

*People  
First:*

***CARING FOR OTHERS  
THE WAY WE WOULD  
LIKE TO BE CARED FOR***



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# Contents

## I

### **Introduction**

[Page 4](#)

## P

### **Preamble**

[Page 6](#)

## D

### **Definition.**

Caring for Others the Way We Would Like to Be Cared For

[Page 11](#)

## 1

### **Chapter I.**

On the Principles of Care

[Page 12](#)

## 2

### **Chapter II.**

On Prevention and Responsibility

[Page 14](#)

## 3

### **Chapter III.**

On the Bases for Dignified Care

[Page 16](#)

## 4

### **Chapter IV.**

On Information, Training and Mentoring in Order to Learn and Teach how to Care for Others and Oneself

[Page 18](#)

## 5

### **Chapter V.**

On Communication and Listening, Leading to Understanding and Acknowledgement

[Page 20](#)

## 6

### **Chapter VI.**

On Decent Treatment and on Our Social Commitment

[Page 21](#)

# Introduction

The charter *People First: Caring for Others the Way We Would Like to Be Cared For* presents opinions, perceptions and social visions of care and dependence in relation to ageing and is the outcome of an extensive participatory process of research and action led by the “la Caixa” Foundation. This process consisted of a range of co-ordinated and complementary initiatives using various methodological approaches:

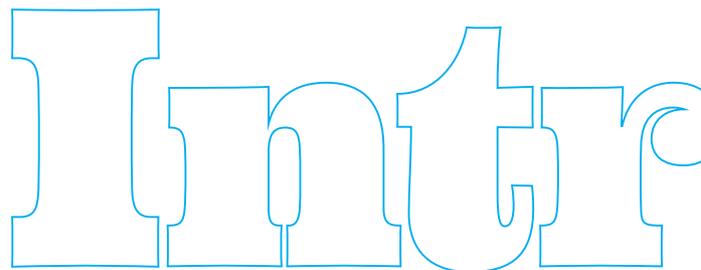
/ The **qualitative study** *Care in Dependency Relationships*, in which the aim is to identify the way in which the people involved in dependency

relationships wish to provide care and to be cared for based on testimony collected in various discussion and three-way groups.

/ A **quantitative study** carried out by means of an online questionnaire answered by professionals and citizens, who gave their opinions regarding responsibilities in care processes. There were 4,784 responses to this questionnaire.

/ **In-depth interviews** with leading experts – university academics, members of associations and professionals – in the field of care.<sup>1</sup>

<sup>1</sup> The experts interviewed were Ángeles Duran (Spanish National Research Council [CSIC]), Francesc Torralba (Ramon Llull University), Eduardo Rovira (Age and Life Foundation), Mercè Mas (association movement of the elderly), Koldo Aulestia (Spanish Confederation of Associations of Relatives of People with Alzheimer’s and Other Dementias [CEAFA]), María Silveria Agulló (Carlos III University) and Jesús Rogero (Autonomous University of Madrid).



*The charter aims to foster debate and to raise the visibility and social awareness of an issue that affects individuals and society as a whole.*

/ **Discussion forums** (Girona, Malaga, Madrid and Bilbao) in which the public authorities, elderly people and carers' associations, experts and professionals in the gerontology sector took part.

/ **Review of the scientific literature** and of various charters and position statements on rights and care in the field of ageing.

The charter *People First: Caring for Others the Way We Would Like to Be Cared For* has been drawn up to present the conclusions of the work done during this process and is intended to

generate debate and to raise the visibility and social awareness of an issue that not only affects people's private lives but also the foundations that underpin the organisation of our society.

The document has been shared with and revised by most of the participants involved in the process in order to guarantee that its content is consistent with the work that led up to it.

The "la Caixa" Foundation wishes to express its gratitude to everyone who has made this charter possible through their active collaboration and participation.

roduction

# Preamble

This charter stems from a series of complex phenomena that range from the socio-demographic evolution of countries like Spain to the diversity of their social structures and models of production and reproduction.

Both the last census of residents (2015) and the European Health Survey in Spain (Spanish National Statistics Institute [INE], 2014) revealed a set of demographic data that compel Spanish society to reflect on and make decisions regarding the future of care for the country's ageing population:

/ Of the 8,573,985 people who are over the age of 65, 31.8 % are older than 80.

/ It is estimated that by 2050, the number of elderly people will have doubled and that almost half of this

population group will be over 80 years old. Consequently, this segment of the population will far outnumber the group aged under 15 (INE, *2014-2064 Population Projections*).

/ By that same year, the number of centenarians will have reached 172,459. In other words, there will be 13 times today's number of people aged a hundred and over. Most of these people (73.4 %) will be very elderly women.

/ Today, 385,000 people aged over 85 live alone, a situation which in itself may present certain risks and hence a need for support and care.

/ With regard to the scale of the issue of dependency, according to the 2014 European Health Survey, 20.73% of the people aged 65 and

over find it difficult to perform one or more of the basic activities of daily living, eating, dressing, bathing, etc.

4,410,900 people who carry out care tasks, of whom 702,000 are themselves aged over 65.

/ These difficulties rise as people grow older, affecting 53.68% of people aged over 85. Consequently 38.79% of men and 61.80% of women in this age group have some kind of difficulty in performing the tasks involved in their own personal care.

/ In addition, hundreds of thousands of women, most of them immigrants, perform paid care work in their capacity as domestic employees. Their work is typically invisible and poorly recognised, either professionally or in terms of pay.

/ An analysis of the instrumental activities of daily living shows that the difficulty this segment of the population faces in dealing with these tasks rises to 47.07% among people aged over 65 and to 82.08% among those aged 85 and over.

/ The scale of non-professional care provided in the home is demonstrated by the existence of

*The scale of non-professional care provided in the home is demonstrated by the existence of 4,410,900 people who carry out care tasks.*

Women play the leading role in relation to dependency and care for the elderly. Though the presence of men is increasing, it is women, especially those aged between 45 and 65, who perform the essential tasks involved in looking after people when this is required.

The increase in life expectancy entails a change in the signification of different ages and greater diversification in the various stages of life. The ageing process includes a period of 'maturity', characterised by a continuity of roles, and advances towards the time of frailty and, in many cases, towards the need to be given care and support.

To put it briefly, society is evolving: the ratio of family support (people aged 45-64 in relation to those aged 80 and over) will fall from 4.75 in 2014 to 1.45 in 2050 (INE), and the number of women entering the workforce will continue to rise.

We are now in the throes of a process of change that is structuring a fairer and less discriminatory society in terms of gender, in which women are moving in increasing numbers into every level of the education system, as a result of which they are looking to participate in the production system on an equal footing.

*There is an evident need to transform the system of organising care, which has traditionally relied on women.*

# AGING IN PLACE

The consequence of this set of circumstances is the need to transform the system of organising care, which has traditionally relied on the work of women in the home.

In today's social scenario, in which it proves difficult to balance work and personal life, women continue to shoulder most of the care responsibilities that arise within the family, from raising children to looking after the elderly. In view of this, there is a need to initiate a debate in which these situations are addressed with a view to constructing a more egalitarian and supportive society. Furthermore, the generations growing old today have different expectations regarding their future life, the care they will receive and the source of that care. Their preferences are for professional services, while keeping their families for affective support and companionship. In short, ours is a complex society in which independence and autonomy are accorded increasing value.

# Prevention Dignity

***CARING FOR OTHERS  
THE WAY WE WOULD  
LIKE TO BE CARED FOR***

**Companionship**  
**Understanding**  
**Commitment**

# Definition

## Caring for Others the Way We Would Like to Be Cared For

Caring is an **action** that is **inherent to the human condition**. We all need to be cared for at some point in our lives because we are vulnerable. Without care, this society would not exist.

Caring and being cared for entails **“putting yourself in the shoes of the other person being cared for or providing care”**.

Dependence and care arise in the context of a shared experience of interdependence, in which people who need help and those who give it find that their daily lives, the exercise of their autonomy and their independence are affected.

*People First*

# Chapter I.

## On the Principles of Care

Relationships mediated by care must be governed by a set of principles that attempt to define the values and philosophy of this care:

/ **Dignity.** This is intrinsic to the respect and equality in the treatment that any person deserves, and to the consequent duty to ensure that their rights as citizens are recognised. Dignity should constitute the basis of decent treatment in the relationships between all the people involved in care.

/ **Autonomy.** This principle implies recognition of people's diversity and their preferences, and is essential in addressing care relationships. Its application requires respect for people's

self-determination, continuing responsibility for their own lives and the right to receive the personalised support necessary for them to make decisions freely and of their own volition.

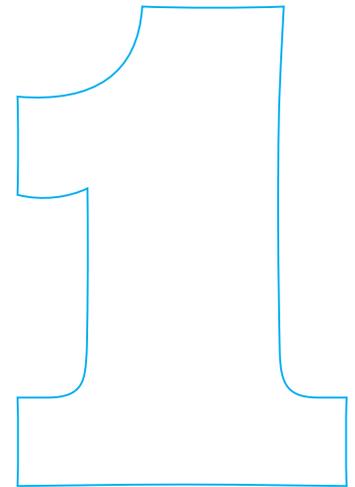
/ **Co-responsibility.** Providing care and receiving care in the manner that people want and need are only

*Dignity should constitute the basis of decent treatment in the relationships between all the people involved in care.*

possible in a model of care shared by men and women. Furthermore, there is a need for collective and individual responsibility through supportive collaboration that encompasses the efforts made by the authorities, not-for-profit and for-profit social initiatives, community participation movements and associations.

/ **Multiparty effort.** The involvement and intervention of various social sectors and areas of knowledge – health, social services, employment, urban design, housing and education – are required in order to meet the needs generated by dependence. This joint effort usually results in enriching interdisciplinary initiatives.

# Principles



## Chapter II.

# On Prevention and Responsibility



Professional circles and citizens concur that much of our ageing process, and our potential dependency on others, may be modified by certain personal decisions and lifestyle choices we make. Some of these actions are detailed below:

- / Promoting autonomy and independence by pursuing initiatives that facilitate **decision-making 'in good time' regarding our own life project.**
- / Helping people to acquire the skills to **look after themselves** that will delay dependency on others: healthy habits, time management, exercise, cognitive training, health checks, etc.
- / Providing guidance on **planning a responsible future** that takes into account housing circumstances, the physical environment, the neighbourhood and the proximity of family and social support.
- / Offering initiatives of a social and community nature that facilitate the **building of social networks** that prevent isolation and loneliness.
- / Working to ensure that towns and cities are both **people- and environmentally-friendly, healthy and protective.**
- / Promoting during **childhood the value of care offered and received,**



as this is the stage when care relationships are more readily established. To this end, it is essential during school years to cover the importance of caring in any generation. It is a matter of addressing in schoolwork values (solidarity, interdependence, reciprocity, responsibility, etc.), strengths (empathy, understanding, patience, tolerance, listening skills, compassion, etc.), experiences of personal interest (the importance of effort for no reward, attempting to do better, human beings' vulnerability, etc.) and learning (gratitude, etc.) from the perspective that they are universal values necessary to social harmony and cohabitation with others, as well as to personal and collective growth.

- / **Raising the visibility of people's uncertainties** in relation to a potential need for care, identifying their preferences over how they would prefer to receive or provide care.
- / **Combatting stereotypes** concerning old age that convey an image of it associated with illness, being a burden and entailing additional expenditure, and preventing an infantilising and inadequate treatment of elderly people.

*Much of our ageing process may be modified by certain personal decisions and lifestyle choices we make.*

## Chapter III.

# On the Bases for Dignified Care

Anyone who provides care can only do so with dignity if they are able to draw on the support of other people, professionals or otherwise, and if they are able between them to improve the wellbeing and dignity of the person being cared for (and at the same time of the carer). In the future, it is foreseeable that people will receive **integrated care** not only from members of their family

but also from various public and private initiatives.

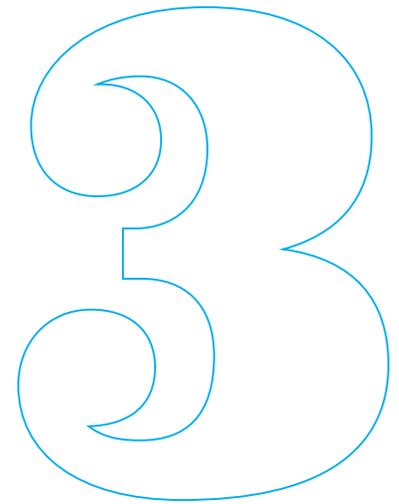
Dignified care needs to be organised around the following criteria:

### / **Integrity:**

- » To improve the quality of life of everyone involved in situations where care is required, intervention must be approached in an integral manner. In

*In the future, people will receive integrated care not only from members of their family but also from various public and private initiatives.*

# Dignity



In addition to addressing the need for help in performing certain activities and tasks that are a part of everyday life, it is important to pay special attention to people's subjective, perceptive and emotional aspects.

» Integral care requires wider use of services, support products and accessible technological resources that will minimise the need for attention and care and, if this is not possible, their provision at a higher standard of quality must be facilitated.

/ **Complementarity:** The current characteristics and scale of the needs of elderly people who require help can only be addressed by means of a set of **complementary responses** from:

- » The social protection system through social and health services and more particularly the development and implementation of Law 39/2006 on the Promotion of Personal Autonomy and Care for Dependent Persons.
- » Development of the use of information and communications technology.
- » The community, which needs to develop a role in protecting and facilitating the everyday lives of elderly people. This encompasses social and association initiatives as well as volunteer activities.
- » The men and women who are friends and relatives in order to ensure a more egalitarian distribution of the care tasks.
- » The people of all ages who provide care.

## Chapter IV.

# On Information, Training and Mentoring in Order to Learn and Teach how to Care for Others and Oneself

The people who require help and their potential carers need on an ongoing basis to be given sufficient accessible information suited to their sociocultural characteristics that addresses their current situation and its possible evolution. This is especially important when the need for care suddenly develops, and carers and the people they are caring for believe themselves to have been abandoned by society in response to a conflict unjustly confined to the private sphere. Information alleviates the sense of isolation and loneliness in the face of society's lack of understanding of this type of situation. In the light of this, the **information must be adapted to the rhythms**

**and limitations that affect the person being cared for.** Similarly, it is essential to identify the needs that may arise over the entire course of progression of the person being cared for in order to foster learning suited to the needs of the dependent person and the capacity of the carer to respond to them, taking into account factors ranging from their physical condition and emotional ties to the possible consideration of available technical aids.

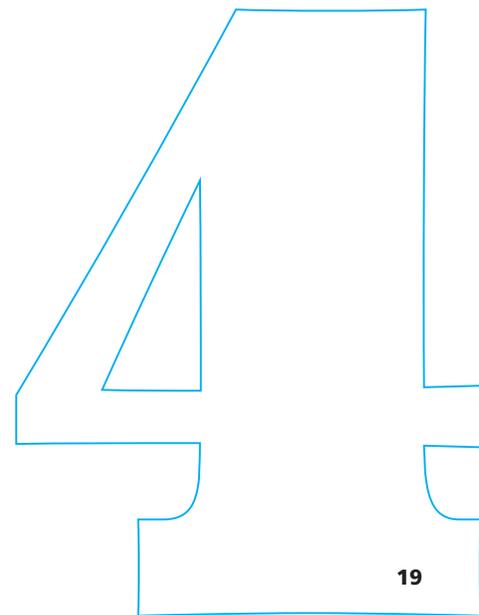
Furthermore, it is essential to construct an **integrated and ongoing model of training, mentoring and mutual support** by creating supervised groups in which personal experiences can be

shared as a way to learn how to better care for others.

Lastly, special attention should be paid to **end-of-life care and support** given that most cases, over and above their intense emotional component, require

specialist knowledge. Combining the efforts of professionals, social initiatives and family members is more necessary at this time than at any other. In addition, spiritual attention for those people who request it should not be ignored.

*The people who require help and their potential carers need to be given information, training and support.*



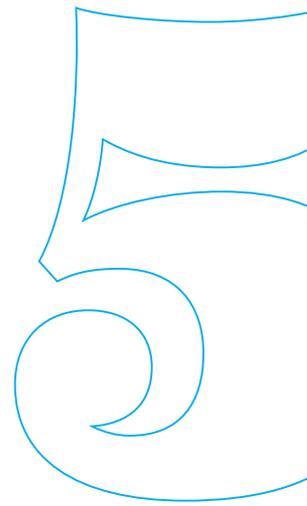
## Chapter V.

# On Communication and Listening, Leading to Understanding and Acknowledgement

Good communication constitutes the first step towards constructing an efficient model of care that directs efforts towards people's wellbeing. **Communication** in ambits where scenarios of dependence occur **makes mutual acknowledgement possible, generates empathy and minimises the unequal relationships that develop between carers and the people they are caring for.** Handling communication correctly encompasses issues such as:

- / Self-help and group intervention to share experiences and relieve tension.
- / Emphasis on the discourses of people involved in scenarios of dependence as the principle from which the models of care to be implemented should emerge.

- / The direct involvement of people with various types of disability, in particular those suffering from cognitive impairment (through their spokespersons), in urban, architectural and home design with a view to improving disabled access and quality of life.
- / The formulation of models of residential support centred on people's needs, preferences and dignity.
- / Raising the visibility and negotiation of moments when help is needed and of those others in which professional attention is offered, which are frequently difficult to balance.



Good treatment

## Chapter VI.

# On Decent treatment and on Our Social Commitment

There is a need to **build a culture of care that sees assistance as more than a private matter**, the responsibility for which is shouldered almost exclusively by families. Instead, issues to do with care should be regarded as a social question that can only be addressed by means of shared responsibility, solidarity and decent treatment.

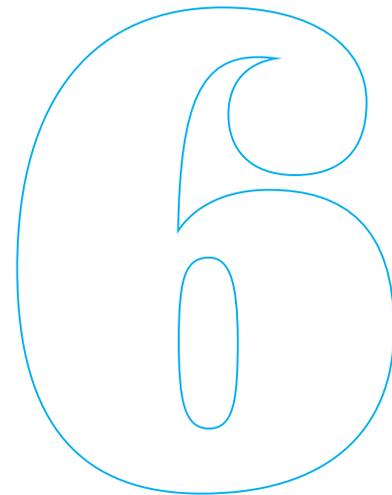
In short, a society in which care occupies its rightful place and is accorded the social status it warrants demands:

/ Sweeping change in the system of production that will tilt and improve the balance between work and personal life.

/ A fair distribution between men and women of the tasks that caring for others generates.

/ A reorganisation of everyday life in the home, workplace and social environment, in which caring and being cared for are visible to the public and are regarded as laudable and ethical.

*Issues to do with care should be regarded as a social question that can only be addressed by means of shared responsibility, solidarity and decent treatment.*



/ Balancing and recognising the rights of the care giver and the care receiver, in contrast with the current situation, in which their rights are often in conflict.

/ Recognition of the role of social, community and voluntary action among all the generations, so that active listening, companionship for people living alone, support for those who are ill, and time generously spent caring for others constitute values taught from childhood and are respected and seen as desirable among citizens.

/ Promotion of the values associated with care (solidarity, commitment, respect, interdependence, etc.) as values common to any healthy society.

In our system of the social organisation of care, we decide the kind of people we are and why we are together: what it is that defines us as individuals and as a society. The possibilities of our wellbeing reside in this. Caring for others the way we would like to be cared for identifies us and dignifies us as people. This is the challenge that we must all take up together.

# Commitment

"la Caixa" Foundation  
June 2016  
[www.laCaixa.es/ObraSocial](http://www.laCaixa.es/ObraSocial)



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