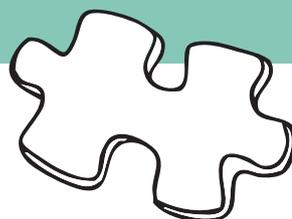


# 1. CARERS

# CARERS



Europe is the continent with the highest number of older citizens, with women who have a longer life expectancy than men, and an ageing process that will continue for the remainder of this century. According to international studies, nearly 20% of the European population is 65 years old or older. It is estimated that this rate will be 25% by 2050.

In addition, people with disabilities represent around one-sixth of the EU's overall working-age population. The ageing process produces significant effects on society, such as the modification of population age structure, the number of generations, without mentioning the fact that there are increasingly older people needing care and less people of all ages able to provide it.

However, despite these well-known trends, about 80% of the time spent caring for people with a disability or for older persons in need of care is still provided by informal carers: family, friends or neighbours. According to the last Quality of Life Survey (2012) by Eurofound, 10 Europeans out of 100 take care of an older or disabled family member several days a week or every day, with a great difference from one Member State to the other and with significant difference between women and men.

Gender differences are more visible in countries where families have to bear most of the care responsibilities: the more care responsibilities are left on families, the higher the gap of the repartition of care responsibilities between men and women. Age groups are also affected differently and, despite a growing number of young carers, the highest share of care is provided by women aged 50 or older.

Lack of services and support to those with family needs, long waiting lists for childcare and care for older and disabled persons, including services promoting independent living, coupled with difficulties in reconciling work and care responsibilities has had a strong impact on employment, especially for women. This has often resulted in having no other choice than reducing working hours or dropping out completely from the labour market. There are also long term effects, since after a longer care period it is very difficult for women to reintegrate the labour market and to obtain the recognition of those skills gained through informal family work.

Care is a very transversal topic and covers many aspects of family life: from the care for young children to the older family member, including care for persons with

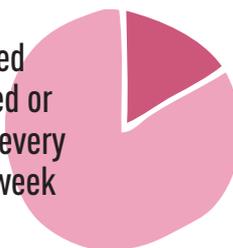
**80%** of care work in Europe is provided by informal carers.



disabilities, young and adult. In this chapter we will present the main challenges, suggest recommendations and showcase examples of practices relating to reconciling work and care responsibilities, focusing on care for family members with disabilities or older persons.

Recommendations and practices for working carers will be outlined in chapter 3 – Reconciling at the workplace, not a matter of size or sector. Child care and support for early age will be detailed in chapters 2 – Women at Work, and 4 – Childcare, Education and Parenting.

**13%** of Europeans aged 50-64 care for a disabled or elderly family member every day or several times a week



## LEGISLATIVE FRAMEWORK

UN Convention on the Rights of People with Disabilities (UNCRPD), to which the EU is a signatory and has to present an official implementation report to the UN Committee. Because of the EU / Member States' competence in this matter, it can be useful to consult the Online Tool that provides an overview of the key instruments needed for the implementation of the UNCRPD and the state of the art in the Member States and the EU. This tool is managed by the Academic Network of European Disability experts (ANED), which also provides the European Commission with analysis of national situations, policies and data.

Directive 2000/78/EC establishing a general framework for equal treatment in employment and occupation. It bans – among others – discrimination on the basis of age in employment and occupation.

Proposal for a Council Directive COM/2008/0426 final - CNS 2008/0140 on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation.

Communication 2008/0420 final: *A renewed commitment*. It establishes a framework for the Commission to carry out different activities aiming to fight against discrimination on different grounds, including age.

Communication 2010/0636 final: *European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe*.

2012 - European Year for Active Ageing and Solidarity between Generations.

Social Protection Committee and European Commission Joint Report: Adequate social protection for long-term care needs in an ageing society (2014).

Social Investment Package, Commission Staff Working Document SWD(2013)41 final Long-term care in ageing societies - Challenges and policy options.

## POLICY POINTERS

### WHO IS A FAMILY / INFORMAL CARER? THE EU CHARTER

The family / informal carer is “a non-professional person who provides primary assistance with activities in daily life, either in part or in whole, towards a dependent person in his / her immediate circle. This regular care may be provided on a permanent or non-permanent basis and may assume various forms, in particular: nursing, care, assistance in education and social life, administrative formalities, co-ordination, permanent vigilance, psychological support, communication, domestic activities, etc.”. This type of care, provided by family and friends still represents about 80% of care activities in Europe, with serious consequences for carers and their families. COFACE has, in 2007, developed a *European Charter for Family Carers* where it states the rights and recognition that every single family or informal carer should have, including the recognition of his/her work, the right to respite care and the right to choose whether and in which form to become a carer.

### CARE AND INDEPENDENT LIVING

Children and adults with disability are to be supported in a way so that they can live lives based on their human rights and Independent Living according to the UN CRPD and TFEU. They are to be able to choose where they want to live, with whom and which support services they need. Nowadays, care is dependent on the families and Independent Living is not a reality for many disabled people and their families. Legislation for respite care, child care allowances, personal assistance and other legislation promoting Independent Living need to be adopted to allow families and people with disability to access services allowing for Independent Living and independent families with a choice to work.

### EUROPEAN CHARTER FOR FAMILY CARERS

The Charter deals with all aspects pertaining to the life of persons with disabilities and their families. Meeting the needs of family carers, irrespective of the cause of the dependency of the person that is being cared for (age, illness, accident, etc.) through targeted measures, contributes to the quality of care and helps preserve a qualitative family life.

Article 1: **Definition of a family carer**

Article 2: **Choice of family carer**

Article 3: **Public solidarity**

Article 4: **Family solidarity**

Article 5: **The place of the family carer within the health system**

Article 6: **Official status of the family carer**

Article 7: **Quality of life**

Article 8: **Right to respite**

Article 9: **Information/training**

Article 10: **Assessment**

## THE GENDER AND AGE DIMENSIONS OF CARE

The gender distribution of care within the family is still unequal and women represent the majority of carers, with great impact on their paid employment. Too often, care duties force women to reduce working hours, terminate work contracts in their early career, take up part-time or low-qualified employment. An alarming phenomenon that cannot be neglected is the one of the so-called “sandwich generation” women, aged 50+ who find themselves in between the need for caring for an elderly person (often parent or parent-in-law) and their grandchildren or their adult children with disabilities. Demographic change means not only an increasing number of dependent older people in our societies, but that today’s parents who are often older than 35 will need care when their children are at a mid-career stage rather than at the end of their career. They will be even less able to count on informal care by their younger family members than today’s dependant older people. Reconciling work and family life at this stage will therefore become even more difficult. This will become even more relevant in the context of a mobile Europe, where workers will increase their mobility throughout the EU and in their own country during their careers, increasing the possibility of geographical distance between the person in need of care and his/her family and friends.

## RECOGNITION OF CARE WORK

Care provided by family members or informal carers is often considered as a natural duty and not recognized as work even if, as noted above, this can have a huge impact on carers’ possibilities to work in formal employment and pursue their careers. For those who have stopped working to be a carer during a long period, re-access to the labour market is extremely complicated. Therefore, recognition of this work should mean also recognition of skills and possibility of training for future employment and not only legal recognition of social rights. At present, without recognition, family and informal carers are exposed to a higher risk of poverty (having to reduce or drop out of labour market with direct consequences on their income) and an even higher risk of poverty in older age, since with their unrecognised work, they would not have set aside social contributions for pension. In addition, the ongoing shift from state-regulated pensions to privately funded schemes reinforces the inequality between informal carers (i.e. mainly women) and non-carers. Income inequality at an older age is often due to unequal amounts of pension income received through private pension schemes, i.e. as consequence of restricted access to good quality and full-time employment.

This is especially problematic for those carers who have to drop out from the labour market a few years before retirement (50+) or those who stay out of employment for longer periods and could only enter paid work in an advanced age (45-50+) because the person they have cared for has passed away. Finding quality employment for those former carers is almost impossible because of their age and their long absence from the labour market. Furthermore, the skills they acquired during their care activities are not certified and they are not able to enter the formal care sector, if they wish so, even if they have worked in care for the previous years. Moreover, being a carer can impact physical and mental health (e.g. back problems due to continuous and repeated lifting of the person cared for, high levels of stress for long periods and risk of depression...) that will not be monitored by preventive and labour medicine centres, since they are not considered to be working.

## ACCESSIBLE AND AGE-FRIENDLY ENVIRONMENTS TO REDUCE THE NEED OF CARE

The need for care of older persons is often not only conditioned by their health status, but also by the lack of adaptation of their environment to their needs. The lack of accessible housing and environments also influences the possibilities for independent living of people with a disability. Creating accessible and age-friendly environments is the key to mitigate the rising need for long-term care, therefore helping informal carers not to lose track of their careers. The World Health Organisation has already developed standards on what 'age-friendly environments' mean.<sup>1</sup> The EU can significantly contribute to the development of age-friendly environments through regional funds. AGE Platform Europe is currently building an innovation network on age-friendly environments featuring especially local governments and municipalities. Drawing from the experiences of the network, a European Covenant on Demographic Change can provide answers and give an incentive to the mainstreaming of age-friendly environments into policy work.<sup>2</sup>

## FLEXIBILITY AND TIME-OFF WORK TO CARE

Labour markets policies and companies' practices often do not reflect the needs of an ageing and inclusive society. More and more workers are forced out of the labour market because of their difficulties, not to say impossibility, of reconciling their work and care responsibilities, may they be for a caring parent, for a family member with disabilities or, as it happens more and more often, for both. With disabled people themselves not being able to access employment, the care remains a life-long responsibility. Two main instruments can be used, for example, to support carers to stay in formal employment: flexible working arrangements and the possibility to take days/hours off work for care. Both instruments can take different forms, including specific leaves or job sharing, telework, flexy-time allowing employees to vary their working hours within specific limits (core hours) from day to day, shift swapping among employees, compressed working week.....

In order to maximize cover for all workers these measures should be regulated by law. However, lack of regulation in some countries should not prevent companies in establishing specific measures, according to their core business and their employees' needs. These measures have proven to produce beneficial effects not only for employees but also for companies, as the employees' loyalty increases significantly. While these measures may seem to be possible only by bigger companies or operating in an "office-setting", SMEs and companies operating in other sectors can also find their own measures to meet the company and the employees' needs. These measures will be discussed in chapter 3.

## SERVICE PROVISION: ADEQUATE, ACCESSIBLE, AFFORDABLE AND QUALITY SERVICES

Taking time off for caring duties must be a voluntary act, not one that is unavoidable due to the lack of adequate care facilities and services persons with support need, and for independent living services for the disabled persons and the elderly. Investment in care facilities and support systems is a major driving force to ease the burden of informal carers. Care facilities can be day-care or residential but should be based on Independent living with choice, control and self-determination of the person to use the service. Services need to be accessible and affordable for all users and their families. Quality of care is one of the key aspects that have to be at the heart of the service provision. The Social Protection Committee released in 2010 a Voluntary European Quality Framework for Social Services, including key quality principles for social services in Europe.

It has been estimated that almost 20 million older people had experienced some form of psychological abuse, nearly 6 million experienced economic or financial abuse, 4 million physical abuse, and one million sexual abuse in Europe<sup>1</sup>. The risk of being the target of mistreatment is very high among older people, especially older women. Violence is also high regarding disabled people. This risk is the result of a complex combination of individual, interactional, social, cultural and environmental aspects. However, the exact extent of the phenomenon is still largely unknown and hardly addressed during debates. However, it has to be recalled that neither elderly abuse nor abuse of disabled happen solely in residential care settings – actually, most cases of elder abuse happen behind closed doors. This is why it is of primary importance that formal caregivers, informal carers and families are accompanied in accessing services, included respite care, and offered peer and psychosocial support to help carers self-assess their situation. Indeed, such measures would help preventing situations of discomfort, depression or burn out.

## INVOLVEMENT OF PROFESSIONAL AND MIGRANT CAREGIVERS

Care (personal and health services) can also be provided by professionals within the home setting. These allow elderly and disabled individuals to maintain their autonomy and stay in the comfort of their own home while postponing or avoiding the onset of dependency.

Professional care within the home setting asks for a very good coordination between an older or disabled person, the professional carer and the family in order to avoid a de-personalisation of services and care. Overall it opens a perspective to respond better to the specific needs of the person in need of support and his/her family.

In more and more European countries it is possible to recognize a trend of hiring migrant carers, mainly women, to care for older and disabled persons in a form of residential care within the home of the person cared for. While this allows the family carer to better reconcile his/her work and care responsibilities, it is important to develop a legislative framework for their employment and skills acquisition/validation to make the system sustainable and to support the quality of care and the quality of life of both the carer and the person cared for. This also avoids that this solution becomes a simple shift of care responsibilities from a person (often women) within the family to another one outside the family, with a consequent shift of difficulties in reconciling work and family responsibilities onto the migrant (see also COFACE Report on Transnational Families – 2012).

# RECOMMENDATIONS

## EU level

- **EU strategy carers**  
the European Commission should, following the European Parliament Interest Group (2014) demand, develop a comprehensive strategy on Family and Informal Carers at EU level that will mainstream recognition and support for carers throughout the European Policies and legislation.
- **EC Recommendation on family and informal carers**  
The European Commission should initiate a Recommendation on the recognition of family and informal carers and for the adoption of provisions recognizing their legal status in Member States. This should be based on the EU Charter for Family Carers (COFACE, 2007) and would be the natural continuation of the existing EU policy documents, including the Social Investment Package and its Staff Working Document on Long Term Care.
- **Carers' leave directive**  
The Commission should inform about the outcomes of the consultation launched in 2011 on carer's leave and prepare a directive on this issue, giving an adequate amount of leave to workers who are faced with care duties for their family members with disabilities or elderly dependents. This directive should contain recommendations for financial compensation during carer's leave as well as the possibility for family and informal carer's to switch from full time to part-time and vice versa. Special attention should be devoted to making it possible for male workers to take up their share of carer's leave as well.
- **Migrant care workers**  
to develop a legislative framework for their employment and skills acquisition/validation that also recognizes the psycho-social and reconciliation needs of the carer

## National and local level

- **Legal recognition of status of family/informal carer:**  
Member States should introduce legal instruments to recognize the status of family and informal carers, including provisions for their social rights and assimilating periods spent caring to employment, especially in the calculation of their pension and for their access to specific medical and social support; their eligibility for training and skills validation.
- **Support and services for carers**  
Respite care services should be provided to all carers. In particular, carers should be enabled and offered opportunities to (self-)assess their needs and physical and mental well-being. Campaigns and information sessions and materials should be made available to the wider public to raise awareness about the existence and the role of family carers.
- Education and training of professionals and staff in the detection of abuse or violence is essential to guarantee good treatment to elderly and persons with disabilities. This could be achieved by incorporating the prevention of abuse in the curriculum of professionals in the fields of health, justice, education and social services and by enforcing an EU framework of quality standards in care provision for the prevention, detection and protection from neglect and abuse in home and residential care settings.

## EXAMPLES

### BELGIUM CARERS' LEAVE AND TIME CREDIT SYSTEMS

Each employee having worked at least 12 months for the same employer, has a right to take carers' leave for a period of 12 months (24 months for single parents to take care for a child up to 16 years old), on the condition of a medical certificate stating that the assistance of the worker is needed for the person that needs care. This leave is remunerated by the government as a lump-sum. There is an additional carers' leave (called "motivated time credit") that can be used for the same purposes, for a maximum period of 24 months, but the conditions are stricter and the remuneration lower. "Motivated time credit" can also be granted to care for children up to 8 years old (additional to parental leave), with an extension, in case of children with disabilities, to 21 years old. Workers in time credit or carers' leave hold their pension rights and the possibility to get back to their jobs. In addition, time-credit can be used not only as a full-time block of leave, but can be spread over years by switching to part-time, for example working at 80%.



### SPAIN LEY DE DEPENDENCIA

The law on the Promotion of Personal Autonomy and Care (BOE-A-2006-21990) has been adopted in December 2006. In its framework, dependent people can receive a grant to support family carers. Its amount varies between €330 and €414 per month, depending on the level of dependency of the elderly. Carers must be registered in the social security system and must pay a full year of social contributions. They benefit from a compulsory rest period and training.



### BELGIUM BELGIAN LAW FOR THE RECOGNITION OF FAMILY AND INFORMAL CARERS

Belgium adopted in 2014, a law (2014/203605) recognising the legal status of family and informal carers, caring for a person with high dependency needs. The law defines a legal status for carers, allowing them to be legally recognized. This status will be granted annually, after a specific application to the social security that will need to be renewed each year. This law is the first step of a longer process as it does not provide carers with specific social rights or financial compensations.



### ITALY EMILIA ROMAGNA REGIONAL LAW FOR THE RECOGNITION AND SUPPORT OF FAMILY AND INFORMAL CARERS

In 2014 the region Emilia Romagna approved a regional law (LEGGE REGIONALE 28 marzo 2014, n. 2) for the recognition and support of family and informal carers. It is a regional law and has, therefore, validity only in the regional territory and for the regional competences like skills recognition and access to trainings organized by regional and local authorities, access to services like respite, support and care, which are regulated at regional level. However, it has no impact on social rights as they are regulated at national level. Despite being regional, it still has a direct impact on citizens' life and can work as a trigger to upscale legislation at a higher level.



## FRANCE FULL PENSION FOR CARERS WHO INTERRUPTED THEIR CAREER

Those carers who had to drop out of paid employment to be a family carer for at least 30 consecutive months can enjoy full pension rights at the age of 65 and those periods will be assimilated to employment as for pension rights.

Décret n° 2011-620 du 31 mai 2011: 

Informal carers, external to the family, can also benefit from this measure if they care for a person with disability receiving an allowance for supporting a carer.

Décret 2005-1588 du 19 décembre 2005: 

## BELGIUM SUPPORT TO FAMILIES WITHIN THEIR HOMES

Flanders: Family care and additional home care (Gezinszorg en aanvullende thuiszorg) correspond to a service provided by a professional in the home of the person cared for. The client pays a set price per hour based on the income of the family. Family care includes personal care (washing, dressing and personal hygiene), help with cooking, laundry and ironing, psychosocial and educational support, guidance and minor cleaning of the house. Additional home care is also available per hour and although there is no set price, providers of services need to take into account the income and the family composition.



## FRANCE RIGHT TO RESPITE CARE

French legislation foresees a right to respite for family carers (Article L114-1-1 Créé par Loi n°2005-102 du 11 février 2005 - art. 11 JORF 12 février 2005). In addition, it is included into the national plans on Alzheimer 2008-2012 or on Autism 2013-2017. In order to respond to family carers' needs for respite, different measures and solutions have been designed: support within the home of the person cared for, with an external person caring while the main carer takes respite, holidays for the person cared for, the carer and the rest of the family, temporary day/night or residential care in external and specialized structures for the person cared for.

## UNITED KINGDOM CARER BREAK VOUCHERS

Since 2003, the Carer Break Voucher enables local authorities to fulfil their obligation to provide all carers with short term respite. The scheme is eligible for carers who look after adults needing substantial amounts of care or supervision, such as people with physical disabilities or sensory impairments, people with a learning disability, people experiencing mental health difficulties, people with long term illness or older people. Carer Break Vouchers are issued by the local authority after an assessment of financial and other needs. Each voucher has a money value and can be used to pay full or part-payment for a range of care services. The vouchers are accepted at hundreds of registered service providers (meeting local authorities' requirements), including Residential or Nursing Homes, Day Centres, Homecare and voluntary organisations. It enables carers to choose to use it either in one lump sum for holiday, ad hoc days of rest or for a few hours respite. Afterwards, local authorities get to know how vouchers have been used, enabling them to ensure an efficient allocation of funds.



## SEVERAL EU COUNTRIES SELF-ASSESSMENT TOOLS FOR CARERS

From 2010 to 2012 a partnership of twelve organisations in nine countries (BE, BG, CY, FR, IE, IT, LUX, SK) has been working, through a EU funded project (Long Life Learning, Grundtvig programme), to identify good practices in the field of awareness raising and training aiming at promoting awareness among carers about their needs. The consortium brought together associations with various scopes (NGOs active in the field of disability or Alzheimer disease, family carers' organisations, and general family organisations). The consortium developed a number of tools that can be used by family carers to assess their needs and well-being in the nine countries.



## EU WIDE CHARTERS AND QUALITY FRAMEWORKS

AGE Platform Europe, together with other partners, has developed a Charter for the rights and responsibilities of older people in need of care and assistance (2010) and a European Quality Framework for Long-Term Care Services (2012) that can be used as a basis for raising awareness and developing specific tools.



## GERMANY INFORMATION CENTRES FOR SUPPORT TO CARERS OR PERSONS IN NEED OF CARE

"Pflegerstützpunkte" are information centres for care and assistance to family carers or people in need of care. Initiated by the states ("Bundesländer), they have been established by the health or care insurances. The care support information centres offer: comprehensive and independent information and counselling on the selection and use of social and support services; coordination of all support services for local assistance and care including support in using these services; interlinking and modifying the social and care services. They cooperate with all institutions and services involved in prevention, rehabilitation, care and assistance. The service is for free.