

European Charter of the rights and responsibilities of older people in need of long-term care and assistance



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PREAMBLE

Human dignity is inviolable. Age and dependency cannot be the grounds for restrictions on any inalienable human right and civil liberty acknowledged by international standards and embedded in democratic constitutions. Everybody, regardless of gender, age or dependency is entitled to enjoy these rights and freedoms and everybody is entitled to defend their human and civil rights.

The European Union recognises and respects the rights of older people who are more likely to come to depend on others for care, to lead a life of dignity and independence and to participate in social and cultural life (Charter of fundamental rights of EU, art. 25.).

Any restriction of these rights, if caused by age and dependency, must rest on clear legal grounds and transparent legal proceedings, must be proportionate, reviewable, and above all, considered in the best interest of the party concerned. Disregard of and contempt for these rights must be considered unacceptable. Member States should develop policies that promote these rights at home and in institutional care settings, and support individuals asserting them.

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In proposing a European Charter “of the rights and responsibilities of the older people requiring assistance and long-term care” within the framework of the DAPHNE III programme against elder abuse, the EUSTACEA partners want to launch a discussion within the EU Member States on how best to recognise and affirm the rights of the most vulnerable older people. Their objective is to give a voice to older people and ensure that they are heard by the whole society.

AGE members and the project partners stress that advancing in age does not involve any reduction of a person’s rights, duties and responsibilities but highlights that a person can be in either a permanent or temporary state of incapacity and unable to protect their own rights.

The Charter recognises that the vast majority of frail and vulnerable older people are women: two out of three people aged 80+ in Europe are women. More than a third of them suffer from Alzheimer’s disease or dementia, making them even more vulnerable to abuse.

Health and long term care, including prevention and early intervention, should be considered not as a cost but as an investment that benefits all age groups. EU health care and long-term care services should be based on solidarity between generations, to reflect the provisions of the Lisbon Treaty which state that the EU “shall combat social exclusion and discrimination, and shall promote social justice and protection, equality between women and men, solidarity between generations and protection of the rights of the child”.

“Although situations of dependency on others and vulnerability are complex: older people themselves, their families, and professional and voluntary caregivers, should all respect the stated rights. The Charter aims to enable everyone to facilitate older people’s access to their fundamental rights.”

The aim of the Charter is to complement and support the charters and other measures which are already implemented in some countries of the European Union and not to replace them. The Charter also aims to raise awareness among a wider public, to stress the rights of the increasing number of people receiving long-term care, and to foster best practices in Member States and beyond. These rights are not fully respected today but our ambition is to fulfil them.

In this way the Charter aims to become a reference document setting out the fundamental principles and rights that are needed for the wellbeing of all those who are dependent on others for support and care due to age, illness or disability.

The accompanying guide complements and clarifies the Charter. It forms an integral part of the Charter and illustrates it with multiple examples of experiences and initiatives identified by the organisations which took part in drafting it.

This guide should enable all stakeholders to take ownership of the principles stated in the Charter and to adapt it to their national or local context.

Right to dignity, physical and mental well-being, freedom and security

As you grow older and may come to depend on others for support and care, you continue to have the right to respect for your human dignity, physical and mental well-being, freedom and security.

Article 1

In particular, you have the right to :

- 1-1 respect for your human dignity and welfare, regardless of your age, race, colour, national or social origin, financial means, beliefs, sex, sexual orientation or identity and the degree of care and assistance that you require.
- 1-2 respect for and protection of your physical, sexual, psychological, emotional, financial and material welfare.

Physical well-being

- 1-2.1 respect for and protection of your physical well-being and safeguarding from any form of physical abuse, which includes: maltreatment and neglect, malnutrition and dehydration, exhaustion, excessive cold or heat, and any preventable physical illness.
- 1-2.2 protection from any form of sexual abuse or mistreatment.

Psychological and emotional well-being

- 1-2.3 respect for and protection of your psychological and emotional welfare and protection from any form of psychological or emotional abuse or mistreatment.

1-2.4 expect that others will not willingly cause you to feel distressed, upset or feel negative or depressed.

1-2.5 be protected from any attempt to separate you from another person whom you wish to be with.

Financial and material security

1-2.6 be protected against all forms of financial and material abuse.

1-2.7 expect that those who look after your financial and material assets will do so in your best interest, if you are not able to do so yourself.

1-2.8 retain your personal possessions until you willingly decide to give them up or until your death. You have the right to protection against being forced to change your will or give up any financial or material means that are rightfully yours.

Protection against medical and pharmaceutical abuse

1-2.9 protection from all medical and pharmaceutical abuse, maltreatment and neglect, including: inappropriate, unnecessary or excessive medical treatment or drug use or denial of treatment.

Neglect

1-2.10 protection from neglect and lack of diligence in providing support, care or treatment.

1-3 protection against threats of any nature. You should be enabled to feel safe and secure in your surroundings and with the people around you.

1-4 have access to social security and social assistance.

Right to self determination

As you grow older and may come to depend on others for support and care, you continue to have the right to make your own life choices and to respect for your free will. This right extends to an appropriate third-party of your choice.

Article 2

Freedom of choice

- 2-1 You have the right to lead a life which is as self-determined and independent as your physical and mental capacities permit, and to receive advice and support in order to do so.
- 2-2 You have the right to expect that your opinions, wishes and choices are respected by those around you even if you are not able to communicate eloquently. You have the right to be consulted and participate in any decision-making processes that affect you. You have the right to choose a place to live that is adapted to your needs, whether in your own home or in formal care settings.
- 2-3 You have the right to retain control of your property and income, and handle your own financial and legal business and transactions with the authorities. You should receive the support you require to do this.

Support for decision-making

- 2-4 You have the right to nominate an appropriate third-party to take decisions and advocate on your behalf.
- 2-5 You have the right to ask for a second opinion on your health situation before following a course of medical treatment.
- 2-6 You have the right to be given sufficient time to consider your decisions carefully, to access relevant documents, and to make your choices having received independent information, advice and guidance.
- 2-7 In the event that you are unable to take decisions for yourself or express yourself at a later date, you have the right to leave advance instructions on decisions relating to your care, to be carried out by an appropriate third-party. Your wishes should be respected at all times even when communicated non-verbally or through the third-party of your choice.

Restraints to your self determination

- 2-8 You may not be subject to any form of physical or mental restraint unless it is a proportionate response to a risk of potential harm. In which case, it must be determined to be in your best interest through a transparent and independently verifiable process that can be reversed. Assessments of your level of mental capacity to make decisions are neither absolute nor enduring and must be re-evaluated regularly.

Right to privacy

As you grow older and may depend on others for support and care you continue to have the right to respect for- and protection of- your privacy and intimacy.

Article 3

Right to private life

- 3-1 You are entitled to respect for your need for privacy. You should have the opportunity for time and space alone, or with persons of your choice, if you so wish.
- 3-2 Your personal space must be treated with respect regardless of where you live and the degree of care and assistance that you require. It should be the goal of all involved in your support, care and treatment to avoid any restrictions to your privacy or respect for your right to intimate relations.
- 3-3 Respect for your privacy is also reflected in the consideration given to your feelings of modesty. You have the right to be treated by caregivers with sensitivity and discretion.



Right to private information and communication

- 3-4 You have the right to privacy of correspondence. Your letters or electronic mail may not be received, opened or read by third parties without your consent. You have the right to make telephone calls in private.
- 3-5 Your right to privacy must also be reflected in the confidential handling of your data and documents. Your personal data are protected by law.
- 3-6 You have the right to expect that discussions about your condition, care and treatment – whether held with you or between appropriate third-parties not - are handled with sensitivity and discretion, and with respect for your privacy.

Right to high quality and tailored care

As you grow older and may come to depend on others for support and care you continue to have the right to high quality, health-promoting care, support and treatment tailored to your personal needs and wishes.

Article 4

Quality of care

- 4-1 You have the right to receive high quality, timely and affordable health and long-term care services that are adapted to your individual needs and wishes and without discrimination of any kind.
- 4-2 You have the right to be attended to by people who have the skills required and adequate support to respond to your need for assistance, care and treatment. Whether you are cared for by professionals, family members or other trusted individuals, they should have received – and should continue to receive technical, structural and financial resources, and the specialised training and guidance necessary to provide them with the assistance they need.
- 4-3 You should seek respite care solutions in order to allow those giving you daily assistance the breaks they need to maintain their own quality of life and to enhance the quality of care they provide to you.

- 4-4 You are entitled to benefit from measures to prevent any deterioration of - or to bring about an improvement in - your condition, and to promote your independence to the greatest extent possible.
- 4-5 You have the right to expect that all individuals, institutions and professional bodies involved in your care, support and treatment should communicate and cooperate with one another and closely align the services they provide to ensure that they are in your best interest.
- 4-6 You have the right to receive timely support for your daily needs.

Tailored care

- 4-7 If and when you enter into residential care, the conditions and costs of your residence should be set out in an explicit contract. Information about your rights and responsibilities should be clear and transparent. You have the right to receive advice prior to, and at the time of your admission.
- 4-8 You have the right to move freely within your surroundings. You have the right to be given support and encouragement for your mobility.
- 4-9 You are entitled to expect that aspects of your background and past lifestyle that are important to you are taken into consideration.

Right to personalized information, advice and informed consent

As you grow older and may come to depend on others for support and care you continue to have the right to seek and receive personalized information and advice about all of the options available to you for care, support and treatment in order to be able to make informed decisions.

Article 5

Right to access to personal and personalized information

- 5-1** You have the right to be informed about your state of health and the available treatment and care options. This should include information and advice about the chances of success or failure, potential effects of medicines, examinations or any other medical intervention on your physical or mental health and daily life, and available alternatives.
- 5-2** You and a third-party of your choice continue to have the right to access your personal medical data and to request the opportunity to inspect all documents relevant to your health.
- 5-3** Your right to refuse to be informed should also be respected.
- 5-4** You have the right to be informed and advised on all possible leisure activities, housing facilities and social care measures you could benefit from regardless of their cost. You should be able to decide which of these you can afford and you should be provided with all the information needed to make an informed decision

Informed consent and advice

- 5-5 Your informed consent or that of the appropriate third-person of your choice must be sought on decisions relating to all of your care and treatment, as well as to any participation in research projects and medical trials.
- 5-6 You have the right to legal advice, representation and defence. Legal aid should be made available if you lack sufficient resources.
- 5-7 Being spoken to openly, tactfully and in terms that you understand is part of your right to information and to giving informed consent.
- 5-8 You or a person of your choice are entitled to receive timely, clear and comprehensive information concerning all of the services that are available to you. This should include their respective costs, and options for adaptation to your needs.
- 5-9 Before concluding or amending an agreement or contract for residential care or other services, you have the right to be fully informed and advised on the content and the possibility of making any future amendments to the agreement, including services and fees. Information about your rights and responsibilities should be clear and transparent.

Right to continued communication, participation in society and cultural activity

As you grow older and may come to depend on others for support and care you continue to have the right to interact with others, and to participate in civic life, lifelong learning and cultural activity.

Article 6

- 6-1 You should be made aware of and given opportunities to participate voluntarily in social life in accordance with your interests and abilities in the spirit of solidarity between generations. You also have the right to be given opportunities to perform paid or voluntary work and to take part in lifelong learning.
- 6-2 You have the right to all the support necessary to enable you to communicate. You are entitled to have your communication needs and expectations taken into consideration, in whatever way these are expressed.
- 6-3 You have the right to move freely to pursue your interests and activities. Should your mobility be impaired, you have the right to assistance in this respect.

- 6-4 You have the right to equal access to new technologies and to learning and support in how to use them.
- 6-5 You have the right to continue to exercise all of your civic rights, including the right to participate in political elections and, if required, to receive impartial assistance to do so. Your right to freedom of choice must be respected and confidentiality concerning your vote must be maintained by anyone assisting you.

Right to freedom of expression and freedom of thought/conscience: beliefs, culture and religion

As you grow older and may come to depend on others for support and care you continue to have the right to live according to your convictions, beliefs and values.

Article 7

- 7-1 You have the right to respect for your values and beliefs, your philosophy of life and/or religious freedom regardless of whether or not these values are shared by those who are supporting you.
- 7-2 You have the right to practice and observe your religion or spiritual beliefs. You also have the right to obtain spiritual or religious care and guidance from representatives of your faith or spiritual beliefs when you wish. You have the right to refuse to participate in religious activity and to reject approaches by representatives of religions, faiths or philosophies of life.
- 7-3 Everyone, whatever their cultural heritage, religious values or practices has an equal right to respect and mutual tolerance.

- 7-4** You have the right to establish an association, join a group, and equally, the right to refuse to join.
- 7-5** You have the right to develop your political or social understanding and convictions and to widen your skills and knowledge in this respect.
- 7-6** You have the right to refuse any unwanted ideological, political or religious pressure, and you have the right to ask to be protected from this.

Right to palliative care and support, and respect and dignity in dying and in death

You have the right to die with dignity, in circumstances that accord with your wishes and within the limits of the national legislation of your country of residence.

Article 8

- 8-1 You have the right to compassionate help and palliative care when you reach the end of your life and until you die. You have the right to measures to relieve pain and other distressing symptoms.
- 8-2 You have the right to expect that everything possible should be done to make the process of dying dignified and tolerable. Those treating and accompanying you at this time should respect your wishes and uphold them wherever possible.
- 8-3 You have the right to expect that the medical and care professionals involved in your end-of-life care should include and offer support to those close to you or other trusted persons, according to your wishes. Your right to exclude certain people should also be respected.
- 8-4 You have the right to determine whether and to what extent treatment, including life-prolonging measures, should be initiated or continued. Your advance instructions should be respected if you are no longer assessed as being mentally competent.

- 8-5 Nobody may take any measures that would systematically lead to your death, except if they are authorised by the national legislation¹ of your country of residence and you have explicitly given such instructions.
- 8-6 In the event that you are not able to express yourself, your advance instructions concerning decisions about your end-of-life care must be fulfilled within the limits of the national legislation of your country of residence.
- 8-7 You have the right to respect for and observance of your religious beliefs and any wishes expressed during your lifetime about the arrangements for care and treatment of your body after your death.

¹ Legal provisions regulating end of life vary from country to country.

Right to redress

As you grow older and may come to depend on others for support and care, you continue to have the right to redress in case of mistreatment, abuse or neglect.

Article 9

- 9-1 You have the right to support or to refuse support whenever you find yourself in a situation of abuse or mistreatment, whether you are receiving residential or home care.
- 9-2 You are entitled to expect care professionals to be trained to recognize signs of abuse and mistreatment and act appropriately in order to safeguard you from any further mistreatment.
- 9-3 You have the right to be informed of the channels through which you can report abuse. You have the right to report abuse or mistreatment without fear of any negative repercussions, and to expect that the authorities will respond appropriately when you make a report. This right extends to those around you, particularly people who are responsible for your care and support.

- 9-4 You have the right to expect to be protected from the alleged situation of abuse or mistreatment when you file a complaint until the case has been fully investigated; this should not require a change of residence if this is against your wishes.
- 9-5 You have the right to treatment to enable you to make a full recovery from any physical or psychological trauma you might have suffered as a result of abuse or mistreatment. You must be given time to recover at your own pace.

Your responsibilities

As you grow older and may come to depend on others for support and care, you should :

Article 10

- 10-1** Respect the rights and needs of other people living and working within your environment and respect the general interests of the community in which you live; your rights and freedoms should be only limited by the need to respect similar rights of other members of the community.
- 10-2** Respect the rights of carers and staff to be treated with civility and work in an environment free from harassment and abuse.



10-3 Plan for your future and take responsibility for the impact of your action or lack of action on your carers and relatives, in accordance with national legislation. This includes:

10-3.1 Nominating an appropriate third-party to take decisions and advocate on your behalf.

10-3.2 Leaving advance instructions detailing your choices regarding your health and welfare including care and treatment during your lifetime and at the end of your life as well as arrangements for your property and financial affairs. If you are unable to do so, it is the duty of your next of kin or your appointed representative to take decisions on your behalf, respecting your wishes wherever possible.

10-4 Inform the relevant authorities and those around you about a situation of abuse, mistreatment or neglect that you experience or witness.



50+ Hellas › <http://www.50plus.gr/english>

AGE Platform Europe › www.age-platform.eu

ANBO › <http://www.anbo.nl>

BIVA › <http://www.biva.de/>

Commune de Saint Josse › <http://www.stjosse.irisnet.be/index.php?id=50>

E.D.E. › <http://www.ede-eu.org/>

FIPAC › <http://www.fipac.it/>

FNG › <http://www.fng.fr/>

MZU › www.mzu.si

NIACE › <http://www.niace.org.uk/>

SPF Sweden › www.spfpension.se

Zivot 90 › <http://www.zivot90.cz/>

This European Charter was developed by the following partners:

European partners:

- ★ AGE Platform Europe, project co-ordinator
- ★ EDE – European Association for Directors of Residential Homes for the Elderly

National partners:

- 50+ Hellas (Greece)
- BIVA (Germany)
- Commune de St Josse (Belgium)
- FIPAC (Italy)
- FNG (France)
- MZU (Slovenia)
- NBO (The Netherlands)
- NIACE (UK)
- SPF (Sweden)
- ZIVOT 90 (Czech Republic)

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