



PALLIATIVE CARE FOR DIGNITY IN OLD AGE

Addressing the Needs of Older People
in Long-Term Care Facilities in Europe

POLICY RECOMMENDATIONS

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Executive Summary

Access to palliative care for older people, including those with dementia, remains inadequate and differs both within and between European countries. This affects the dignity and well-being of people with life-threatening or serious health-related conditions. There is an urgent need to address the lack of access, quality and availability of palliative care, particularly given the strong proven benefits that palliative care can bring to older people. Palliative care aims to address the physical, social, psychological and spiritual care needs, thus improving quality of life.

We recommend that palliative care be recognised as a right for all those who can benefit from it, and that policies aim to enforce this right across the spectrum of age, health conditions and living arrangements. This includes long-term care facilities (nursing or care homes) for older people. Based on consultations organised with older people and people with dementia and their carers, the Palliative Care for Older People in Care and Nursing Homes in Europe (PACE) project has resulted in important recommendations for policy and decision-makers to ensure the implementation of accessible and quality palliative care.

These recommendations cover issues

related to palliative care for older people in long-term care facilities, specific issues for people with dementia living in long-term care facilities and general issues linked to the provision of palliative care.

Recommendations include:

- Adopting policies to support long-term care facilities to implement evidence-based palliative care programmes, by allocating specific funding and facilitating the exchange of good practices.
- Educating health and social care professionals to deliver palliative care to older people.
- Encouraging managers of long-term care facilities to step up the integration of palliative care in their services, in order to mainstream palliative care provision in health and social care services and policy departments.
- Policymakers should aim to create an enabling societal environment, by raising awareness of what palliative care entails and its benefits, and challenge the misconceptions and stigmas associated with it, including those experienced, in particular by older people living with dementia.

Introduction

The provision of better palliative care for older people in Europe is an urgent public health priority. There are around 98 million people aged 65 and over in Europe. This number is progressively increasing and between 2016 and 2080, the proportion of people over 80 years of age will double [1]. Older people are more likely to die from chronic conditions and often experience multiple and complex health problems and disabilities, including dementia. Despite this, they are among the people with specific needs who may face additional barriers to accessing and using palliative care including pain relief [2, 3].

There are three levels of palliative care provision (a palliative approach, generalist and specialist palliative care) [4]. Many older people could benefit from these different levels of palliative care. General palliative care is provided by non-specialist physicians and health care professionals who have basic palliative care skills and competencies. It is complementary to specialist palliative care, which is defined as the involvement of a multidisciplinary team, service or clinician specialised in palliative care. Those working in specialist palliative

care provide consultation, care and support to people with more complex care needs.

PACE (Palliative Care for Older People in care and nursing homes in Europe), addressed the topic of palliative care for older people living in long-term care facilities [a]. The project has provided a better understanding of existing palliative care systems in Europe. PACE has identified the extent to which residents in long-term care facilities access palliative care and the impact that an innovative general palliative programme has on improvements in the quality of palliative care in these facilities. PACE advocates for a palliative care culture for all long-term care facilities, with a minimum of general palliative care available to residents and specialist palliative care services accessible when needed.



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[a] In the PACE project, a long-term care facility was defined as “ a collective institutional setting where care is provided for older people who live there, 24 hours a day, seven days a week, for an undefined period of time. The care provided includes on site provision of personal assistance with activities of daily living. Nursing and medical care may be provided on-site or by nursing and medical professionals working from an organisation external to the setting” [17].

This document has been developed as part of the PACE project and provides recommendations on palliative care for older people, with and without dementia, living in these facilities. The recommendations are based on discussions with a range of stakeholders including older people, people living with dementia, carers, representatives of these groups from different organisations and the PACE partners.

Palliative Care: Benefits and Challenges

The advantages of palliative care have been recognised in many national and international reports. Palliative care aims to assess and manage symptoms, provide dignity and improve the quality of life for people facing problems associated with life-threatening or life-limiting illness and their families. It can help to prevent and relieve suffering and pain. Palliative care provides a holistic approach to care that aims to address physical, social, psychological and spiritual issues [5].

The right to palliative care is not explicitly specified in existing international human rights treaties, but it appears in several general comments that interpret existing treaties [6]. Moreover, the right to health is articulated in international covenants (e.g. article 25 of the Universal Declaration of Human Rights). The United Nations Committee on Economic Social and Cultural Rights interpreted palliative care as part of the right to the highest attainable standard of health [7], and the United

Nations has acknowledged the provision of palliative care services as a legal obligation of governments and health care systems. Furthermore, it has been suggested that the denial of access to pain relief, in the case of severe pain and suffering, might be considered as a human rights violation [8].



Some relevant international documents on palliative care include:

- Parliamentary Assembly of the Council of Europe Recommendation 1418 (1999) on the protection of the human rights and dignity of the terminally ill and the dying.
- The European Association for Palliative Care (EAPC), the International Association for Palliative Care (IAHPC), the Worldwide Palliative Care Alliance (WPCA) and the Human Rights Watch (HRW) (2013) The Prague Charter: Palliative Care, a Human Right.
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- World Health Assembly (WHA) Resolution 67.19. (2014) Strengthening of palliative care as a component of comprehensive care throughout the life course.
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- Parliamentary Assembly of the Council of Europe (2018) Resolution 2249 The provision of palliative care in Europe.
- United Nations Open-ended Working Group on Ageing (2018), Report of the 9th session.

In the European context, in 1999, the Parliamentary Assembly of the Council of Europe [9], in its Recommendation 1418, encouraged Member States to recognise palliative care as a legal entitlement. In 2018, as advocated by the signatories of the Prague Charter [10], it recognised the importance of access to palliative care as fundamental to human dignity and advised Member States to recognise palliative care as a human right and to fully integrate it into their health-care systems [11]. In the case of older people, the Council of Europe adopted in 2014 a non-binding recommendation on the Promotion of Human Rights of Older Persons, with a specific section on palliative care [12]. It emphasised that any “older person who is in need of palliative care should be entitled to access it without undue delay, in a setting which is consistent with his or her needs and preferences, including at home and in long-term care settings”.

Yet equitable access to palliative care is still an issue worldwide. Several policy documents have addressed the topic of access and existing inequalities related to palliative care. The World Health Assembly (WHA) Resolution on Palliative Care in 2014 was the first ever global resolution on palliative care, and it called upon WHO and Member States to improve access to palliative care as a core component of health systems and to reduce existing inequalities in access to palliative care [13]. More recently, the Lancet Commission [2] produced an extensive report covering issues related to palliative care, pain relief, serious health-related suffering and universal health

coverage worldwide. Within Europe, the Parliamentary Assembly of the Council of Europe have also recently produced a report calling for better access to palliative care [11]. The Lancet Commission report emphasised that, whilst many high-income countries have addressed the alleviation of pain and suffering associated with life-threatening health conditions and end of life, many people living in low and middle-income countries have no, or limited access to, palliative care and pain relief. It highlighted the lack of “real progress” since 2014 and the need for an accountability framework to measure and report on the progress of global and national institutions. Similarly, the report from the Parliamentary Assembly pointed out that regrettably hundreds of thousands of people in Europe still do not have access to appropriate palliative care services. In particular, the lack of access to appropriate pain treatment and management, leading to unnecessary suffering and pain,



From the PACE six-country epidemiological study:

The symptom burden in the last week of life of residents in all countries studied may require improvement. A considerable proportion of nursing home residents are perceived by staff as dying with physical and emotional distress [i]. Pain, discomfort, difficulty swallowing and lack of well-being were the most frequent symptoms within each of the countries studied with between 52% (England) and 90% (Finland) of the residents experiencing pain in the last week of life, between 62% (England) and 90% (Finland) experiencing discomfort, and between 58% (England) and 81% (Finland) having had difficulty swallowing [i]. The use of end-of-life medication is also very variable across countries and warrants further research to guide practice [ii].

and the lack of social support for patients and caregivers have been extensively identified as issues of concern [2, 11, 14]. In view of these gaps, the need for an international human rights instrument that binds states to implement a true right to palliative care for older people has been identified [6].

Important barriers and shortcomings which have been identified in research and policy documents include poor public awareness of palliative care and public misconceptions, lack of palliative care policies and regulation of opioids, lack of resources, and lack of training and educational opportunities for health and care professionals and for informal caregivers [2, 11, 13]. Some of these European and international policy reports have provided standards and recommendations on how to tackle these barriers and improve access to palliative care including: fully integrating palliative care into national health-care systems; allocating funding and human resources; including palliative care in all national health policies and budgets; providing support to informal caregivers; including palliative care in the education and training of health-care professionals; improving public awareness of palliative care; removing legal obstacles that restrict access to pain-relieving medicines and raising awareness of opioid-based treatments; fostering partnerships with civil society; and consulting people with life-threatening and life-limiting conditions and their carers on the development of policies and services.

Palliative Care and Dementia

The specialty of palliative care has evolved over many years from a focus on end-of-life issues in oncology to a much broader scope, including not just end-of-life care but care of “those who are seriously ill and chronically ill, as well as those requiring high levels of individual care who would benefit from the palliative care approach” [11]. It can be provided early in the trajectory of illness together with other therapies or treatments aimed at cure or prolonging life. The European Association for Palliative Care (EAPC) published a White Paper in 2013 where the need for optimal palliative care for people with dementia is recognised [15]. It contains a set of 11 core domains and a total of 57 recommendations about optimal palliative care in dementia. The White Paper provides a framework giving guidance for clinical practice, policy and research.

People with dementia living in long-term care facilities often have more complex needs than other residents [16]. An important challenge linked to the organisation of palliative care for people with dementia is the prognostic uncertainty of their disease, as the course of dementia is somewhat unpredictable and varies considerably between individuals. Also, as dementia progresses, people may be less able to defend their interests and rights, to make decisions and to communicate their preferences, especially if they do not have adequate support.

About the Policy Recommendations

The policy recommendations presented here have been developed in the context of the PACE project, by AGE Platform Europe [b] and Alzheimer Europe [c], in collaboration with the PACE project partners. Two user forums (2015 and 2018), a mid-term policy conference (2016) and two public and patient involvement consultations (2017) were organised in Brussels in collaboration with PACE partners. In these events a wide range of stakeholders were consulted. These included members of organisations representing older people involved in AGE's task force on Dignified Ageing, members of the European Working Group of People with Dementia [d] and their carers and representatives of national Alzheimer associations. Feedback from the stakeholder events was reviewed and priorities and key areas of concern were identified. The policy recommendations were formulated to closely reflect what was learnt from this process. They were circulated for feedback from representatives of the different groups

involved in their development, which was then incorporated into the final report. There may be other issues of relevance to palliative care for older people but this document focuses on the main concerns and discussions within the various PACE consultations. Significant differences exist across Europe in the way that palliative care in long-term care facilities has been addressed in policy, legislation and practice. With this in mind, we have developed recommendations which can be adapted to the particular situation in each country. In countries where specific policy, legislation and/or practices exist, these recommendations could be used as a tool to review and improve them by ensuring that all relevant concerns have been addressed. For countries which are only just starting to address this issue, these recommendations could guide the development and implementation of palliative care.

[b] AGE Platform Europe is a European network of organisations of and for people aged 50+. AGE aims to voice and promote European seniors' needs and expectations, and to raise awareness about the issues that concern older people most. For further information, visit: <https://www.age-platform.eu/>

[c] Alzheimer Europe is a non-governmental organisation aiming to provide a voice to people with dementia and their carers, make dementia a EU priority, promote a rights-based approach to dementia, support dementia research and strengthen the European dementia movement. For further information: <https://www.alzheimer-europe.org/>

[d] The European Working Group of People with Dementia was set up by Alzheimer Europe in 2012. The group is composed entirely of people with dementia, they work to ensure that the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of people with dementia. For further information: <https://www.alzheimer-europe.org/Alzheimer-Europe/Who-we-are/European-Working-Group-of-People-with-Dementia>

Policy Recommendations

The recommendations have been divided into the following three categories:

- A. Issues related to palliative care for older people in long-term care facilities
- B. Specific issues for people with dementia living in these facilities
- C. General issues linked to the provision of palliative care.

A. Palliative care for older people in long-term care facilities

A.1 Regulatory context

An important concern raised in the different consultations was the lack of binding national standards and policies addressing the provision of palliative care for long-term care facilities in many countries in Europe. Often policies or standards exist but are not specific for these settings or are for specific medical conditions (e.g. cancer). Participants of the user forums felt this often results in patchy and unsystematic practices across countries. Also, older people living in these settings and their families do not have a clear understanding of what to expect and how their palliative care needs should be addressed.

To address the above issues, PACE recommends:

- The right to palliative care for people living in long-term care facilities should be recognised and promoted.
- Binding national regulations or policies addressing the minimum standards in the provision of palliative care in long-term care facilities should be developed, which should contain provisions about how to make the implementation of sustainable and high-quality palliative care possible.
- Older people, their carers and staff members should receive clear and accessible information about the palliative care that they should be able to expect or should provide in these facilities.



From the PACE EU mapping survey:

Across Europe, there is a great diversity in the national policy, funding and regulatory structures within which long-term care facilities for older people operate [iii, iv]. In Belgium, the Netherlands and England a wide range of initiatives exist on different levels to develop palliative care in long-term care facilities. In Poland, and especially in Italy and Finland few initiatives exist to develop palliative care in long-term care facilities and there is no evidence of engagement by or within long-term care facilities with palliative care initiatives or care provision [iii, iv]. Even though some countries have more initiatives for palliative care in this sector, there is room for improvement in quality of end-of-life care in the six countries studied in PACE (Belgium, the Netherlands, England, Poland, Italy, Finland) [i].

A.2 Implementation of a general palliative care approach in long-term care facilities (LTCFs)

There are currently some evidence-based programmes and interventions, such as the PACE “Steps to Success” programme, which have demonstrated value and effectiveness. The implementation of a palliative care approach in long-term care facilities requires the support and commitment of the whole organisation. Palliative care needs to be an important issue for those responsible for running the long-term care facilities, and all staff and volunteers need to be offered adequate palliative care training and support.

An important issue of concern raised, particularly in the consultations with people with dementia, was the lack of involvement of older people living in long-term care facilities, their carers and families in developing, implementing and evaluating palliative care programmes for these facilities. Their involvement could help to ensure that their needs, preferences and priorities are addressed. It could also promote transparency and trust from the wider community and contribute towards changing existing misconceptions of palliative care.

To address the above issues, PACE recommends:

- Governments should set aside and allocate stable funding to enable long-term care facilities to implement evidence-based palliative care

programmes. This could include the development of flexible and sustainable incentives and support for long-term care facilities that commit to the implementation of evidence-based palliative-care programmes.



The PACE Steps to Success Programme

was developed, tested and adapted as part of the EU-funded PACE project. It aims to improve a general palliative care approach for older people in care and nursing homes. A comparison was made between the facilities that received the training and those that did not. The trial results will be published in 2019 [v,vi]. For the future, we recommend implementation of the PACE Steps to Success Programme, in a flexible way in terms of timing and order, adapted to the facilities' context, with the help of well-trained facilitators, and together with close and ongoing evaluation and monitoring. For people with complex palliative care problems or end-of-life symptoms, specialised palliative care services should also be easily accessible to long-term care facilities in all countries.

The "Steps to Success Programme" will be freely available in several languages on www.eapcnet.eu/



From the PACE six-country epidemiological study:

The quality of end-of-life care in the last month of life can be improved in all countries. The nursing and care staff rated different aspects of the quality of care as having room for improvement, such as knowing treatment preferences [i]. Physician visits to long-term care facilities varied widely but are important and they appear to be related to more initiation of palliative care and better recognition of the dying phase [vii].

Knowledge of nurses and care assistants concerning basic palliative care issues such as management of pain or weight loss or the use of feeding tubes is suboptimal in all studied countries, although there is substantial heterogeneity between countries and facilities. Palliative care knowledge appears to be particularly low among staff in Poland and in Italy [viii].

- Policy makers at European and national level should promote the sharing and dissemination of good practices in palliative care in long-term care facilities and collaboration between countries.
- The curricula of professionals and the definition of roles in health and social care should be adapted so as to fully include the provision of palliative care among their skills and responsibilities. Communication skills should be prominent, as palliative care involves effective communication with people receiving it.
- Palliative care should be part of the education and training for all staff and volunteers working in long-term care facilities, and should be included in their ongoing professional development.
- Further research should be undertaken to better understand how to tackle the challenges and barriers for implementing palliative care programmes in long-term care facilities across Europe, and in particular in countries with less expertise in this area.

A.3 Sustainability

The maintenance, monitoring and evaluation of implemented palliative care programmes are of great importance. To date, some palliative care programmes are just piloted and run for a short period of time but there is no long-term commitment to maintain them as part of the ethos of care of the facility.

To address the above issues, PACE recommends:

- Incentives and support should be developed for long-term care facilities that commit to implementing sustainable evidence-based palliative care programmes in the long term.
- Directors and managers of long-term care facilities should develop and maintain an ethos or culture which promotes a palliative care approach for residents and carers.
- Issues such as ongoing training (both for existing and new staff), adequate numbers of staff per resident, monitoring and evaluation of the programme, etc. should be regularly monitored and appropriate action taken if and when necessary.
- Further research should be dedicated to the monitoring and evaluation of palliative care programmes in long-term care.

B. Specific recommendations related to people with dementia in long-term care facilities

All the issues addressed in the preceding sections are important for people with dementia. However, there are a few additional issues to be considered because of the specific characteristics of dementia such as cognitive impairments which may hinder effective communication with staff and ultimately affect quality of life. In the case of dementia, current misconceptions about palliative care are amplified by the stigma of dementia (including prejudice, negative attitudes and stereotyping) and failure of high-level policy makers to recognise people with dementia as being entitled to palliative care. Another problem is the lack of a formal diagnosis of dementia for many people living in long-term care facilities in Europe. This may prevent them from accessing palliative care which is suited to their specific needs linked to having dementia.

To address the above issues, PACE recommends:

- Governments should officially recognise, as stated in the WHO definition of palliative care, that people with dementia are amongst those entitled to palliative care.
- Governments should officially recognise the importance of advance care planning and the role of advanced directives which could include personal wishes related to palliative and end-of-life care, and raise awareness amongst people

with dementia and staff in long-term care facilities about their importance.

- Management and staff in long-term care facilities should be attentive to the possibility of stigma surrounding dementia (e.g. including stereotypes about capacity, decision making and quality of life) and challenge it.
- Management and staff in long-term care facilities should receive appropriate dementia training as well as training in how to provide high-quality palliative care to people with dementia.
- People with dementia and carers should contribute towards developing and improving palliative care for people with dementia (e.g. through Patient and Public Involvement activities).



From the PACE six-country epidemiological study:

Although there are important country differences, the population currently living and dying in long-term care facilities generally is very complex. For example, between 47% and 74% (depending on the country) have multiple comorbidities at the end of life and at least 60% have a diagnosis of dementia, often at a very severe or advanced stage [ix].

C. General issues linked to the provision of palliative care

Whilst the focus of PACE is on the provision of palliative care in long-term care facilities, more general/broader issues were also raised in the discussions with stakeholders. These concerns resonate with and lend support to the issues and recommendations highlighted in previous research and policy reports. Main topics included:

1. Misconceptions about palliative care, in particular a tendency to associate palliative care with the end of life and dying and to specific medical conditions such as cancer. These misconceptions are prevalent among the general public but also among many health and social care professionals and policy makers. They can profoundly impact the willingness to seek or refer a person for palliative care and the experience of people receiving it.
2. Lack of, or inequalities in access to appropriate palliative care services puts older people's well-being and dignity at risk. It can be considered as a potential breach of their human rights. Every person in Europe, regardless of age, condition or place of residence, should enjoy the same opportunity to access timely and appropriate palliative care services when needed.
3. Due to the fragmentation and lack of coordination in the provision of these services, people requiring palliative care do not all benefit from fully integrated care.

They often, for example, have to communicate the same information repeatedly to different health and social care professionals, make several visits or receive conflicting information about their condition/treatment.

In line with previous international documents, to address the above issues, PACE recommends:

- Public awareness should be raised about what palliative care entails in order to highlight its benefits and challenge misconceptions.
- Access to palliative care should be considered when implementing the right to long-term care, as stated in principle 18 of the European Pillar of Social Rights. Furthermore, it should be recognised as a human rights issue, and be included in ongoing discussions about older people's enjoyment of human rights.
- Palliative care should be considered as part of a cross-sectoral policy and be mainstreamed in relevant health and social care policies, strategies and legislation which focus on older people's health and well-being, including in policies to implement, develop or improve integrated health and social care.
- Researchers and policy makers should work together to analyse and better understand existing health and social care structures and develop solutions to tackle the challenges and barriers for the provision of integrated palliative care across Europe.

Conclusions

The provision of high-quality palliative care has received increasing attention from authoritative international and European institutions and researchers across the globe. The recommendations provided in this document have been developed in the context of the PACE project and have involved a range of stakeholders including potential future users of palliative care. The recommendations are in line with, and build upon, other existing international

recommendations. Furthermore, the recommendations also address more specific issues related to people both with and without dementia living in long-term care facilities. We call upon European and national policy makers, service providers and researchers to prioritise, consider and address the issues outlined in this document to improve the access of older people to quality palliative care.

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More PACE publications forthcoming in 2019

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