



EUROPEAN CHARTER OF THE RIGHTS OF CITIZENS OVER 65 WITH CHRONIC PAIN



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Assumption

Given that the following non-profit organisations represent the majority of older Europeans and/or those Europeans living with chronic pain:

- Federanziani
- SIAH Senior International Association for Health
- Age Platform
- Pain Alliance Europe

and that their goal is to safeguard the rights of citizens over 65 years of age with chronic medical conditions, they therefore undertake to prepare the following consensus document on the right to treatment.

Overview on a European Union Level

The European Union recognises:

in art. 25 of the Charter of Fundamental Rights of the EU (Charter of Nice, Official Journal 2000/C 364/01 of 18/12/2000 p. 0001-0022), the rights of the elderly:

"The Union recognises and respects the rights of the elderly to lead a life of dignity and independence and to participate in social and cultural life."

and, in art. 35, the right to health care:

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

It is stressed that these rights are fully binding upon all EU institutions and Member States with the entry into force of the Lisbon Treaty, as well as the Charter of Nice, which has the same standing as the Treaties.

In addition, the important milestone represented by the European Charter of Patients' Rights (Active Citizenship Network, 2002) clearly sets out the following rights:

The right to preventive measures, the right of access, the right to information, the right to consent, the right to free choice, the right to privacy and confidentiality, the right to respect of patients' time, the right to the observance of quality standards, the right to safety, the right to innovation, the right to avoid unnecessary suffering and pain, the right to personalised treatment, the right to complain, the right to compensation.

In December 2010, the Council of the European Union (EPSCO Council) invited Member States to develop patient-centred policies for health promotion, primary and secondary prevention, and the treatment and care of chronic disease in cooperation with policy makers and especially patients' organisations.

Focus on the Care of Chronic Pain in the Elderly

■ Definition

Chronic pain refers to pain "that extends beyond the usual course of an acute disease or beyond the expected time of healing" (IASP definition). Lasting over time, chronic pain can have serious adverse effects on psychological health and quality of life.

Chronic pain as a disease is virtually unknown to health professionals and the public in general, although in fact chronic pain is associated with degenerative, neurological, and oncological diseases, especially in the advanced and terminal stages of the disease, and as such takes on the characteristics of global pain, linked to motivational, physical, psychological, and social factors, as evidenced in the documents of World Health Organisation WHO.

■ Epidemiology and Social Impact

According to WHO, chronic pain affects an important part of the world population, altering their physical, emotional and working capabilities, with a financial commitment probably similar to that advocated for neoplastic or cardiovascular functions.

Chronic pain is one of the most significant causes of suffering and disability in the world (Lohman et al., *BMC Medicine* 2010, 8: 8; <http://www.biomedcentral.com/1741-7015/8/8>) A WHO study shows that people who live with chronic pain are four times more likely to also suffer from depression or anxiety, and also indirectly influence outcomes by reducing adherence to treatment (Gureje O, Von Korff M, Simon GE, and Gater R, "Persistent pain and well-being: a World Health Organisation study in primary care", *JAMA* 1998;280: 147-151).

One European in five suffers from chronic pain, one in four of whom suffers from severe chronic pain. This totals 100 million people in the 28 European Union countries alone. Half of those with chronic pain do not receive any treatment, and some are not even taken seriously. On average, people with chronic pain live for only 7 years following diagnosis.

19% of adults suffer from moderate-to-severe chronic pain, impacting severely on the quality of their work and social life. Of these people, few are treated by pain specialists and approximately half receive inadequate treatment for pain. In addition, each country has its own peculiarities.

Chronic pain produces enormous costs to society, both direct costs in terms of health and social care, and indirect costs in terms of the inability of patients and their caregivers to

work. 21% of European patients suffering from chronic pain are unable to work, and of those, 61% claimed that the disease has significantly affected their status in the workplace. According to the Pain Proposal European Consensus Report, chronic pain could be costing Europe 300 billion Euros a year. The prevalence of severe chronic pain is highest in Norway, followed by Poland and Italy (Breivik H, Collett B, Ventafridda V, Cohen R, and Gallacher D, "Survey of Chronic Pain in Europe: Prevalence, Impact on Daily Life, and Treatment", *European Journal of Pain* 2006; 10 (4): 287- 333 (11), and *The Painful Truth*, 2013).

"Pain relief is a fundamental right, and is recognised as such by the World Health Organisation (WHO) and Human Rights Watch. Therefore, the Member States of the European Union should consider the treatment of chronic pain and access to health care as public health priorities." – Hans Georg Kress, at that time acting President of EFIC (now EPF/EFIC - European Pain Federation /European Federation of IASP Chapters - EFIC brings together the European associations involved in pain medicine that are affiliated with IASP - the International Association for the Study of Pain).

It is essential to contextualise the epidemiological reality, taking into account that older people are the segment of the population that is growing most rapidly around the world. By 2050 the number of people over 60 worldwide is estimated to exceed 2 billion, surpassing the number of children. In Europe, the population of over-60s will increase from 87 million people in 2010 to 148 million in 2060, with only 8% of this population living in developing countries. For too long we have ignored the human rights of older people, who still remain vulnerable to abuse, discrimination, and more (<http://www.opensocietyfoundations.org>).

Today, more than ever, it is of the utmost importance that each National Health System responds to the changes in health and social care needs required by an aging population and the increase of chronic illnesses with all their related issues. This includes guaranteeing access to treatments, continuity of care, ensuring quality, safety, equity, and so forth. It is paramount that all countries safeguard patients' rights.

■ Critical Points

- Not all European citizens are aware of specialized pain management centres and even when these centres exist, patients do not know because they are not correctly informed
- no care pathways for patients with chronic pain (elderly or not) involving general practitioners, nurses, specialists, pain specialists, caregivers and patients
- no European network of hospitals for the treatment of chronic pain yet, and with the entry into force of the EU Directive n. 24 of 9 March 2011 on cross-border care, this deficiency is more pronounced than ever
- no guaranteed access to health care and continuity of care in all EU countries
- no acknowledgment of pain assessment in the elderly as the fifth vital sign to be identified and monitored in every health care setting.
- no recognition of chronic pain as a possible cause of disability
- no shared best practices and guidelines on chronic pain in the elderly Europe-wide
- no projects and research on the perception of pain in the elderly and the specific problem of pain in people with cognitive disorders
- no projects and research on pain management

- no prioritising of pain-management research into the European Horizon 2020 research program
- no European references for undergraduate and postgraduate pain-management education for all health care professionals.

Proposal: The Rights of Citizens Over 65 with Chronic Pain

It is proposed that the following rights, in addition to the rights already expressed by the European Charter of Patients' Rights (Active Citizenship Network, 2002), are respected, with a call to action:

1) Right to be believed by health care professionals, public administration and politicians.

2) Right to be informed in an appropriate way for elderly people in their language, involving patients' associations or organisations representing individuals.

- on both therapies and medical devices
- on specialized pain management centres for chronic pain in all European countries
- on diagnostic and care pathways that should be standard at European level.

3) Right to diagnosis, appropriate treatment and follow up for people suffering from chronic pain to take control of their own life.

Informing the elderly patient of the right to eliminate/reduce the pain and not accept pain as an inevitable event.

4) Right to free and informed choice

explained by the medical practitioner in an understandable way, supported by the family doctor, and also shared with the caregiver.

5) Right to equality regardless of age, gender and nationality.

The elderly patient has the right to be treated for chronic pain regardless of gender, age, state of mental health, and socioeconomic status.

6) Right of access to appropriate and timely chronic pain therapy.

7) Right to continuity of care

Whatever care is provided must be guaranteed over time, in the modality and in the locations required.

8) Right to innovative treatment

9) Right to be treated by an educated health care professionals

10) Right to receive pain education

ASSOCIATIONS AND EXPERTS WHO CONTRIBUTED TO THE PREPARATION OF THIS DOCUMENT:



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NOTES

The Charter of Fundamental Rights of the European Union, also known as the Nice Charter was solemnly proclaimed first time on 7 December 2000 in Nice and a second time in an adapted version, December 12, 2007 in Strasbourg[1] by Parliament, Council and Commission. With the entry into force of the Lisbon Treaty, the Nice Charter has the same legal value as the Treaties, in accordance with art. 6 of the Treaty on European Union, and therefore arises as fully binding on the EU institutions and the Member States and, at the same level of treaties and protocols attached to them, such as the summit of the European Union regulations. It responds to the need emerged during the Cologne European Council (3 and 4 June 1999) to define a set of rights and freedoms of exceptional importance that were guaranteed to all citizens of the Union.

The Treaty of Nice is one of the founding treaties of the European Union, and it concerns the institutional reforms to be implemented in view of the adhesion of other States. The Treaty of Nice amended the Maastricht Treaty (TEU) and the Treaty of Rome (TFEU). It was agreed at the Nice European Council on 11 December 2000 and signed on 26 February 2001 after being ratified by the then 15 member states of the European Union, entered into force on 1 February 2003. The objective of the Treaty of Nice is relative to the size and composition of the Commission, the weighting of votes in the Council and the extension of qualified majority voting, and finally to the enhanced cooperation between the countries of the European Union.

