

UN Consultation on Palliative Care - Feedback from the PACE UK Team

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1. In your country/ region, how is long-term care for older people defined and provided for in legal and policy frameworks? What types of support and services are covered?

In the UK, long term care facilities, or care homes, are either nursing homes or residential homes. Nursing homes provide personal and nursing care with qualified nurse(s) on duty 24/7, whereas residential homes provide personal care only [1]. In both cases, medical care is provided by external primary care services (external to care home). Care homes specifically for residents with dementia, elderly mentally ill (EMI) homes also exist, as either a home or unit within a home.

2. What are the specific challenges faced by older persons in accessing long-term care?

As the majority of care homes are run by the private sector (for-profit) [1], the cost of care is high and unregulated. Some older adults choose to remain living in their homes for as long as possible to avoid selling their own property or using life saving to pay for care (most people do not have insurance to cover the cost of long term care). The extent to which the quality of care provided by care homes varies depending on the financing of the facility and the individual staff, and is unclear.

3. What measures have been taken/are necessary to ensure high quality and sustainable long-term care systems for older persons, including for example:

- **Sufficient availability, accessibility and affordability of services on a non-discriminatory basis?**

There are around 8,000 care homes in England, offering a range of services, i.e. nursing/EMI care at various costs[2]. As the majority of care homes are provided by the private sector, costs are driven by market forces. Local authorities provide a financial assessment for older adults entering care homes to determine if financial support can be provided but this is only provided for those with very little financial resources. The CQC standards include the requirement that care or treatment must not discriminate on the grounds of any of the protected characteristics of the Equality Act 2010 [3].

- **High quality of services provided?**

All care homes in England and Wales are regulated by the independent Care Quality Commission (CQC), equivalent organisations exist in Scotland and Northern Ireland. The CQC monitors, inspects and regulates care homes to ensure they meet the standards determined by the CQC. Performance ratings for each care home are published online, available for residents and relatives to see [2].

Websites allowing residents and relatives to write reviews of care homes are also becoming common, such as carehome.co.uk.

- **Autonomy and free, prior and informed consent of older persons in relation to their long term care and support?**

Older adults who are paying their own care home fees have the choice to choose which care home they are admitted to [4]. Residents funded by the local authority are required to choose a care home the local authority is prepared to pay for. In cases where a resident would prefer a more expensive care home than the ones provided by the local authority funding, a third party contribution, i.e. from a family member, can be used to top up the funding provided [4].

- **Progressive elimination of all restrictive practices (such as detention, seclusion, chemical and physical restraint) in long-term care?**

Liberty Protection Safeguards, previously known as Deprivation of Liberty Safeguards are a legal requirement in England and Wales. Briefly, care homes are permitted to use restraints and restrictions providing they are in the resident's best interest. If the restrictions and restraints used will deprive a person of their liberty, care homes must request permission from their local authority. In practice, the use of restraints is rare.

- **Sustainable financing of long-term care and support services?**

Payment for care is determined through means testing (a financial assessment) by a local authority [4]. If a resident's capital (including savings and property) and income is above £23,250, they will likely have to pay towards their care fees. If the capital and income have a total value of less than £14,250, the resident will qualify for Local Authority funding. Property is not included if short-term care is required, or if the property is still occupied, i.e. by a partner. Insurance policies are available today for an individual care but these are provided through the private sector and are rarely purchased. Prior to the last general election, a cap on the amount a resident would have to pay for care was going to be set at £72,000. The implementation of a cap has been delayed until 2020. Some local authorities offer a deferred payment scheme, whereby the cost of care is delayed until a later date, possibly until death, after which the cost is reclaimed from the deceased estate [4].

Two funding streams are available for older adults with severe health problems; NHS Continuing Healthcare funding is assessed by two or more nurses and, if met, all care costs are met by the NHS [5]. Residents are regularly reassessed to confirm the criteria are still met. NHS Funded Nursing Care is provided to residents who do not meet the criteria for NHS Continuing Health Care but have been assessed as needing care from a registered nurse [6].

- **Redress and remedy in case of abuse and violations?**

Safeguarding is a key priority for the CQC [3]. Actions to support safeguarding include:

- Checking that care providers have effective systems and processes to help keep care home residents safe from abuse and neglect.
- Using Intelligent Monitoring of information we receive about safeguarding to assess risks to care home residents using services
- Acting promptly on safeguarding issues, alerting local authorities and the police if required.
- Speaking with people using services, their carers and families to identify any safeguarding issues.
- Holding care home providers to account by taking regulatory action to ensure that they rectify any shortfalls in their arrangements to safeguard care home residents, and that that they maintain improvements. Regulatory action includes carrying out comprehensive and follow up inspections, requiring providers to produce action plans, taking enforcement action to remedy breaches of fundamental standards, and taking action against unregistered providers.

4. What other rights are essential for the enjoyment of the right to long-term care by older persons, or affected by the non-enjoyment of this right?

The CQC standards include the requirement that care or treatment must not discriminate on the grounds of any of the protected characteristics of the Equality Act 2010 [3].

5. In your country/region, how is palliative care defined in legal and policy frameworks?

The End of Life Care Strategy, published in 2008, is the official government strategy for palliative care in the UK [7]. In addition, a coalition called Dying Matters was formed to raise awareness of death and dying [8]. Recommendations from the strategy included staff training on palliative care and key competency development, such as communications skills. Good coordination of care across organisations and comprehensive, documented needs assessment for all patients was recommended, in addition to further resource allocation for palliative care services [9]. In terms of research, the development of a national assessment tool, surveys of bereaved relatives and further funding opportunities were highlighted [9].

6. What are the specific needs and challenges facing older persons regarding end-of-life care? Are there studies, data and evidence available?

A number of challenges exist in providing palliative care to older adults in the UK [10, 11], including:

- Creating and implementing appropriate outcome measures
- Ensuring equitable care for older adults with dementia
- Developing integrated care across the services i.e. between primary care and care homes.
- Ensuring preferred place of death where possible
- Ageism in health and social care

- Over and under treatment
- Poly-pharmacy
- Lack of dementia-friendly environments
- Poor understanding of the concept of frailty

7. To what extent is palliative care available to all older persons on a non-discriminatory basis?

General palliative care in England is provided through NHS services. The care provided will depend upon the specific knowledge and skills of the GP and community nurses. Specialist palliative care is available through hospices, home care teams and hospital teams but access may be limited by resource constraints as 80% of hospices are Third Sector organisations.

8. How is palliative care provided, in relation to long term care as described above and other support services for older persons?

General practitioners and district nurses provide primary care to care home residents. The relationship between care homes and GPs varies; some care homes have one GP who provides care for all residents, other have numerous GPs who provide care for one or more resident. Many hospices have good links with care homes and employ liaison nurses, or offer specialist palliative care consultations.

9. Are there good practices available in terms of long-term care and palliative care? What are lessons learned from human rights perspectives?

A number of initiatives have been implemented to improve palliative care in care homes; such as:

The Gold Standards Framework

The gold Standards Framework (GSF) aims to improve the quality of end-of-life care for residents, through developing the coordination and collaboration between nursing home staff and other practitioners to reduce resident transfers to hospital at the end-of-life. Evaluations in care homes suggest that the initiative leads to improvements [12-15]

Six Steps to Success

The Six Steps to Success programme is based on the NHS End of Life Care Programme, the Route to Success in End of Life Care – Achieving Quality in Care Homes [16]. It is a facilitated education package consisting of six workshops. Evaluation studies have identified improved ACP and staff communication in care homes that adopted the programme. The programme has been used in the PACE Study, and RCT comparing “Pace Steps to Success” with traditional care in long term care facilities in terms of patient and family outcomes, quality of dying, quality of palliative care, cost-effectiveness, and staff knowledge and attitudes [17].

References

1. Froggatt K, et al., *Mapping palliative care systems in long term care facilities in Europe in PACE Work Package 1 and EAPC Taskforce Report*. 2016, Lancaster University Lancaster, United Kingdom.
2. Care Quality Commission. *Care Quality Commission. The independent regulator of health and social care in England*. 2010; Available from: <http://www.cqc.org.uk/>.
3. Care Quality Commission, *Statement on CQC's roles and responsibilities for safeguarding children and adults*. 2015, Care Quality Commission: London.
4. Age UK. *Do I have to sell my home to pay for care?* 2017; Available from: <https://www.ageuk.org.uk/information-advice/care/social-care-and-support-where-to-start/paying-for-care-support/do-i-have-to-sell-my-home-to-pay-for-care/>.
5. National Health Service. *Your guide to care and support: NHS continuing healthcare*. 2018; Available from: <https://www.nhs.uk/conditions/social-care-and-support/nhs-continuing-care/>.
6. National Health Service. *What is NHS-funded nursing care?* 2015; Available from: <https://www.nhs.uk/chq/Pages/what-is-nhs-funded-nursing-care.aspx>.
7. Department of Health, *End of Life Care Strategy – promoting high quality care for all adults at the end of life*. 2008, Department of Health, London.
8. Hospice UK. *Dying Matters*. 2018; Available from: <https://www.dyingmatters.org/>.
9. Morrison, R.S., *A National Palliative Care Strategy for Canada*. *J Palliat Med*, 2018. **21**(S1): p. S63-S75.
10. Seymour J, et al., *Dying in Older Age: End-of-Life Care*. 2005, Bristol, Policy Press.
11. Payne, S., et al., *Quality indicators for palliative care: debates and dilemmas*. *Palliat Med*, 2012. **26**(5): p. 679-80.
12. Badger, F., et al., *An evaluation of the impact of the Gold Standards Framework on collaboration in end-of-life care in nursing homes. A qualitative and quantitative evaluation*. *Int J Nurs Stud*, 2012. **49**(5): p. 586-95.
13. Kinley, J., et al., *The provision of care for residents dying in U.K. nursing care homes*. *Age Ageing*, 2014. **43**(3): p. 375-9.
14. Hockley, J., et al., *The integrated implementation of two end-of-life care tools in nursing care homes in the UK: an in-depth evaluation*. *Palliative Medicine*, 2010. **24**(8): p. 828-838.
15. Hockley, J. and J. Kinley, *A practice development initiative supporting care home staff deliver high quality end-of-life care*. *International Journal of Palliative Nursing*, 2016. **22**(10): p. 474-481.
16. Kinley, J., et al., *Developing, implementing and sustaining an end-of-life care programme in residential care homes*. *International Journal of Palliative Nursing*, 2017. **23**(4): p. 186-193.
17. PACE Consortium. *PACE - Palliative Care for Older People in care and nursing homes in Europe*. 2018; Available from: <http://www.eupace.eu/>.