

**Services for Supporting
Family Carers of Elderly People in Europe:
Characteristics, Coverage and Usage**

EUROFAMCARE

**WP 16:
European Carers Network, Carers Charter and Carers Day**

Report including deliverable 17
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This report reflects the authors view. It does not necessarily reflect the European Commission's view and in no way anticipates its future policy in this area.

Work package number:	16	European Conferences and European Carers Day
Start date or starting event:	Month 1	31
Completion date:	Month 3	35
N° of the partner responsible:	1 Hamburg (8) AGE	
Objectives		
<ul style="list-style-type: none"> ■ The core group will open the discussion in two European conferences, one in the first year (month 3) with the aim of integrating the Pan-European group especially, as well as the International Advisory Board (IAB) in the further development of the project. At the end of the project a second European conference will be opened to a still broader group. The project partners will present the final results of the project and discuss them with experts to support dissemination with the aim of stimulating further discussion and promoting changes in the situation of family carers all over Europe. ■ After having finished the reports the consortium intends to initiate a Carers Day all over Europe with the involvement of local media. 		
Methodology and study material		
<ul style="list-style-type: none"> ■ To prepare and conduct two 2-day conferences in two of the partners countries. For the first conference the co-ordination centre will invite the entire partnership of the project, including the core group, the pan-European partners, the International Advisory Board (IAB). For the closing conference additionally members of the National Advisory Groups (NAGs) of the core research teams as well as other representatives from the European Commission and other European organisations, selected experts and journalists will be involved. Partners will share the responsibility for presentations depending on their responsibilities for work-packages during the whole project. Results will be discussed with respect to implications for European policy for carers. The results of the conference will be published at an international level through the Internet, and media will be contacted directly to underline the importance of the work of family carers for the individual people as well as the whole society. The final meeting of partners will follow the conference. ■ The target group for the Carers Day should be especially the family carers all over Europe. This event should be supported by the local authorities. The partners will push the idea in their countries and will give input from the results of the project. 		
Deliverables		
No 17: European Carers' Charter as a political sign to support family carers in Europe		
Not listed: Internet presentation of conference results		
Milestone 8		
Final Conferences.		
<p>The project partners have developed their expertise and the knowledge on the situation of family carers all over Europe. The results will be disseminated on different levels and by different means throughout Europe. The target groups are individuals as well as institutions at micro, meso and macro levels. A European network for the further development of research and policy changes in carers' situations will be established to support continuity after the end of the project.</p>		

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1 Introduction

The purpose of WP 16 is to make ensure that the issue of family care for older people is on the political agenda in all European countries, and to raise awareness on the situation, needs and circumstances of family carers. Therefore the objective of WP 16 was to establish an international Carers' Network, compile a Carers' Charter and initiate an international Carers' Day. The compilation of a European Carers Charter is deliverable 17 of the project.

In this report we describe the steps taken to achieve these goals. In the beginning of the project the main focus was on establishing a Carers' Network. EUROFAMCARE established a Pan European network for research on family care in 23 European countries and supported the foundation of EUROCARERS - A European Association Working for Carers.

The topic of the Carers' Charter and the Carers' Day have been discussed first in a working group of EUROFAMCARE, which – in a second step – was combined with a group from members of EUROCARERS, because it became clear that the tasks would not be finalized in the duration of the project. EUROCARERS will ensure the continuation of work.

We are very grateful to the members of EUROCARERS for their co-operation and support of this work package.

2 European Carers Network

2.1 Objectives

One of the objectives of WP 16 was the establishment of a **European Carers' Network** for the further development of research and policy changes in carers' situations, and to ensure continuity after the end of the project.

In 2003 EUROFAMCARE established a Pan-European Network for research on family care in 23 European countries.

In November 2004 a working group, initiated by the EU project CARMEN and supported by members of EUROFAMCARE, met in Maastricht (in the context of EUROFESTATION) and drafted a declaration of intent for the establishment of an European wide Organisation on Informal Care. The new Organisation is now called "EUROCARERS – a European Association Working for Carers" and is an international non-profit and non-governmental association. Its aim is to advance informal care and represent and act on behalf of all carers (and their organisations in Europe), irrespective of their age or the particular health need of the person they are caring for. Therefore, the main tasks of EUROCARERS consist of building up a broader European network and to gather, to disseminate and to exchange information about informal care between R&D-organisations, carers' organisations and policy makers within Europe. Members of EUROCARERS are representatives of carers' organisations all over EUROPE, recognised nationally or nationally acclaimed experts on informal care issues.

2.2 Developments

So far EUROCARERS had four official meetings: in Maastricht, London, Brussels and Hamburg. At the first Meeting in Maastricht (7-9 / 11 / 2004) the participants established five working groups.

- **Carers' Charter:** Hanneli Döhner, Germany: co-ordinator, Brigid Barron, Ireland, Marja Pijl; Sandrina Sangers, The Netherlands, Tiina Autio, Finland, Isobel Anderson (has been replaced by Imelda Redmond), UK, Åke Fagerberg, Sweden, in 2005: Raimondo Mandis, Italy, Jyostna Patel, Brussels, Susanne Kohler, Germany
- **Policy & Mission:** Noline Tamsma (has been replaced by Laura Christ), The Netherlands: co-ordinator, Isobel Anderson (has been replaced by Imelda Redmond), UK, Caroline Glendinning, UK, Marja Pijl, The Netherlands, Mary McMahon, (Ireland), in 2005 Geraldine Visser, The Netherlands
- **Activities:** Trudy Schreuder Goedheijt, The Netherlands: co-ordinator, Tiina Autio, Finland, Myra Lewinter, Denmark
- **Membership & Governance:** Netherlands Institute for Care and Welfare, The Netherlands: co-ordinator, Hanneli Döhner, Germany (research), Christine Marking, Belgium
- **Funding:** Patrick Michielsseune, Belgium: co-ordinator, Tiina Autio, Finland, Brigid Barron, Ireland, Carers UK, Henk Nies, Netherlands Institute for Care and Welfare, Utrecht, The Netherlands

The meetings in London (3 / 2005) and Brussels (9 / 2005) as well as several telephone conferences focused mainly on the steps to be taken to establish a new organisation: drafting the statutes, the mission statements, a logo and funding. The Hamburg (11 / 2005) meeting provided a platform for linking the members of EUROCARERS with the Pan European network and for promoting the drafting of a European Carers Charter (see below).

2.3 Results

After the first meeting in Maastricht a “Declaration of Intent” for the establishment of a European-wide organisation on Informal Care was written. This document provides the framework for the establishment of a European wide organisation to represent the interest of carers in the Member states.

In March 2005 the first draft of the **Statutes for a European Association working for carers** was finalised. The statutes state that the international non-profit and non-governmental “association shall pursue philanthropic, advocacy, scientific and educational ends with regard to the representation of carers. It will seek to advance informal care and represent and act on behalf of all carers (and their organisations), irrespective of their age or the particular health need of the person they are caring for” (EUROPCARERS Draft Statutes, March 2005). The articles are concerned with: Name, Head, Office and Purpose, Members, General Assembly, Board, Executive Committee, President, Vice president and Treasurer, Amendment and Dis-solution.

At the same time, **Internal rules of a European Association Working for Carers** were established. They are supplementary and subordinate to the statutes. They define the criteria for membership. “All full members must:

- be located within the EU;
- have a predominant interest in the advancement of informal care;
- have a European or national remit, or, depending on the structures of national health and social service systems, a sub national or regional remit;
- be not for profit;
- be legally constituted according to the laws of the country in which they are established and adhere to the Association’s Statutes;
- adhere to the Association’s Statutes.” (Draft Internal rules, March 2005)

In 2005 a **Mission statement** was drafted. Therein it is written that “Eurocarers brings together organisations representing carers and those involved research and development on carers’ issues, with the aim of:

- Stimulating and supporting the development of carers’ organisations in countries and regions where these do not exist;
- Supporting carers and their organisations through the collection, exchange and dissemination of information, experience, expertise and good practice;
- Contributing to policy development at regional, national and EU levels, supported wherever possible by evidence-based research;

- Creating and facilitating opportunities for co-operation on cross-national research, policy and practice, particularly the exchange of information on innovations and good practice;
- Interpreting relevant EU policy developments for member organisations working at national and regional levels and involving these organisations in EU policy developments;
- Collaborating with other interest and advocacy groups at national and supra-national (EU) levels, including organisations representing disabled people, women's organisations, organisations campaigning against social exclusion and poverty – in order to promote recognition of carers and carers' interests and shape a policy environment that is more favourable to carers." (Mission statement, November 2005)

The **European Carers Charter** is in progress and a first draft has been distributed (see below).

Since 2 / 2005 the **EUROCARERS' newsletter** is published quarterly. It gives information about EUROCARERS and member organisations. In addition to this, it contains news about European research, new literature on informal care, European policy and about national or European organisations concerned with carers' issues. It is produced on the internet in pdf and html and has links to websites of other European platforms (like AGE). At the moment it is hosted by EIZ (Expertise Centre of Informal Care in Utrecht), but will become independent on a later stage.

A Clearing House / website is still in progress. It will function as a centre of expertise on informal care with the aim to make better use of existing information and expertise on good practise in the field of informal care. It also intends to provide an interactive forum for the exchange of information and discussion about informal care. It will be accessible on a website and will be developed in several phases and will be accessible to the public.

Lastly, a **Logo** has been approved.

2.4 Further work

The registration of EUROCARERS will take place in 2006 in all probability in Brussels. The intention of EUROFAMCARE to establish a broad European Network on informal care has been successfully achieved.

3 European Carers Charter

3.1 Objectives

In the Technical Annex of EUROFAMCARE (2002) a “European Carers Charter” had been defined as one of the project deliverables. But the need for a European Carers Charter emerged simultaneously in different settings all over Europe.

A European conference held on 30 January 2004 in Dublin organised by “Caring For Carers Ireland” entitled “Carers Charter – a European Challenge” was involved in this issue. At this conference, Marja Pijl from the Netherlands gave a presentation where she emphasised the political challenges of establishing a European Carers Charter. (Her presentation is included in this report.)

In November 2004 members of the EU funded project CARMEN initiated in Maastricht (see above) organized by NIZW and supported by EUROFAMCARE, the first meeting for an international non-profit and non governmental European organisation for informal work. One of the aims of EUROCARERS is the establishment of a European Carers Charter.

These stakeholders established in 2004 in Maastricht, under the umbrella of EUROCARERS, a working group, co-ordinated by Hanneli Döhner (co-ordinator EUROFAMCARE) to draft a EUROPEAN CARERS CHARTER, which would be relevant across the EU Member States.

All 23 Pan European partners of the EUROFAMCARE project were asked with the help of a questionnaire about Carers’ Organisations, a Carers’ Day or a Carers’ Charter in their country. The evaluation showed that so far only four European Countries took the initiative to develop national or regional carers Charters.

In 2004 a report was written on the content of six different national / regional Carers Charters. The annex of the report contained all the unresolved questions concerning a common Carers’ Charter.

A second meeting was held in London where the procedures for the legal establishment of EUROCARERS, the statutes, the logo and tasks for the working groups were discussed. For the Charter working group, a first draft (March 2005) of this report has been disseminated, it was developed further and was sent to EUROCARERS and to the EUROFAMCARE partners for their response.

In May 2005, a questionnaire with all these open questions was sent to all working group participants requesting comments. The answers were summarized and those topics where the working group participants disagreed were highlighted.

Within the framework of the EUROFAMCARE final conference in Hamburg on the 17th / 18th of November 2005, a Charter workshop was organised where critical issues were discussed by members of EUROCARERS and the Pan European Network.

The results of the discussion were evaluated and a first EUROPEAN CARERS CHARTER DRAFT was written which has been circulated to all interested participants requesting comments.

A Charter is not finished, more work needs to be done in order to have a version that serves the needs of all carers all over Europe. EUROFAMCARE, who initiated the drafting of the Charter now places the responsibility on EUROCAREERS who will complete this task.

The objective of the report is to document the steps that have been undertaken to compile a European Carers Charter and to present the draft version.

3.2 Comparison of National and Regional Carers Charters and Questions for the Development of a European Carers Charter

3.2.1 Objectives

A comparison of the existing National Carers Charters was made to describe similarities and differences, and to examine the Carers Charters from the perception of carers under the following headings:

- Carers as experts
- Carers as workers
- Carers as clients

It was also interesting to check the Charters of other groups at the European level to see how they are structured and their legal status. Questions for further discussion in the working group are formulated at the end of this paper.

3.2.2 Structure of the charters

We found six Charters on carers which have been drafted. In Great Britain, charters have been developed with the support of the authorities at the county level: there are three Charters from the Counties of Cheshire, Wigan-Borough and Suffolk. Ireland, the Netherlands and Finland have developed national carers Charters.

In the UK, political committees developed the charters with carers and professionals. The aim is to inform carers and to clarify the obligations and responsibilities of the counties. The Irish, the Dutch and the Finnish Charters were developed by self-help / support groups. They address political bodies and require rights from the government.

In their structure the British versions are similar. They begin with a locally oriented preamble. In the Wigan-Borough Charter, the chapters are divided according to special target groups: the whole of society, carers and professionals. The length varies between three and eight pages.

The Irish charter was available as a flyer in a DIN A5 size with four pages. The first page contains the logo of the authors and a general appeal. The second page shows an overview of the 16 articles of the charter and on the third page there are some explanations. On page four the organisations that developed the Charter are listed. The Dutch charter was available as one page of DIN A4 size. The Finnish Charter is available in the form of a poster and a small DIN A6 brochure and consists of 10 articles with brief explanations. It is called: "Family care giving – way of life, challenge and opportunity. Ten theses on family care giving".

3.2.3 Content

In this chapter you will find a synopsis of the charters. The charters all agree on the following:

- Access to relevant information
All countries stress the need for easily accessible information about the care of their relatives.
- Practical help
The necessity to provide adequate services for practical help is seen as a priority in all countries.
- Entitlement to respite care / break
Here we find strong agreement in all the Charters, although the British Charter formulates this point as one point of the chapter on practical help, whereas the Irish, the Dutch and the Finnish have a separate point for this topic.

The following aspects are in five of the six charters:

- Right to financial support
The British charters underline the right to be informed about the available financial benefits while the Irish and the Dutch charters focus on the right to get financial support. Only the Finnish Charter doesn't explicitly demand financial support for carer.
- Awareness
Carers should be seen in their role as service provider to society (Cheshire, Finland); as individuals (Wigan-Borough); or as carer (Suffolk, Ireland) from the community.
- Freedom of choice
Carers should have the choice to become / be a carer or not (not in Ireland). The Finnish Charter doesn't explicitly mention free choice, but demands that institutional care must be available when caring responsibilities become too much for the carer.

The following aspects are mentioned in four of the six charters:

- Co-ordination of services
The British Charters define a right to co-ordinated services, that is, co-operation between all parties involved in care will take place. The Finnish charter demands that municipalities, parishes and organisations must cooperate in order to support care givers.
- Participation
The involvement of carers in the assessment for and the development of services / help should be stipulated (not in Wigan-Borough and Finland).

The following aspects are found in three of the Charters:

- Support Services (Ireland, Netherlands, Finland)
- Emotional Support (Ireland, Netherlands, Finland)
- Training (Ireland, Netherlands, Finland)
- Counselling (Suffolk, Ireland, Finland)

The following aspects are found in one to two Charters:

- Regular assessment (Ireland)
- Involvement of family member (Ireland)
- Acknowledgement (Ireland, Finland)
- Planning for the future (Ireland)
- Infrastructure of care (Ireland)
- Equality (Cheshire, Finland)
- Employment (Netherlands)
- The right to a personal life: Care giving must not be the only meaningful thing in care givers life. Care givers have the right to rest, to joy and to feel good. Care giving does not presuppose sacrificing. (Finland)
- Caring relationship as a human relationship (Finland)
- The health and functional capacity of family carers must be looked after (Finland)
- Right to have peer support (Finland)

The Charters have different targets: on the one hand, from the political level to carers (Cheshire, Wigan-Borough, Suffolk) and on the other hand, from the carers and their organisations to the political level (Ireland, Netherlands, Finland).

On financial issues, the British Charters only gives information on financial benefits, whereas the others talk about financial support or financial compensation itself. They also include a commitment to carry out certain tasks, for e.g. the Counties commit themselves to making sure that their employees are well informed about services and their rights, the carers commit themselves to talking openly about their problems.

In Irish society, the moral duty to care for relatives is strongly anchored and this is reflected in the abandonment of the principle to demand the right to choose to be or not to be a carer. The participation of the carers in the planning process for service provision, take guidance from the charter to involve carers as partners. The right to an adequate infrastructure of care enables the carers to become aware of their choices for care arrangements.

The Finish Charter states that Finland cannot manage without family care giving. Family care giving must not be just an alternative to institutional care. However institutional care must be organised when caring responsibilities become too much for the carer and sufficient respite care options must be provided for the cared for persons of working family care givers. The Finnish Carter has the most demands concerning the wellbeing of the carer, like regular health checks of carers, peer support, relationship and the right to a personal life.

The Dutch Charter looks at carers as a special kind of worker. They demand the compatibility of care and paid employment.

3.2.4 Perception of carers

3.2.4.1 Carers as experts

If carers are defined as experts it is necessary to look at the content of their expertise. Carers are experts on the biography of the cared-for, needs, preferences and the network of the cared-for. Because of their practical experiences, they are able to assess the effectiveness of the services used from the point of view of the cared-for. The carers often see themselves as experts. But it is important to point out that carers are not a homogeneous group. The expertise of carers range between low and high. All Charters contain aspects, which define the carer as expert. In particular, in planning, developing and providing services has been shown to be an important know-how of carers.

There are developments that show that carers are increasingly accepted as equal partners, though, it is not obvious that this means the same as the term “carer as expert”. The partnership approach might be a better term and includes the necessity to use the know-how of all partners involved to solve concrete problems.

The following articles of the carers’ charters argue for “carers as experts”:

- Recognition of their expertise and skills – **Suffolk**.
- Involvement of carers in monitoring services and the importance of taking into account their experiences in the evaluation of services – **Suffolk**.
- Involving carers in all stages of the planning, development and the delivery of services – **Wigan-Borough**.
- Professionals cannot develop services alone, they need the views of carers and the cared-for to ensure they are responding appropriately to individual needs – **Wigan-Borough**.
- Carers being involved in multi-disciplinary reviews – **Wigan-Borough**.
- Involve carers in the planning, development and provision of service – **Cheshire**.
- Carers have the right to be recognised for the central role which they play in community care – **Ireland**.
- Carers have the right to involvement at all levels of policy planning, to participate and contribute to the planning of an integrated and co-ordinated services for carers – **Ireland**.
- Family care must be given its due value. Finland acknowledges that it cannot manage without family carers and that carers “silent know-how” must be fully appreciated in planning – **Finland**.

3.2.4.2 Carers as workers

Analysing family care as work is oriented to the entitlement and demand for an adequate payment. Work is defined as all target-oriented activity to satisfy the needs of the individual and the general public.¹

¹ www.wissen.de

(The acceptance of family care as work causes rights of free choice of work, adequate payment and the claim for social security and can be deduced from the European Social Charter.²

The organisation of care includes the utilisation of unpaid support of families. Without this contribution, care could not be financed under today's conditions. Would the widely accepted social contract / agreement, that families are responsible for unpaid help in care, be questioned by the definition of care as work? Demographic developments are a challenge for a new definition of the role of families.

All the charters contain elements where they see carers as workers. In all the charters, we find the demand for financial benefits. The Dutch charter formulates this aspect most explicitly.

The following articles from carers' charters argue for carers as worker:

- Carers have the right to financial support and recompense which does not preclude carers taking employment or in sharing care with other people – **Ireland**.
- Deciding whether to become a carer or not – **Cheshire**.
- Carers should always have the choice of starting, continuing or ceasing to be a carer – **Wigan-Borough**.
- Carers need an income to maintain a quality of life for themselves and the person they care for – **Wigan-Borough**.
- Carers are entitled to financial compensation – **The Netherlands**.

3.2.4.3 Carers as clients

The perception of carers as clients is the most commonly held view. Social services look first for the elimination of deficits. Financial support is only given for basic social deficits. The carers need services / support to carry out their tasks for the cared-for. Experts provide these services. Professionals often focus only on deficiency. Assessments for professional help takes into account the resources of family carers.

The following articles from carers' charters argue for carers as clients:

- Carers have the right to have counselling made available to them at different stages of the caring process including bereavement counselling – **Ireland**.
- Carers have the right to an infrastructure of care, a supportive network to which they can relate when the need arises – **Ireland**.
- Encouraging staff to provide carers with information about particular care needs of the person they are looking after so that carers can look after the person more effectively – **Cheshire**.
- Ensure that all agencies are aware of the problems faced by carers and treat them with sensitivity and respect – **Cheshire**.

² European Social Charter (revised) – <http://conventions.coe.int/treaty/en/treaties/html/163.htm>

- Offer carers information or advice so that they are able to understand what benefits they are entitled to – **Cheshire**.
- When we assess the needs of people being cared for, we will listen to carers so that we can provide services to suit them as well as the person they care for – **Cheshire**.
- Identifying carers who need information, advice and support – **Wigan-Borough**.
- Helping more carers to get help when they need it – **Wigan-Borough**.
- Encouraging carers to speak openly about their role and creating the right opportunity in which to do so – **Wigan-Borough**.
- Professionals give a commitment to develop services and respond to carers consistently – **Wigan-Borough**.
- Information which is easy to understand and accessible to everybody including people whose first language is not English and people who have sensory disabilities – **Wigan-Borough**.
- Providing an honest, open approach about their situation – **Wigan-Borough**.
- Ensuring the person they care for is available when the practical help is being provided – **Wigan-Borough**.
- Listening to confidential benefit advice – **Suffolk**.
- To have an assessment of their own needs – **Suffolk**.
- Should receive the right kind of support - **Finland**.
- Should be provided with information, concerning their rights and services, training and guidance - **Finland**.
- Should receive health and rehabilitation services - **Finland**.
- Should get regular breaks and vacations services - **Finland**.

3.3 List of Questions

At the Eurocarers meeting in London the Charter working group made a list with questions regarding a common European Carers Charter. The questions mainly referred to political aspects and the objectives of a common charter, to carers and their wellbeing and lastly, financial issues.

List of questions:

- **Objectives**
 - Why do we need a charter for carers?
 - Who are the initiators / founders?
 - What are the general objectives of the charter?
 - Who are the addressees of the Charter?
 - Legal framework of the Charter?

■ **General / political aspects**

- Do we need a definition of the role of families in European societies as a basis for the European Charter for family carers?
- Does society expect prior care from families?
- Does society expect from all its members a voluntary engagement for the people who need care?
- How should the appreciation for the voluntary and family carers be expressed?
- Do we want informal care as a right, a duty or an obligation?
- Choice as a requirement or a luxury?
- Is an exclusively professional home care wanted?
- Do we support the principle to favour out-patient care over in-patient care?

■ **Aspects of Carers**

- How do we view the carers: as expert / partner, worker, client or a mixture?
- What are the special needs of family carers?
- Does the charter meet these needs?
- How do we identify the basic needs of carers?
- How do we support the carers to satisfy their needs?
- Do the services meet the needs of heterogeneous group of carers?
- Should there be a free choice for the kind of services?
- How should carers be involved in the development and providing of services?
- How should carers be involved in the political decision-making process?

■ **Finances**

- How should financial support be offered?
- Should we view the carers as workers?
- Should family care be paid for?
- Should there be an entitlement for care leave (like maternity leave)?
- Should allowances in kind and / or cash benefits made available?

3.4 Evaluation of the Charter Questionnaire

The list of questions was extended, transformed into a questionnaire and sent to all working group participants requesting comments. The evaluation showed that the respondents mainly agreed on the most of the topics. The objectives of a Charter:

- **Recognition**, of the

- Crucial role carers play
- Economic and social value
- Burden of care
- Discrimination (e.g. difficulties to combine work and care)

- **Definition of Carers rights**

- Lead the policy development (development of appropriate services) on local, national, and European level.
- Reference for carers.

- **Inspiration for those countries with no support for carers**

Respondents also unanimous suggested that EUROCARERS should be named as the initiator of the Charter (EUROFAMCARE, Carers Organisations). As addressees (those who later can sign the charter) participants proposed several institutions, but added that there can be no definite list of addressees:

- Politicians, decision makers on national or European level
- People developing services for carers
- Carers organisations
- General public
- AGE members
- Family carers

There was also a clear agreement on the **kind** of support demanded for carers. Information, respite care, training skills, emotional and moral support, financial support, promote health and well being, provide the possibility to combine employment and care were topics suggested to support carers. However, the disagreement was quite high on the measures that have to be taken to improve the situation of carers. So, very little accordance could be found in the view of the role of family carers (Is caring a duty? How do we view Carers: as experts, workers, clients, partners ...?), the kind of financial support (allowances in kind, wages, insurances), the possibility to combine care and employment (care leave, day care centres, flexible working hours) and the principle to favour outpatient over inpatient care (Is family care really always the better solution?).

Besides respondents mentioned that a charter should consider aspects of future planning, and the need for a more proactive, preventative approach with far greater innovation in the type and range of support, it should stress the fact that caring is a temporal experience which needs changing over times and last but not least bear in mind the consequences that care is seen as a female duty.

3.5 Charter discussion workshop in Hamburg

The evaluation of the questionnaire showed that the views on some aspects were very homogeneous and others differed very much between carers stakeholders. Hence a discussion of all persons involved in the process of the Charter compilation became necessary to be able to achieve a common statement. Therefore the working group organised a EUROCARERS meeting within the framework of the EUROFAMCARE final conference in Hamburg on 17 / 18 November and invited also interested partners of the Pan European network to discuss critical issues of the Charter questionnaire.³ On the agenda were the political challenges of establishing a Carers Charter, the possible articles in that Charter and the further procedure.

In the first part of that meeting we described the work carried out by EUROFAMCARE on the idea of the Charter for the new participants. Then there were short presentations on the Charter development procedures in Ireland and Finland.

The input for the policy challenges came from Marja Pijl from The Netherlands. She was concerned with the word Charter, because usually a Charter is a “written grant of rights given by a sovereign or a legislature” (Pijl, minutes Lewinter). Instead she suggested the name declaration, manifesto or statement and pointed out that the document should state principles rather than be party political. After a long discussion on that issue the anchorman “summed up the general consensus that a ‘declaration’ would be more suitable than ‘Charter’ but it should be connected to other existing legislation, international declarations and national Charters etc.” (minutes Lewinter).

Another subject discussed was how to see carers: as workers, clients, experts or partners. Two reasons for seeing carers as a special kind of workers have been mentioned. The first relates to the fact that European policy makers want as many people as possible to participate on the labour market. By considering family carers as workers they could be seen as contributors to society. The second reason is that if carers can be accepted as workers it would be possible to use already existing national and international conventions to argue for better working conditions. The counter-argument was that most carers don’t want to be seen as workers, because they don’t see caring as a job but as a vocation. Others argued that carers want to be seen as experts (especially in terms of the biography of the person in need) or as equal partners. There was a long discussion on these comments and no real compromise was found. The anchorman finally summed the discussion by suggesting that we should talk about aspects of different *roles*, not carers as workers, clients, experts.

The question if care is a choice or a duty was another critical subject. Some stakeholders held the view that care is a duty, but carers have to be supported to fulfil their tasks. Others see caring as a choice. Everybody has the free choice to decide whether and to what extent he wants to be involved in caring. The kind of view depends very much on the national background of the stakeholder.

Of course it was not possible to solve all the dissensions in the little amount of time. In the contrary the awareness increased that compiling a Charter / declaration is a process, that may take some years to realize, but that it was important to initiate the process (minutes Lewinter).

³ for Participants and Agenda see Appendix

The working group decided that a first draft should be written and then handed over to all interested partners requesting comments. The discussion should go on by email until the next Charter meeting.

3.6 European Carers Charter (Draft version)

The first draft tried to include the comments of the working group and results of the discussion, the EUROCARERS' mission statement and EUROFAMCARE results and is based on EU / UN Charters like the European Social Charter (revised version), the 2002 Madrid International Plan of Action on Ageing and the Charter on Fundamental Rights.

3.6.1 Preamble

Definition of Carer

Carers are defined as people who take care of someone, irrespective of their age, outside a professional or formal framework and who has a chronic illness, disability or other long lasting health or care need (Definition of EUROCARERS statutes).

Informal care is defined as care provided outside a professional framework but within some form of emotional relationship, e.g. by family members, loved ones, friends or neighbours, but not through formalised volunteering, by people of any age to people irrespective of their age or health needs over a longer period of time (EUROCARERS Definition in the Green paper on demography).

How do we view carers?

- To be a carer is not a profession, it is a social role for a certain time in life.
- Carers should be seen as equal partners in the care arrangement with a special expertise. In some respects, carers are the experts, (e.g. biography, preferences of the cared-for), in other respects, they are clients (lack of information, need for emotional support) and often they are the persons who do the main care work.
- Even if we don't see carers as workers, we can claim that they need at least the same status and social protection as other workers.

Demand for the Carers Charter and demographic change

There will be more people needing care but at the same time that the pool of potential carers is shrinking:

- There will be more older people who are likely to need care and more carers (especially women) who will need to retain their links with the job market if targets on labour market participation are to be met.
- Individualisation of Western societies and changing family structures, which mean that often there is only one carer.
- All over Europe at least 10 % of the adult population are carers at any given time.
- 80 % of all persons in need are cared for by their relatives. The role of family carers is crucial therefore, it is a matter of social justice to give them certain rights and protection.

Aim of the Charter?

The aim of the Charter is not to regulate matters relating to informal care in EU member states but to:

- Recognise the crucial role of carers in our society, the social and economic value and the value of caring;
- Raise awareness on the potential burden caused by care-giving;
- Highlight the discrimination many carers are facing and promote equality (poverty, exclusion);
- Promote the empowerment of carers by defining their rights and by ensuring that carers become aware of their rights;
- Bring family care onto the political agenda, as a reference for all policy-makers;
- Promote social inclusion of carers;
- Promote the development of services that can support carers.

Who are the initiators?

- EUROCARERS and the participating organisations
- Those who have developed national and local Charters
- Representatives of Carers Organisations
- Researcher on informal care

Who are the addressees?

- General public
- Carers
- Policy-makers (Regional, National governments, European Institutions)
- Services Providers
- Carers organisations
- The Charter should be a guideline for the National Action Plans (which are drafted in the context of the implementation of the Lisbon Agenda and the Open Method of Co-ordination)

Where is the Charter based on?

- Charter of the Fundamental Rights of the European Union
- European Social Charter 1961 (revised 1996)
- United Nations Universal declaration of Human Rights
- Madrid International Plan of Action on Ageing, 2002 (Regional Implementation Strategy)
- The Charter will be based on the Christian, Western idea of man, as in the Charter of Fundamental Rights: Human dignity, freedom, equality and solidarity

Name of the statement?

A “Charter” does not necessarily have to be a base for legislation, but can also be used to make existing rights more visible. It could also be named Declaration, Manifesto or Statement.

3.6.2 Articles – key elements**Article 1: Recognition**

Carers must be recognized for the central role that they play in community care and in creating a community of caring.

Article 2: Information

Carers need easy access to Information, Guidance, Advice and Training.

Article 3: Choice

Carers should have the right to choose freely whether or not to be a carer and to what extent they want to be involved in caring.

Article 4: Support

Carers need support in their role as carers: financial, practical and emotional.

Article 5: Respite care

Carers need the opportunity to take time off from caring. Therefore they need access to substitute / respite care arrangements that are appropriate and acceptable to the carer and the cared-for.

Article 6: Health protection

Carers need health protection.

Article 7: Social inclusion

Carers have the right to participate in society and to keep up their social networks.

Article 8: Combine care and Employment

Carers need to have the choice to combine caring with paid employment.

Article 9: Social security / income replacement benefits

Cares need to be granted all rights linked to long-term social protection – e.g. pension / accident insurance, income replacement benefits so that they are not at risk of longer-term impoverishment and social exclusion as a consequence of care-giving.

3.6.3 Articles of the Charter / Declaration / Manifesto with rights, comments and examples of good practise

3.6.3.1 Article 1: Recognition

Carers must be recognized for the central role they play in community care and in creating a community of caring.

- Caring is very valuable to society (socially and economically).
- Political decision-makers in Europe have to acknowledge that we cannot manage without family care-giving.
- Carers are largely invisible to the public, although more than 80 % of all people in need are cared for by their relatives.
- Caring is a very demanding task.
- Many carers find it difficult to speak up for themselves therefore it is essential to raise awareness of their issues.

Political declarations and Madrid International Plan of Action on Ageing, 2002

Part I – Article 15

We recognize the important role played by families, volunteers, communities, older persons organisations and other community-based organisations in providing support and informal care to older persons in addition to services provided by Governments.

Political declarations and Madrid International Plan of Action on Ageing, 2002

Part II – A Issue 1 Active participation in society and development

19. A society for all ages encompasses the goal of providing older persons with the opportunity to continue contributing to society. To work towards this goal, it is necessary to remove whatever excludes or discriminates against them. The social and economic contribution of older persons reaches beyond their economic activities. They often play a crucial role in families and in the community. They make many valuable contributions that are not measured in economic terms: care for family members, productive subsistence work, household maintenance and voluntary activities in community. Moreover, these roles contribute to the preparation of the future labour force. All these contributions, including those made through unpaid work in all sectors by persons of all ages, particularly women, should be recognized.

3.6.3.2 Article 2: Information

Carers need easy access to Information, Guidance, Advice. Information should be comprehensive, accurate and appropriate, accessible and responsive to individual need.

- “The development of good and accessible information systems for family carer in all countries is critical.” (EFC)

- Clear and easily accessible information about their rights, rules and regulations, e.g. financial compensation and support facilities.
- Easily accessible information must be offered to all care-givers, including for carers of migrant origin.
- Training and guidance must be tailored to individuals and address every phase of the caring situation.

European Social Charter

Part II – 23 The right of elderly persons to social protection

To enable elderly persons to remain full members of society for as long as possible, by means of provision about information about services and facilities available for elderly persons and their opportunities to make use of them.

3.6.3.3 Article 3: Choice

Carers should have the right to choose freely whether or not and to what extent they want to be involved in caring.

Caring for their family members themselves is what most people want. But there are situations when home care is not the best solution for neither the carer, not the cared-for:

- The Carer is exhausted.
- The relationship between the carer and cared-for is disrupted. “There is a tacit assumption when we speak so warmly of family care, that families are always wonderful. Many families are indeed, but on the other hand many families have histories which are not always so positive and for some people family has been a horrible experience. In those cases, being cared for by a person who is strongly disliked makes the caring relationship again a horrible one. This is the second reason why I am strongly opposed to obliging people to care for their relatives. If there exist hard feelings between the carer and the caree, it is dangerous to require the one to care for the other.” (Marja Pijl)
- The Carer isn't able to comply with other responsibilities anymore, such as looking after their own children, going to work etc.

Therefore it is important that carers have the choice to decide whether they feel able to care or not, to what extent they want to care (also to prevent violence in the caring situation or illness of the carer) and also to choose which tasks they undertake for the cared-for person, e.g. Carers should be able to choose whether or not to provide intimate care.

Fund. Rights of European Union:

Chap. I / Art. 5.2 “No one shall be required to perform forced labour.”

Chap. II / Art.15.1 “Everyone has the right to engage in work and to pursue a freely chosen or accepted occupation.”

3.6.3.4 Article 4: Support

Carers need practical and emotional support in their role as carers

- “Services need to be flexible to fit different needs and different groups, e.g. special needs of spouse carers.” (EFC)
- “Policy and planning must develop services to cover the needs of ageing migrants.” (EFC)

Practical support, like

- Flexible home care services of high quality for the person in need which meets the needs of both carer and cared-for including personal care, nursing care and household tasks like shopping, cleaning, gardening
- Training courses on skills for better and more confident caring (how to lift patients, how to communicate with persons suffering from dementia etc.)
- Sitting service, twilight and night-time care
- Home adaptation, provision of aids and appliances
- Use of telecare support systems
- Meals on wheels
- Handyman service
- “Any service offering emotional support to carers, either on a one to one basis or in a group, is sensitive to individual needs, confidential, offers continuity and is accessible to all carers.” (Carers Act, UK)

Emotional support, like

- Professional advice
- Telephone hot line
- Self-help groups
- “National and EU standardized comprehensive needs assessment procedures for older persons should be developed and include a separate assessment of the current and future role and needs of family carer.” (EFC)

European Social Charter (revised)

Part II – 14

The right to benefit from social welfare services

- *To promote or provide services which, by using methods of social work, would contribute to the welfare and development of both individuals and groups in the community, and to their adjustment to the social environment*
- *To encourage the participation of individuals and voluntary or other organisations in the establishment and maintenance of such services*

*European Social Charter (revised)**Part II – 23**The right of elderly persons to social protection*

- *To enable elderly person to choose their life-style freely and to lead independent lives in their family surroundings for as long as they wish and are able by means of*
- *Provision of housing suited to their needs and their state of health or adequate support for adopting their housing*
- *Health care and services necessitated by their state*

*Political declarations and Madrid International Plan of Action on Ageing, 2002**Part I – Article 12*

(...) The empowerment of older persons and the promotion of their full participation are essential elements for active ageing. For older persons appropriate sustainable social support should be provided.

*Political declarations and Madrid International Plan of Action on Ageing, 2002**Part II – An Issue 3 Integration of older migrants within their communities*

- *Encourage supportive social networks for older migrants*
- *Design measures to assist older migrants to sustain economic and health security*
- *Encourage housing design to promote intergenerational living, where culturally appropriate and individually desired*
- *Assist families to share accommodation with older family members who desire it*
- *Remote linguistic and cultural barriers when providing public services to older migrants*

3.6.3.5 Article 5: Respite Care

Carers need the possibility to take time off and relief. Therefore they need respite care arrangements that are appropriate, confident and acceptable to carer and the cared-for.

- *Carers often work for 24 hours a day seven days a week without a break. Like every other worker carers need time off. They need breaks during the day time, days off every week and holidays as every other person. If they don't have the opportunity to take time out, there is a risk of burn out, becoming ill, depressive and violent.*
- *The well-being of carers must be secured with the help of vacations and breaks.*
- *Time off must be organized according to the individual wishes and needs of carers.*
- *Individual respite care alternatives must be developed.*
- *Good quality, appropriate and acceptable to both carer and cared-for.*

- *Respite care can be provided by different formal and / or voluntary organisations: it can be provided at home or in institutions. It can be for as short as a few hours or it can last several weeks.*

European Social Charter

Part II – 2 The right to just work conditions

3. To provide for a minimum of two weeks of annual holidays with pay

5. To ensure a weekly rest period which shall, as far as possible coincide with the day recognised by tradition or custom in the country or region concerned as a day of rest

Charter of the fundamental rights

Chap IV / 31.1 Every worker has the right to working conditions which respect his or her health, safety and dignity.

Chap IV / 31.2. Every worker has the right to limitation of maximum working hours, to daily and weekly rest periods and to an annual period of paid leave.

3.6.3.6 Article 6: Social Inclusion

Carers have the same rights as others to participate in society and to keep up their social networks.

- Carers often feel as if they don't have a personal life anymore. They don't find the time for their own interests, for leisure and for friends.
- Caring must not be the only meaningful thing in a carers life.
- Carers have the right to rest, joy and to feel good.
- Society must prevent the marginalisation of family carers.

In line with the objectives set out in EU Policies for Social Inclusion: Joint report on Social Inclusion (COM (2003) 773 final).

Charter of the fundamental rights

Chap. II / 25: The Union recognises and respects the rights of the elderly to lead a life of dignity and independence and to participate in social and cultural life.

3.6.3.7 Article 7: Health protection

Every carer has the right to health protection

European Social Charter:

Part I – 11 Everyone has the right to benefit from any measures enabling him to enjoy the highest possible standard of health attainable.

Part II – 11 Right to protection of health

- *To remove as far as possible the causes of ill-health*
- *To provide advisory and educational facilities for the promotion of health and the encouragement of individual responsibilities in matters of health*

Charter of the fundamental rights:

Chap. IV / Art 35 Everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices. A high level of human health protection shall be ensured in the definition and implementation of all Union policies and activities.

Charter of fundamental rights:

Chap I / Art. 3.1. Everyone has the right to respect for his or her physical and mental integrity.

3.6.3.8 Article 8: Possibility to combine work and care

Carers need the possibility to combine caring with (full-time) paid employment.

Caring can lead to poverty and social exclusion if it prevents carers from participating (full-time) in the labour market. When carers leave their jobs or reduce their working hours in order to provide care this will result in reduced earning. Thus carers are more likely to be in poverty in later life as well as losing earnings in the short-term.

With reference to the Lisbon Strategy goal (raising the employment rate of women to 60 % by 2010) family carers need the possibility to combine care and employment.

This requires special measures in the workplace:

- flexible employment arrangements (opportunities to change hours, working from home, take a break and changes to the responsibilities at work)
- entitlement to time off during working hours
- entitlement to days off e.g. 5 days p.a. emergency or family leave
- rights to periods of unpaid leave without loss of job security (similar to maternity leave)
- flexible retirement age (people in their fifties face a greater probability of becoming a carer)
- recognition and understanding from employers

This also requires adequate support services for the cared-for person:

- flexible services which can adjust to the needs of (working) carers and the person cared-for. They need to be flexible, suitable and of high quality
- day care centres for all people in need of care also for those with behavioural problems
- volunteers for sitting services
- flexible short-term care arrangements

Charter of the fundamental rights

Chap II / Art. 15.1. Everyone has the right to engage in work and to pursue a freely chosen or accepted occupation.

Charter of the fundamental rights

Chap III / Art. 23 Equality between men and women must be ensured in all areas, including employment, work and pay.

European Social Charter (revised)

Part II – The right to equal opportunities and equal treatment in matters of employment and occupation without discrimination on the grounds of sex

- *Access to employment, protection against dismissal and occupational reintegration*
- *Vocational guidance, training and rehabilitation*
- *Terms of employment and working conditions, including remuneration*
- *Career development, including promotion*

European social Charter (revised)

Part II-27 The right of workers with family responsibilities to equal opportunities and equal treatment

- *To take appropriate measures*
- *To enable workers with family responsibilities to enter and remain in employment, as well as to reenter to take account of their needs in terms of conditions of employment and social security*
- *To employment after an absence due to those responsibilities, including measures in the field of vocational guidance and training*
- *To ensure that family responsibilities shall not, as such, constitute a valid reason for termination of employment*

*Political declarations and Madrid International Plan of Action on Ageing, 2002**Part II – A Issue 2*

25. Factors affecting older women in the labour market deserve special attention, in particular those factors that affect women's engagement in paid work, including lower salaries, lack of career development due to interrupted work histories, family care obligations and their ability to built pensions and other resources for their retirement. A lack of family friendly policy regarding the organisation of work can increase these difficulties. Poverty and low income during women's earning years can often lead to poverty in old age. An integral goal of the International plan of Action is to achieve age diversity and gender balance in the work place.

Political declarations and Madrid International Plan of Action on Ageing, 2002

Part II – 28 Actions

i) Recognise and accommodate the caring responsibilities of increasing proportions of workers for older family members, persons with disabilities and persons with chronic diseases, including HIV / AIDS, by developing, inter alia, family friendly and gender-sensitive policies aimed at reconciling work and care giving responsibilities.

3.6.3.9 Article 9: Adequate social security policies to compensate carers financially

Carers need all rights to social protection like pension, accident insurance, income replacement benefits so that they are not at risk of long-term impoverishment and social exclusion as a consequence of care-giving.

Carers are facing financial problems due to informal care (co-payments for health care, increasing costs for health care, expenses for travelling, telephone, medical device). Carers who don't have paid employment or reduced working hours may have income loss. To prevent carers from suffering from financial impoverishment and poverty, financial compensation for carers is needed to support them.

“Ensuring that carers are adequately covered by social insurance during the time spent on caring should be a minimum EU standard contributing to the reduction of long-term poverty amongst those who undertake family care, especially women.” (EFC)

It will be necessary to

- examine the options to recompense carers more adequately to reflect the value of the work they do and the employment-related income they may forego whilst working;
- ensure that carers have an income which is considered to be earnings not social assistance;
- examine the costs of care and recompense carers adequately;
- to ensure that carers do not suffer insurance or state pension disadvantages because of periods of caring (participation in pension schemes).

European Social Charter

Part II – 12 The right to social security

2. To maintain the social security system at a satisfactory level at least equal to that required for ratification of International labour Convention No. 102 Concerning Minimum Standards of Social Security to endeavour to raise progressively the system of social security to a higher level.

European Social Charter

Part II – 13 The right to social and medical assistance

To ensure that any person who is without adequate resources and who is unable to secure such resources either by his own efforts or from other sources, in particular by benefits under a social security scheme, be granted adequate assistance, and, in case of sickness, the care necessitated by his condition.

European Social Charter

Part II – 23 The right of elderly persons to social protection

To enable elderly persons to remain full members of society for as long as possible, by means of adequate resources enabling them to lead a decent life and play an active part in public, social and cultural life.

European Social Charter

Part II – 30 The right to protection against poverty and social exclusion

a. To take measures within the framework of an overall and co-ordinated approach to promote the effective access of persons who live or risk living in a situation of social exclusion or poverty, as well as their families, in particular, employment, housing, training, education, culture and social and medical assistance.

Ref to the Joint Report on Social Inclusion 12 December 2003 (COM (2003) 723 final)

“There is, however, general agreement across all Member States that a level of formalisation of care provision is increasingly necessary, to support but not to supplant the role of the family. To this end, the majority of Member States have now an established carer’s leave and / or carer’s allowances system in place which allow elderly people to be cared for in the family hoe, whilst having contributions or fiscal measures in place to ensure the carer is not financially discriminated against.”

3.7 Further tasks?

To compile a European Carers Charter that serves the needs of all carers takes time and discussion between all partners involved. EUROFAMCARE initiated the compilation of the Charter and prepared the first draft but now placed the responsibility on EUROCARERS who will accomplish the task. Members of EUROFAMCARE will stay in this group and continue to support further work.

3.8 Appendix

- Questionnaire
- Evaluation
- Minutes of the Hamburg meeting (Myra Lewinter)
- Paper of Marja Pijl

4 European Carers Day

4.1 Objectives

One important mechanism for raising wider awareness of family care is an International Carers' Day. The plan was that the EUROFAMCARE consortium would initiate a Carers' Day all over Europe for family carers. The partners of the Pan-European Network should push the idea in their countries and give input from the results of the project. The event should be supported by the local authorities and with the involvement of local media. However, a European Carers' Day needs a lot of preparation and support and can only be achieved with concerted action of a well-established international network.

4.2 Development

The activities at European level regarding the European Carers' Day have been extended widely. In 2003, EUROFAMCARE established the Pan European Network for Family care in 23 European countries (see above). The co-ordinator made contact with several related European organisations for carers and harmonised its activities with those of other networks.

The above described initiatives for the Pan European network and the establishment of EUROCARERS were inevitably necessary preliminaries for the implementation of an International Carers' Day. Literature research and expert interviews provided important information on several national carers' days / weeks.

Table 1: Carers' Day and Carers' Charter

Carers' Day or Charter	No Carers' Day or Charter	No Response
<ul style="list-style-type: none"> ■ Finland ■ (Germany) ■ The Netherlands ■ United Kingdom ■ Ireland 	<ul style="list-style-type: none"> ■ Austria ■ Belgium ■ Czech Republic ■ Denmark ■ France ■ Hungary ■ Italy ■ Malta ■ Poland ■ Portugal ■ Slovenia ■ Spain ■ Switzerland 	<ul style="list-style-type: none"> ■ Bulgaria ■ Greece ■ Luxembourg ■ Norway ■ Sweden

Table 2: Existing Carers' Days / Weeks

Country	Carers' Day / Week	Dates	Activities and objectives
Finland	Nat. Carers' Day	Carers' Day on December 5, 2004	Information, campaigns
	Nat. Carers' Week	(date may vary), Carers' Week in calendar week 49	
Germany	Regional Carers' Day	No fixed date	Acknowledgement, appreciation, exchange, information
The Netherlands	Nat. Carers' Day	November 10, 2004 (during the Week of the Chronically III)	Yearly theme, entertainment and free services for carers
United Kingdom	Nat. Carers' Day	As part of the Nat. Carers Week (date may vary)	Yearly theme, celebration, awareness, support
	Nat. Carers' Week	June (calendar week 24)	
Ireland	Nat. Carers Weekend	First weekend in March	<p>National Conference, National Respite Break, Yearly theme</p> <p>Therapies, Relaxation, Exchange of Information, Information Stands and Talks.</p> <p>Celebration of the work of Family Carers and their contribution to the national economy.</p> <p>To raise awareness of the important role of Family Carers amongst policy makers, decision takers, service providers and the wider community.</p>

4.3 Results and further tasks

Due to the considerable amount of preparation and support required to organise an International Carers Day, this is now planned for 2006 under the patronage of EUROCARERS. EUROFAMCARE has prepared the ground, but it was unrealistic to implement the event in 2005.