



NATIONAL COUNCIL OF ETHICS FOR THE LIFE SCIENCES

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**NATIONAL COUNCIL OF ETHICS
FOR THE LIFE SCIENCES**

**Opinion on the vulnerabilities of elderly people,
especially of those who reside in institutions**

(July 2014)



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Memorandum

INTRODUCTORY NOTE: The Memorandum is an instrument of introductory reflection on the Opinion, and is solely the responsibility of its authors. As such, it is not subject to a vote in the plenary of the CNECV.

1. Context

For decades, the progressive ageing of the population has been at the heart of national and international demographic concerns. This topic is often approached as a starting point for the confrontation between the significant upsurge in the number of older people and the decrease in the number of births in Western countries, eventually leading to the search for solutions to elevate birth rates. In fact, the increase in the life expectancy of citizens in the Western world is a wonderful phenomenon, which is linked to the number of years that an elderly person can live with reduced autonomy, and this issue similarly deserves reflection.

Conversely, a culture of appreciation for old age has not been encouraged, and a culture of youth has been in place since the 1960s. A person over 65 is often considered to be "an older person", "an old person" and the condition of the elderly is associated with weakness, frailty and disease; this leads to a notion of unproductiveness, and old age is understood as a source of economic burden for the community. To make this situation worse, there are reported cases of abandonment and isolation – often emotional isolation – and the number of complaints about mistreatment is increasing.

The economic crisis and the inability to reverse budgetary deficits have led to a decrease in people's available income. Furthermore, some statements and attitudes have shown a lack of appreciation for retired citizens, leading to the reinforcement of those perceptions and the installation of stereotypes and prejudices. The approach to this stage of a person's life cannot be limited to an understanding that it is a burden, a social problem that must be solved by providing assistance. To reverse this perception, which is unfair, distorted and stigmatising for older people, and instil a cultural change, an ethical and humanist reflection is thought to be necessary. This reflection should identify challenges and indicate the guiding ethical principles for the actions of the state, intermediate local communities, families and care providers. This reflection is equally important for preventing and removing the threat of conflict and rupture between generations.

The present reflection takes the following perspective on the modern structure of societies: people are living increasingly longer and, therefore, we can all expect to go through a stage of our lives in which there will be progressive debilitation and a growing dependence on others for everyday actions. This means a gradual reduction in autonomy, perhaps even reaching the state of being unable to participate in the decisions regarding our own lives. This stage of life is linked to specific demands for



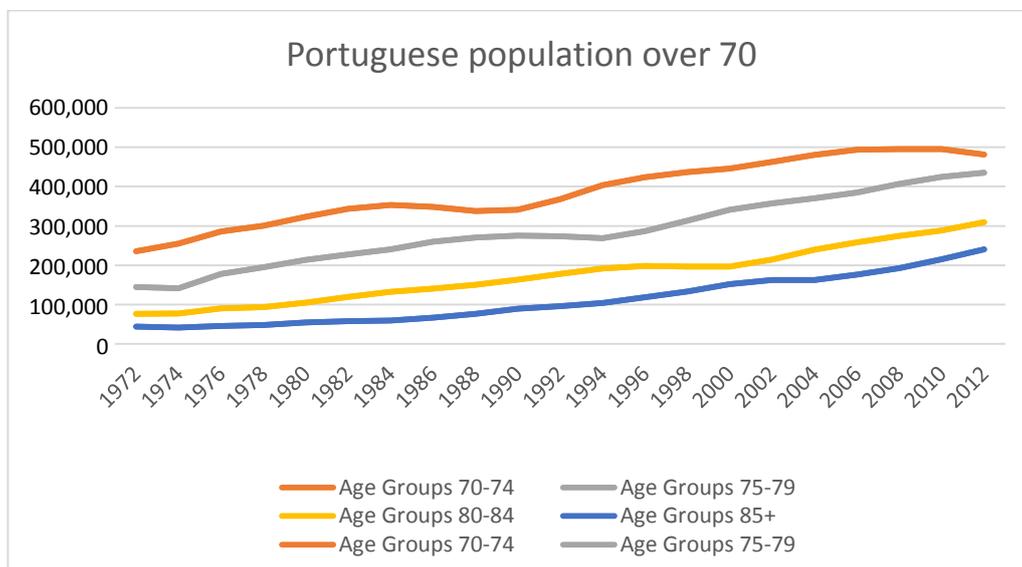
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monitoring and long-term care, including special health care. At the same time, there is currently a reduction in the number of carers available and, often, the conditions are not met for people to be cared for in their own homes or in the homes of their children or other family members.

In this context, the number of elderly people living in collective residential institutions has increased. Therefore, the particular vulnerability of these people may be worsened by distance from relatives, relocation, and the relinquishing of their personal items and routines.

Although, formally, it cannot be said that the rights of citizens aged over 65 are under threat, it has become more and more necessary to proclaim the equal value and dignity of people at every stage of life, especially when vulnerability is involved. The goal of providing elderly people with the best care possible for the best life possible is simply a demand of justice arising from respect for their lives in the past and recognition of the importance of their participation in the present.

2. Data on the elderly population



Between 1972 and 2012, the absolute number of Portuguese people aged over 70 increased continuously in every one of its age groups¹. It should be noted that the increase over the forty-year period is clearest among the oldest people. In the same period, average life expectancy rose from 68.5 (♂ 65.3 / ♀ 71.5) in 1972 to 80 (♂ 76.9 / ♀ 82.8) in 2012.

¹ This data has been extracted from **Pordata**, a project of the Francisco Manuel dos Santos Foundation. Director: Maria João Valente Rosa. www.pordata.pt



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The 2011 census revealed 2,010,064 residents aged over 65 – representing 19% of the population – whereas in the 1970 census they represented only 9.6%. The average annual increase in the number of elderly people in the last 40 years is highest for older groups: 1.3% per year for the 65-69 age group and 4.2% per year for the over 85 age group.

3. Special needs in health care

Equally relevant is the "average healthy life expectancy" indicator, which is 60.7 years for men and 58.7 years for women, according to the INE². A comparison between this data with data on average life expectancy indicates an expected "unhealthy" period of life lasting 11 years for men and 22 years for women.

A significant proportion of elderly people inescapably develop into a state of dementia or, at the very least, accumulate incapacitating health complications that require special, costly care. It should be noted that while female longevity is certainly greater than male longevity, it is also women who have the most serious health indicators.

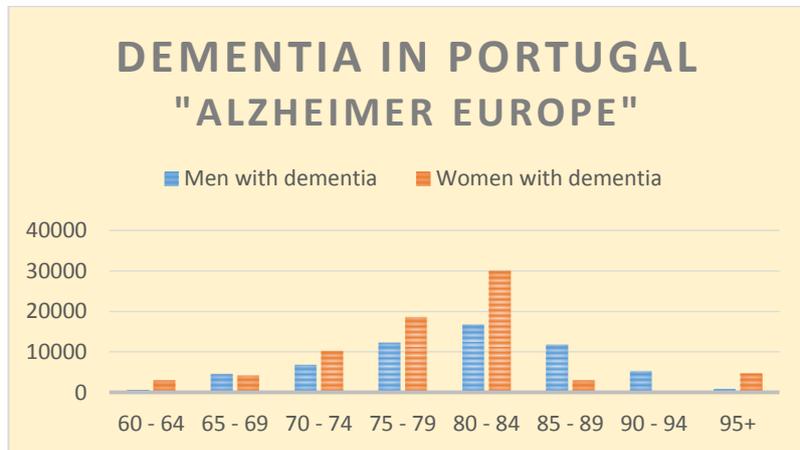
One study on the population base performed in Valladolid, in north-eastern Spain, published in 2013 by Tola-Arribas *et al*, concluded that "*the prevalence [of dementia] was greater in women than in men (11.2% vs. 4.9%, $p < 0.001$) and greater among people with lower education levels. [...] The prevalence of dementia adjusted for age and sex among people aged 75 or over was 12.4% (95% Confidence Interval: 10.5-14.3). The gross prevalence of dementia in 113 people resident in institutions was 52.2% (95% CI: 43-61.4)*".

Another study performed in the north of Portugal, published in 2010 by Belina Nunes *et al*, found that "*the prevalence of cognitive impairments was greater in rural populations than in urban populations, 16.8% (95% CI: 14.3-19.8%) vs. 12.0% (95% CI: 9.3-15.4%), with a 'prevalence ratio' (PR) of 2.16 (95% CI: 1.04-4.50) among the oldest people and of 2.19 (95% CI: 1.01-4.76) among those who had vascular risk factors*".

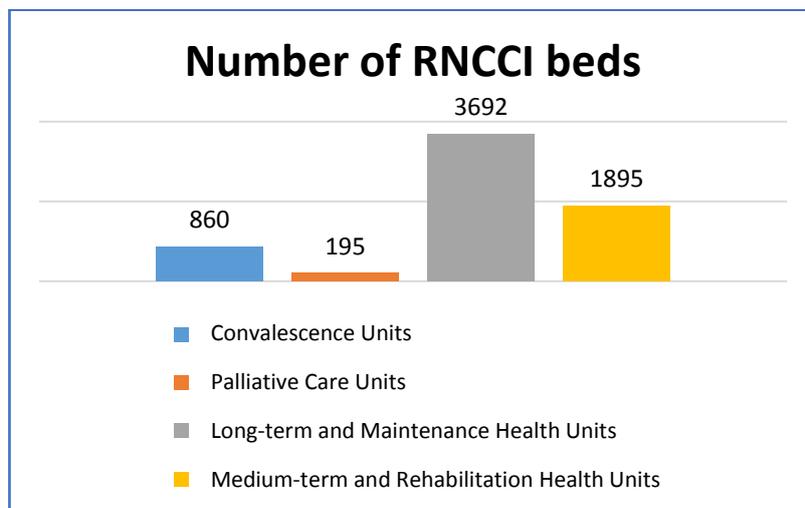
² Instituto Nacional de Estatística (Statistics Portugal). Viewed on 24/06/2014 at http://www.ine.pt/ngt_server/attachfileu.jsp?look_parentBoui=124268975&att_display=n&att_download=y



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"Alzheimer Europe"³ calculates that in Portugal (2012) there are 182,526 people with dementia, representing 1.7% of the total population.



In accordance with the information provided by the RNCCI (National Network of Integrated Long-term Care), the occupancy rate for the 6,642 officially recorded beds in April 2014 was between 90% and 97%, which appears to indicate the need for measures to increase supply.

The social responses currently in place for elderly people vary depending on their level of autonomy and precise needs⁴: Home Care, Social Centre, Day Centre, Night Centre, Holiday and Leisure Centre, Fostering for Elderly People, Nursing Homes, Retirement Homes.

³ **Alzheimer Europe** is a federative organisation of 36 Alzheimer's associations in 31 European countries <http://www.alzheimer-europe.org>



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4. Hearings

The CNECV heard the following experts: Dr. Miguel Menezes de Carvalho, coordinator of the thematic unit "Right to justice and security" of the Ombudsman; Dr. Cristina Colaço, of the Social Intervention Unit of the Social Security Institute; José Maria Lourenço and Dr. Maria Isabel Plácido, of the Luís Pereira da Mota Association, a not-for-profit private social solidarity institution based in Loures, which accommodates 199 elderly residents and manages many social support actions; Professor Constança Paúl, of the Biomedical Science Institute of Oporto, coordinator of studies on different aspects related to ageing.

The Ombudsman's experience, in view of supervising respect for the human rights of elderly people and in the context of the Ombudsman's Support Line for Elderly Citizens, has shown that in the last 10 years the line has been used 3000 times per year to make complaints. The fifth most common issue was "mistreatment within the family or in institutions" and the sixth was "retirement homes" (the four most common issues were of a legal or administrative nature). Results obtained in the field of inspections of collective institutions for elderly people were also reported. The critical aspects emphasised relate to issues of humanising the space, atmosphere and provision of care services, the difficult preservation of respect for the user's wishes, the maintenance of relationships with families, and the difficulties of proceeding towards the ideal goal of institutions' being true "homes", in the sense that they reproduce some aspects of family life.

New vulnerability profiles, age-linked, have been identified, specifically the situation of elderly people who do not have autonomy or who progressively or suddenly lose it. From a certain age bracket onwards, women's vulnerability worsens, not only because the number of elderly women is greater than the number of elderly men and because of the feminisation of poverty, but also because of the persistence of social representations of women as the main carers and that they should care for themselves. The need for change was acknowledged, as responses are directed towards autonomous people.

Of those assisted in 2013 by the National Social Emergency Line (144), 21% were over 65 years of age, corresponding to an average of 53 emergency or crisis situations per month. The social observatory indicates a "*prevalence of elderly people in situations of social and/or geographical isolation, which makes it more difficult for them and others to draw attention to their needs*" and "*complex, serious frameworks of vulnerability that challenge existing resources (e.g. the need for multiple/constant care)*".

⁴ Classification by the *Instituto da Segurança Social, IP* (Social Security Institute) and Executive Law no. 64/2007 of 14 March 2007, with the wording arising from amendments approved by Executive Law no. 99/2011 of 28 September 2011.



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It was considered important for each community to be able to care for its elderly people, starting within the family. The need to strengthen responses to maintain family bonds and closeness was highlighted, as well as the absence of support for families who care for their elderly members at home. As critical aspects of residence in an institution, the risk of isolation and inactivity was stressed; it is important to prevent abandonment by families by encouraging the cooperation and active participation of other family members and users' participation in managing their day-to-day life. The need to guarantee vocational training for carers and respect for the dignity and privacy of elderly people resident in institutions was also emphasised. Finally, it was maintained that "*institutions, whether public, social or private, should define a 'Code of Ethics': an instrument that shall seek to achieve principles (vision and mission of the institution) and shall similarly guide the action of staff and managers, making clear the responsibilities and position of the institution as regards the different groups with which it interacts*".

Issues of equity of access to care in our country, with particular attention on the existence of countless 'illegal homes', demand a reflection on the forms of financing for homes and the system of funding per user, which fails to consider personal needs.

In recent years, the number of people with high dependence and great needs has increased, and so the social response should be diversified. The state should make choices in this field; specifically, the social response should be directed towards the most dependent people and on assistance, favouring social support for the provision of informal care within the family whenever possible. It appears to be necessary to guarantee the quality of equipment and services, along with the suitability of carers' profiles and the training of professional carers, the diversity of types of services (home care, day centres, assisted living facilities, collective institutions, institutions for highly dependent people), and different opportunities for choice considering the range of people's needs and the supply available.

5. Legislative framework

Article 72(1) of the Constitution of the Portuguese Republic establishes that "The elderly shall possess the right to economic security and to conditions in terms of housing and family and community life that respect their personal autonomy and avoid and overcome isolation or social marginalisation." Article 72(2) states that "The policy for the elderly shall include measures of an economic, social and cultural nature that tend to provide elderly people with opportunities for personal fulfilment by means of an active participation in community life." The principle of non-discrimination requires that the exercise of rights and freedoms recognised by the Portuguese Constitution and by the European Convention on Human Rights should be ensured without discrimination, namely on the grounds of age (Article 13 of the CRP and Article 14 of the ECHR). The right to private and family life (Article 8 of the ECHR) and the right to liberty (Article 5(1) of the ECHR) are particularly at issue in this context. Nonetheless, these general guidelines seem not to have implemented a sufficient realisation of legislation in



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terms of the particular situation of elderly people, in general, and those that reside in institutions, in particular.

There is no legal act that, as in other legal systems, links the different aspects of protecting the rights of elderly people. Law no. 38/2004 of 18 August 2004, which establishes the general foundations of the legal regime for the prevention, empowerment, rehabilitation and participation of people with disabilities, although it envisages actions by the state that may benefit elderly people, such as the general principles and rights defined therein, does not include elderly people as a priority target. Executive Law no. 391/91 of 19 October 1991, which contains the regime for foster care for elderly people and adults with disabilities, does not form part of a coherent, integrated system. In the Civil Law field, the classic instruments of protection for those with disabilities show themselves to be inadequate for the situation of elderly people, and are unsatisfactory both in terms of the models of judicial intervention, action and supervision by the Public Prosecutors' Office and in terms of resolutions for possible conflicts of rights.

It was possible to draw some conclusions from the information available: the concerns of successive governments have focused on regulating the quality of social support establishments, supervising the provision of services and simplifying the procedures for licensing them. There is also legislation regarding home care and cost-sharing by users and their relatives for the use of social services and facilities.⁵

6. Characterisation of the special situation of vulnerability

The progress reflected in the increase in average life expectancy for people in Portugal is similarly linked to an unveiling of a stage of life that is characterised by progressive frailty and loss of faculties for a long period of time.

The loss of autonomy and dependence on care provided by others often makes residence in collective homes inevitable. The particular vulnerability of elderly people in these circumstances immediately raises the issue of willingness in the elderly person's decision. There is a general view that

⁵ Regime on licensing and supervision of service provision and social support establishments (Executive Law no. 33/2014 of 4 March 2014, which amends the licensing and supervision regime for social service provision and establishments, regulated by Executive Law no. 64/2007 of 14 March 2007, which envisages the principles of simplification and streamlining of the licensing regime laid down in Executive Law no. 92/2010 of 26 July 2010, and adjusts the legislative referrals and references contained in Executive Law no. 64/2007 of 14 March 2007). Similarly, Executive Law no. 99/2011 of 28 September 2011, which regulates the licensing and supervision regime of this type of establishment in mainland Portugal. In the Autonomous Regions of the Azores and Madeira, the executive law applies, under the terms of Article 131 of Law no. 32/2002 of 20 December 2002, with the necessary adaptations arising, namely, from the specific nature of the competent services for these issues; it lays down the licensing and supervision regime for social support services and establishments in the field of social security; it defines the conditions for the organisation, operation and installation of residential structures for elderly people.



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the legal solutions that aim to overcome elderly people's incapacity to make decisions are not requested and decided in a timely manner.

The vulnerability of elderly people who live in collective institutions arises from many, complex factors that are, specifically, cognitive, social, cultural and related to income available or funding provided by the state. The "mental health" factor appears to be the most relevant, as this Council mentioned, in fact, in Opinion no. 77/2014 on Bioethics and Mental Health.

The protection of the dignity of people in this stage of their life and under these circumstances demands added defence of their rights and special attention on aspects related to care.

Life in a collective institution represents a difficult balance between respect for autonomy and aid in dependence, respect for freedom and for the desire to be alone and stimulation of personal development, respect for privacy and the choice to have leisure time and encouragement to participate in collective activities.

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Opinion

Whereas:

- People have equal dignity in all stages of their life, a condition that should be respected especially in the stages where a particular vulnerability is involved;
- The same chronological age does not imply the same vulnerabilities in elderly people;
- Progressive frailty and loss of faculties, as observed over a long period of time, are common processes but, at the same time, each one unique in people's lives as they age;
- From the due recognition of the contribution made by people to society throughout their lives and appreciation of their participation in the present arises the intention to provide elderly people with the best possible conditions;
- It is a mission of the state and a duty of civil society to, directly or through all intermediate communities, guarantee the rights of elderly people and to encourage the provision of the services necessary for them, namely supporting their families with that task;
- State support for families is an essential condition for the care of its elderly members and for the strengthening of intergenerational cohesion and cooperation;
- The state should foster a sense of responsibility in each and every citizen for the task of caring for elderly people by creating incentives and supporting initiatives by associations and intermediate communities and by providing an appropriate framework and appropriate regulation;
- Where there are not conditions for elderly people to be cared for in their own home, the home of their children or of other family members, it is often inevitable that they become residents in collective institutions,

The CNECV wishes to call attention to

- The vulnerabilities of elderly people, which should be especially recognised in the event that they live in collective institutions;
- The specific ethical demands in the field of monitoring and care provided to elderly people who reside in collective institutions;
- The absence of an adequate legal framework for the protection of the rights of elderly people and age-dependent vulnerabilities;



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- The specific nature of health care to be provided to elderly people who reside in collective institutions.

Therefore, the CNECV issues the following recommendations:

- 1) That public policies aimed towards elderly people do not merely have an assistance basis, but directly look for the integral good of each human person, contemplating their active participation in social life.
- 2) That a programme is developed to support families who care for or wish to undertake the care of their elderly members.
- 3) That initiatives aimed at supporting elderly people and their families and that facilitate interaction with younger generations created by local authorities, associations and other bodies are stimulated and reinforced.
- 4) That a programme is developed for institutions that accommodate elderly people, defining common goals and differentiated solutions.
- 5) That elderly people can remain in their usual place of residence, with its respective spatial, psychological, emotional and relational setting, for as long as possible.
- 6) That elderly people have access to adequate preventive, corrective, long-term, rehabilitative and palliative health care, preferably in their own homes.
- 7) That when elderly people are admitted into institutions, their wishes are considered carefully and it is considered whether or not the situation requires special care and conditions that cannot be provided in their home.
- 8) That the legal solutions designed to overcome elderly people's inability to make decisions shall be requested and decided in a timely manner, so as not to delay the formal appointment of a legal representative or health care proxy.
- 9) That situations of incapacity are acknowledged, where necessary, by experts that declare themselves to be independent and have no conflicts of interest.
- 10) That respect for privacy is provided to elderly people who reside in collective institutions, without prejudice to the non-intrusive offer to participate in recreational, cultural, religious or other activities.
- 11) That respect for the personal identity and freedom of choice of elderly people who reside in collective institutions are especially protected, above all regarding the use of their own clothes and personal items and the possibility of receiving or refusing to receive visitors.



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12) That the right of elderly people to accept or refuse health care is recognised and that institutions provide a culture of respect for their previously expressed will and of combatting therapeutic obstinacy.

13) That the right of elderly people who reside in institutions to receive or refuse religious support is recognised.

14) That attention is paid to the vocational and human training of care providers who work with elderly people and that this training also covers ethical principles and human rights.

15) That Elderly People's Statutes are prepared in a participatory process and adopted under legislative procedure; and that the creation of committees for the protection of elderly people is discussed.

Lisbon, 21 July 2014

The President, Miguel Oliveira da Silva

Rapporteurs: Members Rita Lobo Xavier and Rosalvo Almeida.

Approved in plenary meeting on 21 July 2014. In addition to the President, the following Members were present:

Agostinho Almeida Santos; Ana Sofia Carvalho; Carolino Monteiro; Duarte Nuno Vieira; Francisco Carvalho Guerra; Isabel Santos; Jorge Sequeiros; José Germano de Sousa; José Lebre de Freitas; Lígia Amâncio; Lucília Nunes; Maria de Sousa; Maria do Céu Patrão Neves; Michel Renaud; Pedro Nunes; Rita Lobo Xavier; Rosalvo Almeida.

Hearings. The following experts were heard in the context of this Opinion:

Dr. Miguel Menezes de Carvalho, coordinator of the thematic unit "Right to justice and security" of the Ombudsman;

Dr. Cristina Colaço, of the Social Intervention Unit of the Social Security Institute;

Mr. José Maria Lourenço, President of the Luís Pereira da Mota Association;

Dr. Maria Isabel Plácido, Luís Pereira da Mota Association;

Professor Maria Constança Paúl, Abel Salazar Biomedical Science Institute.