YOUNGCARE

RELIEF FOR YOUNGER PEOPLE IN NEED OF CARE AND THEIR INFORMAL CARERS



RECOMMENDATIONS FOR POLICY-MAKERS

LONG VERSION

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Introduction

Informal caregivers play a crucial role in providing care as they usually do most of the care work. About 80% of all the people in need of care in Germany are cared for at home (BIFG, 2023). The percentage of informal caregivers within the general population differs from country to country and can reach up to 15%, as is the case in Italy (ISTAT, 2021). Yet, caregivers are often working invisibly and without financial compensation. Despite existing social regulations providing different kinds of support in cash and kind to people in need of care and their caregivers, quite often care is still primarily seen as an individual obligation.

Above all, it is the individual who has to take care of the care.

Husband caring for his wife (Portugal)

"I can tell you exactly when I got married, when I dated, when I had children. I can give all those dates. Now, when I became an informal caregiver, I don`t know. It was a role I took on, without knowing that this had a name."

(Saavedra & Dantas, 2023)



About YoungCare

Young adults – individuals aged 18-64 – face significant challenges when they need care or become carers themselves. While regularly being part of the workforce, they might lose their income or even the entire family income. Besides, they are often not only in the middle of their working life, but they may also be raising children and caring for older relatives. Caring is crucial and time-consuming, and it is very likely not the only task to be performed. Young adults in need of care are often overlooked by care services that typically focus on older adults or children. As a result, they frequently struggle to receive age-appropriate support tailored to their specific needs. To tackle this situation, the Erasmus+ project "YoungCare" aims to raise awareness of this precarious situation, create support services and help improve the structural conditions for this group.

Support us and bring attention to the circumstances of young adults in need of care and their informal carers!

The YoungCare project aims to develop and promote strategies to support both informal caregivers and young adults with care needs and disabilities. Finding suitable support offers for this group is a significant challenge. Through targeted strategies and support mechanisms, like an online learning platform, YoungCare aims to alleviate the burdens faced by them and improve the quality of care received by young adults.



Research within YoungCare

There is very little public data on our target group, as interviews with younger people in need of care and their relatives are rare. To improve this situation, desk research and 52 interviews with caregivers, people in need of care and experts were conducted and evaluated in the Netherlands, Germany, Italy, Lithuania, and Portugal.

The research focused on various aspects such as the national health and social care systems as well as topics that emerged during the interviews such as education, employment, housing, family and social life, or examples of good practice. We drafted and published five national reports about the situation within the consortium countries: Germany, Portugal, The Netherlands, Italy and Lithuania.

If you wish to learn more, the reports can be found here:



Be Informed...

The YoungCare project aims to provide learning opportunities and make constructive recommendations for improvement. For this purpose, we discussed the results of our research with 37 experts from 14 different European countries at two European roundtables. The roundtables served as a platform for discussing the project findings and gathering further insights from experts across Europe.

1. Informal carers need time to fulfil all their obligations!

Relatives of young people in need of care usually take on the role of carers while still of working age. At the same time these caregivers are often raising children, or they have to care for their parents too. Caring is often a mid-life task, and caregivers must juggle multiple roles.

Statistics on informal carers (of all age groups) show how time-consuming care can be. According to a recent survey conducted by a German health insurance company, for example, informal carers spend an average of 49 hours a week caring for their loved ones (Schwinger & Zock, 2024).

2. Carers need money to care!

Being of working age and a caregiver at the same time often means that carers (must) reduce or quit their employment. Therefore, it is not just the income of the person in need of care that may be lost. Caregivers might also experience a reduction in, or loss of, their own income too. According to the aforementioned study, a good half of informal carers, who work part-time, have had to reduce their working hours due to caregiving. More than one in four people have completely given up work due to caregiving (ibid).

Besides, special care needs can be expensive: living conditions might have to be changed, and medical treatments may have to be paid for. For example, in addition to the benefits in cash and kind provided by the public health system in Germany, additional private costs for long-term care amount to an average of 290 euros per month (ibid.)



3. Carers need less complexity and clear information to care!

Informal caregivers face the challenge of navigating fragmented support systems, which can be public and private, national and local, and part of the health and the social systems at the same time. Caregivers may have to understand the legal system to claim all their rights, while having to deal with overwhelming or unclear medical information at the same time.

Informal carers are often not even aware of their role as carers at the beginning of caring (WHO, 2024). An example from Lithuania shows how lost informal caregivers can be when they are overestimated in their abilities as carers: after a serious head injury, coma and month of hospitalisation, a mother had to decide either to take her impaired daughter home, or to place her in a nursing home. Recently retired, she dedicated her life from then on to being an informal caregiver, not only for her daughter but also for her granddaughter who was a teenager at that time. Although she had no prior experiences, it was assumed that the mother would know and be able to take care of her daughter with disabilities, who was partially paralysed, could not walk, and had difficulty orienting herself. She did not get any help until she became in need of care herself:

Lithuanian mother caring for her daughter and grandchild

"When I took her home from the hospital. [...] Moreover, there was no help from anywhere. The Social Department? No, nobody, nobody came (for 12 years) until I broke my leg here about five years ago."

(Naujanienė et al., 2023)



4. Caregivers need access to psychological support!

Informal caregiving is mainly an unknown, time consuming, intimate and finally very challenging task. It can lead to stress with negative impacts for both the caregiver and care recipient. Having to cope with stress and the daily responsibilities of family life can make social and work relations difficult to manage.

Even when there are psychological support or legal requirements, as in the case of Portugal (Segurança Social, 2022), it does not mean that they are always available or met or affordable (van Boekel & Bernitt, 2023; Fröhlich et al. 2023; Naujanienė et al. 2023; Saavedra & Dantas, 2023; Verricelli et al., 2023). Caregiving should never be at the expense of the health of the caring person. However, as our interviews demonstrated, similar situations occur frequently:

German wife and mother who cared for her husband

"I worked so much I had a stroke."

(Fröhlich et al., 2023)



5. Care has to become more gender-balanced!

Informal as well as professional care is largely provided by woman. In the Netherlands, for example, 57% of all caregivers are female (van Boekel & Bernitt, 2023). In OECD countries 60% of all informal caregivers are women. However, because of spousal care, more men are involved in informal caregiving than in formal care (WHO, 2024). However, with increasing care needs, the percentage of informal female carers seems to increase as shown by a study conducted in Germany (Hielscher et al., 2017). As long as there are more women providing care, gender inequality grows. Being a young carer often means earning a low income and being barely socially secure at the same time (Fröhlich et al., 2023).

6. Care must be valued!

Care is mainly seen as a natural, family duty, and caregivers tend to be overlooked with all the tasks they take over. Their efforts are often even disregarded within their families (ibid.). At the same time, society does not fully appreciate the benefits caregivers deliver with their voluntary care work.

For every person that is informally cared for at home, public spending on social care can be reduced. It is estimated, for example, that 80% of caregiving in Portugal is carried out by non-professional caregivers, with a majority being women (Teixeira et al., 2017). If these caregiving responsibilities were to be taken over by formal public services, public spending would amount to four billion euros annually, as mentioned by Eurocarers in 2017 (Araújo & Soeiro, 2021).



...Take Action!

1. Provide affordable, accessible and available care!

To relieve the burden on informal carers, it must at least be possible for those in need of care to be temporarily cared for outside their homes or by other carers. Options may include respite care in the care recipient's home or short-term care in an external facility during the day, overnight or on weekends. Informal caregivers need professional ambulatory and inpatient care services to supplement and guarantee home care. Policies must guarantee that professional care institutions required for these purposes are affordable, accessible and available to informal carers and care recipients at all times.

To complement professional and informal care, local low-threshold respite care services, like neighbourhood and voluntary help in general, should be promoted. For more complex cases, establishing a dialogue with informal caregivers is essential in order to better meet their needs.

Examples of good practice:

Support centres for independent living (Portugal)

The Support Model for Independent Living (MAVI), launched in 2019 in Portugal, is a pilot project aimed at empowering people with disabilities to live independently. The programme breaks the cycle of institutionalisation and reduces reliance on family caregivers, offering crucial benefits to informal caregivers as well. Through the establishment of Support Centres for Independent Living (CAVI), the MAVI programme delivers personalised assistance to individuals with disabilities, promoting autonomy and inclusion.

More information can be found here:
https://www.inr.pt/vida-independente



Neighbourhood help paid by the social care insurance (Germany)

In some German federal states like Hessen, it is possible that so called “offers to support daily life” such as accompanying care recipients to the doctor, shopping for them or simply spending time with them can be done by registered neighbourhood helpers. They can receive a compensation from the person in need of care who gets the money back from the public health system.

More information can be found here:
https://familie.hessen.de/gesundheit-und-pflege/pflege/nachbarschaftshilfe



2. Guarantee reliable and sufficient financial support!

Policies must guarantee financial support for carers. Next to the financial support for those in need of care, like a disability pension, caregivers must be financially supported themselves. Options to offer this support range from formalising informal care by employing caregivers (Eurocares, 2024) to facilitating the combination of care and paid work with flexible work arrangements and (paid) care leaves. The latter is essential to support carers of working age who wish to continue their paid employment or education. A proper work-care balance can lessen the need for income support.

Financial benefits to caregivers can take the form of care-allowances or tax relief to supplement their income. In addition, there are income compensation benefits if caregivers have to reduce

or quit their employment. A person in need of care can also hire a professional caregiver using a personal budget financed by the social security system.

Long-term informal caregivers often dedicate years of their lives to domestic care. They need support if they want to go back to the formal labour market. Besides, informal care should be socially secured to ensure caregivers' financial stability beyond their caregiving role. Contributions for social benefits (e.g., pension, healthcare, unemployment and accident insurance as well as social care insurance) cannot be caregivers' sole responsibility.

In addition, financial support for necessary medical treatments and/or changes in the living environment of the care recipient should also be guaranteed by appropriate policies. All in all, financial support must be reliable and sufficient to cover living expenses and social security costs.

A good practice example:

Informal carers as paid professionals (Sweden)

While individual co-payments for care services are open in some countries, such as Germany, they are capped in others like Sweden. Such limits and the general provision of a fully comprehensive care insurance, instead of a partially comprehensive insurance, provide people in need of care and their relatives with greater financial stability and predictability. In addition, informal carers can be employed by Swedish municipalities as official carers ('Anhöriganställning'). This allows them to be financially secure.

More information can be found here:
https://anhoriga.se/stod--utbildning/fakta-om-anhoriga/fakta-om-anhorigstod/anhoriganstallning/



3. Simplify the care system by providing clear information and digital solutions!

Policies must ensure an understandable and accessible social care system for all members of society. An example is the use of easy language as well as common languages spoken by migrants so that they can understand social rights without difficulty. Information about the benefits of the social support system must be easily accessible to all. Existing services must be visible in the public eye, and applications for benefits must be easy to understand. In general, accessibility can also be improved with the digitalisation of the social care system. However, this includes measures to improve caregivers' digital literacy as well.

In addition, it is important to reduce or prevent the fragmentation of support systems and minimise administrative loads. Despite the significant contributions made by informal caregivers, there is often a hierarchical system in the care sector, where informal carers are treated as secondary contributors (Eurocarers, 2024). Informal and professional care should be viewed as equal. Collaboration and dialogue between the two groups need to be facilitated and be part of educational standards in the relevant fields.

A good practice example:

Accessibility Toolkit (The Netherlands)

A toolkit (from the Netherlands) helps municipalities to make their website inclusive for all. It contains a step-by-step guide to convince the municipality of the need to be accessible, an accessibility test, tips on how to organise a demonstration, and advice on how to contact target group experts.

More information can be found here:
https://iederin.nl/doe-mee/zelf-lokaal-aan-de-slag/toolkit-toegankelijke-gemeentewebsites/



4. Provide prevention and assistance for mental overload!

Policies should facilitate an all-encompassing psychological support network for carers. This includes the training and further education of psychotherapists as well as prompt and accessible access to psychological help in case of need. To prevent psychological burdens for caregivers, further support like offering professional advice and counselling for caregivers as well as enabling self-help groups should be considered. Yet, informal carers do not often perceive themselves as carers and, therefore, sometimes do not see the added value that counselling can bring. Therefore, existing offers must be publicised by 'advertising' them to the target group.

The balance between individual capacity to care for someone and the burden of care needs to be determined at an early stage. For that, more recognition is needed of the difficult position of informal caregivers through awareness campaigns and school programmes. Informal caregivers need to be and feel heard, and personalised support measures should be facilitated to better fit their unique circumstances.

Examples of good practice:

Psychological training (The Netherlands)

There are different training opportunities to address caregiver burnout. Programmes, such as those offered by Mantelzorg Academie in the Netherlands, are useful to train formal caregivers to recognise and mitigate the burnout experienced by informal caregivers, enhance support and improve care quality.

More information can be found here:
https://www.mantelzorg.nl/pro/academie/verdiepingstraining-herkennen-en-tegengaan-van-overbelasting-bij-de-mantelzorger-gebaseerd-op-de-richtlijn-



Psychological support (Lithuania)

Seeking timely psychological help is very important. This Lithuanian website shows that looking for help is a sign that you care about your emotional health and quality of life. It outlines many ways to access psychological support and mental health services.

More information can be found here:
https://pagalbasau.lt/gaukpagalba/



Engaging in self-help groups (Germany)

Another possible action is joining self-help groups. In Germany there are about 100,000 of them. Self-help groups are funded by the national health system (statuary health insurance) (§20h SGB V) because of their health prevention or rehabilitation activities to the benefit of their members.

More information can be found here:
https://www.bundesgesundheitsministerium.de/service/begriffe-von-a-z/s/selbsthilfefoerderung.html

One way to find opportunities for self-help is in.kontakt (Germany), an app which enables family carers to network with each other online. It can be downloaded for Android at https://play.google.com/store/apps/details?id=de.appack.project.wir_pflegen&gl=DE&pli=1 and for Apple at: https://apps.apple.com/de/app/in-kontakt/id1451957216

Self-help groups for informal caregivers can be promoted even more extensively by the national health system. Due to the caring activities, it is unthinkable for many carers to take on an additional commitment. Many events in everyday care work are difficult to plan. That is why making a firm commitment to attend meetings seems unrealistic and can produce even more stress. As this is a difficult challenge for the development of self-help groups, this is why self-help groups for caregivers receive more comprehensive support from volunteers (§45d SGB XI).

More information can be found here:
https://www.nakos.de/data/Texte/2024/DAGSHG-Pflegeversicherung-Landesverordnungen.pdf



5. Equalize gender inequalities in caregiving!

Policies should enable potential caregivers to retain their standard of living and social security benefits if they have to reduce or even quit their employment to care for someone (see also: 2. Guarantee reliable and sufficient financial support). Doing that, opportunity costs for informal caring can be reduced: Deciding who will take over caregiving for a close family member like a parent or child is based on several individual reasons: from emotional closeness and physical proximity to questions of family and social obligations, as well as personal skills. However, economic and financial aspects play a crucial role too. As soon as a carer has to reduce or even quit paid work, opportunity costs rise, if the person with the higher income decides to become the carer.

Besides, higher wages and benefits can improve the appeal of jobs in the care sector and make it more attractive for women and men to do care work professionally. In addition, public campaigns combating gender stereotypes should improve the image of care work performed by men to let it become normality.

Examples of good practice:

Paid work leave (Italy)

Paid work leave enables caregivers to take time off for caring while retaining their jobs. In Italy employees who are caregivers (relatives up to the second degree of kinship with persons with severe disabilities) are entitled to paid work leave up to three days per month.

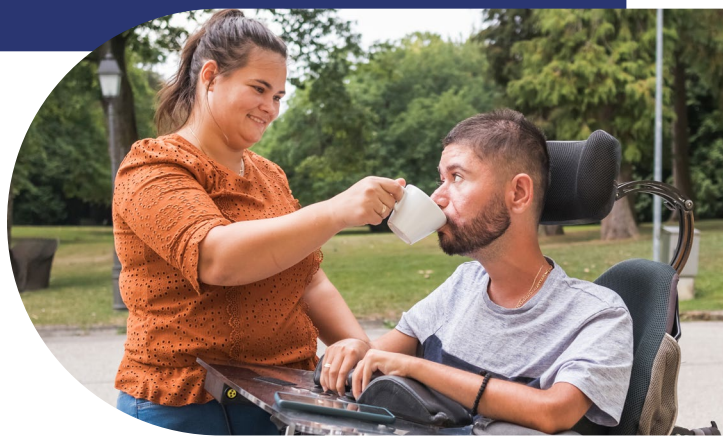
More information can be found here:
https://www.gazzettaufficiale.it/eli/id/1992/02/17/092G0108/s



Pension contributions (Germany)

In Germany the social care insurance pays pension contributions for informal carers who do not regularly work more than 30 hours a week while regularly looking after one or more care recipients for at least ten hours. Contributions are paid until the carer receives a full old-age pension and reaches the statutory retirement age.

More information can be found here:
https://www.bundesgesundheitsministerium.de/themen/pflege/online-ratgeber-pflege/leistungen-der-pflegeversicherung/leistungen-im-ueberblick/soziale-absicherung-fuer-pflegepersonen.html



Sickness benefits for informal caregivers (Lithuania)

Sickness benefit for caring for a family member is paid when the need to care for them results in loss of income from work.

More information can be found here:
https://socmin.lrv.lt/lt/veiklos-sritys/socialine-parama-kas-man-priklauso/slaugau-seimos-nari/



6. Appreciation of informal care within politics and society!

Informal care cannot be taken for granted and it is not just a private matter. Care is a public obligation. Informal caregivers offer significant help to their relatives, and support the social security system. In the European Union, informal caregivers account for about 80% of all caregiving time. This is valued at between 2.4% and 2.7% of the European Union's GDP (Huis in 't Veld, 2022).

That is why informal care has to be visible within families, society and politics. Caregivers must be recognised and appreciated by society. They deserve our gratitude!



Further Project Results

On top of these policy recommendations, YoungCare also delivers the following outcomes:

1. **Compendium: "YoungCare Guidance: Orientations for Younger People in Need of Care and Their Informal Carers"**
   This Compendium highlights the gaps in service provision and their impacts on the lives of young people in need of care and their informal caregivers. This is highlighted through portraits, testimonials, and practical knowledge.
   The Compendium can be found here: Compendium

2. **A low-threshold learning platform**
   The platform provides practical and nationally-oriented tips on housing and living, leisure and mobility, participation and employment, as well as care and support for informal caregivers of younger people in need of care.
   The platform is available here: https://edu.youngcare.eu/

3. **Recommendations for professional carers**
   The recommendations aim to raise awareness of the issues faced by young adults in need of care and their informal caregivers.

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