Palliative care in long-term settings: a new web resource

At the 10th Congress of the European Association for Palliative Care (EAPC), an initiative was launched on palliative care in long-term settings. Katherine Froggatt and Katharina Heimerl have set up a web resource to facilitate international collaboration and report on the project.

New and important challenges are arising with the increase of the aging population, particularly in developed countries, where a significant proportion of older people now die in long-term care settings. In the UK, for example, about 20% of those aged 65 years or more die in care homes. Similarly, in Austria, increasing numbers of deaths take place in nursing homes: in 2003, 13% of all deaths occurred in such settings. As a result of this demographic shift, there is increased recognition, throughout Europe and in other Western countries, of the importance of providing palliative care in nursing homes and other long-term care establishments for older people. Such long-term care settings tend to be marginalised when it comes to funding for care and research. There is a need to maximise resources and expertise, to enable further development of research and provision of palliative care in these settings.

With this in mind, an exploratory meeting was held at the 10th Congress of the European Association for Palliative Care (EAPC), in June 2007 in Budapest. The meeting was attended by 26 representatives from eight countries (Austria, Australia, Belgium, Germany, Ireland, the Netherlands, Spain and the UK). The participants identified a number of common questions and issues regarding palliative care in long-term care settings, and felt that there was the potential for international collaboration.

Key points

- In developed countries, a significant proportion of older people now die in long-term care settings.
- There is increased recognition of the importance of providing palliative care in nursing homes and other long-term care settings for older people.
- Participants at a meeting held during the 10th Congress of the European Association for Palliative Care (EAPC) identified the benefits of developing an international network of researchers, educators and practitioners working in the field of palliative care in long-term care settings.
- A web resource has been set up to facilitate the worldwide sharing of initiatives, information and contacts.
- Future initiatives could include the mapping of palliative care provision in long-term care settings across Europe. Any initiative of this sort should be undertaken in partnership between palliative care and long-term care providers.

Identifying the problems

Palliative care is a distinct area

At the meeting, the participants discussed the extent to which palliative care in long-term care settings should be considered a distinct area. While it was recognised that many palliative care issues that arise in long-term care settings
apply to older people in general, it was also agreed that there are specific issues that warrant separate consideration. These specific issues concern definitions, resourcing and wider relationships between long-term care settings and providers of other types of health and social care, for example community-based nurses and GPs.

Definitions
Given the range of countries represented, each with their own terminology for long-term care settings (see Table 1), we agreed that we would focus on facilities that provide care for older adults, such as nursing homes, residential care homes, residential aged care facilities and continuing care units. We also agreed that we would not include prisons in our remit.

There is a lack of knowledge and evidence when it comes to defining what good palliative care means in long-term care settings. This makes it more difficult to request appropriate resources to support its development.

Staffing and continuity of care
In many countries, an increasingly mobile working population is leading long-term care homes to employ non-nationals to look after their residents, with the subsequent issue of different cultural sensitivities between residents and staff.

The problem of the transitional status of the staff, who frequently move on to other jobs, was also raised at the meeting in Budapest. The high turnover has implications for the efficiency of staff education and training. Another issue identified was whether appropriate education and training in palliative care is provided in all long-term care settings – and how.

The participants also found that ensuring continuity of care in long-term care settings could be challenging at times, because of the staffing issues mentioned above but also because of difficult relationships between the different care teams and health institutions.

The benefits of a network
The participants at the Budapest meeting agreed that there would be benefits in developing a network of interested researchers, educators and practitioners working in the field of palliative care in long-term care settings. These benefits would include:

- Identifying and sharing successful models of service delivery
- Facilitating opportunities for international collaborative research.

However, we also recognised that it is better to collaborate with providers of long-term care rather than to impose palliative care models on them. We advocate engaging in a working partnership approach, which would entail helping hospices and specialist palliative care services to engage with long-term care settings.

A helpful starting point might be, ‘What do providers of long-term care want and need with respect to the provision of end-of-life care?’

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Table 1. What are long-term care settings called in different countries?

<table>
<thead>
<tr>
<th>Country</th>
<th>Care provided for people with high levels of need</th>
<th>Care provided for people with lower levels of need</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td>Nursing home (high care)</td>
<td>Hostel (low care)</td>
</tr>
<tr>
<td>Austria</td>
<td>Nursing home (Pflegeheim, Altenpflegeheim)</td>
<td>Home for the aged (Altenheim, Altersheim)</td>
</tr>
<tr>
<td>Canada</td>
<td>Long-term care home (nursing home; municipal homes for the aged; charitable home)</td>
<td>Retirement home</td>
</tr>
<tr>
<td>Germany</td>
<td>Nursing home (Pflegeheim, Altenpflegeheim)</td>
<td>Home for the aged (Altenheim, Altersheim)</td>
</tr>
<tr>
<td>The Netherlands</td>
<td>Nursing home (Verpleeghuizen)</td>
<td>Home for the aged</td>
</tr>
<tr>
<td>Sweden</td>
<td>Nursing home</td>
<td>Old age home</td>
</tr>
<tr>
<td>UK</td>
<td>Care home (nursing)</td>
<td>Care home (personal care)</td>
</tr>
<tr>
<td>USA</td>
<td>Nursing home</td>
<td></td>
</tr>
</tbody>
</table>

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Figure 1. A new web resource has been set up to facilitate international collaboration. It is hosted by the website of the International Observatory on End of Life Care.
In the next issue...

- What do patients expect from a palliative care service? What is their experience? How satisfied are they? Sophie Barrow and Patrick Blosfeldt present the results of an audit conducted among patients from the Great Yarmouth and Waveney Macmillan Specialist Palliative Care Service.

- In a contribution to the ongoing debate on euthanasia, Lukas Radbruch, Norbert Krumm and Frank Elsner discuss the cases of two patients who were offered palliative sedation.

- Claire Douglas, Fliss Murtagh and John Ellershaw explain how to use the Liverpool Care Pathway for the Dying Patient (LCP) in patients with advanced chronic kidney disease.

- Social care still does not get as much attention as it should, say Felicity Hearn and colleagues. To re-emphasise the ‘social’ aspect in palliative care, they propose a new model of assessment and support.

- Manuela Trapanotto and colleagues report on life-limiting and life-threatening illness in children from the Veneto region, Italy, using a new method to assess paediatric palliative care needs.

- What are the challenges faced by UK palliative care provision in its different settings? Scott A Murray and colleagues give us the full picture, plus information about current national initiatives.

- In the northern Netherlands, GPs can get 24-hour telephone advice on how to manage patients dying at home, who suffer especially from nausea and vomiting. Florien van Heest and colleagues tell us what difference the scheme has made.

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The participants discussed ways in which to share resources and information on an international level. It was agreed that a web resource should be established for people engaged in providing care, education and research in the area of palliative care in long-term care settings.

This web resource has now been set up and is hosted by the website of the International Observatory on End of Life Care, under the heading ‘Palliative care and long-term care settings for older people: worldwide resources’ (see Figure 1, page 245). It provides a place where initiatives, information and contacts can be exchanged internationally. Resources can be identified by country and by type, enabling people to identify what is available in countries that share common languages.

Where do we go from here?

Future initiatives, subject to funding and resources, could include the mapping of palliative care provision in long-term care settings across Europe. This could mirror the work already undertaken on palliative care provision in specialist hospices by the International Observatory on End of Life Care. It is important that any initiative of this sort is undertaken in partnership between palliative care and long-term care providers.

We hope the new web resource and future meetings at the EAPC conferences will be the start of collaborations across Europe, and worldwide, to develop high-quality palliative care services and research for people living and dying in long-term care settings.

Acknowledgment

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References
4. The web resource can be viewed at: www.ceco-observatory.net/information/ltc (last accessed 09/05/08)

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