YOUNGCARE

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



RECOMMENDATIONS FOR PROFESSIONAL CAREGIVERS

LONG VERSION

Co-funded by the European Union

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Introduction

Informal caregivers play a crucial role in providing care, and usually do most of the care work. About 80% of all the people in need of care in Germany are cared for at home. The percentage of caregivers within the entire population differs from country to country and can reach up to 15% as in the case of Italy. 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.

"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."

(Husband caring for his wife from Portugal)



About YoungCare

Young adults – individuals aged 18-64 – face significant challenges when they need care or become carers themselves. While being part of the workforce, they might lose their income or even the entire family income. Besides, they are 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. 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 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

In some project countries, there is very little public data on our target group, and interviews with younger people in need of care and their relatives are rare. To improve this situation, desk research and a 52 interviews with caregivers, people in need of care and experts were conducted and evaluated.

The research focused on various aspects such as the national health and social care systems as well as topics that emerged during the interviews like 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 research results 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. Collaboration between professional and informal caregivers improves care quality!

Collaboration between formal and informal caregivers is increasingly important when caring for people with disabilities and care needs. Informal care is high on the political agenda in many countries. Therefore, care delivery increasingly occurs within the care triad: carers, informal caregivers and care professionals. Collaboration is not always simple and effective and, to address this, a collaborative research project between ESHPM, Zinziz, Genero, MantelzorgNL and 4 care organisations has developed practical tools that enhance the development and implementation of informal care policies by supporting formal and informal caregivers and clients to improve mutual collaboration.

A study from 2024 (Different views on collaboration between older persons, informal caregivers and care professionals Teyler van Muijden MSc, Leonoor Gräler MSc, Job van Exel PhD, Hester van de Bovenkamp PhD, Violet Petit-Steeghs PhD) highlights the importance of recognising the different views of the care triad in order to increase the involvement of informal caregivers.

By fostering collaboration, all parties involved can align their efforts to provide well-rounded care tailored to the needs of each individual.

> "Returning home was particularly tiring; good support was provided by the Byron Centre and also by the general practitioner who became an important reference point. The transition to the local services worked effectively; all the paperwork for financial support and aids had been submitted."
>
> — Italian national with acquired disability

2. Hological support is essential for caregivers!

Caring for others can be emotionally draining. Informal caregiving also affects the health of informal caregivers. Many studies have highlighted the association between caregiving and poor physical and mental health (European Commission, Directorate-General for Employment, Social Affairs and Inclusion, 2021; Schmitz and Westphal, 2015). Providing psychological resources and mental health support helps caregivers maintain their well-being and continue delivering quality care.

On this topic, an online programme developed by the Centre for Psychotraumatology at Vilnius University in cooperation with Linköping University (Sweden) has been created in to support informal caregivers who face psychological challenges when caring for family members.
In Germany, depending on your health insurance, online portals list a number of quality-approved health courses, such as relaxation training courses, which are subsidised by the respective health insurance providers.

Portugal has a mental health app that allows the user, who might not necessarily be an informal caregiver, to self-assess anxiety and depressive symptoms. It provides access to tools for managing emotions, improving sleep and adopting healthy lifestyles.

Psychological support for caregivers is essential to ensure effective and sustainable care, while preserving the mental and physical health of caregivers.

> "Due to the situation at home, my bucket is always half full and therefore overflows more quickly than, for example, colleagues who are not informal caregivers"
>
> — Dutch caregiver



3. Training empowers informal caregivers!

Many informal caregivers lack the necessary skills to handle medical tasks, recognise burnout, or use assistive technologies. Offering targeted training programmes ensures they feel confident and prepared in their caregiving role.

Informal caregivers acquire a wide range of skills and experience through their caregiving responsibilities. However, these abilities are often overlooked, despite their potential to enhance the caregiving experience for both carers and those they support. Acknowledging and developing the skills of informal caregivers is also a valuable investment for society, as their role is essential to the sustainability of long-term care systems. Moreover, recognising and strengthening these skills can help prevent social exclusion and increase caregivers' opportunities to stay active or reintegrate into the workforce. On this topic, there is a very useful tool that includes existing types of training and what works best on the basis of literary reviews: https://eurocarers.org/wp-content/uploads/2018/09/Eurocarers-Skills-and-training_final.pdf



4. Digital platforms and tools streamline care coordination!

Technology can bridge gaps between professional and informal caregivers. Integrated digital systems improve communication, facilitate information sharing, and connect caregivers to essential resources and support networks.

Digital platforms and tools have emerged as pivotal in enhancing care coordination between professional and informal caregivers, particularly for individuals requiring assistance due to disabilities. These technological solutions facilitate seamless communication, efficient information sharing, and access to essential resources, thereby improving the caregiving experience.

The development of digitally integrated healthcare service platforms has shown promise in connecting people with disabilities, their caregivers, and healthcare professionals. For instance, a study aimed to conceptualise and validate a platform using Internet of Things (IoT) devices to collect patient-generated health data (PGHD). This platform has enabled caregivers to monitor

health outcomes through mobile applications, while healthcare professionals could oversee these metrics via web systems, facilitating timely interventions and personalized care plans.

IT applications tailored for informal caregivers provide support and resources essential for effective caregiving. These applications, ranging from mobile apps to web-based platforms, assist in building informal care teams, offer educational materials, and help manage medical appointments. By coordinating care among all involved parties, these tools enhance the caregiving process and ensure that caregivers are well-equipped to handle their responsibilities.



5. Care must be person-centred and goal-oriented!

Effective care is not one-size-fits-all. By prioritising the unique needs of each care recipient and setting shared goals, professional and informal caregivers can work together to provide meaningful, individualised support. Person-centred and goal-oriented care is a healthcare approach that prioritises the individual needs, preferences, and goals of care recipients, fostering collaboration between professional and informal caregivers to deliver tailored support. This model recognises that effective care is not uniform but should be customised to each person's unique circumstances. An article by Lee A Jennings, James W Mold (Person-Centred, Goal-Oriented Care Helped My Patients Improve Their Quality of Life) highlights how crucial it is to focus on activities and relationships that are important to people in need of care with the goal of improving their quality of life.

The Dutch national report for the YoungCare project shows that current care and support offers are mostly regarded as insufficient. One of the main problems is the lack of personalised care in the Dutch healthcare system. Treatments are often too generalised, information is withheld, and consultations are inadequate. The lack of patient-focussed care is highlighted by the case of Titus Radstake, a strategic advisor on 'patient perspective' at Erasmus MC and social entrepreneur. Titus suffered a burn-out due to his demanding job and eventually fell into a depression. He was treated by his GP with anti-depressants, but they had severe side-effects. Titus set himself on fire, leading to severe 3rd degree burns and lifelong care needs. If care professionals had listened to him and had responded better to his needs, the situation could have been avoided.

"What is missing, according to the family, is a strong support structure, and a mother's perception is that she has few points of reference. There is a lack of a customised approach from the institutions, aimed above all at social integration, which is often instead offered by private voluntary associations, at the expense, however, of the families."

— Italian mother of a person born with a disability



...Take Action!

1. Practice active listening!

Professional caregivers should adopt **active listening** as a fundamental approach to fully understand the needs, emotions, and expectations of people with disabilities and their families. Active listening goes beyond simply hearing words. It involves empathy, attention to non-verbal cues, and a willingness to engage in meaningful dialogue. This approach allows caregivers to establish a **relationship of trust** with the person receiving care and their informal caregiver, ensuring that their voices are acknowledged and respected.

Caregivers should also be trained in **communication techniques** that foster open dialogue, such as paraphrasing, asking clarifying questions, and using affirmative language to validate concerns. Creating an environment where individuals feel comfortable expressing their preferences and fears, without judgment or dismissal is crucial.

Additionally, professional caregivers should take into account **cultural, linguistic, and personal differences** that may influence how people communicate their needs. This means adopting a flexible approach that accommodates diverse backgrounds, ensuring that no one feels excluded from decisions regarding their own care.

A good practice example:

Communication courses (Netherlands)

In this context, some Dutch courses that deal precisely with communication with informal caregivers are worth mentioning: Working with COM intervention; Communicating professionally with caregivers; Good cooperation with informal caregivers for nurses and carers.



2. Develop a person-centred life project to promote independent living!

Professional caregivers should actively **collaborate** with people with care needs, their families, and other stakeholders to design and implement a **personalised life plan** aligned with the individual's aspirations, capabilities, and support needs. The objective is to go beyond mere assistance and instead empower the person with disabilities to **lead an autonomous and fulfilling life**.

This life plan should take into account:

- **Personal goals and aspirations** such as education, employment, social participation, and independent living arrangements.
- **Adaptive strategies** to enhance autonomy, including assistive technologies, mobility aids, and home modifications.
- **Skills development** i.e., focusing on self-care, decision-making, and social interaction to strengthen independence.
- **Support networks** to ensure that family members, professionals, and community resources work together to provide holistic assistance.

Professional caregivers may also advocate for **inclusive environments** that enable people with disabilities and care needs to exercise their rights and make meaningful contributions to society. By emphasising **empowerment and self-determination**, caregivers help shift the perspective from dependency to capability.

Examples of good practice:

Genootschap Gepersonaliseerde Zorg (the Netherlands)

The Genootschap Gepersonaliseerde Zorg is an organisation based in the Netherlands that aims to make personalised care a standard practice in healthcare. This type of care is actively and systematically adapted to the needs, preferences and values of the patient. To achieve this goal, the Genootschap gathers knowledge and practical experience, shares what works well and promotes its vision in the healthcare sector.

Independent Living Project in Bologna (Italy)

The Municipality of Bologna has launched an innovative experiment for adults with disabilities, called 'Individual, Personalised and Participatory Life Project'. This project focuses on the rights and needs of people with disabilities and their caregivers, actively involving citizens, practitioners and associations. The aim is to create customised pathways that improve the quality of life and promote the autonomy of the people involved.



3. Foster interdisciplinary collaboration to improve service coordination!

Effective care for people with disabilities requires a coordinated approach that brings together healthcare providers, social services, educators, employment agencies, and community organisations. Professional caregivers play a key role in ensuring that these services work in synergy rather than operating in isolation.

Interdisciplinary collaboration allows for: a) a comprehensive assessment of the individual's needs, considering medical, psychological, social, and educational aspects; b) Consistent and seamless care, preventing gaps in service delivery and ensuring that different professionals communicate effectively; and c) a shared decision-making process where all stakeholders, including people with disabilities, actively participate in shaping their care plans.

An essential framework that supports this collaborative approach is the **Triangle of Care** (https://carers.org/triangle-of-care/the-triangle-of-care). This model emphasises the partnership between professionals, carers, and individuals with disabilities to create a more holistic and effective care environment. By recognising the crucial role of informal carers alongside professional support, the Triangle of Care enhances communication, reduces fragmentation in service provision, and ensures that the needs of both individuals and their families are fully addressed.

Professional caregivers should be proactive in facilitating regular case meetings, exchanging information with other service providers, and advocating for systemic improvements that enhance service integration. Breaking down bureaucratic barriers and fostering team-based collaboration ultimately leads to more efficient, person-centred care.

A good practice example:

MAVI (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**. (INR, 2022)

This model emphasises the co-creation of services, actively involving people with disabilities in decision-making and promoting their independence through personalised care.

4. Identify and provide support for informal caregivers to reduce their burden!

Informal caregivers, such as family members, often take on significant responsibilities without formal training or adequate support. Over time, this can lead to **physical exhaustion, emotional stress, and financial difficulties**. By actively recognising the challenges faced by informal caregivers, professional caregivers may guide them toward **available resources** that can alleviate their burden.

Essential areas of support include:

- **Psychological assistance** - Offering access to counselling, peer support groups, and stress management programmes.
- **Financial aid and legal support** - Helping caregivers navigate available benefits, subsidies, and work arrangements.
- **Training and education** - Providing informal caregivers with knowledge on best practices to manage disability-related challenges.
- **Respite care options** - Ensuring that informal caregivers have opportunities to rest while their loved ones receive temporary professional care.

Professional caregivers should work towards creating a **supportive ecosystem** where informal caregivers feel recognised, valued, and empowered rather than overwhelmed and isolated. A **culture of shared responsibility** between formal and informal caregivers enhances the overall quality of care and prevents burnout.

A good practice example:

Verpleegkundigen & Verzorgenden Nederland (The Netherlands)

The V&VN (Verpleegkundigen & Verzorgenden Nederland) website offers tools and guidelines to support informal carers (mantelzorgers) and prevent overload. Increasing staff shortages and an ageing population in the Netherlands have increased the responsibilities of informal carers, exposing them to the risk of overload. ‘Mantelzorg’ is a new guideline that provides guidance and tools to recognise and address signs of overload in caregivers at an early stage.

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, and points out many ways to access psychological support and mental health services.

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



Digital networking for caregivers: The “In Kontakt” App (Germany)

To support caregivers and reduce social isolation, Germany has launched the “In Kontakt” app. This digital platform connects caregivers, enabling them to share experiences, exchange advice, and access emotional support. By fostering a sense of community, the app helps mitigate loneliness and strengthens the network of informal and professional caregivers, ultimately improving the quality of care provided.

Counselling and mental health services: Public Services (ASL) (Italy)

Regional Health Services (ASL). Most Italian regions offer free or low-cost psychological support through the Local Health Authorities (ASL). Caregivers can request counselling services by contacting their local ASL, which may provide individual therapy, group therapy, or counselling sessions. The services often focus on stress management, coping mechanisms, and emotional support, allowing caregivers to navigate the challenges of their role while maintaining their own mental health.



5. Ensure accessible and clear information about care services and rights!

People with disabilities and their families often struggle to navigate the complex **bureaucratic and administrative systems** that regulate care services. Professional caregivers should ensure that individuals receive **clear, accessible, and up-to-date information** about their rights, available services, and how to access them.

This includes:

- Providing **simple explanations** of medical and social care options.
- Helping families complete necessary paperwork for disability benefits, assistive services, and care programmes.
- Directing individuals to **reliable resources**, such as government agencies, advocacy groups, and online portals with relevant information.
- Ensuring that information is available in **multiple formats**, including easy-to-read guides, digital platforms, and in-person consultations for those with literacy or accessibility barriers.

Professional caregivers could also act as **advocates**, raising awareness about policy changes and fighting for better transparency in the healthcare and social welfare systems. An **informed individual** is more empowered to make choices that best suit their needs and preferences.

A good practice example:

YoungCare website

The YoungCare website is dedicated to the 'YoungCare' project, which aims to improve the circumstances of young adults in need of care and their informal caregivers. This project involves partners from several European countries: Germany, Italy, Lithuania, the Netherlands and Portugal.

The 'YoungCare' project offers a guide with practical content for informal carers and young adults in need of care, as well as an e-learning offer.



Further Project Results

Beyond 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 adults in need of care and their informal caregivers 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 policy-makers and professional caregivers**
   These recommendations aim to raise awareness of the issues faced by young adults in need of care and their informal caregivers.
   The Recommendations for policy-makers can be found here: Recommendations

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