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TRANSNATIONAL STOCKTAKING REPORT

CATRO Bulgaria - care4carers Consortium

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Project Information

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I. Executive summary

It is estimated that informal carers provide **over 80%** of all long-term care in Europe, with an especially heavy burden falling on **women**. The role of family carers (family members or friends providing unpaid care) is thus critical and will grow in importance even more in the future due to the **ageing population** and increase of **age-related diseases**. Despite the high toll this (often) underestimated and misunderstood role takes on so many people in Europe, this group remains **largely neglected** when it comes to the availability of a structured support system, designed **specifically for them**.

The Care4Carers project seeks to fill this gap through the development of an **innovative and interactive support programme** designed to address informal carers' specific needs. In particular, the project aims to develop **individually tailored counselling offers** for family carers to support their re-entry into the labour market, to facilitate the reconciliation of caregiving and work life, to strengthen their abilities to develop new career perspectives, to improve their knowledge on the job market and job application techniques, to promote their social, personal, and professional competences. To shape these offers in the most adequate way, the project partnership consisting of **7 partner organizations** from Austria, Bulgaria, Cyprus, Denmark, Germany, Greece, and Italy conducted a **thorough transnational research** on the overall state of informal family care and the existing good practices for support schemes in each country. Through qualitative interviews the partners identified the **main challenges** family carers face, their **fears and hopes** regarding balancing work and care or re-entry and re-integration into the labour market, as well as the **opportunities** for personal and professional growth they see in the care situation. Moreover, the research further identified the **learning needs** of both family carers and (counselling or training) professionals working with them – the two main target groups of the project.

Different national and international studies show that the sector of informal care in the 7 partner countries is significant even if not all of them provide **official statistics** on the exact number of family carers. This translates also to the existence of **specific institutional structures** and **available funding** for these groups (or lack thereof, respectively). While some of the countries like Denmark, Austria and Germany already have a certain support system in place, others like Bulgaria, Cyprus, Greece, and Italy rather remain with underdeveloped structures, lack of sufficient state funding or even legal recognition of the carers' role to begin with. There is also a **difference in the way family care is perceived in society:** while in the eastern/southern countries caring for a family member is rather viewed

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as a family matter, in the central/northern partner countries this issue is institutionalized and better regulated. In all 7 countries, however, with a varying extent, female family carers face **difficulties reconciling work with care** and are (more often than not) forced to leave their job.

Despite the striking number of informal carers in most partner countries, the desk and field research findings confirmed that the issue of informal care is **not properly addressed** everywhere. There don't seem to be enough (specifically targeted) initiatives on a state level to support carers and **the system rather relies on NGOs and relevant associations** of patients to provide mainly psychological support also to their families and carers. While psychological and emotional issues are indeed one of the main challenges faced by family carers, the research shows that health risks, social exclusion and isolation, financial difficulties, reduced employability chances were also identified as common struggles.

When it comes to career counselling and integration in the labour market, the picture looks even more fragmented. **Some steps have been taken** in certain countries to ensure more flexible working conditions for carers who are already in the labour market, reconciling care with work. Yet, there are **barely any provisions** meant for carers who are not in the labour market for a certain period and many, especially those in a more advanced age (50 and above), consider it impossible to reintegrate back into it. Not being able to get back to work (for different reasons) is one of the main fears, expressed by interviewed family carers. This is observed in combination with the general **lack of awareness** among many caregivers about the competences they acquire during the care episodes. There are some carers, who are, from the distance of time, able to identify certain personal and professional competences they have developed, which can be put into use during job seeking. Yet carers **need guidance** by professional educators and career counsellors during the process of realizing their strengths, formally recognizing them as well as expanding them further.

At the same time, the research shows a **gap in the provision of training related to family care,** which is meant for counsellors themselves. Despite identifying some general coaching approaches and specific competence assessment methodologies they use in their work, most of the professionals interviewed have **little experience** with the target group of family carers. There is also **little knowledge** among trainers and counsellors concerning the existing support options for family carers in their respective country (funding schemes, tailored training, psychological relief, career counselling, peer-to-peer support). As a response to the perceived by both sides **lack of easily accessible information**, the project provides a compilation of existing offers suitable for family carers

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and good practices in each partner country. The list is **openly accessible on the project website** and can be used as reference by both target groups.

II. Introduction

Family carers (or informal caregivers) are family members who provide mostly **unpaid care** to elderly or chronically ill relatives. Although family members account for the biggest group, family carers can also involve friends, acquaintances, neighbours, and others providing care to a sick or older person. It is estimated that informal carers provide **over 80%** of all long-term care in Europe, with an especially **heavy burden falling on women**, who provide about two thirds of care (Hoffman & Rodrigues, 2010). The role of family carers is thus critical and will grow in importance even more in the future due to **the ageing population and increase of age-related diseases**.

In this light, a **comprehensive and well-designed support system** for carers is highly relevant and constitutes an important long-term investment for the whole society. The work of family carers is both physically and mentally demanding, and often requires a **complete lifestyle change and shift in priorities**. Due to the nature of their work, carers find it often difficult to effectively combine care, career and personal life, which may result in the **lack of privacy**, **professional growth** and **free time**. Family carers are also likely to experience **exhaustion**, **stress,** and **work overload**, leading to burnout and mental health problems, such as depression and anxiety. In order to minimise the negative impacts of caregiving, well-designed support structures are needed. Currently, the provision as well as the quality of support systems differ significantly across Europe. Most countries do provide some help in the form of **training or counselling**, but only a minority offer these in a well-structured way, even though they can play a **crucial role in the overall well-being of caregivers** and may serve as an effective instrument in reducing social exclusion and isolation.

About the C4C project

While it is widely acknowledged, as outlined above, that family carers are in need of comprehensive support systems, one crucial aspect is neglected in many countries: **preparation for reintegration into the labour market after the caring period**. Family carers often interrupt their careers for the care work, and then face difficulties during the reintegration phase into the labour market, as shown in different research studies[1] from several European countries. This is where the project *Care4Carers* sees an important intervention field for adult education. *Care4Carers* is a collaborative Erasmus+ project that started in March 2022 and brings together 7 partners from 7 different countries. It aims to fill the gap of support provision by strengthening the position of family carers through the development of an **innovative support programme** designed to address carers' specific needs – a low threshold, flexible offer, which is a combination of career counselling, qualification, competence development, career orientation & job application training.

About the report

Therefore, the partners set out to research and analyse the **overall state of informal family care** in their countries and the **existing good practices for support schemes**. In the research process, the partners attempted to identify more clearly the **main challenges** family carers face, their **fears and hopes** with regard to balancing work and care or re-entry and re-integration into the labour market, as well as the **opportunities for personal and professional growth** they might see in the care situation. Moreover, the research tried to further identify the **learning needs** of both family carers and (counselling or training) professionals working with them. This will allow the partnership to create better tailored project outputs, which can really help strengthen the position of (female) family carers and increase their employment and inclusion rate in the labour market by **improving the reconciliation of work and care situations**.

The report was prepared based on an approach combining **desk research** covering the 7 partner countries and nearly 60 **qualitative interviews** with family carers and selected experts working with this target group (career counsellors, psychologists, members of carers' associations, nurses, family care experts and adult educators). The findings of this report will serve as a **basis and source of recommendations** for tailoring the ensuing Care4Carers offer. They are intended to ensure that the educational needs of the target groups are adequately met by the project further on as well as to provide **valuable insights to potential stakeholders** from the adult education, social services, and even political decision-making sector in view of developing relevant initiatives.

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[1] https://eige.europa.eu/publications/gender-equality-index-2019-report/informal-care-older-people-people-disabilities-and-long-term-care-services
https://eurocarers.org/wp-content/uploads/2018/09/Eurocarers-Work-Life-balance_final.pdf

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III. Findings and analysis

1. The state of non-professional family care in the partner countries

a. Overview and general tendencies

The sector of informal care (as part of the long-term care system) in the 7 partner countries seems to be quite large, even if some countries provide **no official statistics** but rather estimate indications on the number of informal carers (estimates are provided in the national sections further on). This lack of official data only proves the **lack of a legal framework** (and, consequently, of a legal definition) for non-professional caregiving, which is one of the core issues this group faces in most countries, as it determines a **chronic absence of institutional structures as well as of funding**. A little different is the case in Denmark, where the term of family care is **rather uncommon** due to the high level of institutionalisation of this matter. The country has a **very institutionalised healthcare and home care system**, so there is no common practice for family members to stay at home and assume the care for their sick relatives. In the rest of the countries, however, either due to a lack of sufficient national infrastructure and/or due to cultural norms, it is common for people to accept that responsibility out of a **sense of family duty** – thus, informal care by family members is often perceived as **self-evident** and a **family matter**.

Even though the share of men among caregivers is gradually increasing, private home care is **predominantly provided by women** in all of the partner countries – it is usually the daughter, spouse, daughter-in-law or mother of the person in need of care. The most significant group of persons requiring care in the partner countries are the **elderly**. The vast majority of people being cared for are above retirement age, followed by a very large margin of **children**.

Both our desk research and field research findings show that in most countries (apart from Denmark, where it is rather common for people during a care episode to have a short sick leave and then return to work), it is **difficult for female family carers to reconcile work with care** for different reasons (unavailability of flexible working conditions, increased level of physical exhaustion, emotional burden, sense of shame and/or guilt etc.) and they are (more often than not) **forced to leave their job** (and the labour market) for an undefined period of time.

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b. Austria

In Austria, family is considered as one of the three main pillars of the long-term care (LTC) system next to the LTC allowance and the LTC fund. The Austrian long-term care system relies on **unpaid family care work, mainly provided by women.** In addition, there is also a variety of public support services targeted at care recipients and their informal carers. However, public provisions are complementing and stabilising rather than substituting family care (Trukeschitz/ Schneider 2012). Thus, the Austrian long-term care system is characterised by a rather **large sector of informal care** (Fink 2018).

According to data collected in 2016, **the majority of persons in need of long-term care receive home-based care provided by relatives or friends at home without additional formal care services** (42%). A third of the people in need of care receive support from a relative or friend and at the same time use formal care services. A smaller share of care recipients lives in nursing homes (21%) and 5% are looked after by privately hired carers at home (24h-care at home) (Fink 2018).

According to data provided by the Austrian Federal Ministry for Social Affairs, Health, Care and Consumer Protection (BMASGK), about **10% of Austrian's citizens are involved in informal and unpaid care** – this constitutes around 950.000 people. Women are representing around 73% of informal carers, where the average age of women providing informal care is 62. Family carers predominantly take care of their (step-)parents (36%) and their spouses/partners (35%). Around 12% of informal carers take care of (step-) children. A smaller share is represented by siblings (3%), friends (3%) or other relatives (2%). A small group of informal carers consists of children and younger people (aged 5-18) who have to take care of their parents or a sibling. **Half of the women providing informal care do not pursue an occupation**. Out of those informal carers who combine care and work, the majority are women taking care of their (step)parents or parents in law (31%). 22% of them work full time and 23% work part-time. **Only 10% of the informal carers supporting their spouse or partner are employed** (BMASGK, 2018).

Among the **main reasons for providing home care are**:

- Multiple illnesses and frailty
- Chronic illnesses
- Chronic cardiovascular problems (BMASGK 2018).

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Assuming care responsibilities in Austrian society is frequently associated with **feelings of normative obligation**. Therefore, it is not surprising that 74% of the people providing home care describe this responsibility as **self-evident/natural**. As per the data, provided by the BMASGK in 2018, other main motives pointed out by the people are:

- Close emotional connection (55%)
- Sense of feeling responsible (50%)
- No other choice (17%)
- High costs for professional care (17%).

c. Bulgaria

Bulgaria is experiencing **negative population growth** since the early 1990s due to the **high level of emigration**. The population also became **considerably older** as it was primarily the younger people in the age group 0-24 who left the country and the **fertility rate dropped** to below 1.5. The share of people aged 65+ and 80+ in the Bulgarian population has been growing and is expected to further increase in the period 2019-2070[2].

The population will continue to grow older due to low birth rates, emigration of younger generations and increased life expectancy. At the same time, the capacity of the existing social and healthcare services in the country can hardly meet the numerous needs of the ageing population, so **the role of informal family care is likely to become even more prominent**. While the prevalence of informal care has grown in the past decades, the decreasing number of younger and healthier family members may reduce the availability of informal carers, which may turn out to be a big problem for the country.

In Bulgaria there is **no established information system** collecting data on formal carers providing long-term care. There is even less information about the number of people providing informal care. Even though no precise data is available, the **prevalence of informal care in the country has been estimated at 10% of the total population** (i.e. about 700.000 people take up the caregiver role).[3] Once again, since no support infrastructure for the family carers exists, it is impossible to be certain about the exact data. In any case, there is little doubt that **the overwhelming bulk of LTC is provided**

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[2] The 2021 Ageing Report Economic and Budgetary Projections for the EU Member States (2019-2070)

[3] European Quality of Life Survey, Eurofound, 2016

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by informal carers in families. This is so, because the cultural traditions in Bulgaria encourage care for elderly people to be provided by family members, who are not trained professionally, but accept that **responsibility out of a sense of family duty**. The provision of LTC is thus considered to be a **family matter**.

Though informal care appears to be of utmost importance it has so far **neither been legally recognised nor financially encouraged within the system of LTC services**. No cash benefits or services in kind, specifically meant to support informal carers are available. And interestingly enough, in line with this, one of the placement requirements of LTC institutions for the elderly is that the clients do not have any family members capable of providing care for them.

Unlike other European countries, Bulgaria does not have a family remuneration system that provides long-term care for the elderly relatives. Instead, the state maintains a **system of personal assistants and home assistants**, **who receive remuneration** to provide basic cooking, cleaning, maintenance of personal hygiene, shopping and other daily tasks. In addition to personal assistants and other home aids, municipalities provide services such as **daily centres for the elderly**, **social rehabilitation and integration centres**, **protected housing**, and **social services in the family environment**.

Despite the growth of services in recent years, the development of informal care, and the increase in the number of beneficiaries, **the scope of these services is still insufficient** because of the ageing population and considerable emigration levels. In recent years, **many people of working age have remained outside the labour market because they care for sick or elderly family members**. Many of them cannot afford to pay for hospices or other services, and, in addition, the capacity of the existing ones is simply insufficient. Again, no estimates or data can be provided on the number of persons who remain unemployed due to necessity to provide family care.

d. Cyprus

Cyprus showcases the signs of an **ageing western society with alarming projections**, significantly with respect to dependency ratios. In the period 2016 to 2070, the old-age dependency, which is the share of the population aged 65 and above as a percentage of the population aged 20-64 is projected to rise from 24.3% to 65.5%. Practically, this translates to **more people of old age and in need of care in comparison**

to the active and working-age residents. The current state of the art in Cyprus with respect to caregiving makes these projections concerning, as it provides **limited opportunities and support to family and informal carers**, who are forced to reduce or leave their professional settings to care for another person in need.

The statistical projections find agreement with other reports [The Ageing Report (2018)], which predict that Cyprus' total population will rise from 1,198,198 inhabitants in 2018 to 1,394,748 by year 2048[4]. Simultaneously, the population aged 50+ is projected to increase from 31,6% to 46.5% in the same time span, exhibiting the signs of an ageing population. Consequently, **the country's ability to respond to issues of older people's needs with respect to caregiving is one that must exponentially be enhanced** with time, as old people and their needs of care will only increase.

In general, there are **no statistics or direct numerical indications on the number of informal carers** in Cyprus. Studies or reports in the field of Long-Term Care (LTC) are scarce and mostly come in the form of EU-led reports or targeted academic research. This prompts us to mostly infer the magnitude of informal carers and their associated issues indirectly, from academic research looking at caregivers or EU reports, which collect some data whilst also providing comparisons with other European regions.

As a matter of fact, the role of informal care is significant in Cyprus, with spouses and partners often being the primary caregivers, often with the help of other members of the household, relatives, or neighbours, which speaks largely on the **absence of adequate state provision.** This can be attributed to the **strong relationships between the family members** as well as the traditional norms, which dictate the caring of relatives as a form of **societal expectation**.

Research results from Cyprus suggest that **gender differences in caregiving have been always a social norm**. The role of a family caregiver is traditionally viewed as the responsibility of women as a filial obligation, and not as a matter of personal choice (Hooker et al., 1992). Research outputs by Papastavrou and colleagues (2012) indicate a general discrepancy with respect to gender, with **caregivers being female more than 70% of the time**, regardless of the care receiver's reason for needing care.

With respect to kinship, a study by Papastavrou and colleagues (2007) indicated **that 48% of caregivers were daughters of the person in need**, followed by spouses (41.3%),

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[4] Source: https://www.populationpyramid.net/cyprus/

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with sons of persons in need only making up 5.8% of the sample group. The discrepancy between sons and daughters taking on the role of informal family caregiver appears particularly important as these people are most often at working age and suffer the issues of being forced out of their working environment to care for their parents in need of care.

With respect to employment, **the percentage of active and working persons is higher among caregivers than non-caregivers**, a pattern only observed in three other European countries (Bulgaria, Lithuania, and Latvia). For one, this speaks on the **lack of comprehensive formal care services**, which would prevent the need for unskilled caregivers to be employed in such a role. Secondly, this also exhibits the **lack of support provision for informal carers**, who as indicated above, mostly choose to work in order to provide for themselves and indirectly their relatives, through subsidising part of their income toward an unskilled worker. Simultaneously, this can be taken as an indicator of the burden of caring, both economically and psychologically, on the family of frail and sick elderly people, which prompts families to seek help in cheap, unskilled labour hands.

A 2007 European commission report (Special Barometer, 2007) examining the concept of informal caregiving, indicated that in Cyprus **54.7% of female informal carers face labour problems due to caregiving, in comparison to 31.7% of informal men carers.** The discrepancy in issues faced by women is also seen in aspects of psychological burden and depression, with studies by Papastavrou and colleagues (2009) indicating a significant effect of those in women but not in men. As indicated by the researchers, this may be attributed to the more emotional coping strategies adopted by women, who **often use denial as a coping mechanism**.

Recent studies looking at caregiving during the COVID-19 pandemic (Bergmann and Wagner, 2021), indicated that Cyprus had the **highest proportion** of people giving and receiving care from someone outside their own household (see figures below). This in part has been attributed to the short physical distances between family members in Cyprus, as well as the **tight familial bonds**, which describe its residents. Societal reasons account for part of the reliance of most people in need towards members of their own family, but are also exacerbated by the lack of comprehensive, tangible support.

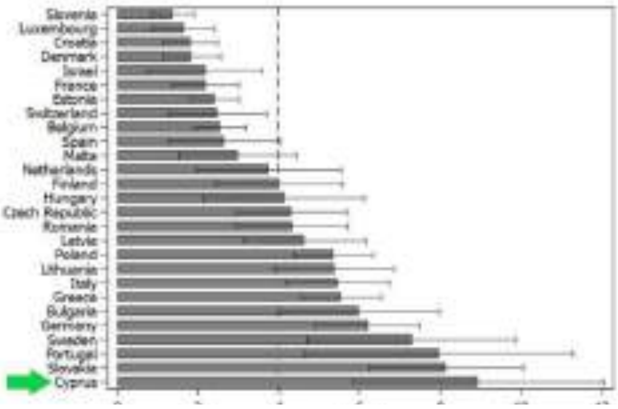

Figure 1 – Percentage of people providing care to someone outside their household during Covid-19 first 2020 lockdown

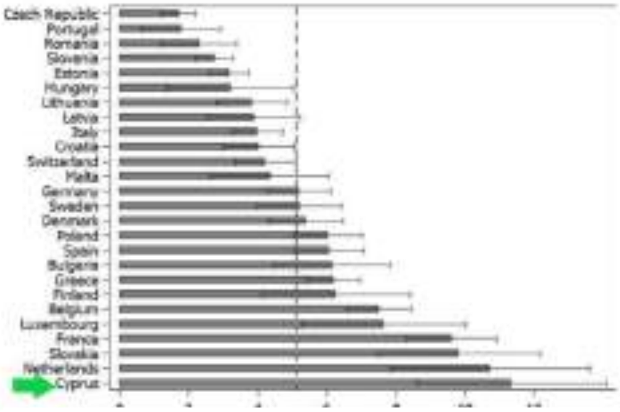

Figure 2 – Percentage of people receiving care from someone outside their household during Covid-19 first 2020 lockdown

Specifically, as outlined by Bouget et al. (2017), **support systems in Cyprus are insufficient or even non-existent.** Cyprus has yet to construct a comprehensive and integrated system of LTC. LTC expenditure as a percentage of GDP is among the lowest in the EU member states, resulting in high out-of-pocket payments. Public spending on long-term care in Cyprus reached 0.3% of GDP in 2016, well below the EU average of 1.6% of GDP.

e. Denmark

In Denmark, the term family care is not common. The country has a **very institutionalised healthcare and home care system**, subsequently there is no culture where it has been common for family members to stay at home to take care of their relatives. **Danish public hospitals and home care services cover the treatment and care for the patient for free**. In terms of a diagnosis of terminal illness there are hospices where the patient can spend the last period of their lives or for a while to recover from a very complex illness.

All the official offers of public support and funds can be provided to be carried out by a family member, a good friend, a colleague etc. as long as there is an agreement between the patient and the non-professional carer, making **home care of the patient performed by a relative fully legal**. Of course, there are some kinds of relations that more often become a care relation, e.g. parents taking care of their sick child in their own home. This will be described further in the following paragraph, but it is important to be aware that **there is no difference in the rights of near relations whether they are family or friends**.

In general, Danish society is built on strong institutions and from a very young age children are being put to day care and at the other end of the continuum, the elderly in need of care, are taken care of in home care or in nursing homes. The Danish labour market is characterised by a **high degree of gender equality**, employing almost just as many females as males. Danish society has had in recent years a **very low unemployment rate**, which indicates that most people are already activated. This is one of the reasons why **not many people leave work to be a carer**.

The majority of Danish employees are in a union, providing them equal rights to security in case of illness, relatives being ill, unemployment etc. Working in a society where most people are secured with a good life, no matter what life changes may occur and what conditions they might suffer, creates a safe work environment. There is a **strong belief in the Danish unions and institutions** and an equally **strong dependency on these public offers**. This is possible because of the high taxation level that is current in Denmark, meaning all the available offers are somehow fully or partially funded by the state from the taxes. Certain care and healthcare offers with a higher degree of service than what is provided by the public service are self-funded.

When it comes to the non-professional family care, there are **no official statistics** of the number or profile of carers. This is most likely linked with the fact that the Danish healthcare and care system is heavily institutionalised, as mentioned earlier. The field research findings showed that **during a case episode many people often prefer to have a short sick leave and then return to work** either when there is a sustainable solution or when the patient/relative has died. This sick leave can be prolonged for 14 days after the death of a near relative.

In Denmark it is often seen that it is **female citizens who become the family carers**. As per law, both parents can get a leave in case their children become very sick, but it is usually the mother who takes the full leave in order to care for the child, and the father who has a flexible scheme at work. When it comes to elderly relatives, it is often their children who get a care-leave and **primarily they are women**. A qualified guess would

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be that **their age mostly varies within 45-60 years**, as they have some experience in life, may not have very small children to take care of, have a stable job situation etc. meaning, these women have a **more stable life situation** than younger or older people.

In general, most people who become non-professional carers, take care of their **sick children**. It is very common that one or both parents get a leave in such a situation of illness of a close relative. One of the most frequent illnesses that requires care and can be a reason for applying for a family caregiver is cancer and COPD. Medical proof must be provided stating that the illness is lasting for a long term or permanently. The patient needs to be the one **applying for a carer**. The municipality then needs to approve that the person is available as a carer, even though they are non-educated and non-professional in this area.

f. Germany

Around 3.4 million people in Germany are in need of care. Three quarters of them are cared for at home, 1.76 million of them usually by their relatives alone. Calculations currently assume that there are around **4.8 million family members providing care**. Out of these, around **2.5 million are employed** - they have to shoulder care and work at the same time. (Source: BMFSFJ)

The most significant group of persons requiring care in Germany are the 80+ olds. **The vast majority of people being cared for are above retirement age, followed by a very large margin of children** (up to 18 years old). People of working age are the least likely recipients of family care.

Even though the share of men among caregivers is gradually increasing, **private home care is predominantly provided by women**, mostly by the daughter, spouse, daughter-in-law or mother of the person in need of care. According to the results of the 2012 GEDA study, 6.9% of adults regularly care for a person in need of care. Among women, this share is significantly higher at 8.7% than among men at 4.9%. This means that almost two-thirds of caregivers **(64.9%) are women**, and just over one-third (35.1%) are men.

The proportion of caring relatives increases rapidly with age, especially among women. The **proportion of family carers is highest in the 55-69 age group**: 11.9% of

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women and 6.0% of men of this age support relatives in need of care. 2.6% of adults provide occasional care, 2.0% provide up to two hours of care daily, and 2.1% provide at least two hours of care daily to someone inside or outside their household. The gender difference is particularly evident among caregivers who provide care for two hours or more a day: 3.2% of women but only 1.0% of men. Accordingly, the proportion of women among caregivers with this level of care also increases: among occasional caregivers, the proportion of women is 58.2%; among those who provide care for at least two hours a day, more than three-quarters (77.2%) are women.

The more time-consuming the care of relatives, the more often it takes place within the household. Around three quarters (74.1%) of caregivers who provide care for at least two hours a day care for relatives in their own household. Persons who provide care only occasionally mainly care for relatives outside their household (66.0%). At 17.9%, the care of friends and acquaintances only accounts for a relevant share of occasional caregivers. For those who provide a high level of care, on the other hand, it is of secondary importance (2.2%).

The **average age of women providing a high level of care is 53.4 years**, while the average age of the men is 50.6 years, which is a good two years higher than the average age of non-carers. Compared to non-carers, those providing more than two hours of care per day are represented in lower proportions in the 18-29 age group and in higher proportions in the 65+ age group.

Caregivers with a high level of care belong more often to **lower** and less often to higher **educational groups** than non-caregivers. When looking at labour force participation, it is noticeable that women and men providing care at least two hours a day are **significantly less likely to be employed** than non-carers. **Family carers practise sport less often** than non-carers and tend to smoke more (the latter is true for women), however, they also consume less alcohol. In general, though, it can be said that they face **greater health risks** due to their lifestyle than the general population. (Source: GBE kompakt)

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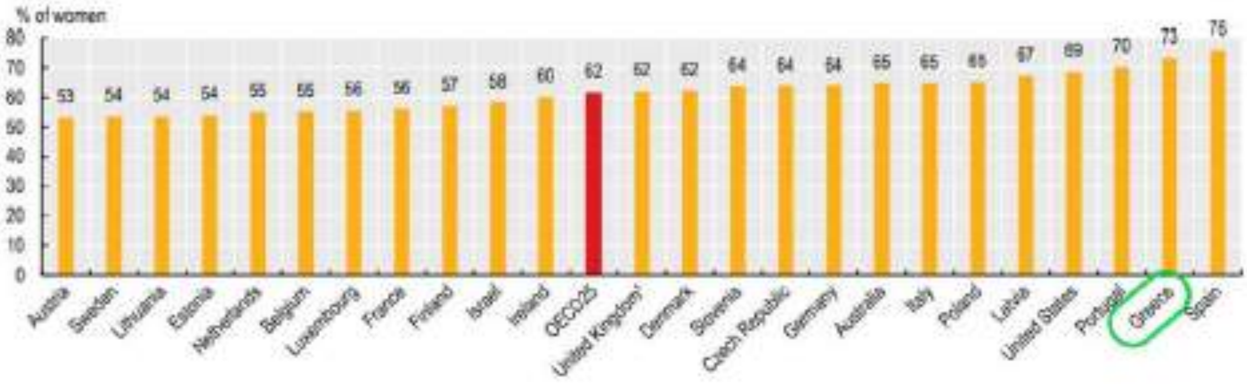
g. Greece

Until recently, the issue of informal care and informal carers was not given much attention in Greece and there was **no official data for the number of informal carers** in the country. However, it is estimated that the number of informal carers amounts to a striking **34% of the Greek population** which is more than 3.600.000 people (Eurocarers, 2021). This rate is due to the fact that **the number of the existing long-term healthcare structures in Greece is low**, which in turn excludes chronically ill people from such services and, thus, related responsibilities are undertaken by their family members, especially women (Koullias et al., 2020).

Moreover, Greece is among the countries that give the existing healthcare services a low rating (Eurofound, 2019), while the perception that the **provision of care is a family duty** is quite widespread in the Greek tradition. In addition to the former, Greek families choose to look after older people as pension benefits constitute a source of income for the crisis-stricken households with unemployed members (Eurocarers, 2021). Provided that **Greece is among the EU countries with the highest percentage of people aged 65 and over** who represent 22% of the total population in the country (Eurostat, n.d.), a number which will further rise in the future, it goes without saying that capacity of the existing services will hardly meet the numerous needs of the ageing population, and **the role of family carers is expected to become more prominent than ever before**.

With regard to the informal carers' profile, the majority of them in Europe, but also in Greece, are female and in fact, Greece along with Spain and Portugal have **the greatest gender imbalance in the provision of informal care** (OECD, 2021). More details on the informal carers' profile in Greece are available from two reports conducted in the context of international projects to support family carers of elderly people in Europe: EUROFAMCARE (Triantafyllou et al., 2006) and INTERLINKS (Kagialaris et al., 2010). According to them, **80.9% of carers in Greece were female** and 76.4% of family carers were married or cohabitating. The majority of family carers (80.9%) cared for one dependent older person, while 16.8% cared for two older dependent persons. As for the relation to the person they provided care to, 17.1% of the carers cared for their spouses, **55.4% cared for an elderly parent** and 13.9% were daughters- or sons-in-law of the cared-for person. Furthermore, 50.7% of family carers shared the same household as the dependent person.

Figure 3. Share of women among informal daily carers aged 50 and over.



Source: OECD (*2021)*

As far as the carers' educational level is concerned, 37.4% of carers had a **low level of education,** 40.6% had finished high school and 22.1% had a high level of education. Almost half (47.2%) of the carers who participated in the survey reported that they worked for a mean of 40 hours alongside with their caring duties (with a maximum of 140 hours a week), while the mean time they spent providing care was **51 hours per week** which highlights the intensity of the care provided. Their income was labelled as low and they were entitled to no benefits, insurance rights or allowances to compensate for the care they provided.

The situation in Greece has not dramatically shifted since then and there are still **no provisions for in-kind benefits and in-cash support for carers** (Eurocarers, 2021). Nonetheless, some **significant steps have been made for the recognition of carers' role**. For example, in 2021 the Law 4808/21 which is the transposition of the EU Directive on Work-Life Balance, brought several changes for the working carers. According to it, carers who are employed either in the private or public sector, in any form of employment (e.g., part-time, temporary employment contracts, etc.) are entitled to the following: an **unpaid carer's leave of up to 5 days per year**, a paid leave of absence for force majeure, an unpaid leave to take care of an ill child or other dependent member of up to 6 working days per year, and last but not least, **flexible working arrangements for carers** (e.g., remote working, flexible working hours, etc.).

h. Italy

The Italian population is known to be ageing rapidly and increasingly. As the most recent statistics of the Italian National Statistical Institute (ISTAT) show, in all the Italian regions the number of citizens aged more than 65 is almost double than those between 0 and 14[5] - a **gap in the Italian welfare and regulatory system** is becoming increasingly evident. This gap is being filled within the families by a silent "army" of individuals who, despite never having received any formal training, find themselves in the role of family caregiver as a result of unexpected circumstances. The care for an ill or disabled family member is becoming more and more a **private matter**, rather than a public one.

From many sources, therefore, it emerges that the phenomenon of non-professional family care is **extremely widespread** in the Italian context, although it is difficult to find reliable data and statistics in this regard precisely because of its informal nature. Caregivers are difficult to identify and quantify as they **lack both legal recognition at national level and institutions** dedicated to them: this means that all numerical data are, more than anything else, estimates, with significant variations depending on the source. Furthermore, there are psychological aspects at stake: on the one hand, caregivers are often **ashamed or afraid of reaching out for help**; on the other, sometimes they are willing to seek help, but they **lack time and knowledge of structures** to do so.

According to 2018 research by ISTAT, it is estimated that there are **over 3 million[6] family caregivers in Italy** (although this number surely is a lower estimate, as different sources suggest 7, 8 or even 15 million, depending on the amount of time and/or the kind of assistance considered in the calculation).

The **lack of a national legal framework** (and, consequently, of a definition) for non-professional caregiving is one of the core issues this category faces, as it determines a **chronic absence of institutional structures as well as of funding**. Over the years there has been an effort to fill in this legislative gap with several different proposals[7]: however, this law-making process has been interrupted in 2020 due to the pandemic situation and has only recently been resumed.

In the meanwhile, regional laws are currently representing the starting point for giving this role a **form of official recognition**: in this sense, the first Italian normative text has

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[5] https://www.istat.it/it/files//2022/04/Report-Indicatori-Demografici_2021.pdf

[6] https://www.lenius.it/caregiver-in-italia/

[7] http://www.informareunh.it/il-riconoscimento-della-figura-del-caregiver-familiare/#:~:text=La%20definizione%20di%20caregiver%20familiare,di%20prendersi%20cura%20di%20s%C3%A9%C2%BB

been regional law n.2 of 2014[8] of Emilia Romagna**,** which recognises non-professional family caregivers as a key element in the local welfare and sanitary services and ensures them adequate support in carrying out their assistance tasks. Over these past years, other regions[9] have followed the example, giving hope of being close to finally reach a much broader recognition. Other future perspectives in this sense are being opened by the National Recovery and Resilience Plan, which includes **specific funds destined to family carers** that are being managed by regional administrations.

Recently, some kind of **legislative definition** of a family caregiver has been given by law n.205/2017, Art.255.1, which establishes a national fund to support family caregivers. The picture of who the caregivers are is an extremely articulated one, although many small research studies conducted at local level show some consistent patterns: the vast majority of caregivers are **women**, **aged over 45**[10]**,** mainly **unoccupied,** and with a generally **low level of education**[11]. The latter is a peculiarly critical fact in terms of their relocation in the employment market.

Male caregivers are usually older than female ones, nearer to retirement age. There are also thought to be around 400.000 young caregivers (less than 15 years old) in Italy and counting: their situation will not be taken into consideration in this research, as their issues concern mainly the education sector.

Regarding the occupational status[12] of adult caregivers, the difficulties of balancing what actually becomes **a full-time occupation** with a regular job leads the carer to make sometimes extremely heavy choices. As already stated, most of them have left their previous job (or have never worked) to be able to provide full-time assistance to their family members. Many turn to **undeclared work**, as its informality provides the **high level of flexibility** they need in terms of time: this is the same reason leading others to choose to work **part-time**, when they have the possibility to do so. Finally, just a very **small number of carers can keep working full-time**. What unites these experiences is that it is a choice mainly influenced by factors external to the subject.

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[8] *Norme per il riconoscimento ed il sostegno del caregiver familiare (persona che presta volontariamente cura e assistenza)* - https://demetra.regione.emilia-romagna.it/al/articolo?urn=er:assemblealegislativa:legge:2014;2

[9] Abruzzo: L.R. 43/2016, Campania: L.R. 33/2017; Autonomous province of Trento: artt. 11 e 12 L.P. 8/2018; Lazio: art. 26 L.R. 11/2016 and DGR 341, 8/06/2021; Molise: DGR 310/2017; Puglia: L.R. 3/2020; Basilicata PdL settembre 2021.

[10] https://www.avvenire.it/attualita/pagine/caregiver-legge-dimezzata

[11] For a representative sample, see the volume *Donne e lavoro di cura, Analisi delle attività di assistenza e cura domiciliare di persone con disabilità e anziani non autosufficienti. Identificazione di buone pratiche attraverso case studies di eccellenza*, Enzo Dellantonio e Alessandro Ceredi (a cura di), [Merano], Cooperativa sociale independent L. onlus di Merano, (2008)

[12] idem

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The care recipient is always a family member or a loved one with **disabilities** or **affected by severe/extremely severe pathologies**: the most frequent case is the **care of elder people**, as over 80% of the old or extremely old non-self-sufficient people are assisted at home by a non-professional caregiver (sometimes with the aid of a professional one). They are often affected by different kinds of poly pathologies.

Also, decidedly frequent is the case of **parents caring for their child** of more than 15 years old, then there are those who care for their partner, their parents or in-laws, and, finally, for their siblings[13].

It is estimated that **over 650 000 caregivers care at the same time for their children and the care recipient.**

As for the **most common kinds of illnesses** or conditions requiring the assistance of a family caregiver, there is **no official data available**, but some hints in this sense can come from the associations which are more active in promoting and assisting the role of caregivers: pathologies linked to the elder age (Alzheimer, Parkinson's disease, conditions linked to the aftermath of a seizure), other kind of pathologies (such a cancer, heart diseases, multiple sclerosis, amyotrophic lateral sclerosis), genetically inherited conditions, and intellectual and relational disabilities.

The reasons behind the choice to become a caregiver seem to be predominantly **practical** (inability to institutionalise or to afford professional care) and of **psychological or moral** nature (affection, sense of duty), as well as **cultural** (especially regarding female caregivers, as usually **women are expected to face heavier sacrifices than men when it comes to family care**[14]).

2. Support structures for family carers

a. General overview

Despite the striking number of informal carers in most partner countries, the vast majority of whom are female, the desk and field research results confirmed that the issue of informal care and the role of informal carers are **not widely recognised or discussed** as it should be. There are **not enough (specifically targeted) initiatives** on a state level to support carers, but NGOs and relevant associations of patients

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[13] https://retecaregiver.it/wp-content/uploads/2020/04/Cura-SimonaLancioni.pdf

[14] https://www.istat.it/it/files/2019/05/ebook-I-tempi-della-vita-quotidiana.pdf

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commonly provide psychological support also to their families and carers. When it comes to career counselling and integration in the labour market, some steps have been taken in certain countries to ensure **more flexible working conditions** for carers who are already in the labour market, reconciling care with work, however, due to the intense psychological burden they often face many obstacles and challenges in the process. Yet, there are **barely any provisions meant for carers who are not in the labour market** for a certain period and many, especially those in a more advanced age (50 and above), consider it impossible to reintegrate back into it. The conducted research shows that **family carers remain a rather neglected target group in the context of career counselling**.

There also seems to be a **gap in the provision of further training related to family care, which are meant for counsellors.** Some of the professionals interviewed had little experience with this target group in particular. There is also little knowledge among trainers and counsellors concerning the situation of family carers as well as existing support options (funding schemes, tailored training, psychological relief, career counselling, peer-to-peer support).

b. Overview per partner country

i. Austria

The Austrian long-term care system is based on **cash benefits and publicly organised social care services** targeted at people in need of care and their informal carers.

The central government and some provinces have recognized the role of informal carers by providing explicit support. **National public support for family carers has been gradually expanded** in the last two decades. Public support for informal carers includes tax deductions, social insurance coverage, and services at the national level and mainly services at the regional level. National cash benefits comprise financial support for replacement care, paid-care leave or part-time work for carers and family-hospice leave and social security benefits for carers.

In addition, the Ministry of Social Affairs is increasingly putting focus on **counselling and information services for informal caregivers** with the aim of contributing to prevention and health promotion, e.g. offer of free talks for informal carers with trained psychologists or social workers.

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Despite a variety of services, **eligibility criteria for financial benefits are rather tight** and are targeted at high-intensity family carers. They all require at least an LTC level 3 benefit (or level 1 in case of approved dementia) and are granted for different duration of time. In general, supporting parents who care for disabled or severely ill children and—more recently—dementia caregivers seem to assume higher priority (Trukeschitz et al 2022).

Despite a variety of existing support structures and offers, there seems to be **little knowledge** among family carers about some of these benefits and the application processes. Moreover, due to the federalist state structure, **coordination and networking of counselling services is limited** at the national level. The **low take-up rate of certain services** is also influenced by people's perceptions of how their community may respond when they begin using these services (in particular in the countryside). This may partly explain the high number of informal carers that do not make use of formal care services (42%).

Short-term institutional care

Short-term residential care enables informal carers to take time off while the person in need of care is temporarily staying at a nursing home. In addition, it allows patients a short time of professional care in a care home after a severe illness or a hospital stay. Depending on the province, the maximum duration of stay varies between six weeks and three months.

Discharge service for carers

In three Austrian states (Upper Austria, Styria, Burgenland) a discharge service is offered to informal carers who need to take a break for a few hours during the day. It is offered for a short time but also regularly for a maximum of 120 hours per year and per person in need of care.

Long-term care (LTC)- allowance

LTC-allowance is one of the two cornerstones of the Austrian LTC-system (besides publicly provided care services). It is designed as a contribution to the cost of care services and is directly paid to the care-dependent person. Although the cash benefits are targeted at the care recipient, they may also serve family carers given that they agree on using the money for care expenses. The amount of the allowance depends on the level of care dependency ranging from 165, 40 € for level 1 and 1756, 50€ for level 7. The cash allowance only depends on the care needs and health status of the person and is not means-tested (against income or assets).

Financial support for 24h-care

Financial support for 24 h-care depends on the care-work arrangement (self-employed vs. employment) and ranges from 550€ to 1100€ per month.

Care-leave benefit/ Part-time work

Care leave and part-time work options were introduced in 2014. Informal carers in paid work (for at least 3 months) and their employers can agree on a reduction of the carers' work hours or care leave for 1–3 months. The care leave and part-time work offer employees the opportunity to take on care obligations at short notice and to organise care arrangements. Basic payment of the paid care leave is of the same amount as the unemployment benefit (55% of net income). The part-time work model for carers allows a reduction of working hours to a minimum of 10 hours per week and users receive 55% of the difference between the former regular income and the current income.

Since 2020 employed informal carers are entitled to these support options for two weeks; beyond that period, they rely on the approval of the employer. Informal carers are eligible if the care recipient is a close relative and has a minimum long-term care allowance level of 3.

If the care needs have increased (and the LTC allowance accordingly) another three months of part-time work or care leave will be possible.

Income loss due to part-time work or care leave is made up of a care leave benefit for a maximum of 6 months.

According to a survey in 2017, 5% of informal carers used the offer of care-leave benefits or part time work for carers (n= 2276) (BMASK 2018).

Family hospice leave

The family hospice leave system was introduced in 2002 and supports family caregivers for up to 6 months while looking after a terminally ill relative. Employed persons with dying relatives or seriously ill children have a legal claim for family hospice leave (it does not depend on an agreement between employee and employer). The informal carers rather give notice no later than 5 days before they plan to take-up family hospice leave and leave from work for palliative care. The leave is granted for a maximum period of three months, with a one-time option of extending the leave by three months. Informal carers in financial distress can apply for an additional supplement (family hospice leave hardship compensation).

According to a survey in 2017, 1% of informal carers used the offer of family hospice leave (n= 2269) (BMASGK 2018).

Unemployed informal carers, eligible for unemployment benefits, can take paid care leave or family hospice leave and receive care leave allowance equivalent to their unemployment benefits. They are not recorded as unemployed during this period and don't have to attend training courses.

Financial support for replacement care

The financial support for replacement care is a subsidy for the cost of care if the main carer is unable to provide adequate support because of holiday, illness or other important reasons (e.g. training courses for carers or measures to strengthen their own physical health). Financial support is provided for a minimum of 7 days and a maximum of 4 weeks per year.

Eligibility is restricted to carers who have been caring for an LTC allowance recipient (LTC allowance level 3 or higher or LTC allowance level 1 in case of dementia). The financial support for a maximum of four weeks ranges between EUR 1,200 and EUR 2,200 and, in the case of dementia, between EUR 1,500 and 2,500. The amount of support depends on the duration of replacement care and the LTC allowance level of the care-dependent person. (Caritas Austria 2022: Wissenswertes für pflegende Angehörige)

Social security benefits for carers

Since 2009, the central government has provided social security benefits for caregivers who have lost social insurance coverage. The benefits address social pension insurance and social health insurance. Main informal carers who are not compulsorily insured any longer and care for a close relative with substantial care needs have the possibility to continue insurance under the pension scheme ('Begünstigte Weiterversicherung in der Pensionsversicherung').

Informal carers who support a relative with substantial care needs have the possibility to self-insure in the statutory pension system ('Begünstigte Selbstversicherung in der Pensionsversicherung'). For both pension insurance options, contributions to the public pension insurance are paid for by the central state. Eligibility is restricted to informal carers caring for a close relative who receives LTC allowance level 3 or higher and does not live in a care home.

Informal carers who are not covered by social health care insurance may contribute to the social health care insurance on a voluntary basis. Informal carers supporting a close relative who receive LTC allowance level 3 or higher entitled to coinsurance under the health insurance plan without contributions. (BMASK 2018)

Tax allowances

Tax allowances are granted to informal carers for exceptional costs related to their care work. These costs include medical expenses, costs for home care (less tax-free subsidies e.g. LTC allow-ance) and costs for 24-hour care.

Support group

At the local level, regular **informal meetings** (once a month) are offered to informal carers, allowing them to exchange their experiences and thoughts. They are usually free-of-charge and often organised in the form of a regular group meeting hosted by a service provider, the local authority, by parishes or other associations.

Online-Platform for family carers

The platform is offered by the Social Ministry (3% have used the offer) and provides information on care allowance, paid care leave, 24h-care, institutional care, social services, dementia, insurance issues, financial aspects. (Link to online platform:)

Telephone citizens' service ('Bürgerservice')

At the national level, a free-of-charge telephone citizens' service, offered by the Federal Ministry of Labor, Social Affairs and Consumer Protection (BMASGK) provides citizens with information on the area of social benefits, organisations, associations and support groups that are active in the field of long-term care and informal care.

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According to a survey in 2017, 7% of informal carers used the offer of carers' talk program (n= 2292) (BMASGK, 2018).

ii. Bulgaria

In Bulgaria, there is **no remuneration system for informal services provided by family members** (unless they are hired as personal assistants as per the rather limiting mechanism established in the 2021 Law for personal assistance). **Monthly-based financial social assistance** can be claimed by someone caring for a seriously ill family member. People are entitled to a monthly allowance if they either live alone or are in a family whose income for the previous month is lower than the differentiated minimum income. This applies to carers acting as either personal assistants (relatives) or social assistants (professional employees). The **right to disability pension** is awarded when the person has at least 50% reduced working capacity. Pensioners with a degree of disability over 90%, who need constant help, receive an additional pension allowance of 75% of the social pension for old age. Monthly benefits for the care of a disabled child are payable regardless of family income. Each year, the Ministry of Labour and Social Policy determines the amount of aid for raising a child with disabilities.

As far as those family carers are concerned, who continue to work during a care episode, the law provides an **opportunity for people to take leave from work to take care of a sick family member**. Every insured person is entitled to 10 days of paid leave per calendar year to provide care to sick family members over the age of 18, or to accompany them for medical examination, investigation or treatment either in the country or abroad. Those who provide the same care for family members under the age of 18 are entitled to up to 60 days in one calendar year. In addition, people may use unpaid leave for the same purpose, but this is subject to employer approval. Periods of up to 30 days of unpaid leave per year do not affect entitlement to old age pension. Interestingly, official regulations set different terms and conditions in relation to granting sick leave for the care of an ill family member at home compared with hospital inpatient care.

Due to lack of funds, there has been a **temporary suspension of the remuneration system that applied to carers acting as personal assistants (relatives)** and social assistants (professional employees), providing care to lonely old people and the disabled (people with over 71% proven permanent disability). Social assistants who provide support with cleaning, personal hygiene, shopping and other everyday tasks are now provided by private companies at different prices depending on the region, combination of services etc.

Since 2021, according to a **new Law on Personal Assistance**, there is the possibility for carers to be hired as personal assistants. While this is a sign that the social care system is in the process of restructuring, **the scope of this law remains rather limited** (allowed to hire personal assistants are only people with a permanent disability or permanently reduced working capacity and children with 90%+ degree of disability). It is neither a sustainable solution to the issue of reduced income for those informal carers who need to leave their job to care for a sick family member, as reality shows that most of the assistants employed under the public programme were former unemployed persons.

State-supported community-based services for carers, such as respite support, training, and counselling are very limited. Some respite support for carers is obtainable from private service providers if the family can afford it financially. Since 2012, training in the professionalisation of care has been held under various schemes within the Human Resources Development operational plan. Though well intended, these efforts lack a comprehensive and systematic approach. There is also an **absence of information about any skill-validation initiatives to help informal carers become LTC professionals.**[15]

As far as **psychological or any kind of peer-to-peer support** is concerned, most offers are provided by non-profit organisations, focusing primarily on the care recipients and only then their carers. No supporting schemes of this type designed specifically for family carers were identified during the research. However, some of these organisations are family carers' best chance at receiving psychological/informational/educational support, which is vital, and they have a long successful history of providing it. To name a couple significant names of such associations:

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[15] ESPN Thematic Report on Challenges in Long-Term Care, Bulgaria, EC, 2018

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"Children with Oncohematological Diseases"

The association was founded by mothers of children with onco-haematological diseases with the mission to defend the rights of children with cancer, to support them in their fight, to help them and their families overcome the emotional and psychological consequences of the disease and to facilitate their social adaptation after treatment. The organisation offers different services not only for the children but for their carers (usually their mothers) and parents too: **psychotherapy, art-therapy, social counselling**, hospital schooling (face-to-face and virtual), recreational summer camps, International Sport Games in Moscow for children cancer survivors etc. The Association opened the first and only centre in Bulgaria for information, counselling, support and work with children with onco-haematological diseases, established in the building of the children's oncohematology clinic – crucial for the mental wellbeing of both children and parents (their home carers). Besides, with European funding they have built the first on the Balkan Peninsula and the eighth in the world Recreation centre for children with onco-haematological diseases with the idea to provide help for children and their parents to recover during, and after chemotherapy. There are volunteers caring for the mental and physical recovery of children and parents for free, and the centre can be used by children with other diseases as well.

"Alzheimer Bulgaria"

The association is engaged in preventive, organisational and coordination activities related to the fight against Alzheimer's disease and similar diseases, informative and other activities to provide assistance to Alzheimer's patients and their families. In Bulgaria, which still lacks a network of professional caregivers for Alzheimer's and other forms of dementia, 24-hour care is usually provided by relatives. Often, they have no previous experience and may find themselves unprepared for the abrupt change that is ahead. So, the association provides **helpful and practical advice to family carers** to make everyday life easier for both the patient and their carers.

iii. Cyprus

Agencies and organisations implementing **health policy programs** in Cyprus are the Multifunctional Foundations, Cyprus Third Age, and the Cyprus Third Age Observatory. These organisations source volunteers to help organise events specifically targeted

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towards the elderly, as well as bring experts in the field of health to inform and guide the elderly and their families on old-age specific issues (Alzheimmer's, mobility problems, neuropathological issues etc.) Additionally, these centres provide entertainment and opportunities for active ageing to the elderly, allowing them to remain active and sociable. Through their widely directed initiatives, the interests of people in the third age are largely taken into consideration, which even if indirectly, decreases the burden of care from informal caregivers.

The GMI (Guaranteed Minimum Income) scheme, and particularly the Social Benefits (Emergency Needs and Care Needs) Decree of 2014, incorporates the **Scheme for the Subsidisation of Care Services** – which was revised in 2015 (N.353/2015) and in 2016 (162/2016). The new Scheme subsidises the social care needs of GMI recipients, including the members of their family unit. **Entitlement to long-term social care is based upon need**, i.e. based on the person's ability to carry out their daily home and personal care and their ability to meet their immediate needs like shopping and transportation. In short, the provision of GMI is irrespective of the activities related to informal caregiving, and only serves as a basis of **social welfare that is blind to the needs of the informal caregiver**, and the extensive out-of-pocket payments often taken on behalf of those they must care for.

The **Social Welfare Services** or the Department of Social Inclusion of Persons with Disabilities are critically responsible for the provision of the GMI and benefits to people with disabilities, and only include the needs of informal caregivers when providing 'Respite Care'. This comes in the form of short-term care for the person in need to allow the unofficial carer to have a break from their caring responsibilities, or to people who live alone and occasionally feel unable to take care of themselves. As such, **no long-term plan is available for informal carers** who can only request this on certain occasions, and with limited availability.

With respect to economic support, a disability benefit is given to families of disabled persons, with women dropping out of the labour market being entitled to a social pension. However, the limited LTC that is provided for those in need appears to dictate **extensive economical support that cannot be covered by the social pension**. This makes the benefit seemingly inaccessible due to the **inherent need for the caregiver to continue working** to be able to support themselves as well as their relative in need.

Despite the National Strategic Plan against Dementia, issued by the Ministry of Health (2017) indicating that the needs of dementia patients go hand in hand with their carers' needs, the **support provided mostly resides in NGO involvement that only focuses on the patient directly**. Consequently, psychological support towards carers stems from conversation about the person who is admitted under a care home or in the above foundations, through conversing with professionals about the patient and their management.

At present, **no entity focuses on the reintegration of informal carers back in the market** in Cyprus, with positive attempts mainly found in past EU funded projects and government-run opportunities for digital literacy and free upskilling to dormant workers, with only one example of a program targeting carers explicitly (more details on it can be found in the compilation of good practices). Moreover, attempts to ameliorate the effects of absence from the market may be found in projects promoting the upskilling of women directly, which are notably those most affected professionally by informal caregiving, but which again do not indicate informal caregiving as a central prerequisite or motive for their development.

iv. Denmark

In Denmark **the state provides most of the help for people with a care dependent illness**, no matter the kind of illness. The patient in need of various help and support, depending on their condition, age, surroundings etc. applies for the support needed. This could be a caretaker in their own home and the person who takes this responsibility is then offered **care-taking leave** from their job and **gets a salary from the municipality** instead in order to provide help for their relative. The carer can apply for a **care-allowance**. The care-allowance is refunded to the employer by the state, so that both private and public employees can have leave of absence without huge differences in salary.

Carers can also be **employed by the local municipality for up to six months** if a close relative or friend has a long-term disease process. This means that a person who is not dying but in need of help and support, can hire a person in their social circle who provides care for them for up to 6 months before finding a permanent solution[16]. This can be a full-time job and can eventually be hard at times, which is why there is also a supporting system for the non-professional caretaker, as this situation can be quite new to many[17].

The supporting system consists of different options for the patient, which also makes the process easier for the caregiver. Some of the most popular are a **psychologist, therapist, social counsellor, a priest** etc. By providing these offers to ease the period of illness, the caregiver is also helped a lot. Another part of the supporting system is the **hospitals' palliative teams**. This is a very strong state driven aspect of the support as well, which generates calmness and safety for both the patient and the caregiver/family. No matter how bad the situation becomes, there is always a professional healthcare person near who can help you. This creates a **safety net, not depending on the persons' individual insurance or income**, which is a crucial factor for the Danish healthcare system. Everyone is treated equally, no matter their circumstances in life.

Leave from work

In Denmark, it is possible to have an **arrangement similar to maternity or paternity leave**, where an employee can apply for caretaking-leave. If they have a close relative, who is declared terminally ill and is expected to need intense family care in a year, it is possible to apply for the leave beforehand, so the employee knows they can leave work as soon as it is needed. This creates better circumstances for the workplace to prepare a substitute and a safe environment for the employee (in the position of family carer). It is against the law to fire a person during their leave, and this creates a very safe employment environment for people who are on caretaking-leave as they can **focus fully on the family care**, instead of stressing about their work situation afterwards. The **state will provide the workplace with a fund**, so they can hire a substitute in the meantime, again just like during maternity and paternity leave.

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[16] https://www.borger.dk/familie-og-boern/Barn-syg-og-omsorgsdage/Orlov-til-pasning-af-syge-og-doeende-paaroerende

[17] https://www.cancer.dk/hjaelp-viden/rettigheder/plejeorlov-syge-doeende/

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Relieved return to work

Plan for reintegration: whenever a person is ready to go back to work, a professional creates a plan for them to increase the intensity of work and work hours. The professionals always try to create it in a very sustainable way, so that they do not risk that the person is experiencing a relapse. The plan is created in cooperation with the person it is meant for, the workplace and the job centre.

A part-time return: it is also a possibility to only return to work part-time during a care episode. A carer can have this option as a stable plan, meaning that it is not something to upgrade gradually so as to transition to full-time employment. However, this makes the whole process of going back into the labour force much easier for many people.

Care for children

In Denmark it is stated by law that **any parent can have paid days of work absence if their children are ill** e.g. if they have a cold, COVID19, influenza or similar. Parents of a child who is so ill that needs hospitalisation or can be treated accordingly at home, can get **daycare salary**[18], provided by the unemployment funding or by the union, of which most people in Denmark are members. If someone is not a union member, **most employers have a similar offer** either way. The child needs to be under 18 and the doctor needs to provide an assessment of at least 12 days of illness. The salary provided is 612 euros every week for a year. After this the parent(s) are supposed to apply for another fund, meaning that if the child suffers from significant and permanent disability or a debilitating chronic illness, you can apply for lost earnings instead of daily benefits. After this, they can similarly apply for the care-taking leave.

Volunteer support

In all municipalities in Denmark, one can find **various organised volunteer associations** which provide support to carers in care of ill relatives. Several examples are listed below.

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[18] https://www.borger.dk/familie-og-boern/Barn-syg-og-omsorgsdage/Pasning-alvorligt-syge-boern

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The Danish Cancer Society

A good example of the volunteer efforts is that in Denmark approximately 400.000 people are engaged in the fight against cancer. Most people are volunteers who spend time and money on helping **patients and relatives** to a better process throughout the illness. The foundation has several offers to both patients and relatives e.g., **dialogue cafes, events about grief, online meetings, social events, call-centres with expertise** etc. They also provide a lot of their help in Ukrainian at the moment.

The National Association of Life & Death

This as well is a foundation that offers support of both **patients and relatives** that are in grief, are preparing to die etc. They work in a more holistic way than the above-mentioned associations and are as an example very good at providing **tools for difficult conversations with children**, they create **podcast episodes about loss and grief**, as well as arranging **national debates** about how our healthcare system works and to promote the offers provided by the Danish healthcare system.

The above volunteer associations are providing help and support for carers as well as for the patients. A common denominator is also their focus on reintegrating into all parts of life after a loss or a period of emergency condition. An example of this is going back to work, providing support such as **dialogue groups, call lines, networks** etc. as a way of helping the carers back on track.

v. Germany

Social care

Within the framework of the federal model project "Netzwerk Pflegebegleitung" a network of 149 locations with more than 2,000 voluntary care companions has been established. They **accompany and support care-giving relatives** throughout Germany.

The Federal working group for crisis phone lines (Bundearbeitsgemeinschaft für Krisentelefone) offers support for family carers, mostly with a **focus of preventing violence**: https://www.beschwerdestellen-pflege.de/images/pdf/Adressenliste-5-2021.pdf

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Multigenerational houses - there are 530 multigenerational houses all over Germany, staffed by volunteers. For people of different age groups, a multigenerational house offers space to meet informally and benefit from each other's expertise. They provide space for joint activities, offer childcare and care for the elderly.

Financial support

Most available support of family carers revolve around the **legal protection of their workplaces**, not so much around direct assistance. Family carers are entitled to a **10-day paid leave** in order to organise the family care or respond to a crisis situation. They are also entitled to an **unpaid leave** of up to 6 months or **reduced working hours**, in order to take care of their relatives themselves, if they can prove a degree of disability. Moreover, family careers can reduce their working hours to a **15h/week** for a period of **two years**, if they can prove they have a relative that requires them to be taken care of. In addition, they can take an **interest-free loan**. Similar measures exist for taking care of the terminal phase of a person without a disability (3 months).

Peer-to-peer support

Pflege-Selbsthilfeverband e.V. - Initiative for humane care is a self-help organisation operating nationwide. It maintains the **family carer forum** at https://forum.pflegenetz.net/ and offers its members telephone and written advice on all topics relating to care.

Pflege Prisma is an **online magazine** focusing on the topic of professional and family care.

Elternpflege is a professionally moderated **discussion forum for family carers**. It gives, among other things, tips about care, and also operates a **user café**.

Aktion Demenz is a civic initiative with a goal of **improving the living conditions** of people with dementia and their companions, including family carers. A core concern is to eliminate the stigmatisation of dementia.

WIR! - Pflegende Angehörige is an **organisation uniting groups of family carers** in Germany committed to achieving political and social goals that would lead to a sustainable improvement in the situation of family carers in Germany.

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Psychological support

Pflege in Not offers **telephone and face-to-face consultations, mediation services, as well as further training /supervision** for both professional and non-professional carers.

Pflegen und Leben offers anonymous, free of charge (provided the users are insured) **online psychological consultations** to family carers.

Training and education

Most available training offers for family carers focus on their **caring competences.** There are dozens of such courses on offer all over Germany. Registration for such services is easy and user-friendly, and the costs are, as mentioned, fully covered by the insurance providers.

Courses targeting other types of competences, such as the ones needed for reentry **in the job market, have not been identified.**

Career counselling

Individual career counsellors can specialise in the situation of family carers. However, **no organised efforts** have been identified targeting their needs. Individual career consultations must, of course, be paid, limiting the opportunities of family carers to make use of them.

The Federal Labour Agency offers **consultations for re-entry into the job market**, however they are not in any way adapted to the specific situation and challenges of family carers.

vi. Greece

Provided that the discussion on carers' role and their visibility in society has only recently started in Greece, there are **not many good practices or systematised support efforts** at country level. However, there are services that are provided to the cared-for persons that may **indirectly alleviate the carers' burden**. For example, the "Home Help" programme provides access to social workers, nurses, and physiotherapists at home free of charge, but only those without family support and lower economic status may enrol in it and receive such services. There are also Open Care Centres for Older People (KAPI) which offer services including **socialisation activities, primary health**

care, prevention, and social services. Moreover, the state provides Day Care Centres for the Elderly (KIFI) which provide day care to older people with no family or while their carers are at work (Kagialiaris et al., 2010). There are similar public services that target other groups of cared-for persons, such as children or adults with chronic diseases, disabilities, or mental disorders.

As for the private sector, there are numerous initiatives by organisations and NGOs that support people with medical or mental health conditions, such as cancer, heart conditions, multiple sclerosis, dementia, autism, drug addictions, which also provide **psychoeducation, counselling, and support to their carers**. For example, the Association of Parents, Guardians & Friends of People with Autism of the Larissa Prefecture routinely provides family support to families of persons with autism and recently launched a helpline providing **psychoeducation, information, and psychological support to family carers** of people with autism[19]. Also, the Association of Families/Carers and Friends for Mental Health, Alzheimer's Disease and Related Disorders (SOFPSI) in the region of Serres provides psychological support and psychoeducation to family carers through weekly group sessions[20]. The Association of Parents of Persons with Disabilities of Kilkis "Vimatizo" provides **individual and group counselling and psychotherapy sessions to the families of persons with disabilities**.

When it comes to career counselling and integration in the labour market, there are not many initiatives for carers who wish to (re)integrate in the labour market. The Greek Manpower Employment Organisation (OAED) is responsible for work matters and employment programmes and opportunities, but its initiatives are not carers-specific, but refer to all unemployed individuals in the country. In this area, the **contribution of European projects** that have been implemented in the country is significant, while European Structural and Investment Funds (ESIF)[21] are often provided through specific programmes aimed to people who may wish to start their own business or become entrepreneurs.

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[19] https://www.autismthessaly.gr/index.php/2021/02/01/grammh-sthrijhs/

[20] https://www.sofpsi-ser.gr/psixoekapideusi-kai-ypostiriksi-ton-oikogeneion-frontiston/

[21] https://www.espa.io/en/what-is-espa/

vii. Italy

As already mentioned in this report, the lack of an organic law at the national level implies the absence of formal recognition and legal protection of the reality of family caregivers, but also the **absence of widespread structures and good practices** spread throughout the territory to support them, to the point that often not even professionals can name them when asked. This consideration applies to all types of entities to which the caregivers can turn to meet their needs: in the vast majority of cases, they can only rely on **structures aimed at a more general public**, and the rare examples of good practices that take into account their situation specifically are mostly sporadic isolated cases acting at a local level.

The process of recognising rights starting from grassroots forms of activism is not rare, however. As seen in the case of the Emilia Romagna regional law, **local institutions often prove to be much more attentive and receptive than national ones**, and their example can be a good starting point for more systematic interventions.

Social care and peer to peer support

A family carer in need of social services can, in the first instance, turn to the municipal and regional administration that provide this type of assistance to all citizens: **general practitioners, social workers and family advice centres**.

Social assistance is managed by individual municipalities (or in the form of a consortium in special cases) and can be accessed by all citizens who are registered at the registry office or have a residence permit. An interview with a social worker can be requested, and after one or more meetings, a decision is made as to whether to take charge of the person, activate specific interventions or refer them to other services, or offer simple advice on how to deal with the difficult situation. These social assistance offices are usually the very **first contact point for the caregivers**, as they offer a precious **referral service**. However, the quality of the service they offer is strongly dependent on the peculiar local situation they are in, and often this kind of assistance is seen by carers as **insufficient and too general**.

Family advice centres offer more specific services than the social worker's office: they deal with promotion and prevention in the areas of women's health, developmental

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age, adolescence, and couple and family relationships. These are areas that intersect in some ways the world of family care, but clearly do not completely overlap with it.

In addition to these two types of realities, we enter the world of **local and sectoral associations**: in particular, those that bring together family members of people with illnesses or specific conditions (parents of children with cognitive or relational disabilities, family members of people with degenerative and/or age-related illnesses, associations involved in advocacy with respect to a particular illness at local or national level[22]...). To give an example, below are listed some significant sectoral national associations:

- ANFASS - Associazione Nazionale Famiglie di Persone con Disabilità Intellettiva e/o Relazionale ("National Association of Families of People with Intellectual and/or Relational Disabilities")

- AISLA - Associazione Italiana Sclerosi Laterale Amiotrofica ("Italian Association of Amyotrophic Lateral Sclerosis")

- FISH - Federazione Italiana per il Superamento dell'Handicap ("Italian Federation for Overcoming Disability")

- Federazione Alzheimer Italia - Alzheimer: informazioni e supporto ad ammalati e famiglie e caregiver ("Alzheimer's disease: information and support for patients, families and caregivers.")

- AIMA - Associazione Italiana Malattia di Alzheimer. Per familiari dei malati e caregivers. ("Italian Alzheimer's Disease Association. For patients' families and caregivers.")

- AIP - Associazione Italiana Parkinsoniani ("Italian Parkinsonian Association")

- ANS - Anziani e non solo ("Elderly and not only")

- AIMAC - Associazione Italiana Malati di Cancro ("Italian Association of Cancer Patients")

- FAVO - Federazione Italiana delle Associazioni di Volontariato in Oncologia ("Italian Federation of Voluntary Associations in Oncology")

- AISM - Associazione Italiana Sclerosi Multipla ("Italian Multiple Sclerosis Association")

- ANT - Associazione nazionale tumori ONLUS ("National Cancer Association – Non-profit organisation")

- A.L.I.Ce. - Associazione per la Lotta all'Ictus Cerebrale ("Association for the Fight against Cerebral Stroke")

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[22] An up-to-date list of relevant associations can be found here: http://www.caregiverfamiliare.it/?page_id=27

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This dense network of associations[23] often represents **the most immediate and detailed point of access to services meant for caregivers**, also having the particular advantage of being able to offer specific assistance for the case in question, as well as **peer support** based on sharing similar experiences.

Funding and financial support

As regards the profile of economic support, one of the key laws is **law 104/1992**, which provides paid leaves and **care leaves** for workers who assist a family member with a serious disability. It consists of 3 days of monthly leave that can be fractionated into hours. This extraordinary leave, paid through compensation, can cover a maximum period of two years. However, the aspect that makes law 104 a very incomplete solution is the fact that **only working caregivers can be advantaged** by it.

More recently, also in the wake of the National Recovery and Resilience Plan (PNRR), other legislation was introduced to provide broader financial coverage.

Law 205/2017 established the **National fund to support family caregivers**. With this, the Ministry of Labour and Social Policy pledged to provide EUR 20 million for each of the years 2018, 2019 and 2020 (then extended until 2023 with a further EUR 30 million manoeuvre) for "the **recognition of the social and economic value of the non-professional care** activity of the family caregiver". These funds are entrusted to the regional administrations for interventions to support caregivers, giving priority to those who care for severely disabled persons, persons who did not have access to residential facilities because of the Covid-19 pandemic, and persons who are following a path to be discharged from these facilities and return to live with the caregiver.

In the case of the Veneto Region, the Regional Council, with Resolution No. 295/2021, approved the implementation measures to make these funds available. In concrete terms, this support will be accessible to caregivers who apply to the social assistance desks: the contribution may range from a minimum of 400 euro to a maximum of 1,000 euro, depending on the applicant's economic status, and will be granted in combination with a customised intervention plan, designed on a case-by-case basis.

For **caregivers close to retirement age**, the 2017 budget law introduced APe Social: a **zero-cost early retirement pension**, along with the provisions of a monthly

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[23] To have a clearer picture of the 3rd sector associations in Italy, the dedicated national register can be consulted at: https://servizi.lavoro.gov.it/runts/it-it/

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compensation until retirement, which 63-year-old workers with 30 or 36 years of contributions, as the case may be, can benefit from by the end of 2022.

Psychological relief

Psychological support tends to be regarded as a secondary or even marginal issue in Italian regulatory culture. The family care sector is, of course, no exception: there are **no facilities specifically designed for caregivers**, but rather the solutions offered by local health authorities (ASL in Italian) to the general public. In this sense, fundamental and valuable is the intervention of the already mentioned **local and sector associations**, which often provide services of this kind, as well as **social assistance**, which directs the carers to the appropriate professionals. The world of **informal and mutual aid groups** is also essential: caregivers identify as a fundamental form of psychological support the sharing of experience with other people facing similar problems.

Training

Again, there are **no solutions specifically designed for caregivers**. The training offer is aimed at unemployed adults or those seeking relocation in general and is entrusted to **organisations such as ENAIP**. The protagonists of the sector point out as crucial the **lack of specific training offerings to carry out such a complex and delicate task** as family care, and there is certainly ample room for the creation of initiatives to fill this **gap.**

Career counselling

As far as employment counselling is concerned, there is also a lack of a general and structured approach to the figure of the carer. There is the counselling activity carried out by **institutional employment centres** and by **accredited bodies such as ENAIP**: in these contexts, individual professionals involved in supporting caregivers point to the use of an approach aimed primarily at **enhancing the skills acquired during the care period**. The starting point is the construction of a personal narrative, which also takes into account past experiences, aimed at acquiring awareness of the value of the new skills learnt while carrying out care tasks, also from an occupational point of view. In fact, this seems to be the most effective way to get around the obstacle of age and the gap on the carer's CV, by building a competence-based curriculum instead of the

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usual chronological model. In this way, caregivers are often directed towards care-related professions: such as, actually, professional caregiving.

The caregivers themselves and the professionals working with them stress that a **change of sensitivity is needed in the corporate workplace**, where initiatives to support caregivers are often fragmentary: there are cases of the possibility of a time bank, or of greater sensitivity on flexibility.

c. Compilation of existing offers for family carers – best practices

A rich compilation of existing offers for family carers in the partner countries, which could serve as best practices can be found in Annex I to the present report. The offers vary depending on the type of support provided: social care, funding and financial support, training and education, peer-to-peer support, psychological support, career counselling and other types of support.

3. Family carers in partner countries

a. Overview of the interviewed profiles

The partners conducted **33 qualitative interviews** in total with family carers (the project's primary target group) from **7 different countries**. All family carers (but one) were **female** with an age range varying **between 34 and 69 years old**. While the educational background and professional occupation were quite diverse (among the interviewees there were nurses, a bank clerk, teachers, shop assistants, a scientist, a lifeguard, a PR and media expert, HR specialist, insurance agents, cleaning maids, economists, social workers, accountant, freelance actor, office administrators etc), **the majority of respondents** (22 out of 33) **were employed** at the moment of the interviews (some reconciling work with care, working part- or full time and some already re-integrated back into the labour market). Out of all 33 interviewees there **7 unemployed family carers and 4 were retired.** Since for some of these family carers, the care episode was already over at the time of the interviews, it is difficult to estimate how many of them exactly kept working during the care, how many of those were employed part-time or full-time and how many had to quit their job during the care episode and go back to work after it was finished.

As far as the cared for relatives are concerned, there were three main types of situations. There were mostly women taking care of **elderly and/or sick parents**

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(dementia, cancer, disabled) and mothers taking care of their **sick children** (autism, cancer). There was also a portion of carers who cared for their **sick spouses**. When it comes to the duration of the care episode, the situations varied significantly – from 6 months through 2 - 8 years to "for life".

b. Challenges faced by the family carers

The challenges faced by family carers are many and, sometimes, decidedly tough. As mentioned in the report above, the **lack of legislative recognition** at national level in some partner countries implies a **chronic absence of adequate and specific support services and funding**. In addition to legal recognition, there is also a strong need for **recognition of the social relevance** of the family carer figure, without which the welfare system of those same countries would be in serious difficulty. But these problems represent only the surface-level issues that can be seen at a first glance.

The heavy burden of care is also often accompanied by a high risk of social exclusion, isolation, psychological issues, economic hardship, health risks, and reduced career and training opportunities. Each and every of these aspects leads to a multitude of considerations.

Health risks

As far as the health profile is concerned, studies in general conclude that caregivers are **physically and emotionally overwhelmed** - carers show **significant increases in the possibility of developing serious illnesses** compared to non-carers[24]. This is due to both stress loads that are often of clinical relevance and to the assumption of negative health behaviours due to lack of time for self-care (lack of exercise, poor diet, lack of rest and leisure). They also show generalised physical symptoms, such as sleep disorders, fatigue and musculoskeletal pain. These factors make the possibility of becoming patients in need of care themselves very real.

Psychological and emotional issues

For the **psychological aspect**, too, the problems are many and varied. There is, firstly, the difficulty of understanding the loved one's condition, the processing of grief in dealing with illness and bereavement. There is also the **problem of self-perception**: frustration, loneliness, lack of awareness of the importance of the tasks they perform,

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[24] https://retecaregiver.it/wp-content/uploads/2020/04/7_Valorizzazione_sostegno_ruolo_Caregiver_familiare_Documento_Agenas.pdf

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low self-esteem, seeing their personal aspirations jeopardised. There is also the dimension of society's **prejudice against the caregiver**, who is often seen from the outside as a person who has made a choice 'of convenience' and lives off the family member's income or compensation related to their condition: this is linked to the person's **sense of shame**, which makes the caregivers struggle to explain their situation to the outside world. It appears very clear that psychological assistance is the core need of caregivers, paving the way for every other kind of assistance: and yet, it is frequently the **last kind of help they seek**, giving priority to more “practical” aspects.

As far as family carers who reconcile care with work are concerned, psychological and emotional burden is one of the major issues they experience along with physical burden and **high cognitive burden of multitasking** when trying to combine care and work responsibilities. Despite their efforts to juggle different spheres of life, they may have a **bad conscience** not to provide sufficient care for the beloved person, neglecting their partner/ family too much or being less efficient at work.

Emotionally, professionals working with carers reported that carers often experience **low self-esteem and self-confidence**, often feel trapped in their situation, as well as **hopelessness and burnout**. With respect to professional reintegration, their negative affective status often translates to a **hyperfocus on their weaknesses** that they believe disallows them from re-entering the labour market. This adds to the existing inertia that is exhibited by carers, who feel as though they cannot escape their situation to the extent that they also feel **no motivation to take targeted action**.

Social exclusion and isolation

Lack of personal time is one of the central challenges of the caregiver: often, in the absence of systems to provide support and relief from the burden of care, the caregivers neglect their own needs throughout the care period, resulting in a vicious cycle of worsened physical and mental health.

Having to leave work and dedicate fully to the care of a sick relative for sometimes unknown periods of time, can often leave one feeling **isolated from the outside life**, neglecting their own personal goals and dreams. During our field research we talked to mothers, looking after their children suffering from cancer. While living every day in fear of whether their child will survive the treatment, it can very often put the children in a condition of immune deficit, where every viral infection could be fatal. This is why

social isolation for a certain period of time is the only option for many mothers. It is not only heavy for the children who cannot attend school, do sports or other activities where they meet with peers, but also for their carers (their mothers in about 95% of the cases), who need to quit their job, cut their social ties with friends and basically give up their personal free time every person needs.

Taking over care responsibilities has big impacts on everyday life of employed family caregivers too. Combining job and caregiving requires a **reorganisation of their everyday life**, with usually very little time left for their own social and recreational needs. Family carers are likely to lose their own spontaneity of meeting friends or going on holidays, which negatively affects their psychological health.

Reduced employability chances

The time factor is also crucial in the **employment field**: caregivers who leave their job tend to **disconnect from the labour market completely**, with particularly severe consequences when the care period ends, and they try to re-enter it. This is reflected on the one hand, in the **difficulty of being competitive at an age considered advanced** to seek employment and, on the other hand, in **having to explain the "gap" on their CV**. As the carer can spend many years caring for their family member, the labour market changes profoundly, both in the aspect of its offer and of the skills it requires. If, to this, it is added a 'weak' education at the start, the road appears decidedly uphill. To make matters worse, there is also the **lack of training and placement offers specifically designed for the special condition of carers** and the **inflexible structure of the world of work itself**. This is problematic in two ways: on the one hand, with the difficulty of reconciling working and caring hours, and on the other hand, with the lack of recognition of the caring years for reaching the retirement age.

In addition to this, consistently across career counsellors, it was reported that carers feel that they will need to make **excessive compromises** in re-entering the workplace, as they believe they will need to sacrifice significant parts of being a carer considering their new job. Specifically, it was reported that people felt unsure if their line manager would be flexible to their care responsibilities, which they often felt as non-negotiable yet misunderstood. Practically, they felt as though they were **'out' of the workplace culture** and would not be able to communicate and attend to the multifaceted needs of organisations and other employees. In terms of soft skills, counsellors reported that carers out of work for significant time felt that they **lacked the character to be part of**

a professional setting, having internalised their role as a carer. In terms of hard skills, carers often felt like they were lacking in basic employability skills like IT skills, foreign language proficiency, or technological aptitudes in general.

Financial difficulties

The **financial burden** is another very common problem encountered by the family carers. While this is not the case in some countries, in others the lack or the insufficiency of financial support for family carers who are forced to leave work poses a great challenge. Moreover, along with caring duties carers may even face increased expenditures, which creates additional burden and pressure on them.

Other challenges

There is also the **difficulty in understanding the needs of the family member**, the absence of proper training to identify and meet their needs, as well as in finding the necessary services and professional help. **Organising the whole care situation at the very beginning** of the care episode represents a main challenge for many. In case of (spontaneous) care needs, family carers are often overwhelmed, as they do not know whom to address and where to access information (**lack of information**). In addition, caregivers have to often overcome **bureaucratic obstacles** in submitting applications for support services.

The **unpredictability of the care needs and the care process** poses another challenge, as caregivers do not have **any planning security** concerning their future. The care situation may take several weeks or several years. In addition, the changing nature of the care trajectory is also hardly predictable, so family carers cannot plan the support services that will be necessary in the short and medium-term.

When it comes to re-entering the job market while providing care at the same time, there is another challenge, which is less common but still surface during our field research. Family carers shared they may have **very little energy and motivation to search for a new job**. They may not know how to handle the fact of providing care in job interviews, as they are afraid that this might be a disadvantage for them. For applying to a new job, family carers think that they **have to provide justifications** and assure that everything is settled concerning caregiving work. When looking for a new job, probably in a new field, they are not sure whether they are skilled enough and might doubt their capacities when they have been taking a break from work for a longer period of time.

c. Opportunities for personal and professional growth

As reported above, interviewees hardly have free time to dedicate on their own needs or dreams. The "burden" of care is sometimes so heavy that they remain blind to their own desires or personal plans for personal growth and professional development, which they feel they need to leave on hold. They are often so preoccupied with practical matters, that thinking about whether they are gaining any new competences that might potentially be useful for them personally at some point is rather not a priority or even something they are aware of. Some of the professionals interviewed also confirmed they observe a **lack of self-awareness about the competences acquired** by the family carers they work with and of the actual importance of their work (often seen as a necessity, something that simply needs to be done).

However, from the distance of time it is sometimes easier to reflect on this aspect. Several interviewees were able to identify multiple skills they gained through the provision of care, on both personal and professional level.

Personal competences

Many of the carers interviewed shared that the care episode made them more **flexible** on a personal, professional, and family level. They gained **resilience,** became calmer, and learned how to not panic so easily in the face of emerging challenges. **Patience and persistence** were other personal strengths developed due to the repeating attempts to find the right 24 hour-care professionals, for example. **Courage, determination**, and the **ability to smile even when faced with critical situations** - a certain kind of ease of handling the whole process turned out to be a coping strategy for some. **Reliability, ability to handle difficult situations**, as well as **empathy and listening skills** were also mentioned as skills that were significantly improved or even acquired during a hard caring period.

All the above competences can have a direct implementation in the sphere of **professional care** for example – something many informal carers consider –but could also be useful in any **service-related industry**.

Professional competences

Some of the main gains in terms of competences that were mentioned referred to acquiring **management and organisational skills**. Family carers have to find suitable care services and adapt the services to changing needs, to coordinate different care services (e.g. home care, physiotherapy and meals on wheels), apply for care allowance, apply for other financial support services if available, monitor the care work done by professional caregivers, organise doctor's appointments… This requires good **time-management** and **problem-solving skills**, which many informal carers pointed out as something they improved throughout the period of care. In addition to that, some caregivers were able to develop **advocacy skills** as they contributed time and energy to improve the caregiving situation at home and stood up for the needs of the person being cared for.

Those reconciling work and care also shared they developed **multitasking skills** in managing their own work and private life combined with care responsibilities, admitting, however, how exhausting this situation can be. In this sense, **stress-management** techniques turned out to also be important in combining care and work duties.

Interviewees reported that they acquired a lot of information on existing benefits for informal carers and care recipients, as well as the health-care system in their country, as a whole. A gain of **medical knowledge** was also mentioned on several occasions, as often family carers have to talk to doctors, do some research on their own when problems occur and acquire some **nursing knowledge** by providing care tasks. First aid and helping someone in an emergency was also another competence worth mentioning in this respect.

d. Fears and hopes regarding family carers' professional situation

With regard to the fears interviewed family carers shared, one needs to make a distinction between **those who are reconciling their care duties with their job** and **those who had to interrupt their career** in order to fully dedicate to the family care.

The **first group of interviewees'** biggest fear is of **losing their job** because of the pressure of care. On one hand, it is the pressure of juggling duties, on the other hand is the fear that their care responsibilities might affect their work performance – family carers are

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afraid that they may have to miss work when they need to accompany the relative to a doctor's appointment or due to an unplanned event of emergency, for example. Flexible working hours and time schedules are generally perceived positively, even if this is not a possibility or a common option everywhere. For self-employed family carers combining care and work seem to be easier due to time flexibility and higher extent of being in control over working conditions and job efforts. However, reducing working hours also reduces monthly income and with this - **financial security and independence**, which was also one of the most commonly expressed fears.

Another concern expressed during the interviews was the **fear of revealing their identity as caregivers** – some are afraid of being labelled or categorised as problematic employees or eventually receive unsolicited advice that could only add to the pressure they experience. Other family carers seem to be reluctant to share their situation in the work context as they consider this a personal matter and would rather be willing to talk to an external coach/therapist than to someone at the company.

For the **second group of interviewees** – those who had to quit their job in favour of their family care duties – the main fear seems to be related to **regaining their financial independence** and the **inability to find another job because of outdated skills**. Re-entering the job market seems to be a challenge for some carers who had to interrupt their carer at a more advanced age, fearing the pause might have fatal consequences for their pension years and further financial stability.

Some family carers shared concerns regarding **not having the financial possibility to study/upskill** in order to find a new, well-paid job. The fear of not being able to find a job that provides economic stability and having to put up with **poor/inconvenient working conditions and/or unrewarding salary** out of necessity.

Both groups, however, had **one main fear in common**: what would happen to their relatives if they could no longer take care of them. The life situations of the family carers interviewed in each country varied but a prevailing observation was that the **fear for the health/survival of the relative they care for** came first and only after came the carers' personal concerns related to their own professional aspirations. On a more personal level, the permanent fear of not being able to cope with the care arrangement at home anymore surfaced (the question at the back of one's head "How long will I be able to cope with this situation?").

The **hopes** the interviewees shared were also related to this aspect for the most part. Several carers hoped that **the person they care for would improve**, as this was considered to be their main priority. At the same time, in the case of countries with a less organised and stable support system such as Bulgaria, Cyprus, Greece, they also aspired that the state would organise and provide related services of high-quality formal care to allow family carers to reintegrate into the labour market more easily.

It is worth pointing out that many family carers agreed upon the idea of the **work being an outlet for the informal carers**. Regardless of the different circumstances, many thought that remaining or reintegrating into the labour market is crucial for both financial and psychological reasons. So, in the long term, some family carers expressed the wish to undergo **further training** so they can grow professionally and move to a good position, hoping to find a job as quickly as possible - a job with continuity and dignity, a job that would enable peace and economic and personal stability.

e. Needs of the family carers

General support needs

One of the main needs, expressed by both professionals and family carers themselves (even if this is especially true for the countries lacking those structures) is the need for a strong **social support net**: in terms of financial support and regulations, of relieve from the burden of care, of self-help groups with individuals living in the same situation etc. - services provided by the state and guidance on the cared-for person's conditions. Some interviewees shared that they wished they would have received support from social services and guidance on how to provide care, being inexperienced and non-formal carers. Having a professional explain the basics and reassure the carer that they are doing a good job can help a lot with the anxiety and insecurity that comes from the sense of taking responsibility for your loved one's life and can remove some part of the pressure that the carers feel at the beginning of the care episode.

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Another need that was mentioned very often and has a lot to do with the above-mentioned feeling of being emotionally overwhelmed is the significant need for **psychological support**. This can be especially true in cases of relatives with dementia or terminal illness, as they often find it difficult to come to terms with the deteriorating health state of their loved ones. In that regard, with most attention towards them stemming from medical doctors of their relatives in care, carers require intervention both with respect to motivating them to seek separate and individualised support, but also to carrying through with it in a consistent manner. Professional support from therapists is only one side of the coin, however. **Self-help groups and the exchange with other caring relatives** who are in the very same position as you, can be of invaluable help, as family care can take a heavy toll on one's mental health. Having someone to talk to, to tell their story, talk about their fears and feel understood and not judged can be extremely helpful for many, as family carers seem to often have the feeling that they are not doing enough but at the same time have difficulty accepting the fact that they need some help themselves. Of course, it should be noted that this is an individual need, which does not come at the same time or form for everybody. Some interviewees showed only little interest in family care networking or self-help groups as they believed they already have enough to think about managing their own care situation and do not want to be burdened by the problems of others.

Another very prominent need that surfaced during the field research is the **easy access to information**. Knowledge of available services varies greatly – not only from country to country but also from people to people. Family cares do need complete information about their options, rights and what range of support services are available – this could be particularly helpful at the beginning of the care episode, when people are most overwhelmed emotionally and find it difficult to find their way in the sea of information online. Having access to adequate and structured information and knowing whom to turn to seems to be a key need for informal carers. Be it the GPs who could play a more proactive role in providing information about existing support services to family carers or a former professional caregiver who could serve as a contact point is a crucial first step. Given the complexity of the care support structure in the different countries, it seems valuable for family carers to have this reference person that they can turn to and ask everything they need to know instead of looking up all the information scattered online.

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Career-counselling is another need, which came up in the interview process. It is needed both in the dynamic processes of progressive shifting away and back into the workplace. Specifically, carers require guidance both in progressively accounting for their family members' needs and hence **re-structuring their approach to work or change occupations** to account for it. On the other side of the coin, family carers also require **guidance in realising their strengths** and aligning them with potential market openings, a process which if done early on, can leave room for upskilling and cognitive restructuring that may be needed in the meantime, so that re-integration is successfully carried through.

A couple of respondents referred to the need for **education and training to raise awareness among society** on certain types of health conditions. In the case of children with disabilities or other disorders, or even children suffering from cancer, social acceptance is important and can save a lot of unpleasant everyday situations, which only add to the emotional burden of both carers and people in need of care. So, related campaigns and seminars that would raise awareness on several target groups could help to increase social acceptance. While this need is not directly related to the family carers themselves, it is a source of pain and concern, which was shared by several interviewees.

Training/learning needs

As regards the needs **during the care episode**, the main training needs expressed by carers revolved around the care duties, not so much around returning to work:

- **exchanges of experience**, such as discussions with like-minded people
- ways of **dealing with stress**, such as a meditation or relaxation training; yoga or body and mind alignment; focusing on your body and inner peace
- an in-depth **study of their patients**: the different intermediate steps in illnesses and how to deal with them
- learn more about care to successfully assume their carers' role as well as **ways to get more information** on existing support and services

In the area of training and education, the mostly free offers of the self-help organisations and the welfare associations are dominant. Central and comprehensive networking and coordination structures are predominantly **lacking**. There are hardly any innovative digital offers. Some of the available options are **not used** because the coordination structures are so complicated that many relatives cannot know everything and are given too little advice.

After the care episode is over, many carers shared they would prefer some **time out before re-entering the labour market** e.g. spend some time in rehabilitation facilities. In particular, if the person they have cared for passed away, they would need some time to grieve. Some interviewees could imagine that they would need **general support in finding their way back to work-life** and compared it with re-entering the labour market after maternity leave as their skills might be outdated. There is a need for **strengthening their self-confidence** as often, not earning money and being absent from the labour market is associated with being less valuable. Also, it needs to be considered that family carers have been in a situation of considerable emotional/ psychological strain, maybe also suffered from depression due to the heavy care situation and need to find again a certain joy of life.

As far as the more technical aspects are concerned, many of the respondents agree that the competences acquired in the field of care should be **exploited and expanded**, as well as being **formally recognized** both from the external world and the caregivers themselves. This view could result in two different training approaches:

- updating and reskilling of competences from their former occupation
- formal training to become a professional carer for those willing to pursue this occupation

In both cases, however, some cross-cutting skills are regarded as crucial areas to improve such as **digital literacy**, **job market knowledge**, **teamwork**, **and motivational support**. Family carers need employability skills that directly impact their access to the job market - more specifically, **interview skills, professional communication, and curriculum vitae design**. Moreover, within professional communication lies the increasing market need to **speak foreign languages, especially English**, as a central prerequisite to labour market reintegration. Finally, **IT skills** and **technological acumen** are important in helping people revitalise dormant skills they used to have but may find it difficult to utilise in an increasingly digitised work environment.

While **these learning needs are complex and may vary** depending on the carer's age, background, education level, previous working experience, etc., the above ones

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seem to be the skill needs mentioned the most. In addition to them, the need to **update the carers on the current situation in the labour market** and the latest developments is also worth mentioning. Knowing more about possible ways to land a job, the changes in the labour market or in a respective professional field is considered to be a good start and prerequisite to prepare for re-entering the job market.

As regards the **format** of a potential training meant for family carers willing to return to the labour market, most interviewees expressed a preference for a **face-to-face training (rather than an online course)**. Even though the majority recognizes the flexibility of online training for carers, they still thought that face-to-face training would add more value to the learning experience because of the personal touch and social and networking aspect attached to it.

4. Professionals working with family carers

a. Overview of the interviewed profiles

The partners conducted **25 qualitative interviews** in total with different professionals (the project's secondary target group) working with family carers from the 7 countries. While being mostly female, the interviewees varied in age (30-64 years old) and professional background and occupation but the common trait among them all was their experience with the group of informal family carers by providing various services. Among the respondents there were (a fair share of) **psychologists**, labour market and **career counsellors**, tutors and **educators, members and founders of carers' associations**, nurses and assistants, a criminologist, and a family care expert.

b. Challenges faced by the (counselling) professionals

Counselling professionals were modest in identifying any challenges they themselves are facing when working with family carers, as they unanimously highlighted the **need for individualised counselling** across different target groups, with **career counselling being highly personal**. One main challenge that emerged, however, especially in the countries with underdeveloped supporting structures, is related to the **lack of appropriate institutions and facilities through which the carers can contact the professionals** and, potentially, to which counsellors could refer the people they are working with. Because of this, it is common for professionals to have only **limited information about** the existing support offers for family carers and about their burdensome situation.

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Nevertheless, when referring to their experience with carers, many of the professionals we interviewed shared **certain patterns** they come across in their work. Several people mentioned the **stigma surrounding family carers** willing to re-integrate to the labour market and the term "shame", which seems to often come up in conversations. Women especially find it shameful or see it as a weakness that they are not ready or able to have a full-time job yet during/after a care episode – they are most often the ones being the family carer but are also the ones who are most vulnerable when going back to work. There is also shame surrounding the care situation itself – caregivers often feel **shame of the years they feel they have "lost" due to family care**, as well as embarrassment in asking for help. This is accompanied by the fact that, in general, the caregiver's important social role is not recognized everywhere, which results in the "outside world" being unable to understand their condition and accommodate their particular needs.

As far as job orientation is concerned, counselling professionals often notice that **family carers are quite uncertain about how to talk about the care situation when applying for a job**. They consider it a big disadvantage when starting a new job, possibly meaning neglecting their own career path and professional development, which does not look good to potential employers. When it comes to re-entering the labour market, another side of this issue are the **bigger gaps in the CV of informal carers** that need a reasonable explanation.

Another pattern, which seems to be faced by many professionals, has to do with the observation that a **carer often finds it difficult to prioritise themselves** or to conceptualise their own needs as comparable to those of their relative in need of care. This often results in carers not looking for the help they need in the first place, as they often do not realise they are deserving of support during this process of going back to work and to their individual well-being after enduring a hard care episode.

c. Coaching approaches and competence assessment methodologies used by counselling professionals

Many of the interviewees underline both the absence of formalised schemes for dealing with family caregivers in particular and at the same time the importance of a specific tailored approach. One crucial point they all stress is **building an effective personal narrative** to guide the caregivers in assessing the value of their own work, in order to be able to convey it to a potential employer during an interview. **Building a**

strong connection and a bond of trust is regarded as the first step both by psychologists and career counsellors.

As far as the communication with family carers is concerned, the professionals we interviewed shared some **general approaches** they use in their work:

- try to always **remain objective** and to explain everything calmly and in detail
- try to be **honest** in their communication
- explain that feeling challenged is **normal** under these difficult circumstances
- help the family carers **feel** that their relative is receiving all the support they need
- show **exercises** that the family carers can also use themselves with their relatives
- share **tips** e.g. on how to eat better, what to use to help them get changed or get out of bed to make it easier for themselves and more comfortable for the person being cared for
- try to help people see the world differently and understand **their own restricting beliefs** that shape their reality (especially with regard to going back to work)

Asked about the specifics regarding the reintegration in the job market after (or even during) a care episode, career counselling professionals shared they utilise **personality and aptitude skills assessment** in the initial phases of their practice. This helps with empowerment of people who, as identified through both counsellors and carers, experience uncertainty, low confidence and self-esteem, and feed largely into their weaknesses. By extension, this allows career counsellors and people they work with to identify the strengths and weaknesses of each person. The benefits of this are twofold: on one hand counsellors can help identify areas for improvement for each individual and help create a competence building plan around it, and on the other hand find job opportunities that align with the interests and personality traits of those interested in re-entering the labour market.

Some **specific methodologies** employed by professionals that interviewees shared:

- Building a **skills curriculum** rather than a traditional (chronologic) one - this allows to overcome the concern about the time gap in the CV.

- **E-factor tree** - a useful scheme for analysing different aspects of employability, matching the client's personal traits and the competences acquired with the employment and narrative of these assets.

- **SWOT-analysis** (Strength, Weakness, Opportunities, Threats) and passing the last years in review of:
  - *What do I take with me from the past?*
  - *What did I learn during that time of caregiving?*
  - *What new things did I learn?*

- **Family board** - a method for constellation used in therapy; it helps to strengthen the skills of the client by putting different wooden figures on a board with each figure representing a certain quality/skill of the person; eventually the personal wealth of skills, qualities and strengths is made visible to the client.

- **Techniques for visualisation** e.g. using a flip-chart and drawing a rough outline of a person - inside the drawing, the client writes down all the skills and competences they acquired during the past (e.g. patience, endurance, persistence, time-management, organisational talent, interface management).

- **Role plays** could be a useful method when working with family carers who are overburdened and have difficulties to set boundaries (e.g. How does it feel to say "NO, I can't do this, this is too much for me"?).

- Using a **list of questions** on several topics such as health & wellbeing, social relationships, free time, financial security, values & ideals, work & performance, care situation, available support etc. to assess the current situation of the person, their current resources, needs and goals for the future.

- Creating a **personal profile:**
  - Self-awareness - how do you perceive yourself (using a list of characteristics)
  - Polarity profile (areas of competency in which you have a strong or weak value)
  - Situation analysis

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- **Stress-management** techniques:
    - Exercises on how to say NO without a feeling of guilt, how to set boundaries and share resources, how to accept help
    - Awareness-training
    - Digital detox
    - Taking a break

- **Employability skills** (CV writing, LinkedIn profile creation) **and interview skills assessment** - specifically, it was highlighted that these skills offer a medium of discussion that does not focus on the individual or the job, but rather the "space in-between", which at the state of uncertainty in which these people often operate, is helpful in creating an action plan with limited introspection.

- **Neuro Agility Profile +** - a technique which provides learning and talent development professionals with a holistic predictive analysis for identifying people's potential and talent as a starting point for developing their strengths and improving their performance; among others this tool can also be used to help the client with better emotional intelligence development and stress management by providing accurate awareness of people's individual neurological design.

- **GCDF** – Global Career Development Facilitator of NBCC International, US is a methodology which covers all aspects of psychological counselling.

- **Cognitive-behaviour approach**

- **Online career tests** - there are very interesting free online tools that can support the clients and help them focus on a certain career topic.

- **Specific instruments** for assessing and evaluating the burden of care (in psychological terms).

As for the **success stories** related to re-integration in the job market shared by the counselling professionals, they mostly revolve either around **family caregivers becoming professional carers** after receiving formal training, or family carers who took on their former job back. There were several cases reported on people who re-oriented professionally by adopting a so-called **job-cause** influenced by the informal care they provided (e.g. founding carers'/patients' associations, anything to do with education and professional care).

d. Needs of the professionals

Most of the professionals perceive the need for **more accurate, tailored instruments** they could use to assist and provide adequate support to family carers. In particular, the following needs were identified during the interviews:

- A **better understanding of the peculiar conditions the non-professional carers face** (in terms of better knowing the illnesses and conditions of their care receivers)
- A deeper knowledge of dedicated structures, regulations, and economic support opportunities - **compact overview of information on existing financial, psychological, and social services** in the respective country
- Regular updates and training on **new instruments and methodologies**
- **Tools for coaching** that are particularly targeted at the group of family carers
- More **possibilities to cooperate with the institutions**
- Knowledge of **good practices from other countries**
- **Network of psychological specialists** career counsellors could turn to for additional support if/when needed
- **System for exchanging information** between the professionals themselves
- Overview of information on **existing forms of workplace support** for informal carers
- **List of carer-friendly companies** offering working models suitable for family carers (e.g. flextime, ability to work at home etc.)
- **Additional financial support** from the State for the career/psychological services provided to make them more accessible to carers
- A platform or a **handbook** (to be updated regularly) with an overview of available support options (not only those provided by the State but also NGO offers) and guidelines for the professionals on how to use them in their work with family carers
- Improved and tailored **communication skills**

Professionals require a variety of **educational material and information** in the topics listed above, which allow for different options to be offered to people at different levels of proficiency in particular skills/knowledge. This material mostly resides in the area of soft skills like interview skills and career perspectives. This is because it was widely reported that out-of-work carers find it difficult to go through job assessment procedures (interviews/competences tests) that are now in place in modern workplaces. Just as for the family carers themselves, the training material needs to extend to hard skills as well like **digital literacy and basic technological acumen**, to respond to the rapid digitalisation exhibited in workplaces today.

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IV. Conclusions and recommendations

There is a **high variety in care situations** with respect to time demands and physical/emotional/cognitive burden with different effects on the labour market behaviour of women carers. The group of family carers is **very heterogeneous**, and each situation is **very individual**, so it is difficult to come up with a universal strategy that fits everyone, as all other areas of the family carer's life have to be taken into account.

There are, however, some general conclusions that can be made, which could possibly serve as a basis for elaborating an adequate training offer and guidelines for both project target groups.

The field research shed light on both the emotional and practical struggles that carers face as well as their general and specific training needs. In general, most career counsellors had **minimal experience with the narrow group of informal carers**, which in part reflects the lack of support-seeking, both psychological and career-oriented, that carers exhibit. This matches some individual comments made by carers, who exhibited a passive stance towards re-integration and suggested that significant parts of their lives were 'over'. Whilst that may reveal a sad truth, it highlights the significance but also the **vitality of this innovative attempt to fortify the potential of carers** in realising their ability to obtain better support, independence, and quality of life.

Many considered that the training program should be **based on the carers' age, educational background, and former work experience**. While this is more difficult to achieve, most agreed that the training program should include **information on how to build their CVs**, evaluation of **what skills and competencies were gained** through their role as carers, as well as **recent updates in the labour market**. **Digital skills** were also considered to be crucial for carers to enter the labour market. Both professionals and carers underlined that it would be very helpful to provide carers with **information on existing organisations and services that they could address for practical support** and help in their carers' role. It should be noted that carers often lack the time to make a thorough research on this crucial aspect – currently (apart from information from peers, which is not by default) the internet seems to be the central space for informal carers to look for support. However, **easily accessible advisory offices** or an **online platform containing useful up-to-date information** would be a very helpful service for informal carers.

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Finally, the interviewees expressed the desire to learn more about different **ways to balance work with care** and **self-care techniques** since the emotional burden of care is not to be underestimated. In the interviews, it became apparent that most informal carers **want to share their story** and would be willing to look for psychosocial relief. They would benefit from someone who listens to them, shows understanding and provides concrete opportunities of support. Coaches could be helpful in these situations by showing different paths depending on the current carer's situation.

As for the **training program's format**, all participants thought that **flexibility is key** for carers to be able to attend. Nonetheless, they also strongly believed that a **face-to-face training would be more helpful** for carers as it would both help them in their social inclusion and at the same time provide a supporting environment with peers who go through a similar situation.

To sum up, the present research showed that most partner countries are lagging in issues regarding the recognition of informal carers' contribution to society and the economy, which are vastly undervalued. Provided that the caring needs of the population are expected to further increase due to the ageing of the population in most countries (and the EU in general), **more resources are needed to support carers** in practice. The Care4Carers initiative was warmly welcomed by both professionals and carers who are expected to benefit from the project activities, especially in terms of carers' reintegration into the labour market, social inclusion, and empowerment.

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