

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

EUSTaCEA project, under Daphne III programme



## Accompanying guide

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## Introduction

- **Elder abuse**

Elder abuse is defined by the World Health Organisation (WHO) as “a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person”<sup>1</sup>. Elder abuse often remains unnoticed and is seldom reported. It can be intentional or unintentional and covers not only physical abuse, but also psychological and emotional, sexual, financial, pharmaceutical abuse, and neglect. The denial of civic rights, discrimination on the ground of age and ageist attitudes are also considered to be forms of elder abuse. Unlike financial and sexual abuse which are always intentional, unintentional abuse often results from a lack of understanding of the older person’s needs and feelings and the carer’s difficulty in reconciling the older person’s needs and wishes with one own’s private and professional demands.

- **Risk prevention**

Although there are huge discrepancies in eldercare among European Union countries, today in most countries, the majority of older dependent people are still cared for by informal carers (i.e. relatives, friends, neighbours). Informal carers often face a high risk of burn-out and social exclusion due to the physical and psychological demands put on them. Professional carers are also often put under huge pressure and are not always offered the training and support they need to perform their work under good conditions. Actions to tackle elder abuse must therefore take on board carers’ needs and the difficult challenges faced by all those – formal and informal carers - who devote significant parts of their lives to care for dependent elders, as their needs and the challenges they face constitute important risk factors. It is the duty of public authorities - together with the care providers - to protect all those who become dependent on others for their daily needs and to enable them to live a dignified life until the very end of their lives. Such measures must go hand in hand with measures to protect and support both formal and informal carers by offering them decent working and living conditions and acknowledging and valuing the huge contribution they make to the community.

- **The European Charter of Rights and Responsibilities of Older People in need of Long-term care and Assistance**

With the support of the European DAPHNE III Programme, a group of partners from 10 countries led by AGE have developed a European Charter of Rights and Responsibilities of Older People in need of Long-Term Care<sup>2</sup> as part of their EUSTACEA project. With this Charter, the EUSTACEA partners seek to set up a common reference framework that can be used across the European Union to promote the wellbeing and dignity of older dependent people. This accompanying guide complements the Charter and is addressed more specifically to older people’s carers, long-term care providers, social services and policy makers. It includes suggestions and recommendations as to how the Charter can be implemented.

<sup>1</sup> See WHO website: [http://www.who.int/ageing/projects/elder\\_abuse/en/index.html](http://www.who.int/ageing/projects/elder_abuse/en/index.html).

<sup>2</sup> [http://www.age-platform.eu/images/stories/22204\\_AGE\\_charte\\_europeenne\\_EN\\_v4.pdf](http://www.age-platform.eu/images/stories/22204_AGE_charte_europeenne_EN_v4.pdf)

- **How is the guide organised?**

This accompanying guide addresses each of the rights included in the European Charter. It explains what they mean and how they can be translated into practice. For each article the guide provides detailed information to different target groups and presents solutions and concrete examples from across the European Union.

The guide does not aim to replace but rather to complement and support existing initiatives which are already implemented in many countries of the European Union. The solutions provided in this guide are only examples of what can be done and need to be adapted to each national legal, social and cultural context and to each individual's history and needs.

- **How to use this guide?**

A colour has been assigned to each target group: policy makers, informal carers, professional carers, social services, LTC service providers and older people's organisations. These colours are used to highlight information and sections that may be most relevant for these groups. Recommendations are sometimes addressed to several groups, as for example for service providers, caregivers and older people's organisations.

**PM**  **Policy makers:** this group includes decision-makers at all levels (European, national, local) who are responsible for the financing, organisation and monitoring of eldercare services. They have the power to legislate on quality standards and are responsible for inspection, enforcement and sanctions.

**IC**  **Informal carers:** they include mainly relatives, but also close friends, neighbours, and community volunteers. In some countries, informal carers include undeclared migrants providing care at home to dependent older persons.

**PC**  **Professional carers:** paid home, community and residential care staff.

**SS**  **Social Services:** Local agencies responsible for ensuring that older people have access to the services they need.

**SP**  **Service providers:** public, private non-profit and commercial agencies delivering services to older people in need of long-term care in institutional, community or homecare settings.

**OP**  **Older people's organisations:** associations whose mission is to advance the interests of older people.

A **checklist of recommendations** for each target group is available at the end of the guide summarising the different recommendations addressed to them.

A **glossary** of the main key words used in this guide is also available at the end of the document.

Some **good practices** are presented in the guide, but a more exhaustive list and further contact details (addresses, telephone numbers) can be found on AGE Platform Europe's website, at the following link:

<http://www.age-platform.eu/en/age-policy-work/quality-care-standards-and-elder-abuse/1077-good-practices>

# 1

## Right to dignity, physical and mental integrity, freedom and security

### The Charter states that...

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 wellbeing, freedom and security.

*"I am not hungry, the only thing I would eat is the yoghurt but I can't open it, so I leave it."*

*"I know that I shouldn't give him money each time he comes, but I feel so lonely..."*

*"Don't worry about those bruises, it must be because she doesn't have a good balance and bumps into furniture."*

Because they happen to older people, such situations are often not considered to be abuse but rather unfortunate consequences of getting old. When an older person loses her/his autonomy, s/he becomes more vulnerable to violence and mistreatment. Without awareness of their rights, older persons cannot know that they are being abused or discriminated against or how to respond appropriately and seek help when they are faced with difficult or distressing situations.

## Recommendations to...

### **PC** **IC** **Caregivers should be aware that they have a key role in protecting older dependent persons from abuse**

Both informal and formal carers must learn to recognise situations where older people can be at risk of elder abuse and should be aware that it is their duty to protect the care recipient's wellbeing, and enable them to feel secure and confident. "Care home workers and support workers have a key role in recognising and protecting people from abuse. They have a responsibility to the people for whom they provide the care, to minimize both the likelihood of abusive situations occurring and the effects that it can have, and to contribute to monitoring anyone who may be considered to be 'at risk'."<sup>3</sup>

### **PC** **IC** **Check if your practices are the right ones**

Caregivers should check that their practices meet anti-discrimination and dignity guidelines. They should be able to advise their clients and families on how to make a formal complaint, including information on appropriate organisations to contact for information, advice and guidance and how to follow the complaint. While it can be difficult to detect the emotional and psychological signs of abuse, any sign of anxiety should be considered as a serious problem, in particular when the person suffers from dementia.

<sup>3</sup> From "Domiciliary care: national minimum standards, regulations", UK Department of Health, 2003  
[http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4083671.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4083671.pdf)

## **PM** **Develop a systematic process to prevent abuse and take complaints into account**

Each service or institution should develop a step-by-step procedure to raise awareness of risks factors and help caregivers or other staff know what they have to do when they suspect or witness elder abuse. Complaints have to be taken seriously and both the older person and the person reporting elder abuse must be protected from any negative repercussions. Initial training programmes and refresher courses for formal and informal caregivers must integrate systematically the ability to observe, detect and handle even the most “invisible” types of elder abuse and discrimination. These trainings should involve a wide range of stakeholders such as caregivers, elder abuse helplines, doctors or the police.

## **PM** **SP** **SS** **OP** **Raise awareness on elder abuse**

Unlike child abuse or domestic violence against women, elder abuse is still taboo. Public authorities, service providers and older people’s organisations must break the taboo and raise awareness of the fact that fighting elder abuse and promoting the wellbeing and dignity of older dependent people is a duty shared by all, public authorities, service providers, relatives, neighbours and friends of dependent older persons.

## **PM** **SP** **SS** **OP** **Provide information on where to call for support**

Older people and carers must receive information on how to report a situation of elder abuse and where to call for support. This information should be provided through widely available leaflets, dedicated websites in plain language and helplines. Information should also explain how a person can access the social benefits and assistance they are entitled to. A staff member can be designated to help persons in residential care settings access this information. This is particularly important for migrants who need help to understand the health and social care system of their host country and may face language barriers.

## **PM** **SP** **SS** **OP** **Cooperate with a wide range of stakeholders**

It is important to mobilise all those committed to promote the wellbeing and dignity of older people.

## **PM** **Create a public body responsible for anti-discrimination and the fight against elder abuse**

A public body should be available for citizens to react to any form of discrimination and abuse, such as an Ombudsman or a public agency fighting against discrimination and abuse. This public body must cover age discrimination on all grounds: employment, health services, social services, etc. and must cover a broad definition of abuse: physical, sexual, psychological, emotional, and financial and material, and neglect.

## Good practices



### ***United Kingdom: Guide on Dignity in care***

This guide provides information for service users on what they can expect from health and social care services, and a wealth of resources and practical guidance to help service providers and practitioners in developing their practice, with the aim of ensuring that all people who receive health and social care services are treated with dignity and respect. 'Dignity tests' allow the professionals to check if their practices respect the beneficiary's dignity. More information available at:

[www.scie.org.uk/publications/guides/guide15/files/guide15.pdf](http://www.scie.org.uk/publications/guides/guide15/files/guide15.pdf)

### ***Czech Republic: Stop violence against older people campaign by Zivot90***

Stop violence against older people is a national campaign developed by ZIVOT 90 to raise awareness on the problem of violence against older people and to trigger public debate on this issue. In 2006 the campaign involved the launch of a leaflet "Stop violence against seniors" (STOP násilí na seniorech), containing advice and contact points for help. The leaflet also contains life stories of older people victims of violence "Voices we do not hear". The campaign continues and Zivot90 runs a free non-stop Help-line SENIOR TELEFON (800 157 157) accessible to all, for assistance and support.

More information can be found at

[www.zivot90.cz](http://www.zivot90.cz)

### ***The Netherlands: the Amstelland police provide information on elder abuse to their staff.***

The Police Amsterdam – Amstelland have developed a small booklet that all police officers can carry with them to recognize signs of elder abuse when they encounter it. The booklet also provides guidelines to what a police officer can do to help and support a possible victim of elder abuse.

More information at

[politie-amsterdam-amstelland.nl](http://politie-amsterdam-amstelland.nl)

# 2

## Right to self determination

### The Charter states that...

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.

*“What I miss is the freedom to choose, to choose when I get up, what to have for lunch, what to wear today.*

*“I don’t understand why I have to take all these medications, they make me feel dizzy.”*

Older people in need of long-term care often see their mobility and self-determination reduced. This can be particularly problematic for older women who depended on their partner for their financial and mobility needs. This can be due to factors including constraints imposed by providers of institutional care and the lack of time of caregivers. For example, some service providers do not encourage older people to go to the shops and choose the products they want, or do not allow people to help prepare their own meals for safety reasons. Some caregivers also address older people in an informal or overly familiar way without first checking that this is what the older person wants. It is important to let older people express their will and opinions and respect their wishes, especially regarding the way they are cared for, their expectations for quality of life and their medical treatment. It must also be understood that the aim of ensuring the safety and security of older people sometimes conflicts with the aim of promoting autonomy. When this is the case, careful judgement must be exercised to ensure that a balance is achieved between the two, and care givers must recognise the older person’s right to take some risks.

## Recommendations to...

### PC IC SP **Involve people in their care**

Maintaining a care recipient’s independence and autonomy must be a central consideration. This might involve designing a personal time schedule including wake-up time, meal times, and sleeping time which accommodates the older person’s wishes as much as possible. Caregivers and service providers must involve people in their care whenever possible. The care recipients must be given the opportunity to express their own views on their quality of life, and if they have communication difficulties they must be supported to do so. This can take a participative form, for example through residents’ councils where residents, family, staff, and public authorities can all participate.

## **PC** **IC** **SP** **Respect the needs and wishes of the person**

When a care recipient moves from their home into residential care, all efforts should be made to ensure that the transition is as smooth as possible and causes the least disturbance to the older person. The choice of care setting must be made in accordance with the care recipient's wishes and the appropriateness of the care setting for their needs and financial resources. Nobody should force people into a choice regarding this or any decision concerning medical treatment and care. The care recipient or their representative must be given time to consider all the available options, including those based on medical grounds. They should be given the opportunity to ask for a second opinion to help make their decision<sup>4</sup> and receive assistance to get relevant information including contact with other people or organisations that can provide this. Finally, care recipients have the right to refuse care, but professionals must ensure that they are provided with all the information on their medical condition and the risks and consequences of refusing care. In the case of a person suffering from dementia, the trusted person, third party or legal representative must be consulted.

## **PC** **IC** **SP** **Take steps to ensure mobility and autonomy are maintained**

Caregivers and service providers must ensure that they promote the autonomy of care recipients by taking measures to preserve their mobility, for example through gentle exercise with support where needed. Any form of constraint to freedom of movement should be applied only if appropriate, i.e. if the person is at risk. Caregivers must as much as is possible encourage older people to eat and drink independently regardless of the time and support needed. When living at home people should keep a kitchen if possible and if the person cannot cook, s/he must be consulted on his/her preferences regarding the composition of their meals. Living accommodation should be arranged to encourage mobility and movement.

## **PC** **IC** **SP** **Provide adequate support for decision-making**

Care recipients have the right to ask for support and help in decision-making, especially when they suffer from cognitive impairment. For example, support to improve levels of "financial literacy" is required to enable older people to understand the legal and financial implications and to take informed decisions when confronted with health problems, death of a relative or moving into residential care. This is particularly important as people find it difficult to admit to a lack of financial knowledge. It is therefore important to empower people to take control of their own finances and to be as independent as possible in their daily life.

## **PC** **IC** **SP** **Rely on a third party if needed and limit restrictions to the person's autonomy**

Where the care recipient's mental capacity is impaired, or if the person has difficulties communicating and can no longer make any form of judgement, then a person should be legally appointed to provide informed consent on her/his behalf. This decision must always be taken in the person's best interest and needs to involve caregivers and professionals when considering whether/how to draw up an advance directive within

<sup>4</sup> The formality of referral of the care recipient to another professional colleague and the information available about alternative options differs between member states and according to the member state's Ethical Code of the Medical Profession.

the context of advance care planning. Carers and care recipients must be given a clear explanation of any restrictions on self-determination and, if existing, on the legal framework concerning these restrictions and the specific areas they cover. Finally, written instructions and informed consent, e.g. stating the implications of treatment, should be signed by care recipients and doctors.

### **PM** **SS** **OP** **Give information on the rights and limits of representation by a third party**

Care recipients must be told about the possibility of being represented by a third party and of giving advance directives, especially for decisions concerning their property and income, and for health and care questions. General information on how to proceed can be provided in the form of a leaflet written in simple language as well as on a website or through an oral discussion explaining the different options and the rights of the third-party representative regarding decision-making. A seniors' helpline, a consumer protection helpline, or a legal assistance helpline can also be developed including financial and legal issues.

## **Good practices**

### ***Alzheimer Europe advice on advance directives (summary)***

Professional caregivers must always ascertain the current wishes of patients even if they have written an advance directive. This statement, to be valid, should respect minimum legal requirements; for example, that the person has the necessary and relevant capacity, is free from undue pressure, has not made a more recent version and has stated wishes that are applicable to the current situation/proposed treatment. If the person is fully competent, doctors should not follow instructions/wishes expressed in the advance directive. If the person is not fully competent and there appears to be a conflict between current and former wishes, the person's current wishes and feelings should be considered alongside those expressed in the advance directive as they represent the person's current mental and emotional state and attitudes. More information is available at:

[www.alzheimer-europe.org](http://www.alzheimer-europe.org)

### ***Involvement of older people in their care – some examples in Europe***

In Germany it is now a quality standard that the nursing homes are primarily the residents' "home" and not the working place of the caregivers. This means, for example, that every resident can decide his/her wake-up time. It is up to the management to organize the time schedule for the staff. In France, the *Conseil de la vie sociale* is set up each residential institution and is composed of elected representatives of residents, families, and staff. Residents can also regularly meet to discuss meals and other services provided in the institution. In Belgium, weekly group discussions are held between carers and care recipients. In a care centre in Flanders, the residents participate in their own care through weekly group discussions made of 15 people. They are consulted about what needs to be changed in their care, environment and care center policy, to enhance their quality of life. A psychologist coordinates these discussions.

### ***Spain: Transport on demand in Castilla y Leon***

*“Transporte a la demanda cuando lo necesites!”* is a programme developed by the regional public authority of Castilla y Leon (Spain), which is a region of wide rural areas with a large number of small towns. The system complements the regular public transport network. The person can reserve a seat in advance through a free telephone number, text message, Internet and the request goes directly to the transport operator or vehicle. The cost per journey is 1 euro and the routes cover a large number of different zones and towns, with daily journeys.

More information is available at:

[www.jcyl.es](http://www.jcyl.es).



### ***Support to independent living in Slovenia.***

Independent and self-controlled life of mobile older people is promoted through programmes to reduce pressure on institutional care and to motivate participants to contribute peer support through volunteer activities. Partly subsidised home care is organised on municipal level for those who are not able to leave their homes. In **Germany**, more and more flat-sharing communities for older people are developing, where not only the flat but also the housekeeper and the care assistance are shared. More information on independent living:

[www.enil.eu](http://www.enil.eu)

# 3

## Right to privacy

### The Charter states that...

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.

*“I don’t like being treated like a piece of furniture. Can’t they talk to me when they wash me instead of discussing between them what they did last weekend? I am not dead yet. I have feelings too!”*

*“It took me three years as a child to learn not to wet my bed at night and now they want me to do it again because they don’t have time to come and help me to the toilet at night!”*

People in long-term care are at greater risk of a lack of privacy and intimacy as a result of their personal care needs. This is particularly true for people living in residential care who have to share their bedroom with another person. Privacy is very important because it plays a key role in maintaining an older person’s self-esteem and wellbeing. In addition, the desire for intimacy does not decrease with age, and there is no age at which intimacy is inappropriate. Confidentiality is also an essential requirement for the preservation of trust between the older person and their caregivers. Older people should be able to expect that information about their health which they give in confidence will be kept confidential unless there is a compelling reason why it should not.

## Recommendations to...

### **SP** **Integrate the respect for privacy in the service management and in the care contract**

All care settings should offer opportunities and facilities to enable people to be alone for a while, talk in private with other care recipients, friends or relatives, and make telephone calls undisturbed and without being overheard. Agreements on these matters should be included in the care contract. Information about who will have access to a person’s room key should also be stipulated in it. For home care, if the person has a door code, this must be confidential and given only to the trusted caregiver(s). The opportunity must be offered to bring some personal things (small items of furniture, pictures, and bed linen) to the residential home even if the person is sharing the room. Visitors must be allowed access at appropriate times. If people share a room, the other resident’s need for privacy, peace and quiet must be respected and the discussions especially on health treatment must be held in places which enable private conversations.

## **SP** **Allow places and moments for intimacy**

Decisions about the personal and sexual relationships that an individual wishes to pursue should rest entirely with them, provided that it does not infringe on the rights of others. Caregivers should treat residents with sensitivity and understanding and must not place restrictions on their ability to have intimate physical relationships. Service providers should guarantee that facilities, such as a private room, are provided to enable residents - regardless of age or infirmity - to continue to have intimate relationships when they choose. Information about the scope of facilities that allow intimate relations must be made available before a contract for residence is concluded.

## **SP** **Have clear rules on respect for confidentiality and data protection**

Everyone who is providing care, including temporary replacement carers and trainees, should be made aware of their contractual obligation to respect the institution's policy on client confidentiality. Caregivers should be aware that a person has the right to refuse some visits. Mail (including electronic mail) must not be handled, opened or read by third parties without the consent of the addressee. In nursing and residential homes a pigeon hole or mailbox for each resident, for instance, can provide a high degree of discretion. If someone is unable to receive or open mail or use channels of communication without help from others, a trusted person appointed in advance by the addressee should assist her/him. Finally, personal data should only be processed with the prior consent of the person concerned or his/her appointed representatives and in accordance with legislation. All staff should receive clear and easy to understand instructions on how to handle personal data which respect data protection legislation and are proportionate to the legitimate aim of the process. Protection is needed against both external threats such as theft and internal threats such as inappropriate access by staff.

## **PC** **IC** **Prevent intrusion into the private sphere and respect the person's modesty feelings**

Caregivers should ring or knock before entering a person's house or room. If the person is able to call out they should await their response before entering (clear instructions must be developed in consultation with the care recipient or her/his trusted person as to what to do in case the staff hears no reply). Where a person has a hearing impairment an appropriate solution should be found (e.g. a light sign installed). The person's feelings of modesty must be taken into account at all times. If an older person does not wish to be treated by a particular individual for a valid reason, the care provider should assign alternative staff to the person's care and this should be agreed in discussion with the person receiving care. Caregivers should also receive adequate training on incontinence care needs. Where facilities such as rooms or bathrooms are shared, caregivers must ensure that the person's privacy is respected while they are receiving personal care such as washing or using the toilet, by closing the doors or screening the area from other people's view.

## **PM** **Develop clear data protection rules protecting the users**

Respect of anonymity, confidentiality and consent of vulnerable people should be priorities when dealing with data protection, especially concerning access to data by research projects. Data protection is dealt with differently in each Member State but caregivers everywhere should be informed on the best ways to handle confidential data of persons in need of long-term care. They must not reveal personal data or information, particularly if it could be detrimental to the care recipient.

## Good practices

### **European Union: European Directive on data protection**

Directive [95/46/EC](#) is the legal reference for protection of personal data within the European Union. It sets up a regulatory framework which seeks to strike a balance between a high level of protection for the privacy of individuals and the free movement of personal data within the European Union (EU). To do so, the Directive sets strict limits on the collection and use of personal data and demands that each Member State set up an independent national body responsible for the protection of these data.

For more information, please consult the European Commission's website: [http://europa.eu/legislation\\_summaries/information\\_society/l14012\\_en.htm](http://europa.eu/legislation_summaries/information_society/l14012_en.htm)



### **United Kingdom: Dignity behind Closed Doors Campaign**

The aim of the campaign is to raise awareness that people, whatever their age and physical ability, should be able to choose to use the toilet in private in all care settings. "Toilet Access and Use" has been chosen as a marker of human rights and dignity. Wide dissemination of educational leaflets, decision aids, standards and check lists to voluntary groups, patient and carer groups as well as to care staff, will make carers and care recipients aware of what they should expect. Giving back control over their most private of functions to dependent people will enhance their independence and rehabilitation, reduce lengths of stay and promote continence. For more information, please visit British Geriatrics Society's website:

[www.bgs.org.uk/campaigns/dignity.htm#aims](http://www.bgs.org.uk/campaigns/dignity.htm#aims)

### **United Kingdom: Red Means Stop!**

Leicester's hospitals have introduced red pegs to further protect patients' privacy and dignity. Thousands of red dignity pegs have been circulated to wards and departments across all three hospitals. These large red pegs are used to clip curtains together around patients' bedsides when they are being examined or require privacy. The pegs not only ensure the curtains are closed properly, but also indicate to other staff that they should not enter. More information is available at:

[www.uhl-tr.nhs.uk/patients/patient-information/caring-at-its-best/red-means-stop](http://www.uhl-tr.nhs.uk/patients/patient-information/caring-at-its-best/red-means-stop)

### **France: Charter of the rights and liberties of the cared person includes protection of privacy**

This charter adopted in September 2003 is legally binding in France. It applies to all care settings. Two articles deal with the protection of privacy: art. 7 (data protection, security, health, medical follow-up) and art. 12 (respect for dignity, wellbeing and intimacy).

***United Kingdom: British Medical association – Confidentiality and disclosure of health information toolkit***

In December 2009, the British Medical Association published the second edition of the toolkit “Confidentiality and disclosure of health information”. The purpose of this toolkit is not to provide definitive answers for every situation but to identify the key factors which need to be taken into account when such decisions are made. The toolkit consists of a series of cards about specific areas of confidentiality relating to children, adults who lack capacity as well as the secondary uses of information. Separate cards have been produced identifying factors to be considered when assessing competence and determining ‘best interests’, security of information and the sources of confidentiality rights and protection. For more information:

[www.bma.org.uk](http://www.bma.org.uk)

# 4

## Right to high quality and tailored care

### The Charter states that...

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.

*“She doesn’t understand why I cry when I have to wait so long on the toilet seat before she comes to help me. I know she is very busy, but if she could only understand how painful it is for me.”*

*“Can’t they put some nice music when we have lunch? That would boost everyone’s appetite!”*

Respect for each person’s dignity, quality of life, and wellbeing should be at the forefront of all decisions relating to the care plan and all caregivers should be aware of the principle of dignity and respect to the beneficiary. They must keep in mind that any deficiency or loss of function, even cognitive, does not in any way modify the humanity of the person cared for and assisted, and that treating others with respect is an expression of self-respect. Care needs are not static. Conditions can change, improve and deteriorate, and they will require evolving responses which can be provided by regular needs assessment in order to adapt the care plan. Good nutrition plays an essential part in good care. Quality service means a service that ensures the person’s wellbeing, that is respectful, affordable, accessible and provides continuity of care. Providing quality care also means to consider the care recipient as a central partner in the care delivery, and not a passive receiver.

## Recommendations to...

### **PC** **Improve the living conditions of the person especially through timely support**

Everything should be done to improve the wellbeing of the care recipient. Support and treatment to maintain or improve the condition of older people suffering from depression or mental disorders should include as necessary measures to rebuild sensations and skills, encourage mutual assistance and cooperation, skills of table setting and tidiness, support in attentiveness and other tools to cultivate the memory. Support for daily needs (getting up, eating, drinking, toilet requirements, and going to bed) should also be delivered within the time the assistance is required: as people age a greater sense of urgency is felt for daily needs and timely support becomes important.

### **PC** **Respect the person’s background and personal needs**

Some aspects of past lifestyle may seem insignificant to carers but can have a strong impact on the quality of life of the care recipient. Respect should therefore be shown to the habits one may have that belong to one’s past and sharing them with the caregivers should strengthen a mutual understanding. An inventory of staff’s language skills and

cultural background matching the care of dependent people with different cultural backgrounds could be developed. Where professional caregivers follow institutional time schedules and rhythms, it is important that these practices be questioned and periodically adjusted to approach the natural rhythms of each care recipient in his/her daily life cycle. That means for example that support given for daily needs should be evaluated and adapted as much as possible to each person's routine pattern.

### **SP** **Ensure that staff are adequately trained and qualified**

Professional care should be provided by competent qualified staff remunerated according to their qualification. Quality of care is to expect that staff/caregivers receive regular training, and that they are properly briefed about the state of health and specific needs of each care recipient. There should be opportunities for informal carers to benefit from professional advice or from training courses in order to lessen the strain and exhaustion they may experience. Nursing homes and especially those caring for Alzheimer patients or with specialised units for residents with impaired mental capacities should offer de-stressing therapies to their staff. Family doctors/general practitioners must receive sufficient training in geriatrics so as to be competent in prescribing reasonable drugs in cases of challenging behaviour from patients with mental illness and dementia. Professional caregivers should also receive training in communication skills to accompany, listen to and understand what is important to each older person s/he is caring for.

### **SP** **Ensure services are adapted to the person's needs**

Social and medical services should be organised to take account of the care requirements brought to them and to ensure that responsive actions are put into place. Social centres, service providers and institutions should provide clear, reliable, accessible and comprehensive information about available services. Sufficient time and complementary information should be given to the older person to read and understand the terms of the contract prior to admission.

### **SP** **Ensure continuity of care and staff coordination**

Quality care is seamless. The care plan should be followed by people who are familiar with the situation and responsible for the concerns of the patient, and involve the patient in the development of his/her care plan. It may happen that to meet her/his care needs different people or services will come to the older person's home to provide care and treatment. It is important that this team of people communicate with each other to coordinate their interventions in the best interest of the care recipient. They should log into a daily care plan register and enter their observations systematically. The register is left in the patient's home in an accessible place and can be consulted by the patient and his/her family and carers. It is good practice to have one key worker responsible for developing the care plan, re-evaluating it regularly and adapting it to any changes in the older person's needs. Finally, coordination meetings and evaluations involving carers, family members, third parties involved in the support of decision-making and medical professionals are essential.

### **SP** **The care plan should include the provision of good, tasty and varied food**

Adequate meals can help to improve health and quality of life. Adequate hydration and the way meals are presented and seasoned are important for the care recipient.

## **SP** **SS** **PC** **Support informal carers in improving the living conditions of the care recipient**

Informal carers must be able to ask and receive all necessary information on the chronic diseases and other health problems affecting the person they care for, the best ways to cope with specific symptoms and what to do if a problem occurs. For example, when an older person returns home after a stroke, s/he will need specific adaptations to be made to her/his living environment. Informal carers need independent guidance as to what equipment to get, whether financial support is available and how to use the material to prevent deterioration of health both of the care receiver and of the informal carer. Treatment should be aimed at speeding up recovery and promoting the wellbeing of the older person as much as possible.

## **SP** **SS** **PC** **Regularly re-assess the needs of the care recipients**

The essential step in developing quality care is regularly to re-assess the needs and expectations of the care recipient. This means that there is a need to listen to the care recipients and to find the best way to respond to their evolving needs and wishes.

## **PM** **Develop mandatory standards for quality long-term care**

Guaranteeing quality of care cannot be left to the service providers alone. Public authorities must set up mechanisms to ensure that quality of LTC care is regularly controlled and to protect care recipients from abuse. This can involve both internal and external quality tools that help caregivers improve the quality of the care they provide. Adopting and implementing mandatory quality standards for professional LTC care helps create an environment that supports quality care and provides comparative information to users to enable them to make an informed choice. Users who are dissatisfied with the service they have received should be empowered to report this to the responsible social or health service.

## **PM** **Enable respite care solutions for informal carers**

When an informal carer provides care, respite care/day centre/short term stay in a residential setting should be available to enable them to have a rest. To ensure access to respite care to all who need it, solutions must be put in place by those responsible for the wellbeing of older dependent people, i.e. social services, municipal councils, or other long-term care services.

## **PM** **Protect vulnerable care workers**

All professional carers should be covered under specific legislation, regulating in particular their working hours and social protection. National or regional bodies should enforce more controls to check that those working in domiciliary care services have the required skills and are adequately protected. Older people who hire their own carer must be aware that they should take into consideration and comply with national employment legislation in particular with regard to working hours and social protection of their carer.

## **PM** **Make quality of long-term care services a priority, especially in public expenditures**

Public spending on providing training on quality care, prevention of for elder abuse and improving working conditions to the staff and living conditions for the care recipients should be seen as an investment in the quality of jobs in the care sector and wellbeing of our elderly population rather than a cost to society.

## **Good practices**

### ***Ireland: « Your right to know »***

From 1st July 2009 the Social Services Inspectorate of the Health Information and Quality Authority is legally responsible for the registration and inspection of all residential care centres for older people in Ireland. Inspection reports provide information to residents, their families and the general public about the standards of care in individual centres. They deal with all aspects of living in residential settings such as residents' rights, management and staffing, and the quality of care provided by the service. Following an inspection, a report is produced and published on the Authority's website outlining the findings of the inspection and making recommendations where necessary. If inspectors find that the residential care centre is not safe or the standards are not being met, there are a number of actions that can be taken in the interests of the residents. More information is available here:

[www.hiqa.ie](http://www.hiqa.ie) and here: [www.hse.ie](http://www.hse.ie).

### ***European organisation EDE: development of a quality management system E-Qalin®***

The E-Qalin® is a practical and user-friendly model of quality management that is orientated to the needs of the residents, their relatives and the employees of residential care homes. E-Qalin® examines specifically the services delivered in the institutions and their effectiveness in respect to the satisfaction of all persons involved. It encourages and formalises the learning within the organisation through self-evaluation and creates scope for innovative improvements and potential development. The system has been developed with the participation of the users. E-Qalin adopted in the home means that all the collaborators are striving for best quality and are working for the wellbeing of the clients. For more information, please visit E-Qalin's website:

[www.e-qalin.net/index.php?id=2&L=1](http://www.e-qalin.net/index.php?id=2&L=1).

The website is in English and German.

### ***France: "France Alzheimer" association help carers to rest***

The charity France Alzheimer was launched in 1985. Family helpers play an essential role with people who suffer from Alzheimer's Disease. To prevent one member of a couple becoming exhausted, since 1988 it organises holiday breaks where couples are supported by trained volunteers and nursing professionals. In 2010, 250 families took a holiday. France Alzheimer is one of 64 national charities and a member of *L'Union Nationale des Associations Familiales*, [National Union of Family Associations]. The provision of holiday options for older couples has been developed in the last few years by other French charity organisations.

For more information, please see the France Alzheimer website:

[www.francealzheimer.org/](http://www.francealzheimer.org/) and the UNAF website: [www.unaf.fr](http://www.unaf.fr)

### **Sweden: Respite care solutions for carers**

Legislation makes it compulsory for municipalities to organise respite care for informal carers. This can mean providing a dialogue partner, a meeting place for informal carers, self-help groups, training about common diseases, daily activities, relief (at home, daytime, short-term from a day up to a few weeks), contributions to home care).



### **Slovenia: the role of the older people organisations**

One of the main objectives of the local older people's organisations (cca. 400) is to provide support to older people living in their neighbourhood. The National Union of older people organisations (ZDUS) promotes the peer support action called Starejši za starejše (Oldies for oldies) where older people help gather information on the living conditions of older people, the municipality or state institutions are informed and help is provided where possible. More than 230 local organisations across Slovenia are participants in this action, mostly financed by the Ministry of Social Affairs.

### **Canada: The Patient Dignity Question (PDQ)**

The PDQ is a simple, open-ended question: "What do I need to know about you as a person to give you the best care possible?"

Research has shown that this single question can identify issues and stressors that may be important to consider when planning and delivering someone's care and treatment. The intent is to reveal the "invisible" factors that might not otherwise come to light – and to identify these concerns early in the process. The Patient Dignity Question is useful during every stage of care and treatment, such as:

- During routine physicals
- While carrying out diagnostic tests
- When admitting patients
- Before providing personal care
- When considering forms of treatment or therapy
- While discussing home care or long-term care arrangements

Not everyone needs to ask the question aloud, but everyone working in health care can consider the question as they reflect on the best way to deal with individuals and their families.

The intent is to get everyone in the health care community thinking about care recipients as unique human beings, rather than focusing only a specific illness or collection of symptoms.

For more information visit:

[dignityincare.ca/en/toolkit.html#The\\_Patient\\_Dignity\\_Question](https://dignityincare.ca/en/toolkit.html#The_Patient_Dignity_Question)

# 5

## Right to personalised information, advice and informed consent

### The Charter states that...

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 personalised 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.

*"I wish I had known before. Now it's too late. I don't have the energy anymore to look for alternative and I have no one to help me."*

*"I can't cope anymore and need to find a solution for my father (with severe Alzheimer) but I can't find the information I need about what is available. I spent hours on the phone and I still don't know what to do."*

Giving information is not a simple process. It requires certain skills from the professionals and sometimes needs to be repeated. Older people in need of care are not passive receivers and need to be involved in their own care decision-making processes, commensurate with their cognitive capacities.

## Recommendations to...

### **PM** **Develop a legal framework protecting the rights and duties of users in all care settings**

Public authorities should develop clear guidelines as to what information need to be included in all contracts for residential, community and care homes services. Model contracts should be available to the public through social services websites, health centres, hospitals, residential homes, etc. Contracts should be open to modifications upon request of the care recipient and information must be provided regarding more adapted services for the user.

### **SP** **Provide clear explanations to carers and users**

Service providers should provide clear leaflets and guides to help the person in need of care access and understand the information they need. When technical or medical terms are used in front of the care recipient, they should be explained in plain and easy-to-understand language. Health and care professionals need training in communication skills and human rights to be able to inform patients properly about their health condition. If migrant carers have communications difficulties they should be given training to be able to communicate adequately with care recipients. If needed, other means of communication can be used to ensure that the patient understands the information such as drawings or videos. All these communication tools have to be user-friendly, i.e. adapted to the older person's needs.



### **PM** **SP** **Promote and facilitate access to one's own personal medical data**

Access to personal medical data must be facilitated for older people in long-term care. This information must be clear and adapted to each national/local context. For example, if medical data is available on a card with chip, care recipient or their representatives must be empowered to access data stored on the card. Doctors should not prevent anyone from having access to his/her personal data. If no digital record exists, patients living at home should be informed of the best ways to keep their own files. Older people living in residential settings should be able to consult their file and ask questions about their condition or treatment when they wish to.

### **PM** **SP** **Promote and regulate the participation of older people in research projects**

Carers need to be trained on how to deliver treatments to older people and what to be cautious about, how to report potential side effects, etc. This is particularly important as older people are sometimes exposed to over-prescription and may not be able to report problems themselves. Too few clinical trials involve older people and little research is done on side effects of poly medication on very old and frail people. This is why participation of older people in clinical trials should be encouraged. They should however never be obliged to participate in research projects but should be informed on the opportunities to take part in clinical trials. Full information must be given to the patient on the benefits, risks and alternatives to any treatment whose effectiveness and safety is not scientifically supported prior to the commencement of treatment. If the person is not able to decide, the consent of a third party must be sought, and participation allowed only if there is a genuine expectation that the treatment will benefit the patient's health.

### **PM** **SP** **PC** **SS** **OP** **Provide user-friendly information on the full range of available services**

Information on the full range of available services and their price should be available through health and social services, and older people's organisations. Health and social care professionals cannot decide on behalf of the person in need of care whether s/he can afford it or not. Help and support on legal issues must also be available through counselling and assistance, services and guides. Details of legal professionals on family law, inheritance and pensions should be available through residential care, institutional care and social services. Public helplines should be available to help older people and carers regarding legal advice and entitlement to legal aid.

## Good practices

***Finland: Helsinki City has developed clear easy-to-understand information on available health and social care services for older people***

“Help at home Services offer” is a leaflet published by Helsinki Home care services with information on available health care and nursing services, domestic help, mobility and other wellbeing services. The leaflet also provides information about fees charged to customers with examples of prices for combined services. For more information:

[www.hel.fi/hki/helsinki/en/Services/Families+and+social+services/The+elderly](http://www.hel.fi/hki/helsinki/en/Services/Families+and+social+services/The+elderly)

***Italy: Legal Assistance for Elderly offered by Anziano e Non Solo***

The project was funded in 2006 by Emilia Romagna Region, under a fund to promote the wellbeing and quality of life of elderly people. The objectives of the project were to raise awareness and prevent abuse against older people. It covered the rights and duties of older people in the city, savings and banks, and how to have access to the justice system. The objective was also to provide information and orientation with the creation of a data base based on FAQs (Frequently Asked Questions) providing information and advice on the most common legal issues related with older people. For more information:

[www.anzianienonsolo.it](http://www.anzianienonsolo.it)

# 6

## Right to continued communication, participation in society and cultural activity

### The Charter states that...

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.

*“When my wife died, I felt really hopeless and isolated. I didn’t know how to cook a proper meal, yet I didn’t want to call for the meals-on-wheels. The lady from the community service encouraged me to join their cooking class for seniors and here I am. At 93, I am enjoying every moment of it! I have made new friends and we have fun together.”*

With age, older people’s social networks tend to decline. It is therefore important to ensure that opportunities for people to meet are supported through accessible public space where all generations can meet, including older persons. Older people should be encouraged to stay connected: isolation is the single biggest risk factor for elder abuse. Lack of participation and influence in society can lead to isolation, inactivity and feelings of meaninglessness which all are factors that may cause depression and abuse. Urban development and transport policies supporting the participation of older people in the community can play a key role in preventing isolation.

Situations of abuse that occur in close relationships or in care homes often result from poor communication. Common obstacles to successful communication are, for instance, impaired hearing, impaired vision, physical disabilities, dementia or other cognitive disabilities, aphasia or, in the case of migrants or ethnic minorities, lack of language skills, and/or cultural differences. Whether this happens within the family or in a care facility, the factors leading to poor communication and isolation must be identified so they can be addressed.

## Recommendations to...

### PM Join WHO Age Friendly Cities Programme

The Age-friendly Cities Programme has been developed by the World Health Organisation to help cities prepare for two global demographic trends: the rapid ageing of populations and increasing urbanisation. The Programme targets the environmental, social and economic factors that influence the health and wellbeing of older adults. The Age Friendly Cities guide identifies eight domains of city life that can be improved to promote the health and quality of life of older people:

- outdoor spaces and buildings;
- transportation;
- housing;
- social participation;
- respect and social inclusion;

- civic participation and employment;
- communication and information; and
- community support and health services.

Cities participating in the Network commit to a cycle of continually assessing and improving their age-friendliness. For more information:

[http://www.who.int/ageing/age\\_friendly\\_cities/en/index.html](http://www.who.int/ageing/age_friendly_cities/en/index.html)

### **PM** **Inform and support care recipients on access to their civic rights**

It is important that municipalities as well as health and social care services, families and friends provide information, support and advice to dependent elderly people regarding their civic rights. It should be public policy to offer support to older people to enable them to vote.

### **SP** **SS** **OP** **Encourage social participation of older people in long-term care**

Social needs should be prioritised even when time is limited for the staff. Voluntary participation in clubs and associations and creative, social, economic, artistic, religious and cultural, as well as democratic and political activity should be encouraged and facilitated including those taking place in the wider community. Opportunities include, for instance, sharing knowledge of, and participation in, household or handicraft tasks within care settings, communal activities, celebrations and functions, as well as having the opportunity to perform paid or voluntary work and to take part in lifelong learning and other cultural activities. Attention should be given to the organisation of services, allowing care recipients to share meals with other residents or visitors. At the same time, older people's wish not to participate in events should also be respected.

### **SP** **SS** **OP** **Provide support to people to respond to their social participation and communication needs and wishes**

Service providers and older people's organisations should provide assistance to enable older people with reduced mobility take part in social activities. If needed, assistance to get outdoors or take a walk should be offered. People should be helped to maintain balance or stability while walking (by the use of a walker frame, walking stick or wheelchair, transportation services and adequate incontinence materials).

### **SP** **SS** **OP** **Promote and encourage access to new information and communications technologies (ICTs)**

Older dependent persons who wish to should be offered support to use new ICT tools and technical aids (computers, mobile phones, hearing and writing aids, audio books, dvd- or cd-players and digital TV) as these can help a lot with communication and social interaction with others

## Good practices



### **Sweden: Culture for Seniors - Culture and health: the Umeå-model**

*Motto: "If the people can't come to the culture, the culture must come to the people."* "Cultural activities for seniors - Culture and Health" began as a project but is now a municipal activity that received the World Leisure Organisation Innovation Award 2010. The goal and purpose of the project is to create opportunities to extend the healthy part of life. The programme targets pensioners. The idea is that events, where possible, should be carried out during the day and in premises that fit seniors. The project began with an investigation which showed that about 90% of our elderly in housing units and in need of home care were under-stimulated. The activities offered were mainly bingo and church services. The preliminary investigation was a complete mapping of potential organizers and producers of cultural activities for older people in the region. More information can be found at:

[www.umea.se/senior](http://www.umea.se/senior)

### **France: Association 'Petits frères des Pauvres' organizes range of activities for socially excluded older people**

The association, created in 1946, whose motto is 'flowers before bread', developed numerous programmes targeting as a priority people suffering from isolation, poverty, exclusion and chronic diseases. The activities are: visits, organisation of holidays, social activities, helpline and awareness raising on elder abuse and living conditions of older migrants. This association works with 8500 volunteers and 510 staff. For more information, please consult their website:

[www.petitsfreres.asso.fr](http://www.petitsfreres.asso.fr)

### **Ireland: Third Age Foundation (TAF) provides activities for St Joseph long-term residents**

The Third Age Centre bus travels every week to St. Joseph's hospital to bring residents from the home to the TAF Centre to participate in an ever-expanding array of organised activities such as arts and craft classes, reminiscence sessions, Go for Life activities, Combined Choral Group, concerts and social events. Some residents have also taken part in public representations and raising awareness of issues of concern to the older person, including the Older and Bolder campaign. The uniqueness of this project lies in the fact that long-stay residents leave the nursing home environment and are brought back into the heart of the community, where they are accompanied by members of TAF. Many of these residents become members of the Third Age Foundation, an additional step to integration in the local community.

The feedback from long-stay residents about their regular visits to the Third Age Centre is very positive: some older people mentioned that their confidence and self-esteem was boosted immensely as a result of being members of the Foundation, while many mention the increased autonomy and independence they feel by being able to take part in these visits on a regular basis. More information can be found at:

[www.thirdage-ireland.com](http://www.thirdage-ireland.com)

### ***Finland: Psychosocial group rehabilitation for older people suffering from loneliness***

The aim of this project was to actively engage older people (>74y) who suffer from loneliness in Finland. Groups of older people living in day hospitals, day care centres, rehabilitation and residential care institutions meet several times a week to chat, and to engage in different activities with the help of staff. The project was an essential step to educate and train professionals in the various levels of older people's care (residential care, rehabilitation centres) to act as group leaders and to build a network of professionals able to implement the group rehabilitation model. The project is a model to develop services to target other groups of older people who need help, e.g. dementia. More information can be found at:

[www.vanhustyonkeskusliitto.fi](http://www.vanhustyonkeskusliitto.fi)

# 7

## Right to freedom of expression and freedom of thought/conscience: convictions, beliefs and values

### The Charter states that...

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.

*"I never asked for that priest to visit me. Who let him in and why is he calling me my son? I don't believe in God and I don't want to listen to him!"*

Society recognises more and more that the right to diversity and caring for people from different cultural backgrounds is a challenge. One's cultural background influences one's beliefs and values, perception of health, illness and death; meaning of suffering and of existence; limits regarding privacy; vision of the role of the family in decision-taking, the autonomy of the person or the way we communicate with the others. A tolerant approach must therefore prevail and every individual should be able to practice his/her religious rites or to follow his/her cultural tradition.

## Recommendations to...

### **SP** **PC** **Promote tolerance and create opportunities to exchange views on differences**

Mutual personal and collective enrichment through social activities, exchange of information and communication should be encouraged. Care must be individualised as much as possible, and must avoid clichés regarding cultural background. Caregivers should also encourage tolerance within care settings and respect the choices and cultural background of the cared person in every decision made, and accept that some behaviors and reactions can be interpreted differently in different cultures.

### **SP** **PC** **Allow private places for practising one's beliefs**

Care recipients in institutional or residential care should be offered dedicated spaces to practice their religion or beliefs, or should be given the opportunity to participate in religious events in the community and be supported in doing so if they wish.

### **SP** **PC** **Prevent proselytism**

Care recipients should not be forced to participate in any event (religious, philosophical, political, etc.) occurring within the home, residential home or institutional setting. Caregivers have to be careful not to let anyone (political, religious or other) visit care recipients unless the older person has requested it, to protect care recipients from proselytism. Visits must be registered with the name and contact details of the visitor, and pressure to get financial support from care recipients must be prevented and reported as financial abuse.

## **SP** **Support people in their wish to associate and participate to groups**

Information and assistance should be provided to a person in care who wants to associate. Institutional care settings should enable the care recipients to attend the weekly meetings of a “seniors’ club” and to participate in the outings and excursions. Keeping contacts with organisations of which the person was a member should be encouraged.

## **SP** **Provide a wide access to diversified information**

Everybody should have access to the media and to all other sources of knowledge. Newspapers from different political backgrounds should be available in all care settings, as well as television and internet support. If needed, assistance must be provided to help people with impaired hearing or vision. Access to information can also be promoted by the organisation of debates within the institution or participation in conferences.

## **Good practices**



### ***Slovenia: Informal round tables on usages and religious practices at Easter***

Daily activities centres are meeting places where all are welcomed. During the Easter festivities they organise informal round tables where different usages and religious practices are discussed, including a more atheist approach with the explanation of the role of spring festivities and rites in many centuries before the rising of monotheistic religions, and in other, non-western cultures. Different cultures meet also around different cuisines, encouraging multiculturalism.

### ***Germany: Special units for migrants in nursing homes***

Some nursing homes and specific institutions have developed special units to enable older migrants to receive care in an environment that respects their cultural and social way of life (special furniture, nutrition, religion-based day structure etc.)

### ***France: special training on religion for carers***

A module on “Ceremonies and religious practices” is now proposed in many further education training courses in France. Older people receiving care are coming from more diverse cultural backgrounds and staff are often unfamiliar with their faiths. It is also recommended that every institution should have an easily accessible space reserved for quiet meditation, prayer and worship, open to visitors of the different religions and philosophical movements. Religious ceremonies should be held in mutual respect.

# 8

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

### The Charter states that...

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.

*"I don't understand how it is still possible today to let people develop such bedsores!"*

*"I love him but I couldn't stand his screams anymore and I slapped him. Now I feel miserable."*

*"I felt her life wasn't worth living anymore..."*

Actions regarding end of life are regulated by national laws that no one should ignore, in particular those who provide care to very old and dependent people. Yet the right to die in dignity is sometimes jeopardised by institutional rules and habits which result in the most deplorable forms of elder abuse because they concern people who have become totally dependent on others and may suffer great pain. Measures are not always taken to alleviate and prevent undue pain (for example bedsores) and to provide emotional support to the dying person and her/his family. Choices of the older person regarding her/his end of life are not always respected.

The right to palliative care and pain control is unfortunately not yet internationally recognised as a fundamental human right. However, awareness is growing and innovative initiatives are being developed in many countries to bring comfort and dignity to elderly people reaching the end of their life.

## Recommendations to...

### **PM** Regulate by law the principles and requirements of palliative care

The World Health Organisation provided some recommendations concerning minimum requirements of palliative care, that includes that all countries should adopt a national palliative care policy, ensure the training and education of health professionals and promote public awareness, and ensure that minimum standards for pain relief and palliative care are progressively adopted at all levels of care. Palliative care can be provided in a special residential unit, at home, as a day patient or in hospital, depending on the country of residence. Information on the different options regarding palliative care must be available in social and health care services, in order to improve access to these services. More information is available at:

[www.who.int/cancer/palliative/en](http://www.who.int/cancer/palliative/en)

### **SP** **Develop quality palliative care in an interdisciplinary approach**

The best possible quality of life for the patient must be found and developed. Palliative care seeks neither to hasten death nor to postpone it but rather to control pain and help people reaching the end of life die in peace and dignity. Quality palliative care should aim to prevent and reduce suffering, with treatment of pain and other distressing symptoms, psychological and spiritual care, to improve quality of life when facing serious complex health problems. Assessment of the quality can be done by measuring whether the care is adapted to the needs and wishes of the care recipient (communication needs, religious/spiritual/cultural/social needs, etc.). An interdisciplinary and multiprofessional approach must be developed, including members from different healthcare and non-healthcare professions and discipline. Team members have to be highly qualified and should have their main focus of work in palliative care. Staff should be trained concerning their approach to facing the end of life and be given the appropriate means (psychological support, respect for the person and for the family, involvement of the family) to respect the person's choice.

### **SP** **PC** **Involve the care recipient in the palliative care and support his/her autonomy**

Palliative care must be guided by the patient's needs and wishes. Decision on the admissibility of medical treatment will be based on care recipient's expressed or presumed wishes (based on views s/he previously expressed) and after questioning relatives or other persons close to the care recipient and responsible for his or her care. The dying person's need for intimacy should also be respected, as, e.g., a single bedroom.

### **SP** **PC** **Involve the families in the palliative care**

Professionals must take more time to talk and listen to the care recipient and their family, providing information in an understandable language on diagnosis, prognosis, treatment and care options and all other aspects of care as well as on reliable access to help on the palliative care provided and on the different services available. Such information should only be provided when the person and/or the family are prepared to accept it. Respite care should be encouraged for carers and bereavement services should be made available to them after the death of the care recipient. In the absence of family members, caregivers who have been close to the older person can be included in a multidisciplinary consultation with the doctor.

### **SP** **PC** **Respect national regulations on the end-of-life**

Each country has developed its own regulations regarding end-of-life decisions, and both formal and informal caregivers must respect the law. However if they object to the decision made for ethical or religious reasons, carers should be protected by a "conscience clause" and should be informed about the procedure to follow to ensure that the decision will still be respected and implemented as requested by the law. When feeling hopeless or overburdened in front of a care recipient in great pain or severely demented, carers should always seek advice and receive support from relevant sources.



## **SP** **PC** **Respect and support the spiritual needs and wishes of the dying person**

Palliative care professionals and voluntary team workers should allow dying patients find meaning and hope through recognition of the spiritual dimension of their experience if the person wishes it. Although they may lack the expertise to address spiritual concerns in depth, palliative team professionals should be able to discuss spirituality with any patient who raises the issue and identify those in spiritual distress so that appropriate referral may be made to spiritual care providers.

## **SP** **SS** **PC** **IC** **Support and respect advance directives**

The cared-for person and her/his family also have to be able to anticipate as much as possible and get information on insurance options that exist, organ transplantation and other decisions regarding end of life. Caregivers and service providers should encourage the care recipients to express their wishes and views regarding end-of-life decisions. Advance directives should be kept in writing by those responsible for the care recipient if the person is considered as no longer competent to take such decision. If there is no written statement, some oral opinions and wishes of the person have to be gathered talking with relatives and other trusted persons. Decisions should always be made in the best interest of the care recipient and in accordance with national legislation.

## **Good practices**

### ***United Kingdom: Charter for Dignity at the End of Life***

In June 2008, the movement “Dignity in Dying” published a Charter for Dignity at the End of Life. The document highlights the need for all people to be given greater choice, control and access to high quality care at the end of their life. “We want to see end-of-life services that are sensitive, responsive and accessible to all. Individuals need to be clear about their wishes, whilst Government must ensure that services meet people’s needs at death, putting choice, control and access at the centre of end-of-life care”. The Charter for Dignity at the End of Life places choice, access to services and personal control at the heart of improvements to end-of-life care. For more information, please visit Dignity in Dying’s website:

[www.dignityindying.org.uk](http://www.dignityindying.org.uk)

### ***Sweden: The Palliative care project in SABO***

The project strives to develop and improve the quality of life and care for older people in Stockholm County Council and municipalities in the Stockholm area. The purpose is to improve the quality of care in the end of life for people living in SABO special housing for older people. The project idea is to test and evaluate different models of education for staff. The focus of training is, among other things, knowledge and quality of palliative care, attitudes and responses. Training in palliative care and nursing care is provided in a team based multi-professional working. More information can be found at:

[www.pvis.se](http://www.pvis.se).

### **Canada: The Dignity Model**

Since 1995, a Canadian research team on palliative care and their international collaborators has been exploring the importance of patient dignity. Their findings show that a patient's sense of dignity can have a profound impact on patient wellbeing and satisfaction with the health care system – and one of the biggest factors is the way patients are treated by health care providers. The team's initial research has been distilled into the Dignity Model, which shows three major categories of factors that affect the patient's sense of dignity:

- **Illness-Related Issues:** How the illness itself affects personal feelings of dignity
- **Dignity-Conserving Repertoire:** How a patient's own perspectives and practices can impact their sense of dignity.
- **Social Dignity Inventory:** How the quality of interactions with others can enhance or detract from one's sense of dignity.

They have developed dignity tools and a dignity protocol to support people who work in end-of-life health care. More information is available here:

[dignityincare.ca](http://dignityincare.ca).

### **Austria: Mobile palliative care units**

The province of Styria organises teams of mobile palliative care in all regions. The network covers the whole province; the teams consist of medical doctors, care staff and social workers who collaborate with the family doctors and the professional and informal carers. Such a team can be called in by all those concerned, the patients, the relatives, the family doctors, etc., and the service is free of charge: the costs are covered by the Styrian Health Fund. Alongside these mobile palliative care teams consisting of professionals, hospice-care teams of volunteers receive a careful basic training before their engagement and are offered further training courses and supervision throughout the time they are doing this work.

For further information

[www.palliativbetreuung.at](http://www.palliativbetreuung.at) or [www.hospiz-stmk.at](http://www.hospiz-stmk.at) (both in German only) or contact Dr.Baumgartner [johann.baumgartner@kages.at](mailto:johann.baumgartner@kages.at)

member of the European Association of Palliative Care EAPC.

# 9

## Right to redress

### The Charter states that...

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

*“When I tried to report elder abuse to my line manager, the next day I received a letter from the Director telling me that I was sacked for moral harassment of other staff.”*

*“She will never complain. She is too afraid and I don’t know how help her?”*

In most cases of elder abuse, victims do not wish to report abuse. There are several reasons for that: they are afraid of losing the relationship with the abuser, they are afraid of the possible consequences of reporting abuse for themselves or loved ones, they lack knowledge about what constitutes abuse and so might fail to recognise that certain actions are abuse. Every person witnessing or having information on a possible case of abuse should make sure that the victim knows how to report it.

## Recommendations to...

### **PM** **Develop dedicated bodies and public information to tackle elder abuse**

Elder abuse must be recognised in national laws in order to ensure the protection of the victims. A free and easy to reach helpline must be set up and clear information must be available to older people, families and caregivers on the existing organisations and competent authorities who are responsible for tackling abuse and can provide support. Free medical or psychological care should also be available through health and social services. The support and care brought by these different services should be coordinated and adapted to the understanding of trauma of a person who has been victim of abuse. These professionals should receive training in this field.

### **PM** **Develop individualised responses to victims of abuse**

Competent authorities have to take seriously into account all complaints of elder abuse and to react accordingly. Family members, carers, and social services must be particularly vigilant and detect older persons who are at risk. When abuse is reported, their priority should be to ensure that the older person will be safe but the response should adapt to the level of risk and nature of the abuse. For example elder abuse resulting from burn-out of a family carer requires a different response from elder abuse resulting from negligence or lack of training of care professionals. If the situation is very serious and the older person needs to be put in a safe environment, sheltered houses or flats should be available through social services.

## **SP** **Check the criminal record of professional caregivers**

Any employer of a caregiver should be able to check if the employed caregiver has any history of abuse and mistreatment, including financial misconduct.

## **SP** **Develop training to caregivers on how to detect abuse**

Caregivers have to be trained to recognise when a care recipient could be a victim of abuse (depression, bruises, anxiety, etc.) including among older demented people. They have to be able to react appropriately and know to which person and organisation they can turn for help, support and further action. This information must be provided to them in clear language when they take up the job and repeated through staff training sessions on a regular basis.

## **SP** **SS** **Provide support and protection to victims and those reporting elder abuse**

Appropriate support and protection must be provided to both the victim and those reporting abuse. Service providers must develop clear procedures and inform both care recipients and their relatives, and caregivers, on what to do in case of elder abuse, whom to report it to, where to call for help and information on how to seek redress. Holding annual information sessions with staff and care recipients can help create an open debate and break the taboo around elder abuse. In residential, community and homecare services, staff Internal Rules should include clear instructions regarding elder abuse. What to do, how to handle it, how to protect and support the older person, how and where to report cases of elder abuse, what to do if the older person refuses to acknowledge that s/he is mistreated, and how to protect those reporting abuse. Staff should also know what to do if the risk for the older person is very serious and decisions must always be taken in the care recipient's best interest.

## **Good practices**

### ***Belgium: East Flanders and the reporting of elder abuse***

In Flanders, anyone who has experienced or witnessed elder abuse at home can contact the Flemish Reporting Point for elder abuse through a central helpline (078 15 15 70) to report the case, ask for information or advice, or request intervention. When an intervention is needed, the Flemish Reporting Point contacts the local Supporting Point for elder abuse. After an initial telephone contact, a home visit is scheduled with the victim to get an overview of the problem and see whether the support team needs to look for a solution to improve the older persons' situation and ensure that this will not increase the problem. This service is free of charge and offers also free advice and training. For more information (in Dutch)

<http://www.meldpuntouderenmishandeling.be>

**France: “Call 3977” helpline for older people victims of elder abuse.**

A very similar initiative was launched recently by the French government to offer support and guidance to victims and witnesses of elder abuse. This helpline is run with the support ALMA France (set up by Prof. Hugonot who was president of the Council of Europe working group on violence and neglect of older persons in the family) and AFBAH (French association for the wellbeing of older and disabled people). More information is available here:

[www.travail-solidarite.gouv.fr](http://www.travail-solidarite.gouv.fr).



**Netherlands: Protocol to report elder abuse for external visitors**

The Dutch province Noord-Holland has taken the initiative of developing a protocol to combat elder abuse. The protocol can be used by external people who come in contact with older people in nursing homes and care institutions, such as the hairdresser, the neighbourhood nurse, the volunteer who brings meals or pays the older person a frequent visit. The protocol is designed to give them a method to recognise and address elder abuse within the limits of their responsibilities. The protocol lists signs of elder abuse they should learn to recognise and recommendations about what to do when they suspect elder abuse. These steps include answers to questions like ‘who do I notify?’ and ‘who is responsible for what?’ The protocol was developed by PRIMO NH on behalf of the Support Points against Domestic Violence of the province. Support Services also exist on the Municipal level. There are specific support points that deal with elder abuse in some municipalities. In other municipalities there are support points that are concerned with the broader field of domestic violence, and therewith also elder abuse. Someone who is in a situation of abuse or a witness of elder abuse can call this support point and ask for help. The support point will then tell them what to do next and how to get help from social and legal services.

*“I wish my Mum had told me what she wanted for her end of life while she was still able to do it. Now dementia has taken away all her mental capacities and I find it so difficult to decide on her behalf because I just don’t know what she would have wished. We never talked about such things.”*

*“We all want to believe that we will have time to deal with such painful decisions later, but the longer you wait, the more painful and emotional it becomes.”*

*“For more than 10 years, I cared for a very dependent old lady in her home. When she died, her daughter threw me out because I was no longer needed. The old lady would never have allowed that. She was nice to me.” (an unregistered migrant carer)*

Older people in need of long-term care and assistance not only have rights but also responsibilities and need to respect the rights of those who live with them (other residents) or work for them (caregivers). When they become dependent on others, older people may not be aware that they have duties toward their carers and should give them clear advance instructions, enable them to work in good conditions and treat them with respect.

The burden of dependency and conflicting relationships between the care recipient, his/her family, and people around them can sometimes lead to situations where the care recipient or his/her family may become verbally or physically abusive towards others, in particular the weakest, in their neighbourhood. Preventing abuse toward other care recipients and staff is an issue which must be tackled together with the risk of elder abuse. Older people in need of long-term care and assistance should be made aware of their duties toward their caregivers (both informal and formal) and other residents. Procedures regarding the prevention of elder abuse must include clear instructions as to what to do if a care recipient becomes abusive toward a carer or another care recipient, paying due attention to the causes and nature of the challenging behaviour (for example, a severely demented person can become very agitated and aggressive toward others but this is not abuse).

## Recommendations to...

### **IC** **Ask for external support from local social and health services**

Informal carers should be encouraged to seek external support and advice when they care for an older person with severe dependency needs to prevent burn-out, and contact local or national help lines specialising in elder abuse for advice.

### **PM** **SS** **Support professional carers' work and protect them from abuse**

Professional carers in all care settings need training, better information, material and if needed personal assistance, and clear procedures on how to receive support and protection if they face abusive situations.

### **PM** **SS** **Develop support for informal carers**

It is more difficult to protect informal carers against abuse as these are often not recognised in their caring role and lack support in their daily activities. Informing, training and giving informal carers the opportunity to have an open discussion about the abusive situation they face, providing them with alternative solutions to reconcile work with caring responsibilities while preserving their income (financial incentives, respite care solutions, care-leave arrangements, etc.), work prospects, and wellbeing are measures that can help protect informal carers from burn-out and abuse. Peer support groups for informal carers can play a very important role in preventing abuse of informal carers. Policy makers should also address the specific challenges that non declared informal workers face in many EU countries, i.e. migrant workers who are often on duty 24h/day, 7 days/week and are often paid very low salaries and no social protection.

### **PM** **SS** **Promote integrated care where all carers (formal and informal) can support each other**

Enabling all carers to exchange their concerns when caring for a "challenging" care recipient can help them understand better the causes and find a collective solution to protect all carers from abuse and improve their working conditions.

### **SP** **Include carers' complaints in the management of services**

In institutions, the rights and responsibilities of both care staff and care recipients must be defined in the contract with the institution and explained in clear terms to both care recipients and staff. A staff handbook issued to all staff should ensure that they know what is expected of them and what they should do in critical situations. Regular staff meetings where carers can be informed about changes in the life or health condition of a care recipient which can have an impact on his/her behaviour (mental health problems, loss of a close relative, etc.) can help staff react in a more appropriate way and identify potential risky situations.

### **SP** **OP** **PC** **Promote advance instructions among older people**

Older people's organisations, service providers and carers should all encourage and support older people to plan for their future care and end of life. It is not an easy topic to discuss but such decisions are part of one's responsibilities and, if possible, should not be left to others. Providing information about the various options and support to those who need it is important and can be done through information in media and leaflets, peer group discussions or individual counselling, etc.

## Good practices

### **COFACE European Charter for family carers**

COFACE (European Confederation of Family Organisations) has developed a Charter for family carers which aims to recognise the rights of family carers and highlight their role and the challenges they face in reconciling their personal, family and / or work life.

To download the Charter, please visit COFACE's website:

[coface-eu.org/en/upload/WG%20HANDICAP/CharteCOFACEHandicapEN.pdf](http://coface-eu.org/en/upload/WG%20HANDICAP/CharteCOFACEHandicapEN.pdf)

### **EAPN Italy: Clubs to prevent burn-out of badanti (informal non family caregivers)**

In the province of Sienna, the Italian member of the European Anti Poverty Network "Un Euro all'Ora" launched a programme to prevent burn-out among informal carers. Their "clubs for caregivers" were mainly targeting families who undertake the complex task of assisting dependent elderly at home and who often hire, on the private market, one or more caregivers, mostly immigrant women that live with the elderly and assist them for most time of the day and night. For these "badanti" (carers), the Clubs represent a unique opportunity to meet in a friendly environment where they can express their needs and receive advice from professionals. More information at:

[www.cilap.eu](http://www.cilap.eu).



### **European Project "Breaking the Taboo" - leaflet on Violence against older women in families: recognising and acting**

This brochure is a outcome of the project "Breaking the taboo", which was co-financed by the European Commission and was carried out from 2007-2009 by project partners from Austria, Finland, Italy, Poland and Germany in collaboration with partners from France, Belgium and Portugal. It aims at breaking the taboo around elder abuse by raising awareness among staff members and line managers of health and social service organisations and giving them some ideas and guidelines on how to deal with this issue. It should help them deal with these often very complex and difficult situations. When the taboo is broken - within teams, within organisations, and within the public - it becomes much easier to improve the situation of the victims and of the 'perpetrators' - who are often overburdened family carers and victims themselves. More information at:

[btt.rotekreuz.at](http://btt.rotekreuz.at)

### **France: "Vacances Ouvertes" help carers to take some holidays**

This non-profit organisation has developed a support programme to help informal carers take some rest during organised holidays. Carers can go on holiday with the person they care for and have some free time while participating professional carers take care of the dependent person. Informative leaflets have been developed to recruit social workers and carers to participate in the programme to enable informal to take a break. This enables the creation of social networks and activities on the issue of care, and the development of solidarity between volunteer professional carers and informal carers.

[www.vacances-ouvertes.asso.fr](http://www.vacances-ouvertes.asso.fr).

## Check list of recommendations

### IC Informal carers:

- Caregivers should be aware that they have a key role in protecting older dependent persons from abuse (art. 1)
- Check if the practices are the right ones (art. 1)
- Involve people in their care (art. 2)
- Respect the needs and wishes of the person (art. 2)
- Take steps to ensure mobility and autonomy are maintained (art. 2)
- Provide adequate support for decision-making (art. 2)
- Rely on a third party if needed and limit restrictions to the person's autonomy (art. 2)
- Prevent intrusion into the private sphere and respect the person's modesty (art. 3)
- Support and respect advance directives (art. 8)
- Ask for external support from local social and health services (art.10)

### PC Professional carers:

- Caregivers should be aware that they have a key role in protecting older dependent persons from abuse (art. 1)
- Check if the practices are the right ones (art. 1)
- Involve people in their care (art. 2)
- Respect the needs and wishes of the person (art. 2)
- Take steps to ensure mobility and autonomy are maintained (art. 2)
- Provide adequate support for decision-making (art. 2)
- Rely on a third party if needed and limit restrictions to the person's autonomy(art. 2)
- Prevent intrusion into the private sphere and respect the person's modesty (art. 3)
- Improve the living conditions of the person especially through timely support (art. 4)
- Respect of the person's background and personal needs (art. 4)
- Support informal carers in improving the living conditions of the care recipient (art. 4)
- Regularly assess the needs of the care recipients (art. 4)
- Provide user-friendly information on the full range of available services (art.5)
- Promote tolerance and create opportunities to exchange on differences (art. 7)
- Allow private places for practicing one's beliefs (art. 7)
- Prevent proselytism (art. 7)
- Involve the care recipient in the care and support his/her autonomy (art. 8)
- Involve families in palliative care (art. 8)
- Respect national regulations on the end of life (art. 8)
- Respect and support the spiritual needs and wishes of the dying person. (art. 8)
- Support and respect advance directives (art. 8)
- Provide support and protection to victims of elder abuse - (art. 9)
- Promote advance instructions among older people (art. 10)

## SP Service providers:

- Develop a systematic process to prevent abuse and take complaints into account (art. 1)
- Raise awareness on elder abuse (art. 1)
- Provide information on where to call for support (art.1)
- Cooperate with a wide range of stakeholders (art. 1)
- Involve people in their care (art. 2)
- Respect the needs and wishes of the person (art. 2)
- Take steps to ensure mobility and autonomy are maintained (art. 2)
- Provide adequate support for decision-making (art. 2)
- Rely on a third party if needed and limit restrictions to the person's autonomy (art. 2)
- Integrate the respect for privacy in the service management and in the care contract (art. 3)
- Allow places and moments for intimacy (art. 3)
- Have clear rules on respect for confidentiality and data protection (art. 3)
- Ensure that staff are adequately trained and qualified (art. 4)
- Ensure services are adapted to the person's needs (art. 4)
- Ensure continuity of care and staff coordination (art. 4)
- The care plan should include the provision of good, tasty and varied food (art. 4)
- Support informal carers in improving the living conditions of the care recipient (art. 4)
- Regularly assess the needs of the care recipients (art. 4)
- Provide user-friendly information on the full range of available services (art.5)
- Provide clear explanations to carers and users (art. 5)
- Promote and facilitate access to own's personal medical data (art. 5)
- Promote and regulate the participation of older people in research projects (art.5)
- Encourage social participation of older people in long-term care (art. 6)
- Provide support to people to respond to their social participation needs and wishes (art. 6)
- Promote and encourage access to new information and communications technologies (ICTs) (art. 6)
- Promote tolerance and create opportunities to exchange views on differences (art. 7)
- Allow private places for practicing one's beliefs (art. 7)
- Prevent proselytism (art. 7)
- Support people in their wish to associate and participate in groups (art. 7)
- Provide a wide access to diversified information (art. 7)
- Develop quality palliative care in an interdisciplinary approach (art. 8)
- Involve the care recipient in their care and support his/her autonomy (art. 8)
- Involve the families in the palliative care (art. 8)
- Respect national regulations on the end of life (art. 8)
- Respect and support the spiritual needs and wishes of the dying person (art. 8)
- Support and respect advance directives (art. 8)
- Check the criminal record of professional caregivers (art.9)
- Develop training to caregivers on how to detect abuse (art. 9)
- Provide support and protection to victims and those reporting elder abuse (art. 9)
- Include carers' complaints in the management of services (art. 10)
- Promote advance instructions among older people (art. 10)

## **PM** **Policy makers:**

- Develop a systematic process to prevent abuse and take complaints into account (art. 1)
- Raise awareness on elder abuse (art. 1)
- Provide information on where to call for support (art.1)
- Cooperate with a wide range of stakeholders (art. 1)
- Create a public body responsible for anti-discrimination and the fight against elder abuse (art. 1)
- Inform on the rights and limits of the representation by a thirdparty (art. 2)
- Develop clear Data Protection rules protecting the users (art. 3)
- Develop mandatory standards for quality long-term care (art. 4)
- Enable respite care solutions for informal carers (art. 4)
- Protect vulnerable care workers (art. 4)
- Make quality of long-term care services a priority, especially in public expenditures (art. 4)
- Develop a legal framework protecting the rights and duties of users in all care settings (art. 5)
- Promote and facilitate access to one's own personal medical data (art. 5)
- Promote and regulate the participation of people in research projects (art. 5)
- Join WHO Age-friendly cities programme
- Provide user-friendly information on the full range of available services (art. 5)
- Inform on and support care recipients' access to their civic rights (art. 6)
- Regulate by law the principles and requirements of palliative care (art. 8)
- Develop dedicated bodies and public information to tackle elder abuse (art.9)
- Develop individualised responses to victims of abuse - (art. 9)
- Support professional carers' work and protect them (art. 10)
- Develop support for informal carers (art. 10)
- Promote integrated care where all carers (formal and informal) can support each other (art. 10)

## **OP** **Older people's organisations:**

- Raise awareness on elder abuse (art. 1)
- Provide information on where to call for support (art.1)
- Cooperate with a wide range of stakeholders (art. 1)
- Inform on the rights and limits of the representation by a third-party (art. 2)
- Provide user-friendly information on the full range of available services (art. 5)
- Promote and regulate the participation of people in research projects (art. 5)
- Encourage social participation of older people in long-term care (art. 6)
- Provide support to people to respond to their social participation needs and wishes (art. 6)
- Promote and encourage the access to new information and communications technologies (ICTs) (art. 6)
- Promote advance instructions among older people (art. 10)

## SS Social Services:

- Raise awareness on elder abuse (art. 1)
- Provide information on where to call for support (art.1)
- Cooperate with a wide range of stakeholders (art. 1)
- Inform on the rights and limits of the representation by a third-party (art. 2)
- Support informal carers in improving the living conditions of the care recipient (art. 4)
- Regularly assess the needs of the care recipients (art. 4)
- Provide user-friendly information on the full range of available services (art. 5)
- Encourage social participation of older people in long-term care (art. 6)
- Provide support to people to respond to their social participation needs and wishes (art. 6)
- Promote and encourage the access to new information and communications technologies (ICTs) (art. 6)
- Provide support and protection to victims and those reporting elder abuse (art. 9)
- Support carers' work and protect them (art. 10)
- Develop support for informal carers (art. 10)
- Promote integrated care where all carers (formal and informal) can support each other (art.10).

## Glossary

**Accessibility:** Concept including affordability, as well as non-discriminatory access based on age, gender, sexual orientation and identity, disability, etc.

**Advance directives:** Instructions given by individuals specifying what actions should be taken for their health in the event that they are no longer able to make decisions due to illness or incapacity, and appoints a person to make such decisions on their behalf.

**Autonomy:** Personal capacity to consider alternatives, to make choices, and to act without undue influence or interference by others.

**Care recipient:** an adult with a chronic illness or disabling condition or an older person who needs ongoing assistance with daily tasks and personal hygiene. The person needing assistance may also require primary and acute medical care or rehabilitation services (occupational, speech and physical therapies).<sup>5</sup>

**Continuity of care:** Continuity of care is the process by which a care receiver and caregivers or healthcare professionals are cooperatively involved in ongoing health care management toward the goal of high quality, cost-effective medical care.

**Dignity:** A state, quality or manner worthy of esteem or respect; and (by extension) self-respect. Dignity in care therefore means the kind of care, in any setting, which supports and promotes, and does not undermine, a person's self-respect regardless of any difference.

**Elder abuse:** a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person (WHO definition). A distinction should be made between 'intentional' and 'non intentional' abuse.

**ICTs:** Information and Communication Technologies. This includes for example telephones, computers, digital television, GPS, etc.

**Independent living:** Philosophy, way of looking at disability and society, and a worldwide movement of people with disabilities who proclaim to work for self-determination, self-respect and equal opportunities. In the context of eldercare, independent living is seen as a step in the continuum of care, with assisted living being the next step.

**Informal carers:** in a great majority of cases care is given by informal carers, i.e. mainly family, but also close friends, neighbours, people from the community or unregistered migrants in some countries.

**Long-term care:** Long-term care brings together a range of medical and social services for persons who are dependent on help for basic daily activities, caused by chronic conditions of physical or mental disability.

<sup>5</sup> Taken from 'Family caregiver alliance': <http://www.caregiver.org/>.

**Older people's organisations:** these organisations aim to voice the interests of older people at all level (health, employment, discrimination, social inclusion, etc) and to influence policy change.

**Palliative care:** Palliative care is the active, total care of the patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of social, psychological and spiritual problems is paramount. Palliative care is interdisciplinary in its approach and encompasses the patient, the family and the community in its scope. In a sense, palliative care is to offer the most basic concept of care – that of providing for the needs of the patient wherever he or she is cared for, either at home or in the hospital. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death. (*source: European Association for Palliative Care*)

**Policy-makers:** this group includes decision-makers at all levels (European, national, local) who are responsible for the financing, organisation and monitoring of eldercare services. They have the power to legislate on quality standards and are responsible for inspection, enforcement and sanctions.

**Professional caregivers:** paid helpers and carers employed by a service provider (hospital, nursing home, community or home care services).

**Quality assessment:** the methodology used to measure of the quality of care provided in a particular setting.

**Quality care:** it covers different dimensions of what is a 'good care' such as: appropriateness, timeliness, continuity, accessibility, affordability, and improvement of the person's wellbeing.

**Respite care:** Provision of short-term, temporary relief to those providing informal care to dependent persons living at home.

**Self determination:** Free choice of one's own acts without external compulsion

**Service providers:** Public, private, for-profit or non-profit-making agencies who deliver care services for older people in institutional settings or at home.

**Trusted person:** The person chosen by the dependent person to represent her/him and help her/him in making decisions or make decision on her/his behalf. The term differs from one country to another.

**Wellbeing:** A concept combining an individual's health, their quality of life, and their satisfaction.

### Organisations involved in the project

#### Project coordinator: AGE Platform Europe



AGE Platform Europe (formerly AGE - the European Older People's Platform) is a European network of organisations of people aged 50+ representing over 28 million older people in Europe. AGE aims to voice and promote the interests of the 150 million inhabitants aged 50+ in the European Union and to raise awareness of the issues that concern them most.

[www.age-platform.eu](http://www.age-platform.eu)

#### Project partners

##### E.D.E. – The European Association for Directors of Residential Homes



E.D.E. (European Association for Directors of Residential Care Homes for the Elderly) is a professional federation of directors/managers of Residential and Nursing Homes from all over Europe. Members in E.D.E. are organisations of home directors coming from 18 European countries and altogether there are 23 national associations.

[www.ede-eu.org](http://www.ede-eu.org)

##### ANBO (the Netherlands)



ANBO is an association in the Netherlands representing senior people. Our primary goal is to provide independence and to promote the interests of seniors to national, provincial, and local governments and authorities. ANBO also gives its members advice and information offers an array of informative, cultural and recreational activities. In addition it arranges discounts through third-party providers.

[www.anbo.nl](http://www.anbo.nl)



### **BIVA (Germany)**

BIVA is a self-help organisation offering its members and the interested public at large information about all questions concerning assisted living and institutionalised care, as well as giving advice on legal questions. As a consumers' lobbying organisation BIVA is involved in legislative procedures on the national as well as on the regional level. BIVA was a member of the work group ("Round Table for Long Term Care") that formulated the German Charter of Rights for People in Need of Long Term Care and Assistance, and represents the perspective of the users in a large number of advisory bodies in the social field.

[www.biva.de](http://www.biva.de)

### **Commune de saint Josse – Association of Family House (Belgium)**

The Association of Family House was created in 1965 to offer a service to help families and older people by the local authority of Saint-Josse-ten-Noode, in Brussels. The philosophy of the association is to promote the wellbeing of the inhabitants of the city, without being discriminated against.

[maison-de-la-famille.be](http://maison-de-la-famille.be)

### **FNG - French National Foundation of Gerontology (France)**

The FNG is a national resource centre working on older people and ageing. It was created in 1967 by the public authorities and the main basic or supplementary social security systems in France national research centres working in the field of health contributed to its creation. It developed for the first time in 1987 a "Charte des droits et libertés de la personne âgée dépendante" (Charter of Rights and Freedoms of the dependent elderly person). A more recent version of the Charter was presented in 2007 and named: "Charte des droits et libertés de la personne âgée en situation de handicap ou de dépendance".

[www.fng.fr](http://www.fng.fr)

fng



### **FIPAC – Italian Federation of Pensioners of trade activities (Italy)**

FIPAC is a large and representative organisation of older people in Italy whose aim is to improve the services provided to older people, to protect their dignity, and to increase their financial independence. FIPAC is a member of the AGE Italy coordination which is managed by Elio d’Orazio and brings together all AGE member organisations in Italy. FIPAC will report and consult with AGE Italy members to increase the awareness and participation of Italian older citizen’s organisations in the project.

[www.fipac.it](http://www.fipac.it)



### **50+ Hellas (Greece)**

50+ Hellas is a Non-governmental and not-for-profit organisation which aims to improve the quality of life of those over 50 years of age in Greece, within a more equal society and through actions and activities affecting all aspects of life. In cooperation with other social partners, it supports and promotes the rights of older people to equal treatment in society, particularly in employment, in health and medical care, in their independence and decent living standards, in their right to participate as full citizens in decision making as well as in the development of policies affecting them. The organisation also promotes the interests and support of dependent older people and their families and the professionals who care for them.

[www.50plus.gr/english](http://www.50plus.gr/english)



### **MZU (Slovenia)**

Mestna zveza upokojencev Ljubljana (MZU Ljubljana) is a federation of 101 local older people’s associations with more than 30.000 members and four decades of the tradition. Apart from voicing the needs and interests of elderly people in the central Slovenian region, keeping the dialogue with public authorities and regularly organising expert session on the most important social items, it runs the advisory service and daily activity centres for elderly people.

[www.mzu.si](http://www.mzu.si)



### **NIACE (United Kingdom)**

NIACE is the National Institute of Adult Continuing Education. It is a membership-led, non-governmental organisation that both represents and advances the interests of adult learners and potential learners at all levels and wherever they learn in England and Wales – especially those who have benefited least from their initial education and training. We believe that adult learning is essential not only to create and maintain a more skilled and knowledgeable workforce, but also for personal development, and for a just, inclusive and democratic society. NIACE works to secure high-quality education and training systems that are responsive to the diversity and complexity of adults' needs and aspirations as learners.

[www.niace.org.uk](http://www.niace.org.uk)



### **SPF - Swedish Association of Senior Citizens (Sweden)**

SPF was the first Swedish organisation for pensioners, established in 1939. SPF is a membership organisation for all who are entitled to a pension regardless of age. SPF is a politically and religiously independent organisation and has approximately 260000 members in the 850 clubs divided in 27 districts throughout the country.

SPF acts, at various political levels, to promote beneficial treatment of issues related to the elderly. SPF influences politicians and inspires its members to take an active part in the decision-making process. Influence, quality of life and freedom of choice are the foundation that SPF's actions are based on.

[spf-pension.com](http://spf-pension.com)



### **Život 90 (Czech Republic)**

Život 90 is a NGO helping older people to be able to actively and meaningfully live in their own home as long as possible. Our goal is to improve quality of life in general by supporting elderly citizens and their right to dignity. In this way Život 90 offers social services including respite care, home care, and Senior Telephone help line. We provide counselling in the social, psychological and legal spheres. We also offer courses (English lessons, ceramics, dance lessons), training (seminar about personal safety), and theatre performances and thus support older people in leisure time activities.

[www.zivot90.cz](http://www.zivot90.cz)

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## The EUSTaCEA project

This guide was developed by the EUSTaCEA Project 'A European Strategy to fight elder abuse', co-financed by the DAPHNE programme from the Directorate General Justice, Freedom and Security of the European Commission. The Daphne programme aims at preventing and combating violence against children, young people and women and protecting victims and groups at risk.

For more information on the Daphne programme:  
[ec.europa.eu/justice/funding/daphne3/funding\\_daphne3\\_en.htm](http://ec.europa.eu/justice/funding/daphne3/funding_daphne3_en.htm).

The EUSTaCEA Project ran from December 2008 to December 2010 and gathered 11 partners from 10 different countries. The project developed a European Charter of rights and responsibilities of older people in need of long-term care and assistance.

For more information on the EUSTaCEA project:  
[www.age-platform.eu/en/daphne](http://www.age-platform.eu/en/daphne)  
or contact  
[info@age-platform.eu](mailto:info@age-platform.eu).

