

Exploring the

**PHYSICAL &  
MENTAL HEALTH**

**implications of  
informal caregiving**





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The link between informal care and both physical and mental health has been widely recognised. Previous studies have predominantly highlighted the adverse effects of caregiving on carers' wellbeing, with a particular emphasis on the stress and burden involved. The provision of care to a dependent family member, friend or neighbour often exhibits all the characteristics of a chronic stress experience. This is due to the prolonged period of physical and psychological strain it generates, the unpredictability and lack of control involved, the potential for secondary stress in various aspects of life such as work and social relationships, and the need for continuous vigilance.

These stressors can lead to psychological distress symptoms for the informal carer (such as anxiety and depression), which in turn can have a negative impact on their physical health. Additionally, caregiving responsibilities can have a detrimental effect on the carer's physical health due to neglecting their own health needs. This can result in unhealthy habits and lifestyles, such as smoking, poor dietary habits, and inadequate sleep patterns, as well as a failure to seek out preventive healthcare measures, such as medical consultations.

Evidence shows a chain of adverse effects whereby carers initially encounter distress and depression, which then triggers physiological changes and deteriorating health habits, ultimately resulting in illness.

Recent studies have consistently shown that informal carers have worse physical and mental health outcomes compared to non-carers. **A 2019 review of 84 studies found that 32% of carers had depression, compared to 16% of non-carers. Additionally, 24% of carers reported anxiety, compared to 14% of non-carers. Carers were also more likely to report physical health problems, such as chronic pain, fatigue and sleep disturbances. Another study from 2020 found that carers had a 26% higher risk of developing cardiovascular disease compared to non-carers.** Overall, the evidence suggests that caregiving can have a significant impact on a carer's health, highlighting the need for support and resources for carers.

## Male caregivers are more likely to experience detrimental effects on physical health, while women more likely to report negative mental health outcomes



Researchers have also identified positive aspects of caregiving that contribute to the carer's overall life satisfaction and psychological wellbeing. Recent studies suggest that providing assistance to others can have the same beneficial effects on health as receiving support. Caregiving can instil a sense of self-worth, provide a purpose in life, allow for the acquisition of new skills and strengthen interpersonal relationships. Consequently, researchers have raised questions regarding the specific factors and circumstances that increase carer resilience, i.e. the ability to maintain wellbeing while providing care to others. It has become evident that the health and wellbeing of carers is a multifaceted issue, with perceived satisfaction and burden differing among individuals and dependent, in part, on the availability of adequate support from both formal sectors and informal caregiving networks.

# Factors Influencing the Wellbeing of Informal Carers

Recent research has highlighted different factors which can influence carers' satisfaction with life (SWL), i.e. the subjective evaluation of their own life circumstances and quality of life.

First, the factors related to caregiving and care recipients that are associated with carers' low levels of SWL include:

- ✱ Being the primary carer/lacking social support;
- ✱ Living with the care recipient;
- ✱ Providing intensive care over extended periods of time;
- ✱ Poor health or functional status of the care recipient and level of disability/dependency;
- ✱ Poor communication and relationship quality with the care recipient;
- ✱ Insufficient training or preparation for the caregiving role/perceived burden of care;
- ✱ Financial pressure;
- ✱ Personal health problems.

**In other words, the adverse health consequences of informal care are especially prevalent in high-intensity caregiving situations. This is particularly evident among carers of care recipients with cognitive impairment such as dementia, which is associated with specific symptoms such as agitation, anxiety, irritability, and behavioural disturbances that occur mainly at night. These symptoms can cause significant stress and burden on the carer, leading to negative physical and mental health outcomes.**

The factors associated with socioeconomic conditions and levels of support that increase carers' life satisfaction include:

- ✱ Adequate financial resources that can help alleviate the financial strain associated with caregiving;
- ✱ Availability of formal support services, such as home health aides, nursing services and adult day care;
- ✱ Strong social support networks, including emotional support and practical assistance from family, friends and community organisations;
- ✱ Education and training on how to provide care and manage stress associated with caregiving;
- ✱ Access to respite care or other forms of relief that can provide temporary relief from caregiving responsibilities and allow the carer to take a break;
- ✱ Ability to engage in social activities outside of the caregiving role;
- ✱ Being in employment;
- ✱ A general sense of control over the caregiving situation and ability to make decisions in the best interests of both the care recipient and the carer.

**30% of non-working carers reported depressive symptoms in the European Quality of Life Survey 2016 compared to 23% of working carers (and 19% of non-carers). This can be attributed to the fact that non-working individuals tend to have lower income levels, making them more susceptible to poverty-related issues, and also because caring responsibilities can have a greater effect on those who are not engaged in paid employment.**

The psychological factors associated with greater informal carers' Satisfaction With Life include:

- ✿ A positive appraisal of caregiving, i.e. perceiving caregiving as meaningful and rewarding, and finding personal growth through the caregiving experience;
- ✿ The use of positive coping strategies, e.g. seeking social support and engaging in problem-solving;
- ✿ Resilience: carers who are able to adapt to caregiving demands and maintain their own wellbeing despite the challenges of caring, exhibit greater life satisfaction;
- ✿ Self-confidence: Believing in one's own ability to provide care and manage caregiving responsibilities effectively;
- ✿ Sense of purpose, which refers to feeling that one's life has meaning and direction. Caring for a loved one can provide a sense of purpose and fulfilment for some carers;
- ✿ Experiencing positive emotions such as happiness, joy, and love, in the caregiving relationship is also a driver of satisfaction with life among carers.

It is worth noting that these factors are interrelated, and may work together to promote greater satisfaction with life among carers.

**Adaptability is a significant factor that influences the coping strategies that carers develop and apply to deal with the challenging situations that arise during caregiving. This ability to cope is known as resilience, which has a direct impact on the carer's personal wellbeing. However, it is important to note that resilience has its limits and may not be enough to ensure good mental health when the situation and risk factors are prolonged in time and intensity.**

Some of the factors mentioned above are inherent to the individual and beyond the influence of social policies. Nevertheless, other factors, such as access to good quality long-term care, the availability of respite care to allow informal carers to tend to their own needs and take part in non-caring activities, or the possibility for carers to balance their work and care obligations, can and ought to be instigated through social policies.

# Possible interventions to improve the Wellbeing of Informal Carers

In order to promote the health and wellbeing of informal carers, two main approaches can be taken, ideally in combination. The first involves providing more appropriate and intensive formal care services to the care recipient, which reduces the level of informal care and the pressure and reliance on the informal carer. The second option is to provide direct support to informal carers, including through respite care, training, counselling and psychological support.

## Respite care

The provision of respite care is often considered a critical and common form of support to help alleviate the challenges of caring and related stress. It involves offering carers a temporary break from their caregiving duties, with the aim of reducing their workload and enabling them to continue to provide care over a prolonged period of time. The most common forms of respite care include day-care services, in-home respite and institutional respite. Longer breaks, such as vacation breaks, can also provide relief for carers.

In recent years, a few innovative models of respite care have emerged across Europe. These include:

The **Dutch “Logeerhuis” concept** involves temporary stays for dependent persons in specially designed houses or apartments, where they receive care from trained professionals. This allows primary carers to take a break from their caring responsibilities.

The **Finnish “Mukavaa kotona” programme** provides home-based respite care, where trained volunteers visit the dependent person’s home to provide care and companionship while the primary informal carer takes a break.

The **French Baluchonage programme** where trained carers take over the care of the dependent person in their own home for a set period of time, allowing the informal carer to take a break. The programme also includes support and training for the carer.

The **Swedish “Eksjö model”** is a model of coordinated respite care where different care providers work together to provide respite tailored to the needs of the carer and the care recipient. The model includes a respite coordinator who works with the carer to plan and organise respite care.

The **Scottish Respitality concept** involves providing carers with free hotel stays or short breaks in local tourist destinations, while their loved ones are cared for by trained volunteers or professionals. This allows carers to take a break and enjoy some time off while also supporting local tourism.

However, despite the benefits of respite care, carers may be hesitant to take such breaks due to concerns about the quality of care and financial constraints. Therefore, it is important to ensure that the services provided are appropriate for the dependent person’s needs and are well-managed and staffed with qualified professionals. Policies that make it easier to access respite care, such as financial support to pay for such breaks, geographical proximity and sufficient availability of respite services, are equally important. Flexibility of respite care, such as availability during hours and days that suit the carers’ schedule, as well as the possibility to combine it with planning and transportation services for the dependent, should be considered.

## Counselling and psychological support

Recent surveys show that carers would welcome additional psychological counselling and information from health professionals. For instance, carers are not always knowledgeable about the disease of the person they care for or have difficulties dealing with disabilities. Counselling has proven effective to relieve carers’ stress. Tailor-made resource on issues relating to stress and caring should therefore be produced and actively promoted.

Counselling and psychological support play a crucial role in supporting informal carers for the following reasons:

**Emotional wellbeing:** Caring for someone can be emotionally demanding and overwhelming. Counselling and psychological support provide a safe space for carers to express their feelings, discuss their concerns and alleviate emotional distress. It helps them manage stress, anxiety, depression and other mental health issues that can arise from their caregiving responsibilities.

**Coping strategies:** Informal carers often face challenges in managing their own wellbeing while caring for others. Counselling can help carers develop effective coping strategies, learn stress management techniques and improve their resilience. They can acquire practical skills to balance their caregiving duties with self-care, leading to better overall wellbeing.

**Problem-solving and decision-making:** Counselling provides a platform for carers to explore challenges and dilemmas they encounter in their caregiving role. Through guidance and support, carers can develop problem-solving and decision-making skills to address issues related to their loved one’s care, healthcare decisions, financial matters and other relevant aspects.

**Education and information:** Counselling and psychological support can offer valuable educational resources and information specific to the care recipients' conditions. Carers can gain a better understanding of the conditions they are dealing with, learn about available support services, access practical advice, and receive guidance on navigating complex healthcare systems.

Many of Eurocarers' members and partners have developed counselling and psychological support initiatives targeted at informal carers, such as:

In Germany, various organisations offer psychological support for carers. For example, the "Deutsche Alzheimer Gesellschaft" provides counselling services, education programs, and support groups specifically tailored to carers of individuals with Alzheimer's disease and other forms of dementia.

In the Netherlands, organisations like "MantelzorgNL" provide counselling services to informal carers. These services include individual counselling, support groups and training programs to enhance carers' emotional wellbeing and provide practical assistance in their caregiving role.

Sweden has carer support centres known as "Anhörigcentrum," which offer counselling, education and respite services to informal carers. These centres aim to provide information about available support, assist with legal and financial matters, and promote the overall wellbeing of carers.

In the UK, Carers Trust, Carers UK as well as local carers' centres offer counselling services, support groups and helplines. These services offer emotional support, advice, and information to carers, enabling them to better manage their caregiving responsibilities.

## Training and education programmes

Carer training promotes carer confidence and enables carers to provide better quality care for longer and in better conditions for themselves and the person for whom they care. Carers who receive training feel better supported in their caring role and more confident. The preventive aspects of well-trained and well-supported informal carers in avoiding or delaying hospital admission and long-term institutional care are also well documented.

Training, especially in core caring skills e.g. manual handling, coping with caring, knowledge of conditions and in situations where carers need to manage and monitor complex medication prescriptions, coordinate and implement complex medical procedures is essential in this respect. Training in stress-management techniques is also useful to prevent informal carers' burn-out and therefore unwanted and unprepared institutional care. Finally, it can also contribute to preventing mistreatment by raising awareness about Human Rights issues related to caregiving, but also by breaking carers' isolation and by drawing their attention to their own wellbeing and life satisfaction.

Informal carers gain a great amount of – sometimes very technical – skills while performing their caregiving tasks. These include personal care (bathing, washing, feeding, dressing, managing incontinence...) as well as specific medical care (e.g. home-based dialyses, management of oxygen/nebulisers, monitoring of blood and insulin levels in the case of diabetes, tracheotomy patient care, blood pressure monitoring, colostomy bag management, administration of medication, diet monitoring, etc.). In addition, carers also develop a wide range of communication skills and often have to deal with challenging behaviours in the context of demanding care needs (e.g. dementia or other mental illnesses). Finally, they also acquire important transversal skills, as they tend to organise and manage care arrangements for their loved ones, involving a range of



health and social care professionals, while also managing their own professional and family responsibilities. Planning, managing competing priorities, sharing information, coordinating, using digital tools are among the skills they apply in their everyday life.

Yet, these skills are generally undervalued even though they could be an important instrument to improve the caring experience both for carers and their caree and to secure carers' crucial contribution to long-term care systems. Moreover, valuing and strengthening informal carers' skills may prove promising to counter their social exclusion and to improve their chances of maintaining an active professional life or to re-enter the labour market.

Across Europe, most social support and training is typically provided through local initiatives and relies heavily on the voluntary sector. Linking the efforts of private voluntary organisations and community associations with public authorities can be important to scale up service delivery, reduce fragmentation and improve the coordination of services.

## Health promotion and disease prevention for carers

Health promotion and disease prevention are crucial for informal carers for several reasons:

Informal carers often experience physical, emotional and psychological strain due to their caregiving responsibilities. Health promotion activities, such as providing information on healthy lifestyles, stress management and self-care techniques, can help carers maintain their wellbeing, reduce the risk of burnout and enhance their overall quality of life.

Caregiving can be physically demanding, leading to increased risks of health problems for carers themselves. Health promotion interventions can focus on promoting physical activity, proper nutrition, regular health check-ups and preventive measures such as vaccinations. It is recognised that a holistic carer assessment is an important step in providing timely, responsive information, advice and support that match the preferences and needs of the individual carer concerned. These measures should be correlated to the level of intensity of the caregiving responsibilities (e.g. carers of people with mental health problems, neurodegenerative condition or with high-level functional limitations) and – therefore - risk of adverse health outcomes.

Since informal carers are at a higher risk of experiencing mental health issues such as anxiety and depression, health promotion efforts can include mental health awareness campaigns, access to counselling or support groups and education on stress reduction techniques. Promoting good mental health can help carers cope with the emotional challenges of caregiving and improve their overall psychological wellbeing.

By providing information on disease prevention and health promotion, carers can be empowered to recognise and reduce potential risks for both themselves and the individuals they care for. This may include education on infection control measures, medication management, falls prevention and other safety-related practices. By implementing preventive measures, carers can minimise the occurrence of accidents, injuries and illnesses among care recipients and themselves.

Finally, by focusing on health promotion and disease prevention, efforts can be made to support carers in maintaining their caregiving roles for longer durations. Promoting the wellbeing of carers helps prevent carer fatigue, reduce the likelihood of premature institutionalisation of care recipients and enables carers to continue providing care more effectively.

However, all of this implies the identification of informal carers in national health and social care systems to enable systematic data collection, to target carers and to inform them about the range of support available to them.

## Work-life-care balance measures

Preserving informal carers' access to the labour market can be beneficial to their health and wellbeing in several ways:

Being employed provides a source of income, which can alleviate financial burdens and reduce stress associated with caregiving responsibilities. **Financial security and stability** allow carers to meet their own needs and the needs of their dependents, potentially reducing financial strain and improving overall wellbeing.

Employment can offer **opportunities for social interaction and engagement** outside the caregiving role. It allows carers to interact with colleagues, build social connections and establish supportive relationships, which can help combat feelings of isolation and provide a sense of belonging.

Having a job allows carers to maintain their own **personal identity** separate from their caregiving role. It provides a **sense of purpose**, achievement, and fulfilment through utilizing their skills and contributing to society. This can enhance self-esteem and overall wellbeing.

Being employed can provide a **respite** from the demanding and continuous caregiving responsibilities. It offers a structured schedule and dedicated time away from caregiving, allowing carers to recharge, engage in activities they enjoy, and prioritize self-care, which is essential for their health and wellbeing.

Many employers offer **extra-legal benefits** such as health insurance, retirement plans and access to employee assistance programs. These benefits can support carers' physical and mental health needs by providing access to healthcare services, counselling and resources for managing stress and caregiving-related challenges.

Finally, employment can offer **opportunities for skill development, training, and career advancement**. By investing in their professional growth, carers may increase their job satisfaction, financial prospects and long-term career prospects, which can positively impact their overall wellbeing.

## Access to good-quality long-term care

This can help reduce the burden on informal carers, allowing them to take time off and attend to their personal needs.

### Information and coordination of services

Carers may not be fully aware of services available to them and may find it difficult to get help from fragmented services. The internet is a source of useful information to the carer, although they are often left alone to address administrative issues. Daily planning of tasks and duties may be difficult for carers and cause burnout. Dealing with doctors' or social workers' appointments and organising respite care appointments may be difficult, especially when combined with personal or familial duties and employment. One-stop shops for carers and their families, i.e. information centres where carers can get the info they need on the help at their disposal (financial, physical, emotional and social) and the caree's condition can prove extremely beneficial to carers' wellbeing.

### **Case (or care) managers**

Carers often find themselves coordinating scattered health and social services. The support of a case/care manager can help alleviate the administrative burden facing carers following an assessment of their needs and those of the person they care for. Managers allow to bridge gaps between health and social care provisions and empower carers with knowledge and skills to face the worries related to their caregiving duties. Professional case/care managers nevertheless need to reach out to carers in a proactive way since they are not always forthcoming in their search for help, may be overburdened by their caring activities or simply afraid to shed light on their own limitations. Identifying carers through adequate professionals trained to support them is therefore key: general practitioners, nurses, pharmacists and other health professionals are all well placed to detect and advise carers or to refer them to a more specialised source of information and support.

In conclusion, if not adequately supported, carers risk to become patients themselves. This is even more likely in the light of demographic ageing since the population of carers itself is growing older. As a result, carers might no longer be able to satisfy the increasing demand for long term care (with serious sustainability issues for European welfare systems) and will convert into a burden for public finances (as they will also require care). If European States want carers to keep on providing care, it is in their interest to put in place adequate long-term care policies and practical support measures for carers.

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