



CONFÉDÉRATION DES ORGANISATIONS FAMILIALES DE L'UNION EUROPÉENNE
CONFEDERATION OF FAMILY ORGANISATIONS IN THE EUROPEAN UNION

DISABILITY

EUROPEAN CHARTER FOR FAMILY CARERS

With the support of **coface**

FOREWORD

The public policy response to the issue of dependency (from any cause: disability, illness, age, accident, etc.) in most EU countries is at present inadequate or non-existent. The gap therefore has to be filled in many cases by friends and family – usually women.

Family solidarity cannot in any sense absolve a state or public authorities of their duty to provide the necessary appropriate help in life for people who depend on someone else to carry out the activities of daily living.

coface-disability believes that recognition of and support for family carers would help to maintain and / or improve the quality of life of care-givers and care-needers alike. The overarching aim of such recognition is therefore to preserve families' quality of life by ensuring the physical and psychological health of carers, preserving the normal family bonds between parents and children and between partners, prevent a slide into poverty, enable work-life balance and preserve the rights of each of all family members.

While **coface-disability** wants more help for those needing care (housing, mobility / transport, education and training, employment, resources, appropriate services, etc.), it also believes that family carers, who give their time (sometimes for want of any alternative) and help free of charge, must absolutely be given recognition through a certain number of rights. These rights should also enable them to make an informed choice as to whether to become a carer in agreement with the care-needer.

A family carer is therefore anyone, women or men, who is not a professional caregiver but by default or choice cares for a dependent person in his / her immediate circle.

This proposed charter aims not only to give recognition of rights for family carers but also to put a public spotlight on them in giving that help, often at the expense of their own personal, family and / or work life.

The ultimate purpose of the Charter is to secure for carers the same rights and opportunities as any other citizens.

1 DEFINITION OF FAMILY CARER

A family 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.'

2 CHOICE OF FAMILY CARER

Persons with disabilities and / or complex dependency needs should at all times have the ability to choose their non-professional carer from among members of their family or immediate circles. If these persons are unable to express their choice, every endeavour must be made so that their wishes are respected. Reciprocally, family carers must have the option of fulfilling their care-giving role on a full or part-time basis to be able to reconcile it with their own work activities. Such choice must be free, informed and open to re-assessment at all times.

3 PUBLIC SOLIDARITY

The fact that persons with disabilities and / or complex dependency needs may choose their own non-professional carers, and the effective solidarities within the family, in no way release the national and local public authorities from their respective obligations towards those receiving and those providing care. Furthermore, such care provision should meet official recognition in terms of social rights and all kinds of social support. Care thus provided could also be subject to legal financial recognition.

4 FAMILY SOLIDARITY

Generally speaking, families are one of the best contexts in which persons with disabilities and / or complex dependency needs are able to fulfil their lives. Solidarity within families should be complementary to and in keeping with public solidarity.

5 THE PLACE OF THE FAMILY CARER WITHIN THE HEALTH SYSTEM

The place of the family carer should be recognised and as such taken into consideration in all health and social protection policies. Such social recognition should 'formalise' the role of family carers. Family carers are entitled to care facilities and various networks providing moral and psychological support to which they may turn when in need.

6 OFFICIAL STATUS OF THE FAMILY CARER

As part of their caring role, family carers should benefit from the social rights and resources required to provide assistance to persons with disabilities and / or complex dependency needs in all daily activities and social life. Family carers have the right to enjoy equal treatment in terms of:

- labour and employment: working time arrangements, holidays / leaves, return to work support, preservation of health and social protection schemes;
- universal access: transport, housing, culture, built environment, communication, etc., through financial compensation;
- retirement: through official recognition of their status as carers;
- validation of acquired skills: through official recognition of prior experience in their caring role.

7 QUALITY OF LIFE

As regards quality of life, both the person receiving care and his / her carer are interdependent. It is therefore appropriate to develop all preventive policies (illness, weariness, excess work load, exhaustion, etc.) enabling the family carer to fully meet the person's needs. Both the carer and the person receiving care should benefit from the support of approved and quality community-based facilities and services.

8 RIGHT TO RESPITE

This is a fundamental necessity to be met in terms of support, occasional and / or emergency assistance, substitution services and / or top-quality temporary care centres during various periods of time depending on needs (holiday, rest, health, etc.).

9 INFORMATION / TRAINING

Family carers should be informed about their rights and duties. They should have access to all information that will help them fulfil their role as carers. They should also have access to all special training programmes aimed at improving the quality of their care giving. A training system should be set up by public authorities in full consultation with the representative bodies.

10 ASSESSMENT

Assessment should be on-going, involving both the person receiving care and the family carer as well as the public authorities:

- assessment of both the person assisted and carer's needs;
- assessment of the services rendered at regular intervals and / or on demand: public authorities should ensure that quality care is properly implemented and formulate any necessary recommendations.

The person receiving care and the family carer are the best placed to determine their needs and how to fulfil them. It is imperative that they either participate or be represented by a person of their choice in the assessment process.

The European Charter for Family Carers is based on the major international conventions and documents drafted under the auspices of the United Nations, the Council of Europe, the European Union, and the European Disability Forum, to deal directly with the life, dignity, rights and full citizenship of persons with disabilities and their families. Beyond disability, it meets the needs of family carers irrespective of the cause of the dependency of the person assisted (age, illness, accident, etc.).

The Charter is designed as a reference tool to be proposed to various organisations representing persons with disabilities and / or complex dependency needs and their families within the European Union, as well as to the European Union's institutions.

The Charter implements the 'Help to Family Carers' project carried out by some member organisations of **coface-disability** between 2005 and 2006. It received the full support of the Administrative Council of the Confederation of Family Organisations in the European Union (**coface**) on 16 March 2009.

→ For more information, please contact the Secretariat of **coface**.



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