# Caring for family carers

## Policies, Services and Recommendations

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Author:
Maria Schwarz-Woelzl
Zentrum fuer soziale Innovation

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This report was carried out within the LLL / Transfer of Innovation project: Transf DependenTIC (Project No. 2008 – 1- ES1-LE005-03191) Work Package 2. The Project aims at supporting informal carers of dependent persons through training and certification of knowledge, competencies and skills. The project transfers the tools from the DependenTIC project (which have been successfully implemented in 23 municipalities in Aranjuez-District in Spain) to Portugal, Italy and Austria.

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# Framing family care - Introduction

Care dependency is a fundamentally life-threatening situation, which may affect both young and elderly people and whose probability increases with age. A central role in terms of supporting and caring for these individuals is played by partners, adult children, other family members, friends and neighbours - the so called „family carers". They provide regular and unpaid support or assistance to someone in need of help, being the main providers of long-term care and representing a group of 100 million people. In relative terms, this corresponds to 25 % of the EU25 citizens (Tjadens, Visser et al. s.a.). In many instances, family care for dependent relatives is the only option available as home care services are poorly developed. This particularly applies to Central and Eastern Europe, as well as the Baltic States (AGE 2008: 2f).
Although the support/care of relatives is crucial for the maintenance of those members of society in need of care and assistance, the attention granted to carers' needs in the fields of policy and practice has until recently been low.

However, the ageing of population and changing family structures have brought the issue of family care to the policy agenda. Recognising that the bulk of care provision is carried out within an informal setting has brought to the fore national concerns regarding the availability and role of family carers (EC 2008: 32) In 2007, European ministers of employment and social affairs declared it a top priority to support family care in a message to their heads of state (Council of the European Union 2007).

### *Research aims and methodology*

This report has been carried out within the LLL / TOI project "Transf DependenTIC", which aims to support family carers through training and certification of knowledge, competencies and skills.

The research within this project is designed to shed light on the challenges for the family care support system, with particular focus on the project's partner countries, namely **Austria, Italy, Portugal and Spain**.
The overall guiding question of this report is how family carers can be best supported in their outstanding contribution to society.
Specifically, the aims of the study are to:

- discuss why the issue of the family care has to find recognition on policy debate here and now;
- explore the socio-economic profile and situation of family carers;
- examine the existing approaches and services for family carers and the carers' satisfaction with these reliefs;
- provide examples of good practice and/or innovative examples in the various fields of supporting carers.

The findings of this research are being used to establish the preferred learning content for the Transf DependenTIC e-learning platform.

The **methodology** within this report is based on desktop research, which involves a comprehensive reviewing of academic literature available in and referring to the project partners' countries. This document uses a number of sources, primarily the reports from the 6th Framework Programme project Eurofamcare. As these reports use different data from different national sources to portray the carers' profile comparability is limited. In order to consider countries other than the four Transf-DependenTIC countries, to fill data gaps and to compensate for a lack of comparability, references to data gathered by the OECD and by surveys commissioned by the European Commission (such as Eurobarometer) have been included.

The **term** 'carer' neither refers to parents caring for a dependent child nor to 'care workers' who are paid to provide home care. Rather it refers to the "Eurocarers" definition, defining "carers" as those who look after family, partners or friends in need of help because they are ill, frail or have any disabilities. The care that they provide is unpaid.

# Family care versus formal care – Mapping long-term care

Given the extended longevity, an increasing demand for long-term care can be expected. Therefore, the EU Member States agreed on the commitment to "accessible, high-quality and sustainable health care and long-term care by ensuring: access for all, to adequate health and long-term care and that the need for care does not lead to poverty and financial dependency; and that inequities in access to care and in health outcomes are addressed" (EC 2008:16) during the Luxembourg Presidency Conference "Long-term care for older persons" on 12 and 13 May 2005.

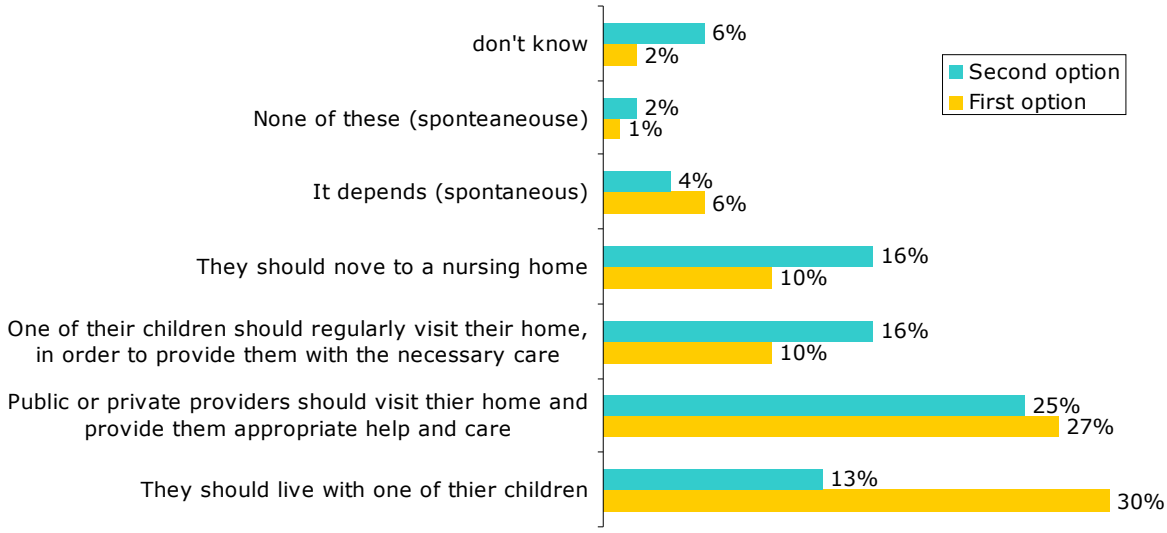
## *Definition of long-term care*

Within the European Union the definitions of long-term care differ. The differences refer to the determination of the length, the identification of the care recipient and the available taxonomies defining the long-term care services provided. Based on the reviews of national reports of the Member States of the EU on long-term care of 2006, the EC (2008: 3) noted that EU Member States use a variety of definitions that do not always concur. Referring to the OECD definition, the EC defines long-term care / LTC as a "cross-cutting policy issue that brings together a range of services for persons who are dependent on help with basic activities of daily living over an extended period of time." Further, "long-term care is usually provided to persons with physical or mental handicaps, the frail elderly and particular groups that need support in conducting their daily life activities" (ibid). LTC is not a short-term intervention; rather it requires a certain minimum number of caring hours. This has a consequence on the support that carers are entitled to receive.
On prior ground, LTC can be provided by three institutions: the family, the market and the state.

## *Public opinions on long-term care*

LTC provision varies across EU Member States in terms of population coverage, the extent of provision and also in terms of the schemes used. As people want to live as long as possible in their own homes, close to their family and friends, the general goal of LTC systems is to help people remain at home, while providing formal care when needed. Hence, there seems to be an EU-wide tendency of focusing on enhancing tailor-made home and community care services and moving away from institutional care. However, three out of ten Europeans believe that the best option for elderly parents is to live with one of their children, or to continue living at their home and receive regular care visits either from a public or private care service provider (27 %) or from their own children (24 %) in the event of dependency.

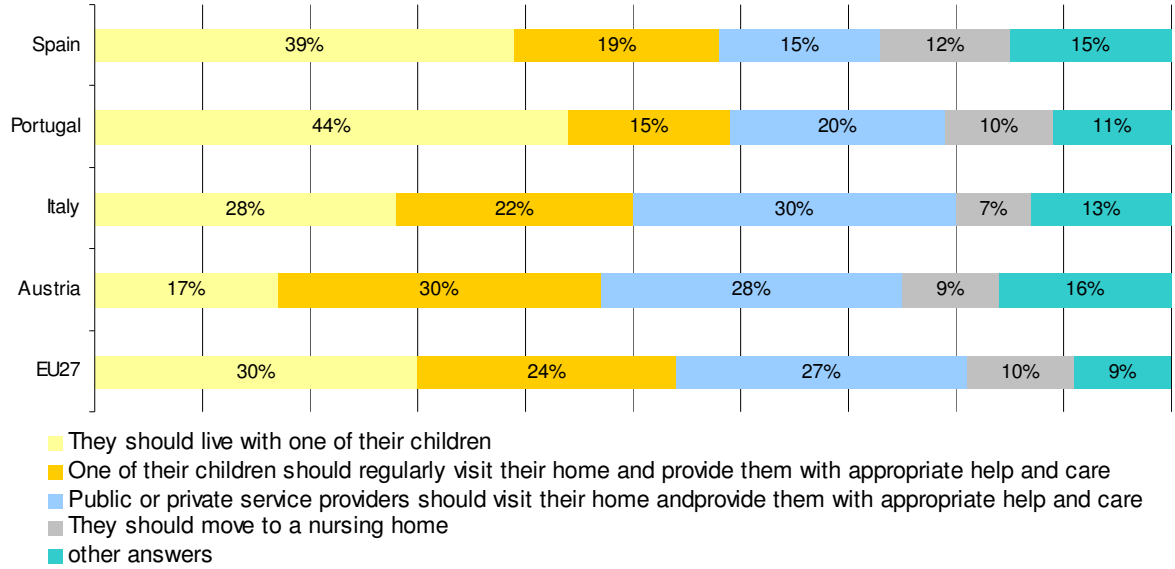
**Graph 1 Best option for an elderly parent living alone and in need of a regular help; first and second option, EU27**




Source: Eurobarometer 2007:66

Comparing the four Transf-DependenTIC partner countries, the views about the best options for elderly frail parents highlights cultural differences in traditional concepts of family. The opinion that elderly persons should live with one of their children is voiced more than twice as often in Spain and Portugal than in Austria, while nursing home are equally less accepted in all four countries.

**Graph 2 Best option for an elderly parent living alone and in need of a regular help, country level**




Source: Eurobarometer 2007:67

## *National policy development on long term care*

In the light of demographic ageing and of concerns over expanding expenditures, the EU Member States committed themselves to reforming their social protection systems and to meet the increasing long-term care needs of the population. As current supply is considered to be insufficient and inadequate in terms of meeting current and especially future needs, this goal is a policy challenge for many countries (EC 2008).

In the following, this report will give a brief overview of Austrian, Italian, Portuguese and Spanish national policies on LTC which may affect the work of family carers.

### Snapshot of the development of the LTC system in Austria

The Austrian LTC policy is rooted in values of the underlying welfare model, where family responsibility has primacy over public provision. In 1993, the universal system of LTC allowances has been implemented, which aims at helping individuals to remain at home as long as possible (cf. Hofmarcher

October 2007). Entitlements for the LTC allowance are granted in seven categories where care needs are defined as "average time involved for regular care and assistance". LTC allowance is awarded only after a thorough medical examination, and if the applicant is in need of at least 50 care hours per month. 82 % of LTC allowance receivers report that the allowance covers a significant portion of costs (Hörl 2005). Up to 80 % of those in need of long-term care are cared for in their own homes by family members, specific outpatient services or by privately engaged carers. At present, around 5 % of the Austrian population receive long-term care benefits (EC 2009: 231).

Challenges ahead for the Austrian LCT systems are to further improve the access to information, guidance and training for family carers and develop strategies to address the increasing need for professional care staff. A number of issues will be challenging in the future: long-term financing, adaptation of care benefits, and a further expansion and improvement of social services (EC 2009: 232).

**Table 1:Long-term care allowance: Scale of benefits, paid 12 times a year.**

| Level | Monthly benefits | Monthly extent of need for care | Further criteria to be met |
|---|---|---|---|
| 1 | 148.30 euros | > 50 hours | |
| 2 | 273.40 euros | > 75 hours | |
| 3 | 421.80 euros | > 120 hours | |
| 4 | 632.70 euros | > 160 hours | |
| 5 | 859.30 euros | > 180hours | Qualified nursing care is required at levels 5, 6, and 7. |
| 6 | 1171.70 euros | > 180 hours | The continuous presence of a carer is required during the day and night. |
| 7 | 1562.10 euros | > 180 hours | No co-ordinated movement of the four extremities with functional use is possible or an equivalent state is ascertained. |

Source: Hörl (2005: 39)

## Snapshot of the development of the LTC system in Italy

The Italian LTC policy is supported by the "Health Plan 2003-2005" which emphasises: "The elderly person lives better at home and within the family network. However, the family is often having economic or logistic difficulties in assisting the OP in need of care at home. It is therefore necessary to support the family in this task" (Polverini, Principi et al. 2004: 32). However, legislation on support for LTC givers is still incomplete and fragmentary and there are significant geographical disparities in supply and quality of LCT provision. The EPSCO Council and the EC (cit. in: EC 2009: 136) criticise that the plan "on the future of welfare in Italy" ignores coverage issues and proposes a model for long-term care which is not related to explicit data concerning the situation on the ground. The reliability of the plan is further undermined by the absence of information on the profile and territorial distribution of the disabled and frail elderly in need of long-term care, of future projections of dependent elderly by age group and gender and of coverage levels of institutional and home care services across the country. . *"To provide a clear example, the report makes no reference at all to the increasing use of immigrant labour, known as 'badanti', to care for elderly people living at home. Italian families have increasingly resorted to migrant women who in many cases work illegally, because of the insufficient supply of public services. It is important to note the very limited development of home nursing services ('Assistenza domiciliare integrate') and the considerable gap between central-northern and southern regions. Similarly, the existence of often very long waiting lists for access to residential care is not mentioned at all."* (EC 2009: 136).

Possible challenges will be to improve efficiency by means of a more rational use of resources and to improve health and LTC service organisation and coordination, while reducing geographic differences in provision (EC 2009: 137).

## Snapshot of the development of the LTC system in Portugal

The availability of long-term care services was very limited until recently. (Sousa and Figueiredo 2004). Since 2006, the National Network of Integrated

Continuous Care has been implemented (over a framework period of ten years 2006-2016). It aims at providing all levels of integrated continuous care (convalescence, mid-, long-term and palliative care). Reforms in the field of long-term care have decentralised budget responsibilities and combine resources from the national and local budgets. Despite some progress, the European Commission criticizes continuing cuts in community-based services. *"The system is still underdeveloped and NGOs play an important role in terms of organisation and funding. Progress has been made (an increase in the number of social services, the adoption of a strategy for disabled persons for the period 2006-2013, the development of an assessment tool to identify and analyse social service needs), but efforts must continue, above all in relation to quality."* (EC 2009: 255) Further challenges will be to enhance the provision of long-term care and to reduce geographical disparities of care supply. (ibid: 255f)

## Snapshot of the development of the LTC system in Spain

Traditionally, the family had the main role in caregiving. The demand for long-term care, however, has increased in Spain over the last decade. Hence, a new system has been created toward Autonomy and Dependency Care (SAAD), designed to increase coverage to all people in a situation of dependency by 2015 through a large boost in provision. It *"aims to ensure equal access by using a common dependency scale and defining a standard catalogue of services (wide range of home care, assistance and adjustment, day centres, night centres and residential care). It also aims to improve the integration of health and social services. Services may be supplied by public or private providers agreed by the public Administration and each region organises service supply.* (…) *The government recognises that this process will take some time and effort to accomplish. Since the Law entered into force, the central government has approved implementing regulations, previously agreed in the Territorial Council as the central operational body. A dependency evaluation scale, a minimum level of protection guaranteed by central government, and the amounts of financial benefits were laid down last year. The intergovernmental cooperation framework was also approved, together with the central government budget allocation criteria to finance autonomous regions.."* (EC 2009: 112) SAAD uses a common

dependency scale, defining a standard catalogue of services, such as home care, assistance and adjustment, day centres, night centres and residential care. As of July 2008, 536,342 people had requested to be accredited as dependent and 326,015 have already been recognised as beneficiaries (dependence degree: high and severe).

The European Commission identified some central challenges for the Spanish LCT system: shortening waiting times for care services provided by the national health system, enhancing the provision of long-term care, and countering regional disparities (2009: 114).

## *Projected expenditures on long-term care*

Due to demographic ageing the spending on LTC as a share of GDP is expected to triple from 4 to 11-12 % between 2005 and 2050 across OECD countries (Fujisawa and Colombo 2009: 4). The projections predict an increase in public long-term care expenditure of 0.7 % of GDP (Table 2). It must be noted, however, that this increase may be higher as the projections are based on current institutional and policy settings, while many EU Member States are only starting to develop a comprehensive framework for long-term care provision (EC 2008: 9).

**Table 2: Estimated expenditure on long-term care and projections until 2050**

In the case of Austria, the public long-term care expenditure of 0.6 % of GDP in 2004 includes federal long-term care expenditure only.

| Country | 2004 | 2050 |
|---|---|---|
| EU-25 | 0.9 | 1.6 |
| Austria | 0.6 | 1.5 |
| Italy | 1.5 | 2.2 |
| Portugal | 0.5 | 0.9 |
| Spain | 0.5 | 0.7 |

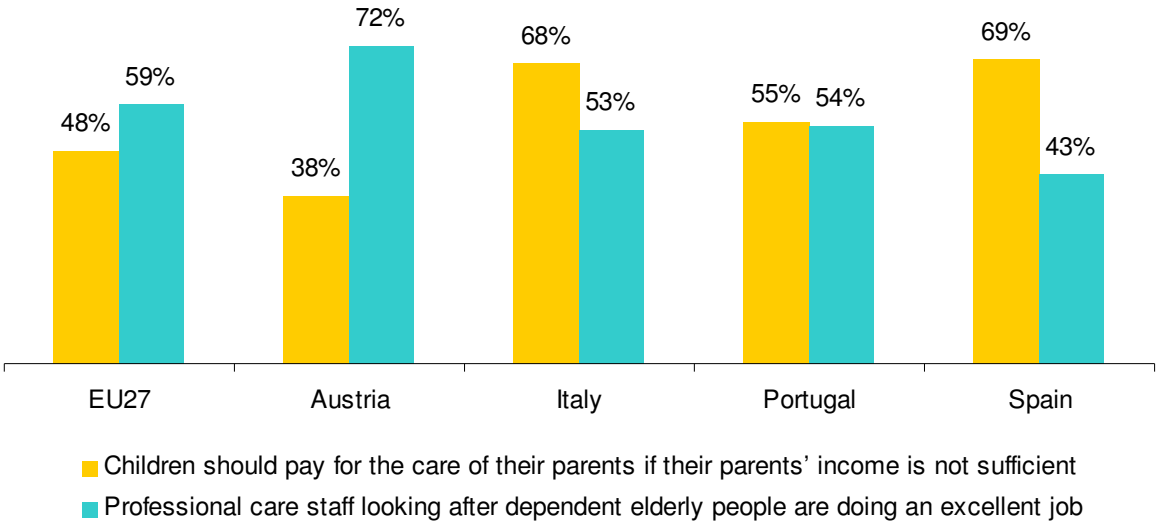
Source: EC 2008: 9

Although home care or community care service are less expensive than acute care in an institutional setting, the share of home care as a component of public spending on long-term care varies. While some countries have increased significantly the public spending dedicated to home and/or community care, in countries "with the least developed LTC systems", this share is still minimal (EC 2008: 15)

## *Social values impacts the national quality of LTC provision*

The role of the state in supporting families in their care-giving responsibilities varies widely across the EU. In countries where families are assumed to be primarily responsible for the care of their next of kin, fewer resources are available for formal services, thus placing greater burdens on family carers (Glendinning, Arksey et al. 2009). Especially in the Mediterranean countries, their contributions are often taken for granted, compared with carers in countries like the UK and Sweden (Mestheneos and Triantafillou 2005).
For example, the opinion that children should pay for the care of their parents if their parents' income is not sufficient is voiced in Spain (69 %) and Italy (68 %) nearly twice as often than in Austria (38 %). In contrast, a high degree of satisfaction with the quality of professional carers is lower (Spain: 43 %, Italy: 53 %, Portugal: 54 %) than the European average (59 %) or the Austrian value (72 %).

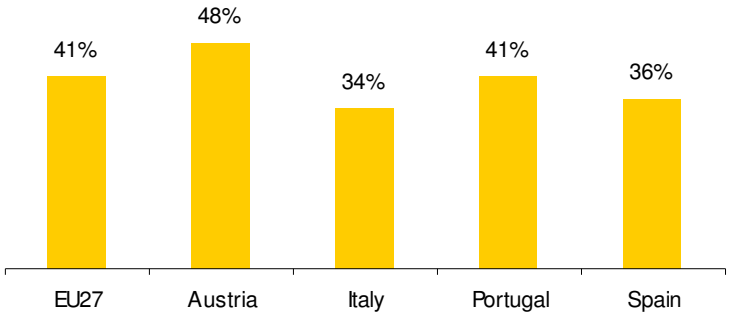
**Graph 3 Q1: Children should pay for the care of their parents if their parents' income is not sufficient. Q2: Professional care staff looking after dependent elderly people are doing an excellent job, % of agreement**




Source: Eurobarometer 2007:70

The country results are certainly influenced by the extent to which it is a common custom in a country to care for dependent people in the home. Italy (34 %) and Spain (36 %) are more critical of the availability of care services for dependent people in their home compared to the European average.

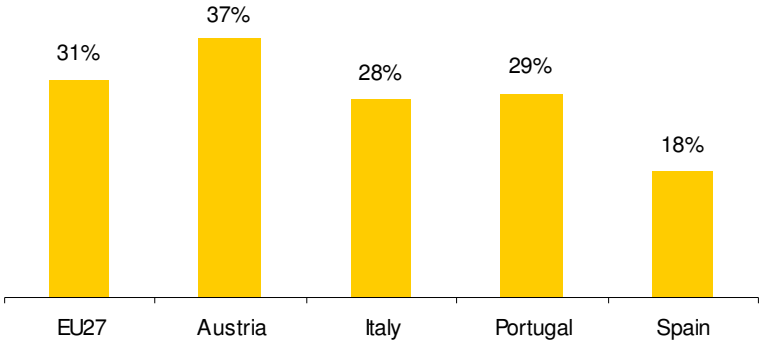
**Graph 4 How easy is it to reach or to gain access to care services for dependent people in their home?, % of "easy" answers**




Source: Eurobarometer 2007: 29

Another reason for a lower satisfaction with the quality of professional service providers in Mediterranean countries than on a European level (31 %) could be the cost of professional care. In Spain, only 18 % agree that this is available at an affordable cost.

**Graph 5 Professional care at home is available at an affordable cost, % of agreement**




Source: Eurobarometer 2007:77

Although national traditions influence differences in these views among countries, wide consensus exists among Europeans that the state should provide and finance long-term care for the elderly (93 %), that the state should pay professional carers to give family carers a break (91 %) and that the state should provide an income to individuals who have had to leave their paid work for caring purposes (89 %). Furthermore, there is widespread opposition to the view that if a person becomes dependent and cannot pay for care from their own income, their flat or house should be sold or borrowed against to pay for it (70 % disagree) (Eurobarometer 2007).

# Family carers still provide the largest share of care - Patterns of family care

As already noted, there is a plethora of evidence for the decreasing provision of family caregiving in the near future. Generally, the number of senior citizens living together with the next generation or with a partner has decreased in the last decades. Research shows a steep decrease in the support provided by non co-resident family members (Da Roit 2007: 253). Furthermore, changing family structures such as smaller families and the increasing participation of women in the labour market, point towards a potential reduction in the availability of family caregivers and a consequently higher demand for formal care (Fujisawa and

Colombo 2009). Additionally, the trend towards providing formal long-term care in the home rather than in an institutional setting may lead, in some countries, to an increased demand for formal home care (EC 2008).
However, family carers still remain the backbone of support for elderly and disabled people in many European countries. Alber and Köhler (2005) estimate that there were about 100 millions carers in Europe in 2003 – about a quarter of what was then considered to be the total European population.
However, caring for dependent family members often involves both the older as well as the younger generation (mostly grandchildren) at the same time.

The Eurofamcare study (cit. in: Glendinning, Arksey et al. 2009: 120) portrays European family carers as following:

- 76 % of main carers of older people were women;
- Carers' mean age was 55;
- Nearly 50 % of carers were children of the older person;
- The median number of hours of caring was 24 hours a week, the mean was 45.6 hours a week;
- The average caring period lasted for five years;
- 41 % of carers were also in employment;
- About one in four carers lived further away from the older person they were supporting than ten minutes by car or public transport.
- Caring involved meeting health needs (sometimes including nursing and medical care); providing emotional and psychological support; helping with mobility and transport; helping with domestic tasks; providing emotional, psychological and social support; managing finances; dealing with welfare agencies; and organising formal care services.
- Caring, although rewarding for many, often had adverse physical and psychological consequences, as well as additional financial costs and/or loss of income. Depression and exhaustion were common, especially among those caring for more hours per week, over a long period and/or without (social) support.

## *Number of family carers in the four partner countries*

In **Austria**, 6.7 % of the adult population can be considered as carers, mostly caring for their parents. More than two fifths of all carers are gainfully employed and care-giving at the same time. One in ten carers (9.1 %) is engaged in caring for at least two people (Hörl 2005). According to estimates for **Italy**, about 11 % of the over 50-year-olds provide care for a family member. This is particularly the case in the South and in rural mountain districts - where formal service provision is lower (Polverini, Principi et al. 2004). The number of informal carers providing care to elderly persons is estimated at 2.3 % for **Portugal** (Sousa and Figueiredo 2004: 12). In **Spain**, on the other hand, 12.4 % of all households contain a person responsible for caring for an elderly family member and almost 21 % of the population identify themselves as carers to some extent (Larizgoitia Jauregi 2004).

## *Family care has a gender*

A significant body of research indicates that family carers are predominantly female, namely as a partner or daughter, but also as a sister, friend or neighbour. A survey among selected OECD countries (Italy, Luxembourg, the Netherlands, Spain, and the United States) by Fujisawa and Colombo (2009) presented an estimate of 60 to 77 %. The findings are echoed by Mestheneos & Triantafillou (2005) showing that women are predominantly the main carers (76 %). Roughly speaking, women provide approximately two third of family care in Europe (Huber, Rodrigues et al. 2009: 56).

**Table 3: Number and share of women among informal LTC workers, 2006 or latest year available**

| Countries | Number | % |
|---|---|---|
| Italy | 2,095,607 | 63.9 |
| Netherlands | 778,000 | 60.2 |
| Spain | 2,085,890 | 77.0 |
| Luxembourg | 2,641 | 70.1 |

| | | |
|---|---|---|
| United States | 27110,718 | 61.0 |

Source: Fujisawa and Colombo (2009)

Men care for fewer hours per week, and the tasks they undertake are less onerous and stressful. Broadly speaking, women are more likely to organise paid work around care, while men tend to organise care around work (Glendinning, Arksey et al. 2009:124).

The majority of European family carers are in the **age group** of 45-64, often caring for both their parents and their children. In countries such as Spain and Austria, most family carers belong to the age group between 40 and 65, while in Italy the average age of family carers is 61.7 for men and 60.8 for women (Huber, Rodrigues et al. 2009).

***Family care by gender in the four Transf-DependenTIC countries***

Among carers in **Austria** there are 281,900 women and 144,000 men. In relative terms, 8.5 % of adult women and 4.7 % of adult men consider themselves as family carers. Care for non-kin is almost exclusively performed by women. Around 10 % of the 50- to 64 year olds identify themselves as carers. Starting approx. at the age of 55 years, an increasing number of people are involved in care for spouses (Hörl 2005). Female carers in **Italy** provide more than 80 % of care (Huber, Rodrigues et al. 2009: 56) whereas the average age is 61 years. Around 10 % of family caregivers are even 80+ years (Polverini, Principi et al. 2004). Similar figures are reported for **Portugal** (approximately 75 %); if the caregiver is male, he is in nearly all cases looking after his wife, whereas female caretakers look after relatives of various degrees of kinship. Two main age groups of family carers can be identified: a) if 65+ years she/he is usually the spouse of the care recipient; b) if between 45 and 55 years she is usually the daughter or daughter-in-law of the person to be cared for. The first group represents approximately 20 % of all family carers, while the second group represents about 64.3 % (Sousa and Figueiredo 2004). Female carers in **Spain** provide also more than 80 % of care (Huber, Rodrigues et al. 2009: 56). In the first instance the carer is a spouse, and if incapable (physically, socially or

psychosocially) or absent, the responsibility of caring falls upon the children, daughters in particular. The age of carers is over 45 in 70 % of cases. Women between 45 and 54 make up 40 % of carers (Larizgoitia Jauregi 2004).

## *Time for caring – Differences between EU-countries*

The number of hours used for caring has an important impact on labour participation. Research indicates care as having a negative impact on the employment of carers. Difficulties in combining paid work and family care particularly seem to affect those engaging in care for a substantial number of hours per week. 15 % of the employed European carers have reduced their working hours as a result of caring for relatives, and most have subsequently experienced a decline in their income (Mestheneos and Triantafillou 2005). However, the amount of time used for caring differs widely between EU countries (Grammenos 2007: 220). In 2001, only half of those caring between 20 and 49 hours per week were employed or self-employed (Arksey, Kemp et al. 2005, cit in: Grammenos 2007: 27). When caring around 20 hours a week or more carers find it increasingly difficult to remain in paid employment.

### *Time used for family care in the four Transf-DependenTIC countries*

Half of the carers in **Austria** spend between 5 and 15 hours per week; while a quarter exceeds 15 hours a week. On average women devote 11.4 hours per week to caring tasks while men spend only 9.0 hours per week. Over three quarters of carers give personal assistance, especially with regard to personal hygiene, bathing, dressing or help with consuming meals (Hörl 2005).
The data concerning **Italy** is subdivided by the status of employment: publicly employed women spend an average of 7.7 hours and privately employed women 8.5 hours, retired "people" (it is unclear whether the report refers to the total population or only to women, A/N) 12.8 hours, and housewives 15.4 hours on caring. Around 60 % of carers declare to be involved in all caring activities, such as "personal care and hygiene", "the preparation and administration of meals", "company", "errands and shopping" and "housework". While women generally

perform all these activities, men are mostly involved in specific activities such as financial matters, repairs and transportation (Polverini, Principi et al. 2004). The figures for **Portugal** indicate that 68.3 % of family carers spend more than 4 hours per day caring for their elderly relatives. 56.8 % perform caring "day after day", and 6.9 % do it occasionally. The data also points to an interesting detail: the hours of caring increase as the relationship becomes more intimate. However 61 % receive support from social agencies, from other relatives and/or from a housekeeper (Sousa and Figueiredo 2004).

In **Spain**, more than half (56 % ) of the people defining themselves as carers engage in this on a daily basis, around 22 % care every week, whereas 14 % care occasionally. The main carer spends seven hours per day on average for caring, and may receive help for one hour a day (Larizgoitia Jauregi 2004).

## *Labour market participation AND family care instead of OR*

European carers are more often non-working than in gainful employment. On European average, just over 40% of family carers are on the labour market (Huber, Rodrigues et al. 2009: 66). 60 % of the non-working carers are retired and 26 % are housewives/ househusbands. If employed, they are more likely to be employed in the public sector (42 %); private sector (37 %) and 17 % self-employed. Only a small proportion of Europeans have given up paid work in order to take care of an elderly parent: 2 % have quit their job completely and 3 % have switched from full-time to part-time work (Eurobarometer 2007: 89), not at least because opportunities to reduce working hours are simply not available in some EU countries.

However, full-time carers are likely to experience some degree of isolation, psychological distress including anxiety, depression and loss of self-esteem (Arksey, Kemp et al. 2005). Therefore, carers who are in paid work may be less vulnerable to social exclusion. Taking advantage of part-time work can have longer-term consequences for labour market positions and career prospects for carers.

***Employment patterns of family carers in the fourTransf-DependenTIC countries***

In **Austria** almost a third of family carers are employed full-time, while just over 10% work part-time (Huber, Rodrigues et al. 2009: 66). About one quarter of all family carers have cut back or abandoned gainful employment as a consequence of their caring responsibilities; depending on the intensity of care this percentage varies between 21 % and 61 % (Hörl 2005). For **Italy** more than half of carers are not working on a full-time basis and 60 % of carers are dissatisfied with their economic situations (Polverini, Principi et al. 2004: 18). There is no national data available regarding employment rates of **Portuguese** carers (Sousa and Figueiredo 2004). In **Spain** 12 % of carers needed to stop working in order to fulfil their caring duties. (Larizgoitia Jauregi 2004).

## *Caring means physical and social burdens for carers*

Caring may bring several constrains to the carer, with might have an adverse impact on the carer's health and wellbeing. When asking for the reasons for caring for a family member, Mestheneos & Triantafillou (2005) found that "emotional bonds" (i.e. love and affection) constitute the main motivation for caring (57 %), followed by a "sense of duty" (15 % ) and a "personal sense of obligation" (13 %). Only 3 % stated having "no other alternative" than to care as their main reason.

It is estimated that between then and 25 % of carers of older people show signs of experiencing heavy burdens (cit. in: Glendinning, Arksey et al. 2009:125). On the one hand, a high proportion of family carers are in poor health, suffering for example from physical strain and musculoskeletal problems, and from emotional strain. A combination of factors - such as the severity of behavioural problems of the person being cared for, cognitive impairments, long-term care perspective, co-residence, not being a spouse carer, higher caregiver burden and depression, higher age, lower socioeconomic status and lower level of family support - results in poor health of carers. Research also shows that many carers were unprepared for the task and felt insecure (Bolin, Lindgren et al. 2007: 428).

On the other hand, carers report positive effects on life satisfaction. For instance, they may experience feelings of appreciation (ibid) and improved affinity in the relationship between their relative and themselves (Tjadens, Visser et al. s.a.: 5). However, the feeling of social isolation and inability to participate in normal social life is a wider phenomenon in European countries. More than half of carers across Europe have problems with friends, feel "trapped" in care, report worse emotional well-being or say care-giving is too demanding (Tjadens, Visser et al. s.a.: 5).

As for **Spain**, data shows that 64 % of family carers are forced to reduce their leisure time, 51 % are tired, 48 % are unable to go on holiday, 39 % do not have time to visit their friends, 32 % feel depressed, 29 % think their health has deteriorated, 26 % do not have time to look after other people as they would like, 23 % do not have time to look after themselves, 21 % have financial problems and 9 % have had conflicts with their partner (Larizgoitia Jauregi 2004).

# Compensating family carers – wide variation of relief

The help offered to family carers for reconciling work with caring responsibilities while preserving their income, work prospects, and wellbeing, varies among EU countries (Huber, Rodrigues et al. 2009: 66). The range of possible supportive measures is wide and may encompass several stakeholders. It can take the form of financial and non-financial benefits.

**Financial benefits** focus on the reduction of the carers' financial burdens. Carer allowances, payments of income during care leave, or also tax and pension credits, available to people in paid jobs and/or to inactive caregivers are measures supporting carers financially.

**Non-financial benefits** – such as respite care, care leave and counselling – reduce the psychological and physical burdens of family caregivers and have a positive impact on the quality of care provided (cf. Fujisawa and Colombo 2009).

Comprehensive and systematic overviews of different measures supporting family cares can be found in Grammenos (2007: 178) as well as in Tjadens et al. (s.a.: 7) – see table 5:

- **Income support** is generally means-tested and cannot be considered as remuneration for the carers' work. Benefits of this kind can be found in the UK.
- **Recognition of the carer's role.** Special allowances for carers are an expression of appreciation for their work. An example is the Finnish Home Care Allowance.
- **Payment equivalent** to the wages of workers employed in home care is possible in Sweden and Denmark.
- **Payment granted to dependent people** intended for them to pay carers with. This practice can be observed in Germany, the Netherlands, the UK and Sweden. There is a tendency to attach some social security rights to these payments.
- **Flexible work arrangements** and **care leave** aiming to maintain the labour force attachment; generally all countries apply some form of such measures.
- **Credits** for periods spent out of employment in order to care. Pension credits are most common. This concerns countries that require a formal relation between the caregiver and the dependent adult but also other countries (Poland).
- Concerning **allowances**, benefits should be designed in a way that supports women's employability. The different schemes ought to bring an income guarantee but also:
    - **Avoid isolation** from the world of work and favour part time in order to keep links with the labour market;
    - **Reduce the duration** of leaves as they might have negative effects on women's employability and **reintegration** by the provision of home help;
    - Promote a **more equal distribution** of family caring responsibilities between **women and men**. Removing obstacles to men's use of

long-term care benefits might be an important step toward greater equality.

**Table 4: Supportive measures for carers in a nutshell**

| | | |
|---|---|---|
| Recognition: legal rights | Formal recognition in Carers Act (UK)<br>Carers´ Charter (IE) | |
| Information, advice & emotional support | Local support centres for family carers (NL, UK)<br>Co-operation between health professionals and family carers with effective work in information, advocacy, counselling and service provision in an ever larger number of towns (GR) | |
| Advocacy | National carers organizations providing support and advocacy (IE, UK, NL, FI, FR) | |
| Financial support | Income compensation: | welfare type (IE, UK)<br>salary (FI, SE) |
| | Expenditure compensation: | tax reductions (FR, IE, GR, IT, NL, ES)<br>allowances<br>paid to carer (AT, BE/Flanders and Brussels, CZ, FR, HU, IE, MT, NO, PL, ES, PT, SI, SE, UK<br>paid to the older person to pay the person providing the care service (NL and DE) |
| | Time compensation**:** | paid respite (reconciliation of work and care, NL)<br>mandatory days off from care (FI, see respite care) |
| Training/Education | Quality guarantee for those training carers (AT)<br>Primary health care centre offering carer training and 'caring for the carer' programmes (ES) | |

| | |
|---|---|
| Peer support | Alzheimer's café (NL) |
| Respite care | Weekly leave of care (FI)<br>Voluntary palliative home care (NL)<br>Short-term care in institutions, day care or replacement of informal caregiver (SE)<br>Services by volunteers (AT, FR, BE, BU, HU, IE, FI, DE, GR, IT, NL, PL, SI, UK, SE, NO) |
| Counselling | DE, UK, SE, NL |
| Recreation and other support | Health check-ups for informal carers (SE)<br>Financial support for purchase of an alarm (SE)<br>Information about complaint procedures, etc. (SE) |
| Technology/ICT | Solution for adjusted housing, adjusted living, and adjusted care (NL, IT, FI, DE, UK, FR) |

Source: Tjadens et al (s.a.: 7)

## *Relief is often not accessible for all*

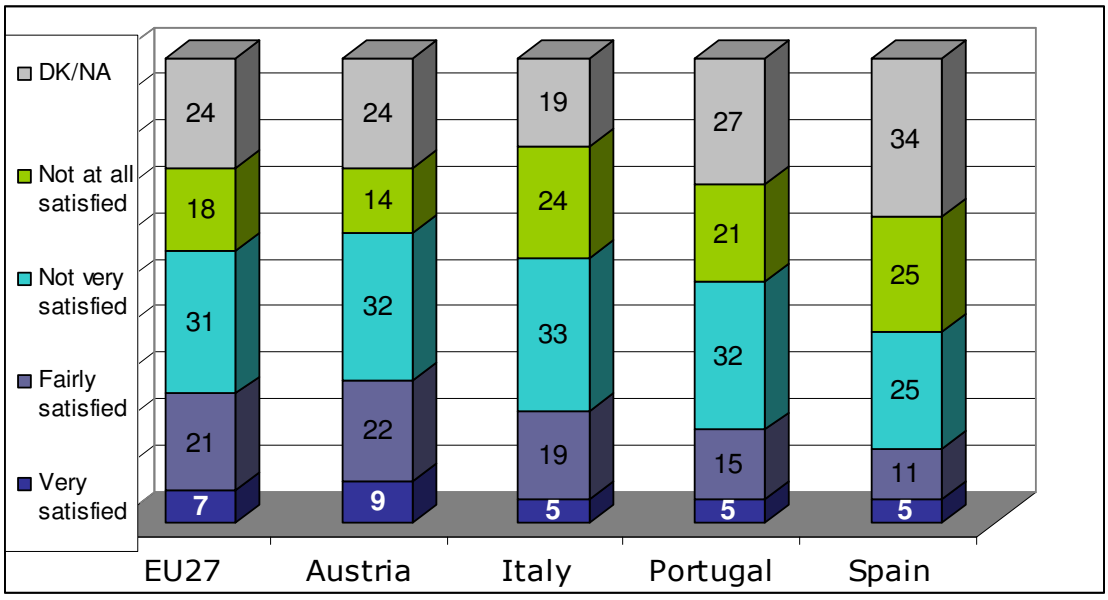
The fact that support appears to be available does not necessarily mean that carers make use of it. This would presume availability, accessibility, appropriateness, acceptability and affordability. However, most carers in Europe are not receiving any support (Tjadens, Visser et al. s.a.: 6).

The findings of Mestheneos and Triantafillou (2005) highlight that less than one third of carers had used any support services, such as respite, socio-psychological and information services, in the past 6 months. Users and non-users of care services viewed the bureaucratic, complex procedures for gaining access, as well as their high financial cost as being the main barrier. The lack of information on available support, low quality and inadequate coverage represent other major barriers, preventing a wider use of services. In all countries services are experiencing problems in terms of distribution, especially in rural areas, and in terms of covering hours when carers may be at work. Information and advice about the disease/ condition and on how to gain access to services were agreed to be critical both for carers and service providers.

## *Satisfaction with public support for family carers*

According to the Eurobarometer 2008, around 30 % of EU citizens were (very & fairly) satisfied with the public support granted to people caring for dependent relatives, whereas almost 50 % were unsatisfied (40 % of respondents in Portugal were not at all satisfied). The country rankings highlight that respondents in the northern and central regions of the EU appeared to be more satisfied with public support for people caring for dependent older relatives than those in the eastern and southern Member States of the EU.

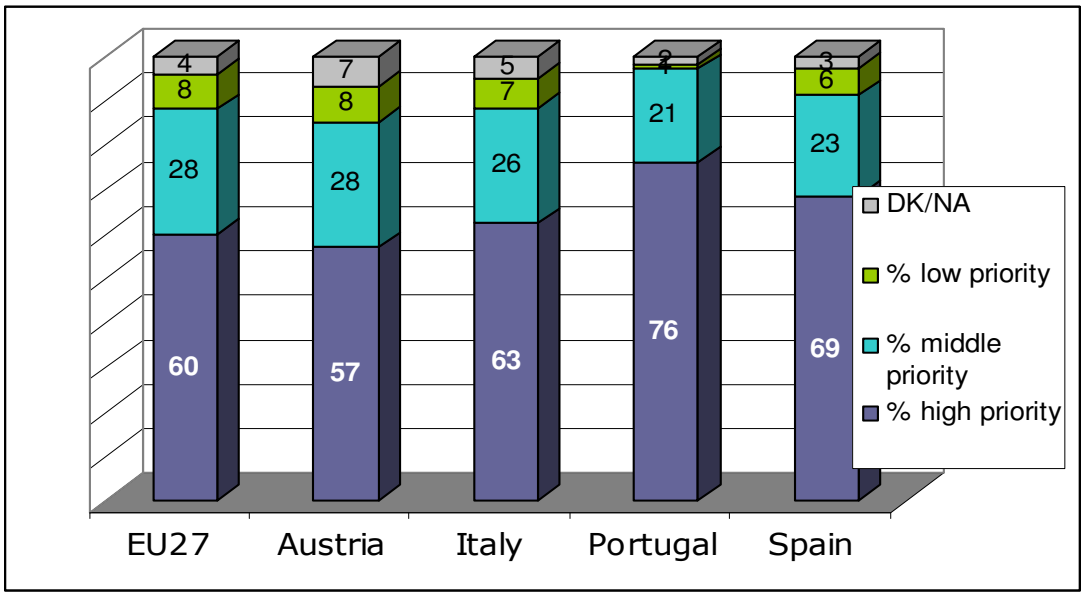
**Graph 1: Satisfaction with public support for people caring for dependent older relatives, %**




Source: Eurobarometer 2008: 19

Inquiries regarding the satisfaction with the right to paid leave to care for dependent elderly parents and relatives and facilitating access to part-time work received similar levels of support: approximately 6 out of 10 respondents thought that policymakers should give such policies high priority (60 % )

**Graph 2: Priority level for policy action: Implementing the right of paid leave to care for dependent elderly parents and relatives**




Source: Eurobarometer 2008: 88

***Selected carers' relief measures in Austria***

Under current law, working carers may claim a care leave for up to a maximum of one working week per year to perform the necessary care for a sick close relative (including parents and grandparents) living in the common household. Care leave is only granted under the provision that no other carer is available. Such care leave can be availed from the time of commencement of employment. Approximately no more than 1 % of all Austrian companies have agreed to these family-friendly standards. Almost all of these companies or agencies belong to the service sector and employ well-qualified female personnel (e.g. insurance companies, banks, software companies, consulting and accounting firms, as well as some governmental agencies, municipalities, and non-profit organizations). Since 2002, persons caring for dying family members are legally entitled to compassionate leave / family hospice leave, which is a protection against dismissal for up to six months. Spouses, parents, children, and grandchildren, as well as adopted and foster children, life partners and siblings are eligible. The family hospice leave is basically an unpaid leave but in some cases financial support might be granted. It entitles leave-takers to one of three different possibilities: either a reduction of working hours, a change of working hours or

an unpaid leave period. Under certain conditions employees on leave retain full health, pension and unemployment insurance coverage (Hörl 2005).

## *Learning from good practice*

Generally, the different measures aim to improve the quality of services provided to dependent people and improve the work-life-balance of carers. However, Grammenos (2007: 207) points out the following approaches when considering definitions of innovative practices in supporting carers:

- awareness-raising campaigns directed at employers;
- extension of local support services to carers including support centres (that provide counselling and training), day care centres and respite care;
- part-time work, flexible work hours and special leave allowances and personal budgets which formalise family caring;
- insurance and pension credits to avoid long-term negative impacts on the carer.

In the following a collection of innovative approaches resp. good practice examples, identified in Austria, Italy, Portugal and Spain is provided.

**Good/innovative practice 1: Funding model "Counselling Cheque", Austria**

A funding model to recipients of the long-term care allowance of at least category 3 requiring 24/7 care was adopted. Currently, the pilot project "Counselling Cheque" is running. The counselling cheque is meant to enable persons in need of care and their care-giving family members to avail themselves of qualified on-site counselling on a broad range of issues regarding nursing and care. A close relative of a person in need of care entitled to at least category 4 of the long-term care allowance is in principle entitled to a financial grant if he/she has been the primary carer of the person in need of care for at least one year and is unavailable (it is correct) due to illness or other important reasons. The grant is contributing to the costs of professional or private substitute care. A pilot project in Vienna, Lower Austria and Burgenland has offered 14 days of holidays and recreation for care-giving family members. In addition to recreation, the holiday stay also includes a social programme (e.g. exchange of experiences

through a moderator…). Any care services required during the stay may be rendered against payment by professional providers. According to the results of scientific studies, care provided by relatives is one of the most important pillars of the system, which must in any event be given continued support. The 2007 Act to Amend Social Security Legislation has improved the situation of care-giving family members in the context of preferential continued insurance or self-insurance in the pension insurance system during periods in which care is provided to a close relative. The Agreement on the Social Care Professions aims at upgrading professions in the area of care for the elderly and disabled and creating an incentive for regular employment in this field. In implementing the agreement, the job profile **"home helper"** is to be introduced **nationwide**. In the past few years numerous options were created for family members providing care: counselling and discussions for care-givers, temporary accommodation in a nursing home if care-givers go on holiday or fall ill, financial support for substitute care for persons with dementia, advice on medication and aids, as well as various ombudsperson offices and information platforms.
Source: EC (2008: 33)

**Good/innovative practice 2: Local Support Centres, Austria**

In Vienna about a dozen Local Support Centres (Soziale Stützpunkte) – operated by the municipality – are serving as information and meeting points for the elderly and for informal carers of all kinds. They are also used by e.g. police departments in dealing with social emergency cases involving elderly citizens. Recently, eight of the support centres have been transformed into more comprehensive units called Health and Social Care Centres (Gesundheits- und Sozialzentren). They give more detailed and far-reaching information, e.g. about day centres, residential homes and respite care, and they also provide certain services.
Source: (Hörl 2005: 57)

**Good/innovative practice 3: Insurance cover, Austria**

Since 2006, in addition to social insurance statutory protection for carers who are relatives, a preferential personal insurance for periods of care for close relatives

was created; according to this, people who are caring for a close male or female relative entitled to a long term care benefit, placing considerable demands on their working capacity in the home environment, may be self-insured in the pension insurance scheme under favourable terms. Only one person may be self-insured for each case requiring care. Care in a home environment is not interrupted if the person requiring care has a temporary stay as an in-patient. In the cases of this newly created preferential self-insurance in the pension insurance scheme for periods of care by close relatives, the Federal Government assumes the fictitious employer contribution, as is the case for the existing opportunity of preferential further insurance in a pension insurance scheme. Through this new opportunity for self-insurance, statutory social insurance protection is also created for those relatives who are carers and who have either not yet been among the insured or for whom taking up the benefits which existed to date for carer relatives was not an issue because they did not fulfil the statutory requirements.
Source: Grammenos (2007: 206f)

**Good/innovative practice 4: Support Service for caregivers, Italy**

In the territory of San Donato Municipality, near Milan, the social cooperative "Solidarietà e progresso" (Solidarity and Progress) has realized a project called **"Support Services for caregivers",** presented in 2001 on the basis of the regional Law 23 / 1999 "Regional policies for the family". The service was free, it was implemented for one year and the project was designed to integrate the socio-sanitary services already existing in the territory. The service aims at providing carers with various forms of support, such as information service, counselling and advice, and first assessments of the project seem to be positive about its impact on the wellbeing of caregivers.
Another interesting form of experimentation called **"Parente-sì"** has been carried out in the ASL of the province of Milan. Its focus was on the re-appropriation of "time for oneself" on the part of carers of elderly people who are assisted in their homes. The experiment, lasting 6 months and involving 20 families that received support for 4 hours a week with the participation of several social operators, has showed how difficult it is for the carers to leave the isolation

in which their caregiving tasks have confined them. This finding has implications for the need of projects that can guarantee continuous care to the assisted person, as well as help and counselling to the carer.
In another Municipality in Northern Italy, Modena, a **counselling service for carers of older people** being discharged **from hospitals** has recently been implemented. Currently this centre, which cooperates within the Specialist School in Community Medicine of the University of Modena and Reggio Emilia, is still operating only a few hours per week, providing mainly a guidance service, but its long-term aim is to strengthen all kinds of support to carers, according to the critical needs mentioned by carers themselves.
Source: Triantafillou and Mestheneos (2006: 22f)

**Good/innovative practice 5: Financial support and security, Italy**

The Florence Municipality, with the legal advice of Studio Come has implemented a project called "Older Adults at Home" (Anziani a Casa) with the aim of overcoming the separation between the private services "market" (based upon family responsibility and usually devoid of security) and the public sector provision (reserved mainly for the minority of citizens belonging to the lower income brackets). There are currently similar experiments, e.g. within the context of the SERDOM project (located in Northern Italian cities such as Modena, Parma and Turin www.comune.modena.it/serdom/ sito/stampa.htm). The novelty of the Florence project lies in the fact that this is the first municipality to respond to the need for both financial support and security, while establishing also a community information service for family caregivers and local solidarity networks.
Source: Triantafillou and Mestheneos (2006: 24).

**Good/innovative practice 6: Training (also) family carers, Portugal**

The Program of Integrated Support for the Elderly aims to ensure the provision of care of an urgent or permanent nature in order to maintain the autonomy of the older person in his/her own home and in his/her family environment; to establish the means for ensuring the mobility of the older person and access to benefits and services; to implement support for families who provide care and

support to dependent family members, namely elderly people; to promote and support initiatives for the initial and in-service training of professionals, volunteers, family members and other people in the community; to promote attitudes and measures to prevent isolation, exclusion and dependency and to contribute to intergenerational solidarity as well as creating jobs. Among others, the **Human Resource Training Centre (FORHUM)** was developed for family members, neighbours, volunteers as well as for health and social service professionals and other members of the community, enabling them to provide formal and informal care.
Source: Triantafillou and Mestheneos (2006: 33f).

**Good/innovative practice 7: Training and variety of support, Spain**

In the autonomous community of the Canary Islands, within its government "Programme of attention for the Elderly in Primary Attention", a programme has been established for supporting carers, which offers training activities to 100 % of carers and promotes plans for community support (self-help groups, associations)
Guipúzcoa county hall (autonomous community of the Basque Country) offers the **Sendian programme for the support of carers**, which comprises different resources: family training, psychological support, self-help groups, weekend breaks, long term breaks, technical help, volunteer programs, economic aid and tax exemptions. The programme is structured in a co-operative agreement between San Sebastian city hall and the provincial council, and is offered to all families providing care.
Source: Triantafillou and Mestheneos (2006: 37)

# Caring for carers' life satisfaction - summary and conclusion

It is not surprising that being gainfully employed has a positive impact on the life satisfaction of caregivers, while caregiving to a higher extent leads to lower life satisfaction (Bolin, Lindgren et al. 2007: 435f). Taking this as a starting point for

policy recommendations, reliefs for the improvement of the reconcilability between work and caring commitments come into the focus of further deliberations. The guiding principle of all policy recommendations found in literature is that carers should never be forced to choose between gainful work and caring.
Based on a large scale analysis of four data sources, Grammenos (2007: 220ff) identified three different approaches of policies and suggested to find a sound mix between these.

***Policies focusing on labour market participation***

Caring obligations requiring more than 10 hours a week may decrease the labour market participation on behalf of carers. Flexible working time arrangements, the possibility of part time work as well as short term leaves in cases of emergency help combine work and care and facilitate reemployment once caring comes to an end. The right to work reduced hours when special care is required combined with the right to return to full working hours when the care is ended is "absolutely necessary". Allowing care and its amount to be a real choice, remuneration and flexible working time arrangements are supportive.
Since the responsibility of care is mostly assumed by women, policies should a) consider the specific needs of women and b) should set incentives for men also to assume caring obligations.

***Policies focusing on securing the provision of care***

Another crucial point for reconciling work and care is to overcome general obstacles towards flexible support provisions, and to provide respite care and day care centres. A modularisation of professional care services may simplify the individual working arrangements as well as the option to combine professional care services with individual ones. Furthermore, information and counselling services, including care techniques, health aspects but also information on how to organise work and health are important. Introducing a "personal budget" for

people with long-term care needs helps to create demand-oriented services for persons in need of care and can be spent on different modularised services.

***Policies focusing on cost control of care***

The assessment of policy proposals often reaches the conclusion that family care is less costly than institutional care, however ignoring the wage loss and expected losses regarding the carer's pension rights.

Analysing the sample countries' policies, Grammenos (2007: 223) identified that the main **recommendations** include:

- Developing social services in order to meet the needs of care dependent people living in the community, most notably those requiring a high degree of care;
- Promoting flexible work arrangements enabling the carer to remain on the labour market;
- Promoting consensual approaches and the involvement of social partners;
- Compensating for negative long-term impacts (notably through pension credits);
- Supporting family carers in order to reduce negative health impacts (including psychological health);
- Favouring the establishment of ordinary work contracts through carer allowances and personal budgets;
- Recognition of the carer's role in the organisation of long term care at a local level;
- Promoting a more equal distribution of family caring responsibilities between women and men, most notably by removing obstacles to men's use of long-term care benefits;
- Designing measures for assisting dependent people which are neutral in their labour market implications;
- Long-term care could be developed as a separate axe for insurance. Dependency may be seen as a separate risk. Complementary public funding

could guarantee a minimum quantity and quality of long-term care services to disadvantaged groups;

- Carers of disadvantaged groups ought to retain a special attention at local level.
- Mediterranean countries and New Member States face a double challenge: developing infrastructures for heavily dependent people and expanding home help. Only this twofold policy may liberate informal carers from heavy long-term care, which keeps women in a disadvantaging situation. Generally, the different measures ought to improve the quality of services provided to dependent people and improve the work-life-balance of carers.

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