


Charter of Rights of Persons with a loss of autonomy

- 1** I have the right to freely determine my life choices and to be treated as a responsible citizen and a normal person regardless of the extent of my loss of autonomy.
- 2** I have the right to a personalised and adapted response to my physical or mental health, my social circumstances and my living conditions at any age from cradle to grave.
- 3** I have the right to a decent income; I am entitled to a life of human dignity and to the coverage of my health costs.
- 4** I have the right to live in my customary environment, whatever it may be, to live a social life in a secure and accessible environment, to use public ways without danger, and to use means of transport adapted to my needs.
- 5** I have the right to be heeded, to respect from those I deal with, and to have easy access to administrative and customer service positions as well as shops without having to queue up.
- 6** I have the right to timely and objective information about my health, to take decisions about medical treatments jointly with my family and my family doctors and to authorize my spouse or a person I trust to take decisions for me if I cease to be capable of doing so for myself.
- 7** I have the right to access care anywhere and at any time, to be given timely and professional care, without protracted waiting for health checks or specialised examinations, and to get responses that are appropriate to my needs through a network of accessible services and facilities.
- 8** I have the right to receive help in order to preserve my independence and improve my situation, my knowledge and my opportunities for social contact, including through the use of new technologies developed out of research.
- 9** Regardless of my health condition, I have the right to be looked after by trained, qualified and empathic health care personnel, to receive help from and for my family, and to receive appropriate care irrespective of the public funding allocated and which is not means-tested on my own financial situation or that of my family.
- 10** I have the right to object to any discriminatory measure based on my age regarding the payment of social contributions and the eligibility to healthcare. In care homes and geriatric institutions, I have the right to participate to the organisation of services and to decision-making relating residents.
- 11** I have the right to receive the full care and attention necessary from trained and qualified doctors and health workers at home but also in nursing homes or old people's homes irrespective of my state of health. If admitted to a combined retirement and care home, I have the right to be attended by doctors and care staff specifically trained in geriatrics.
- 12** I have the right to a dignified end of life. Care and assistance for the terminally ill must be provided by specialized, skilled personnel. Palliative care and pain relief must enable everyone to end their lives naturally and in comfort, respecting their beliefs and heeding their wishes.





For a Charter of Rights of Persons with a Loss of Autonomy

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Introduction

The ways social protection systems in all EU countries address the changing needs of citizens differ widely and are determined by different well-established economic, social, legal and cultural factors. This makes it virtually impossible to compare national social protection and welfare models which, although they stem from a common origin, have evolved and developed in different ways informed by a wide range of experiences. As a result, the ways these systems address new challenges do not easily fit into neat pigeonholes. This has produced wide differences where some states have brought in specific laws, administrative regulations, and charters of services relevant to new social needs while others have made provision only when compelled by social circumstances. This situation has become ingrained in many areas of social protection in EU countries.

However, among the most sensitive of the "new" issues to develop is clearly that of increasing care needs, something which the demographic and economic situation brought on by the recent crisis has made a matter of the utmost urgency.

FERPA has recently done a thoroughgoing analysis of measures that countries have put in place to meet this new challenge. The research, published as "Dependency (or loss of autonomy) in the Member States", highlighted the ongoing entrenched differences between the systems established to address the needs for care and the means of caring for the most vulnerable citizens.

Generally-speaking, people with care needs very often tend to be of advanced age and unable to carry out all the normal activities of their life in a continuing, permanent and complete manner.

This may be as a result of an accident, illness, or the physical or psychological consequences of work, social and economic circumstances, relationship issues or age.

These conditions are reflected in a wide variety of arrangements and needs, which necessarily require interventions adapted to the individual case. The rights of persons with care needs are the same as those of any other citizen. But the condition of the





“vulnerable” individual, who may also be suffering neglect in his own family, or in a nursing home or even in a residential facility, makes a genuine CHARTER OF RIGHTS even more so necessary.

The FERPA Executive Committee has therefore decided to draw up a list of needs that the most vulnerable and dependent people may have in the course of their lives.

With this CHARTER, FERPA aims to call attention to the problems that people with some level of care needs meet daily, in the hope that scenarios can be framed in the foreseeable future to increase the level of protection of citizens' rights in the different national circumstances and in the longer term, to chart a way forward that will promote universalised patients' and citizens' rights while leading to a harmonization of the systems that deal with social and health issues. This is crucially important, particularly as regards freedom of movement and circulation within the European Union and the process of ever closer integration between the peoples and citizens of Europe.

This CHARTER calls for attention from civil society, national and European institutions and, because it is very much a function of present-day European reality and the trends playing out in national social security systems, anyone else whose actions or omissions may be instrumental in protecting or violating these rights.

If the substantive provisions of this CHARTER are to be given any practical effect, everyone actively (or even passively) involved in protecting people with care needs must shoulder his/her own responsibilities. Indeed, the rights are linked to both duties and responsibilities. That is why the CHARTER must apply to all individuals, accepting that differences like age, sex, religion, socioeconomic status, literacy levels etc. may affect individual social welfare and health care provision needs.

The points expressed in this CHARTER are a concrete expression of fundamental rights and as such must be recognized and respected regardless of financial, economic or political constraints taking criteria of relevance and sustainability into account.

In bringing this CHARTER to a wider audience, it must be borne in mind that those dealing with people with care needs may very often directly or indirectly infringe their rights without even realising it. Mindful of that, we call on all those who can support such actions – institutions, care providers, families – to work together to educate the public on the issue, notwithstanding that politics, society and culture have significant responsibilities to bear.

Brussels, October 2010