Palliative Care in Long-term Care Settings for Older People: findings from an EAPC Taskforce

The work of the European Association for Palliative Care (EAPC) Taskforce on Palliative Care in Long-term Care Settings for Older People is now completed. How can such care be improved? Elisabeth Reitinger, Katherine Froggatt, Kevin Brazil, Katharina Heimerl, Jo Hockley, Roland Kunz, Hazel Morbey, Deborah Parker and Bettina S Husebo briefly describe the Taskforce’s methods and key findings.

A changing demography across European and other developed countries is leading to an older and, in many cases, more dependent population. Consequently, the demand for long-term care is changing. This has, in turn, led to the consideration of new models of service delivery, funding and quality management in the long-term care sector.\(^1\)

A significant proportion of older people (defined as those aged 65 and over) die in long-term care settings – approximately 20% in the UK\(^2\) and 15% in Austria.\(^3\) Older people living in long-term care facilities (LTCFs) in Western societies often have non-cancer co-morbidities, and there is a high prevalence of dementia in this population.\(^4,5\)

Palliative care is acknowledged as an appropriate approach to support these people as they are nearing death and is being promoted in LTCFs in a number of ways.\(^6\) However, there are challenges in the implementation of new approaches, partly due to the complexity of care provision.

For many years, the European Association for Palliative Care (EAPC) has encouraged a focus on palliative care for older people in LTCFs.\(^7\) In 2011, to further develop activity at a European level, the EAPC Taskforce on Palliative Care in Long-term Care Settings for Older People was formally recognised.\(^8\) Its aim was to identify and map the different ways of developing palliative care in long-term care settings across Europe. This paper summarises the work of the Taskforce, its methods and some of its key findings.

A Europe-wide mapping exercise
Thirteen European countries were involved in the work of the Taskforce: Austria, Belgium, France, Germany, Ireland, Italy, the Netherlands, Norway, Portugal, Spain, Sweden, Switzerland and the UK. The initial task was to establish a European network of experts. These ‘country informants’ had to have relevant practice, research and/or educational experience, as well as links to specialists in their respective countries.

Once country informants had been identified, a two-phase mapping exercise was conducted in collaboration with them.

- Phase 1 involved the collection of contextual information about palliative care and long-term care provision for older people in each country. The information obtained concerned: the older population; the nature and types of long-term care settings; the wider funding and regulatory contexts; and key drivers for change.

- In Phase 2, country informants were asked to identify, in their respective countries, initiatives in the fields of clinical practice development, education and research that had been designed to improve palliative care in long-term care settings. Data about each initiative, their focus and impact were collected, summarised, collated and made available as a compendium, which can be found on the website of the International Observatory on End of Life Care.*

The initial task was to establish a European network of experts
As the data used in this mapping exercise were already in the public domain, ethical approval was not required.

**Key findings**

**Country contexts**
The 13 countries involved in this mapping exercise ranged in population size from 4.5 million (Ireland) to over 80 million (Germany). As a proportion of the population, the percentage of individuals aged 65 and over varied from 11.4% in Ireland to 21% in Italy. In most countries, more than 15% of the population were aged 65 years and over. The proportion of long-term care beds available for older people varied from 16 beds per 1,000 inhabitants in Italy to over 84 beds per 1,000 inhabitants in Sweden. The information about the country contexts (summarised in Table 1) gives an idea of the complexity of the health- and social care sectors within which palliative care is being provided in LTCFs.

**Identified initiatives**
Over 60 initiatives promoting palliative care provision in LTCFs have been identified, to date, in Austria, Belgium, France, Germany, Ireland, the Netherlands, Norway, Spain, Sweden, Switzerland and the UK. To classify these initiatives, the Taskforce members agreed on a typology adapted from work in relation to organisational change. The typology considers the level of change at which initiatives are focused: individual level (staff, family, resident); group or team level; organisational level; regional or network level; and national level. Examples of the types of initiatives are given in Table 2.

The identified initiatives can also be classified according to who the change is focusing on in the first place – staff members, family members or residents. For example, educational initiatives can be designed either for care workers, for interdisciplinary team members or for family members – the final outcome being better care for residents. Some of the initiatives sought to address issues encountered in clinical practice. Others took a broader perspective, looking at change in the wider cultural context within which care is provided; for example, change through organisational development. For details about all initiatives, see the compendium* and the Taskforce’s report.**

### Table 1. Country context information

<table>
<thead>
<tr>
<th>Topics</th>
<th>Findings</th>
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<tbody>
<tr>
<td>Types of LTCFs</td>
<td>Care in LTCFs is generally provided at two levels: for people with high dependency and those with low dependency. In some countries (e.g., France, Germany), care is also provided in a third tier linked to hospitals</td>
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<tr>
<td>Status of long-term care providers</td>
<td>A mixed economy of providers (public, not-for-profit and private) exists in most countries. Public sector funding of providers of long-term care dominates in countries with a strong social model, such as Norway and Sweden. Not-for-profit providers are significant in Germany, Italy, Austria and France; they are often affiliated to faith-based groups (predominantly Christian). Private providers are dominant in Ireland, Spain and the UK, but are also present in other countries</td>
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| Funding                 | Funding reflects the wider structures for health- and social care provision and thus comes from mixed sources:  
• Public funding through health- and social care  
• Personal funding from individuals (private insurance or own capital/income; family contributions)  
In a number of countries, public funding is allocated through means testing. Funding can be different for healthcare and for social care |
| Regulation              | The long-term care sector is regulated in all countries. This occurs either at a national or at a regional level. Specific regulations for palliative care in nursing homes exist in a few countries (e.g., France, Germany) |

LTCFs = long-term care facilities

### Table 2. Types of initiatives designed to promote palliative care provision in long-term care settings at different levels

<table>
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<tr>
<th>Level of change</th>
<th>Types of initiatives</th>
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| Individual level         | - Assessment tools  
- Communication and information interventions  
- Education  
- Leadership development  
- Clinical assessment tools |
| (resident, family, staff)|                                                                                        |
| Group/team level         | - Interprofessional education  
- Interprofessional rounds |
| Organisational level     | - Shared working between palliative care, hospice teams and LTCFs  
- Specialist palliative care units in LTCFs  
- Organisational development |
| Regional/network level   | - Regulation  
- (Inter)professional networks |
| National level           | - Legal frameworks  
- National strategies  
- Funding policies  
- Standards and guidelines for palliative care in long-term care |

LTCFs = long-term care facilities

### Complexity of implementing change
A number of factors influence how palliative care in long-term care settings can be improved in Europe. These factors include:

- Whether or not long-term care facilities are acknowledged as being home for the older people who live there
- Whether differentiated service provision is available to meet varying levels of need
- What the roles of the different types of providers are
Whether the importance of quality management and assurance processes for supporting development is recognised
Who is responsible at what level for improving care within both palliative care and long-term care.

The development of palliative care within LTCFs is a complex process that needs to occur at multiple levels. Many of the initiatives we identified illustrate this. For example, in order to improve care for individual patients, a pain assessment initiative will require collaboration between the LTCF and the local specialist palliative care organisation while at the same time fitting in the broader framework of national guidelines. Similarly, national policy initiatives require implementation at regional, organisational and local levels if they are to have an impact upon the delivery of care to individual patients.

The role of long-term care organisations as mediators for change and new developments requires further consideration. The organisational context for change is important in long-term care settings, as organisational culture influences how individuals and teams work. Furthermore, for organisational change to happen, bottom-up initiatives involving residents, families and staff need top-down support.

Our review of current initiatives also shows that there are sustainability issues. Many initiatives have their origins in short-term project work or research grants, have not yet been appraised and their further development is uncertain.

The future

Our Taskforce sought to identify and map the different ways of improving palliative care in long-term care settings across Europe. Its work provides a useful base for further work in clinical practice and research. Although now completed, this work is part of a wider process of international collaboration, and it is anticipated that expertise and experience will continue to develop and be exchanged.

References

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* The Taskforce's compendium of initiatives can be found at: www.lancs.ac.uk/shm/research/ioelc/projects/eapc-taskforce-ltc

** The Taskforce's report is available at: www.eapcnet.eu/themes/specificgroups/olderpeople/longtermcaresettings.aspx

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Declaration of interest
The authors declare that there is no conflict of interest.

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