours and coping skills; access to healthcare; gender and culture). While the average level of health has continued to improve in the last few decades, large inequalities in health persist both between and within EU Member States. These health inequalities can be observed along a social gradient and, to put it simply, the higher one’s social position, the better one’s health is likely to be: ‘Life expectancy is shorter and most diseases are more common further down the social ladder in each society’.¹³ Poverty, social exclusion and health issues therefore tend to reinforce each other.

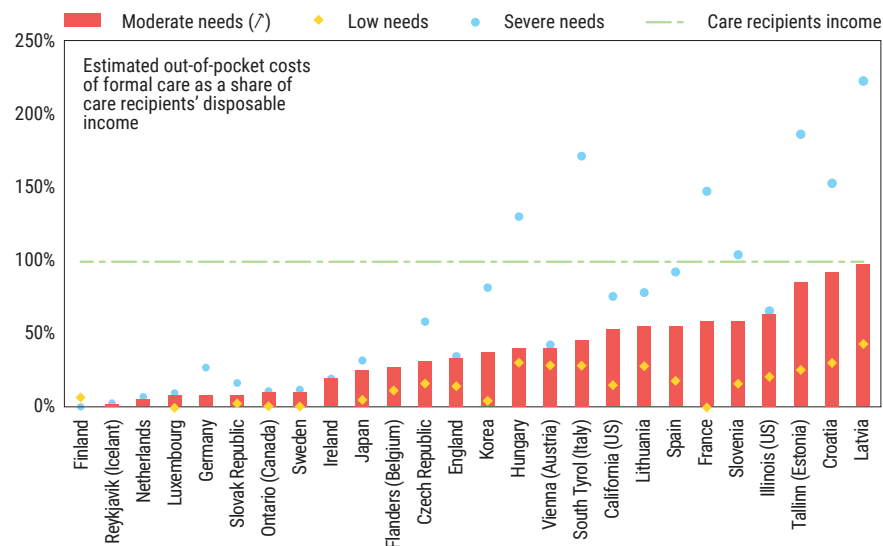
Accordingly, the general understanding is that **people in low socio-economic groups are more likely to require (informal and formal) long-term care because of their relatively high need for assistance**. Yet, professional home care services - even for moderate needs – remain unaffordable for many of them since people with low income are left the most exposed to out-of-pocket home care costs in many countries, despite means-testing. Consequently, institutional and informal care continue to be seen as preferential alternatives¹⁴, with the latter being more in line with people’s preferences. Socio-economic inequalities in the use of informal care can therefore be observed across Europe¹⁵.

It should nevertheless be mentioned that **countries with higher levels of social protection for long-term care services seem to present lower rates of informal care and smaller gender inequality in caring**. Consequently, addressing the socioeconomic determinants of health can also help alleviate the prevalence of informal care. Social protection against LTC risks is essential to support carers and women in particular. Finally, measures aiming to identify informal carers and assess their needs should pay specific attention to lower socio-economic groups.

The out-of-pocket costs of informal care

Out-of-pocket costs of care as a share of old age income after public support, for home care by severity of needs (Panel A) and for institutional care by level of income (Panel B)¹⁶

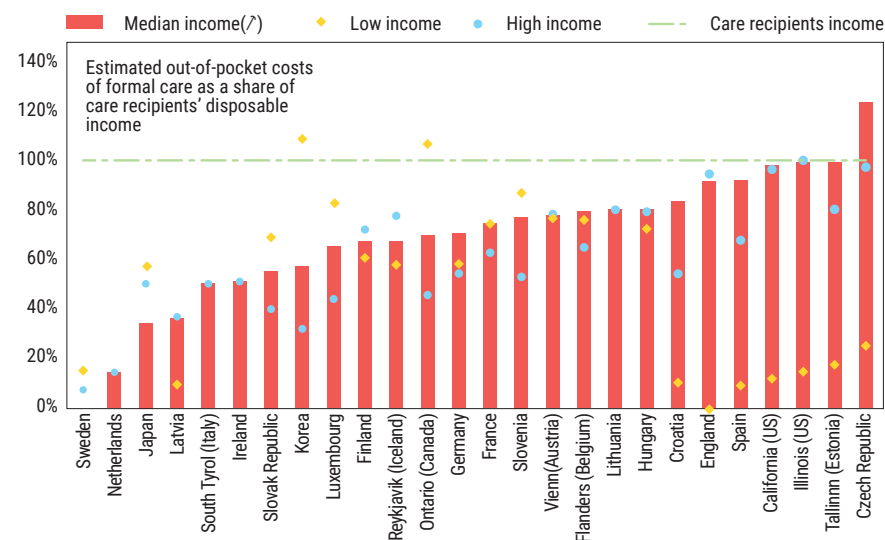
Panel A - home care for older people earning a national median income and no net wealth, by severity



Informal carers may also experience significant financial hardship as a result of their contribution to the costs of care. Long-term care needs are unpredictable by nature and their costs vary substantially depending on the level of needs, the quality of care and the financing system in place, among other factors. While many people will never have long-term care needs, others may develop severe impairments and require intensive support or even institutional care. Furthermore, LTC needs can persist over a long period of time.

People are usually expected to contribute to some extent towards the costs of their care. These out-of-pocket costs, i.e. the amount that a person is expected to pay from their own resources to access professional LTC, after social protection has been taken into account, can reveal catastrophic for both care users and their informal carers⁷. When people are completely protected from all LTC costs (which is rare), out-of-pocket costs are non-existent. When these costs are limited, people can afford to cover them without being impoverished. When out-of-pocket costs exceed the affordability threshold, paying for formal care pushes people with LTC needs into relative poverty. Alternatively, they may decide not to buy all of the care they need and suffer a reduced quality of life as a result.

Panel B - institutional care for older people with severe needs and no net wealth, by level of income



Note: Low, moderate and severe needs correspond to 6.5, 22.5 and 41.25 hours of care per week, respectively. Low income is the upper boundary of the 20th percentile of income and high income is the upper boundary of the 80th percentile of income, both among people of retirement age or older. Detailed descriptions of care recipients' needs are available in Annex A.

Source: OECD analyses based on the OECD Long-Term Care Social Protection questionnaire, the OECD Income Distribution Database and the OECD Wealth Distribution Database.

Across countries and regions, out-of-pocket spending for care tends to be lowest for low needs and highest for severe needs. Yet, even with public support, high out-of-pocket costs, can quickly become unaffordable when adding the basic costs of living at home (e.g. food and accommodation), which can amount to 50% of a person's income in some cases. Care recipients may then have no choice but to turn to relatives, friends or others for financial support or informal care, to avoid going without care.

equipment that are not - or not totally - covered by social protection systems, but are key to the wellbeing of the care recipient (i.e. incontinence aid, physiotherapy....) Moreover, housing adaptation, which not only allow care to be delivered at home and avoid unnecessary hospitalisations but also meet the preferences of most dependent people, can necessitate significant expenditures for families. Many carers are also faced with additional overheads, such as transportation costs or energy bills, as a result of their caregiving.

Care poverty¹⁷

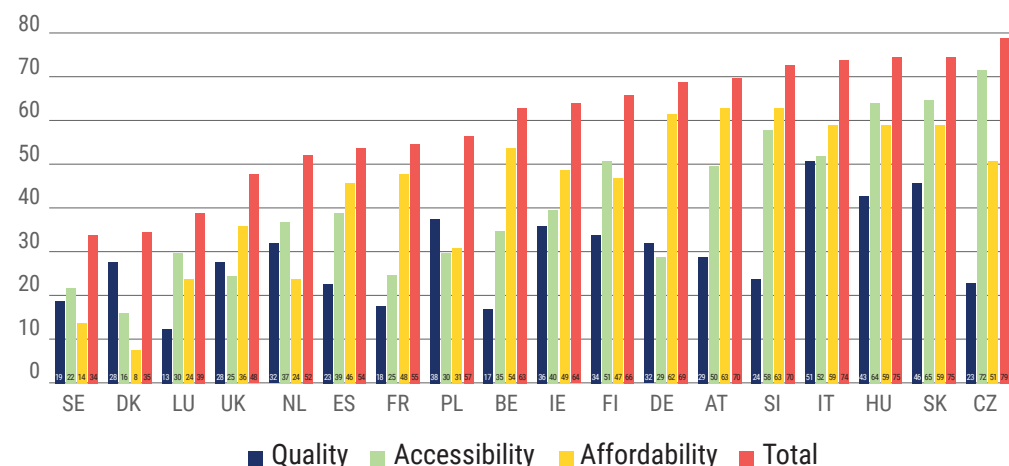
Care poverty is the deprivation of adequate coverage of care needs resulting from the interplay between individual and societal factors. It is a situation where people in need of care do not receive sufficient assistance from either informal or formal sources. The concept has been developed to point out how this inadequate coverage is not just an individual issue but a phenomenon linked to social and economic disadvantage and societal inequality.

Care is a basic human need, a necessary component of wellbeing and human dignity. Deprivation of such support therefore indicates a major social inequality. The lack of adequate care does not only reflect other dimensions of inequality (e.g. poverty or gender and ethnic discrimination). Instead, care poverty is a social phenomenon and a type of inequality in itself.

Studies on the topic have allowed to identify various predictors of care poverty. These include a person's health status, number of functional limitations or living alone. Surprisingly, gender, ethnicity and education level seem to predict care poverty only rarely. Income inequalities are closely linked to care poverty, which is not surprising since economic resources greatly enhance the capacity to purchase for-profit care and pay user fees for public care services. Still, poverty alone does not necessarily lead to care poverty. This is both because informal care resources can compensate for the lack of formal care and because care policies can bring new opportunities to people in low-income groups.

In addition to devoting their time and energy, informal carers also often contribute to the costs associated with the chronic condition of the person for whom they care. For instance, many informal carers sponsor the purchase of additional care and

Prevalence of proxy-reported unmet formal care needs in 18 European countries.
(Source: Vilaplana Prieto & Jiménez-Martín, 2015)



In addition to devoting their time and energy, informal carers also often contribute to the costs associated with the chronic condition of the person for whom they care. For instance, many informal carers sponsor the purchase of additional care and equipment that are not - or not totally - covered by social protection systems, but are key to the wellbeing of the care recipient (i.e. incontinence aid, physiotherapy....) Moreover, housing adaptation, which not only allow care to be delivered at home and avoid unnecessary hospitalisations but also meet the preferences of most dependent people, can necessitate significant expenditures for families. Many carers are also faced with additional overheads, such as transportation costs or energy bills, as a result of their caregiving.

Non-working informal carers are disproportionately affected by poverty. In 2016, 45% of non-working carers found themselves in the lowest income quartile (compared to 25% of non-carers) while 54% of them had difficulty making ends meet (compared to 38% for non-carers).

Eurofound, 2017

It should be added that, the costs of caring may also force people in vulnerable situations to seek full-time employment even if they would have preferred to be involved to a limited extent in the provision of care to a loved one. This generates a trade-off between caregiving and paid work and may have negative consequences on the quality of the care provided to the person in need, who may see his/her care needs unmet and/or be institutionalised against his/her personal wishes. Consequently, in many countries today, **people in vulnerable situations are denied the choice of caring arrangements that best meet their needs and preferences.**

Although informal carers provide a huge contribution to our societies, informal carers often have difficulties to make ends meet. **While evidence shows that informal carers are disproportionately affected by poverty and social exclusion, policies aimed at supporting informal carers remain insufficient in the EU.** Public authorities play an important role in supporting low-income carers – either directly via carer benefits and support packages or indirectly through care benefits targeted at care recipients. Improving these measures should be a priority so as to prevent carers' poverty and inequality, including via proper financial support. Many carers do not claim the full range of benefits to which they may be entitled, due to excessive red tape or a lack of information. **Given that the majority of informal carers in Europe are women, the financial impact of care on carers' socio-economic status is also a major gender equality issue.**

A survey carried out in France in 2017 highlighted that 66% of informal carers in the country contribute financially to the costs of care and spend €2,049 per year on average to support their loved one.¹⁸

A 2022 study by the Rowntree Foundation showed that, nearly a quarter (24%) of informal carers in the UK, about 2.76 million people, were living in poverty in 2019/20, compared with about one in five (21%) of non-carers. The poverty rate among working-age carers increases with the number of caring hours, particularly above 20 hours per week.¹⁹

A study conducted in Italy underlined the negative impact of a chronic disease on the income of patients (and their family). In the case of cancer, financial difficulties are associated with outcomes such as the patient's quality of life and survival. Researchers define the negative impact of the disease on the financial situation of the patient in the long run as 'financial toxicity'.²⁰



The opportunity costs of informal care



Informal care has a considerable economic and societal value. According to the EU Care Strategy, informal carers provide 33 to 39 billion hours of care per year. This unpaid work can either be approached as an in-kind contribution to society or as a cost, depending on the valuation method used. When applying the proxy good method, i.e. an estimation of the cost that would be paid to replace informal carers by professionals and therefore a proxy of their contribution, the value of informal care amounts to 2.7% of EU GDP. When applying the opportunity cost method, i.e. an estimation of the benefits forgone due to informal care, its value is equivalent to 2.4% of EU GDP. It is interesting to note that the estimated value of carers' contribution to society is slightly higher than the cost of informal care. More importantly, both methods reach a value that far exceeds the current public expenditure on long-term care (1.7% of GDP in the EU).

While the majority of informal carers in the EU are in employment, their labour market participation is inversely proportional to the intensity of the care they provide. 64% of informal carers are currently employed, compared to 67% of the overall population aged 18-64. While 71% of informal carers providing less than 10 hours per week of care are employed, the employment rate of those providing more than 40 hours per week drops to a staggering 35%.

Women, in particular in the age group 45-64, are more likely to leave the labour market as a consequence of their caring responsibilities (their employment rate is 54% compared to 59% overall in this age group). Women with caring responsibilities in this age group who drop out of the labour market face an annual wage loss of €18.000 net on average, with an impact on their pension entitlements later on in their life²¹. Informal care also causes costs for society as a whole, including losses in taxation and social security revenues due to informal carers' reduced labour market participation, and expenditure on carers' benefits.

Being a carer is major obstacle to social inclusion through employment throughout the life cycle

One of the core mechanisms whereby informal care generates more poverty and social exclusion is the obstacle it constitutes with regard to employment. This negative impact is observed at various stages of the life cycle.

- Providing care to a relative on a regular basis during youth can be a **significant impediment to completing education and training**, as well as to enjoying a normal social life. This has in return a detrimental impact of the opportunities the carer would be in a position to seize on the labour market.
- Informal caring, even with a low intensity, constitutes an important organisational constraint, which makes it **impossible for an informal carer to apply for jobs requiring availability and flexibility according to the needs of the employer**. Though, such requirements tend to be more and more a prerequisite in news forms of employment.
- Working carers struggle to conciliate their responsibilities at work with their caring duties, which often lead them to **reduce their working time or even to quit their job**, to the detriment of their income security.
- On the work place, being an informal carer is **an obstacle to professional development, career progression and promotion**. Indeed, informal care are less likely to participate in training, and to obtain more responsibilities. (Ligue des droits de l'homme, 2016)
- At school, university or on the workplace, informal carers are subjected to **isolation and stigmatisation**, reflecting a society where the value of informal caring is not recognised. (Employers for carers, UK, 2015)
- All the limitations in relation to training and employment have a very negative impact on the level of income informal carers will benefit from at the age of **retirement**.
- Given their overrepresentation among informal carers, women are the most impacted by the obstacles listed above. Informal caring is a key determinant of the **gender pay gap** as well as the **gender pension gap**.

While improving the provision of formal care remains the main answer to reducing pressure on informal carers, measures are also needed to support those who decide to provide informal care in order to mitigate the negative consequences of care responsibilities. The full implementation of the EU Work-life balance Directive, including access to flexible working conditions and care leaves is essential to allow informal carers to remain in the labour market for as long as possible. Alongside this, there is a role for employment support that helps carers reskill and return to work after a period of caring and to support carers with the capacity to work to access opportunities. Meaningful financial support to informal carers (e.g. care allowances) is also essential to recognise their work and compensate for their loss of income. Finally, informal carers' access to social protection should be reinforced. In particular, the periods of informal caregiving should be taken into consideration the calculation of pension entitlements in order to bridge (gender) pension gaps later on in life.



Informal care as a determinant of negative health and social outcomes

Informal care, especially over time or at higher intensity, can have detrimental effects on carers' health and well-being. Informal carers tend to experience poorer physical and mental health than non-carers. There is also evidence that the burden of caring is most acute among marginalised groups, for example those who are socially isolated, or of lower socioeconomic status²².

Research has found various adverse effects of informal carer on carers' physical health. Informal carers are at increased risk of illness, and specifically musculoskeletal conditions, cardiovascular disease, generalised cognitive deterioration and function, and poor sleep²³. Moreover, carers are less likely than others to meet their own health needs. This can result in harmful habits and lifestyles (smoking, inadequate food or sleep habits) and failure to take preventive health measures (such as medical consultations).

Informal carers may also experience psychological distress symptoms, such as anxiety and depression as a result of their caregiving. Caregiving increases stress and lowers psychological health, which is likely to manifest in hypertension and cardiovascular conditions²⁴. Some studies demonstrate that mortality rates are higher among carers who report emotional strain than among non-carers²⁵. Here, gender differences can be observed as male caregivers are more likely to experience detrimental effects on physical health, while women are more likely to report negative mental health outcomes.

Generally, evidence shows a progression of negative effects: carers first experience distress and depression, which are followed by physiologic changes and impaired health habits that ultimately lead to illness.

The prevalence of mental health problems among informal carers is 20% higher than among non-carers²⁶, and particularly high for people who provide very intensive care (more than 20 hours per week). Depressive disorders, anxiety, anger and hostility are frequently associated with heavier caring duties.

Many of the informal carers who provide intensive caregiving are older people themselves or have a limiting disability or health condition. Among informal carers who themselves have a limiting disability or health condition, 28% report undertaking caring activities for 20 hours a week or more. (Eurofound, 2017)

41% of non-working carers, and 27% of working carers consider their health as fair or bad compared to 22% of non-carers. (Eurofound, 2017)

Being in a vulnerable economic situation makes it even more difficult to overcome the difficulties attached to informal care. On the contrary, employed carers with higher education, those with fewer difficulties making ends meet have higher levels of satisfaction with life. (Hlebec & de Oliveira, 2016)

Caring places demands on carers that affect their physical and mental health. Based on this, a few recommendations can be formulated to prevent carers from experiencing negative health outcomes:

- support to informal carers should aim to lessen the impact on their mental health, with targeted support for depression, anxiety and stress when required;
- measures to prevent poor physical health that arise as a consequence of caregiving (e.g. injuries, back pain, high blood pressure) are an important part of supporting informal carers;
- carers with pre-existing long-term conditions and disability should receive specific attention as part of any support package;
- reducing the perceived emotional, physical and social hardships associated with caregiving and improving the quality of life of informal carers is important; and
- some groups of carers informal carers are at greater risk of poor health than others and should be targeted in priority.

Addressing the health needs of informal carers – what to do?

Poverty and social exclusion of both informal carers and their carees represent a major economic issue. Indeed, from a macro-economic point of view, missing out on the contribution of informal carers who would prefer to be active on the labour market but remain outside of it, paying no taxes or social contributions, as a result of their caregiving activities means a huge opportunity cost for our societies and a waste of human capital. The fact that informal carers are more vulnerable than other groups to poverty and social exclusion contributes to a less equal society, which in turn tends to perform less efficiently.

From a micro-economic point of view, losing trained and experienced workers, who may decide to quit their job or reduce their working time because they are not able to balance work and care anymore, means a huge cost for an employer. To such an extent that many companies are now developing innovative support measures and HR policies in order to retain those among their employees who are also informal carers. (Carers UK, 2016)

The economic value of the contribution brought by informal carers should also be better evaluated. Without their benevolent contribution, our long-term social and health protection system would simply not be sustainable. It would also have an impact on the poverty level in our societies: indeed, because they provide care freely and often share costs associated with dependency, carers contribute to buffer the risk of poverty in old age. The capacity to rely on informal care is considered as an element of the social capital of a person (Myck, 2017).

This is why, in order to ensure that our social, health and long-term care systems can still count with the vital contribution of informal carers in the future, more investment should be devoted to supporting people who are willing to care, through tailor-made services and income support.

Some public policies reinforce the negative impact of informal caring

The lack of acknowledgment of carers' contribution and the specific difficulties they face has led to the implementation of policies with a detrimental and aggravating impact on their situation.

- Against the backdrop of public deficit containment, **activation policies** have been developed across European countries and are accompanied by severe conditionality criteria to access unemployment benefits. The unemployed are invited to take up jobs under increasingly low acceptability criteria (flexible hours, distance from home...). Where strict conditionality is implemented, the specific situation of informal carers who can only take up a job that is compatible with their caregiving responsibilities, may not be considered. Informal carers may then lose their unemployment benefits, and be pushed outside of the labour market. As a result, while spending time and energy in the provision of care to a loved one, informal carers are often labelled as "inactive", and get only reduced employment support and counselling. (European Anti-Poverty Network, 2016)
- In the context of **austerity policies**, informal carers have been excessively hit by budget cuts affecting the provision of social, health and long-term care services. Yet, access to affordable and quality services is key to support informal carers in providing quality care.
- The **work-life balance of carers** – typically a woman of working age – is a thorny issue which is rarely recognised as such in policy making agendas. Only a few countries – namely those with universal and comprehensive long-term care systems – make the necessary arrangements to enable carers to remain in employment and preserve their work-life balance (Eurofound, 2015), (European Commission, 2016).
- The **lack of accessible long-term care services** of adequate quality reinforces the prevalence of informal care and the social exclusion of carers. People from a low socio-economic background often have no choice but to assume caregiving responsibilities toward a relative, due to the lack of affordable alternatives. Hence, they end up trapped in a vicious circle, as their caring duties draw them away from new opportunities. In some countries, the trend to move away from residential care has not always been coupled with the provision of adequate community-based services. (ESPN/Spasova, 2018) This implies a growing level of responsibilities for families, friends and neighbours.
- In some countries, an **income support** is provided to informal carers, either directly or to the dependent person who can use it to compensate the services provided by a carer. Financial support provisions vary greatly in terms of amount and eligibility across countries, and may be assorted of burdensome administrative procedures for dependency assessment. In most cases, they clearly fail to prevent informal carers from being exposed to poverty. Support services, likely to break the isolation affecting informal carers are also lacking.

Build policies on a better understanding of how the distribution of caring responsibilities impacts on key challenges: social cohesion, gender equality, and quality of long-term care.

Although the negative impact of carer duties on one's socio-economic status has been regularly underscored both by researchers and informal carers themselves, the amount and distribution of the caregiving responsibilities across income groups and gender are rarely among the indicators selected to inform and assess public policies against their capacity to strengthen social cohesion. **More detailed comparative data should be collected and analysed across the EU**, and more qualitative research should be undertaken so as to better understand the mechanisms at play at national or regional level.

The impact that poverty and social exclusion can have on the **quality of the care provided** should also be better analysed. Indeed, less affluent informal carers tend to **use less services**, and the difficulties they face are likely to impact on the quality of life of the person they care for (European Commission, 2014).

In the absence of adequate financial compensation, people in vulnerable situation who would be willing to give precedence to their caregiving responsibilities over their participation in the labour market are discouraged to do so due to the negative impact such a decision would have on their financial situation. This leads to negative consequences for the quality of the care received by the dependent person, who might see his or her **needs unmet and/or be institutionalised against his/her preferences**.

Better and more comparable data should be collected, and relevant indicators should be defined to inform public policies. Comprehensive strategies should be put in place at all levels likely to buffer the negative impact of caring duties throughout the lifecycle, **allowing those who want to provide care to a relative to do so with the recognition and support they need and deserve and without being economically punished for their choice**.



EC President Ursula Von der Leyen, SOTEU address 2021

If the pandemic taught us one thing, it is that time is precious. And caring for someone you love is the most precious time of all.

The European Care Strategy [aims] to support men and women in finding the best care and the best life balance for them.

Progress can be driven at the level of the European Union (EU)

The design of employment and social policies, including the organisation of welfare systems, remains a competence of the Member States. In these matters though, the EU role is to complement and coordinate EU governments' initiatives, in accordance with Article 3 of the Treaty on the European Union. Consequently, a series of policies and instruments managed by EU Institutions are relevant to the economic situation of informal carers across Europe, and can be used as leverages to foster change at national or regional level.

These include notably:

- The extensive range of **comparative data and studies** regularly published by the European Union as well as the EU research supported through Horizon 2020 and other funding programmes. While the existing EU data already provides enlightening elements of comparisons and analysis, these instruments should include a stronger focus on the impact of informal care on the socio-economic status of carers.
- Stressing the need to foster employment, in particular for women, the EU has been promoting the **reconciliation between work and private life**. Though initiatives have been primarily focusing on parents, the situation of informal carers is also considered. In April 2017, the European Commission encouraged member states to recognise that "parents and people with caring responsibilities have the right to suitable leave, flexible working arrangements and access to care services. Women and men shall have equal access to special leaves of

absence in order to fulfil their caring responsibilities and be encouraged to use them in a balanced way” and to allow parents as well as carers to a compensated leave of 5 days per year and the right to request flexible working arrangements (European Commission, 2017).

- The **EU active inclusion strategy**, adopted in 2008, aims at including people excluded from the labour through three interrelated policies: adequate income support, access to quality services, and inclusive labour markets. This strategy should guide policies targeting informal carers in a situation of poverty and social exclusion (European Commission, 2016).
- The EU has been stressing the **need to invest in fully-fleshed and accessible health and long-term care services** as well as credit care duties in pension systems as a necessity to address the challenges of our ageing societies and ensure the sustainability of our social protection systems. These recommendations are followed-up annually with the member states in the **European Semester process**.
- **The development of innovative ICT-based solutions in the area of health and long-term care** is supported at the EU level in the framework of European Innovation Partnership on Active and Healthy Ageing. Such innovative solutions, provided they remain accessible to all, can be very instrumental in facilitating the combination of work and care. ICT -based tools can also be used to reach out to informal carers, offer them online information and training, and help them break their isolation and find a space where they are able to connect and exchange with peers.
- The development of relevant training pathways specifically aimed at informal carers can deliver positive results in terms of empowerment of informal carers, and help them valorise their skills on the labour market. Indeed, informal carers develop medical, communication as well as transversal skills through their caring experience, which are not formally recognised, though likely to be valued on the labour market. In this domain, innovative projects are supported within the **European Erasmus + programme** which aims to modernise education, training and youth work across Europe.
- **European Funding instruments** (European Social Investment Funds, Cohesion Fund...) can be used to boost investment in the health and long-term care sector, including in human capital. European programmes can support transnational innovative projects to the benefit of informal carers.

Conclusions

Informal care is a complex issue which is having an increasing multidimensional impact on our ageing societies. Policy choices made today to recognise and value informal care adequately, or not, will have tremendous impact not only on the future of our health and long-term care systems, but also on the level of cohesion and poverty in our societies. Along with ensuring access to all to qualitative long-term care services (European Commission, 2017), policies at the EU and national levels should ensure that those willing to provide care to their relatives are not pushed to the margins of society and away from opportunities on the labour market.

Eurocarers will continuously advocate at the EU level to ensure that the impact of informal caring on poverty and social exclusion is considered in relevant policies, and will continue to support carers’ organisations active at national and European levels in their endeavours to translate EU incentives into concrete improvements in the life of informal carers.





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