

## Patients need to be provided with real choice in end-of-life care

As the government publishes palliative care competences, **Jacqueline Pooler** discusses the importance of choice over place of death – and the right kinds of bed to enable this

THE government's new end-of-life care competences have highlighted once again the importance of providing high-quality palliative care (National End of Life Care Programme et al, 2009).

While there is now greater emphasis on helping patients choose where they might want to die, the details of some of the practical issues when that choice is at home need to be addressed. By scrupulous assessment, healthcare professionals, care planners and commissioners can help patients achieve their choice.

Last year, an advert in a magazine caught my eye. The caption was: 'You've got your own bed. So why die in someone else's?' This was part of Marie Curie Cancer Care's Delivering Choice Programme.

It seemed to touch at the very heart of end-of-life care in a non-sentimental, practical way. Rarely are these details of how and where one might die raised in public in such a way.

It made me reflect on three issues that are a core part of my working life.

First, the advertising campaign drew my attention to the intimacy of dying in one's own bed and the powerful image that it creates. But is that the reality? This will be an unlikely event for most of us, as the number of deaths in hospital continues to increase.

Second, where a patient lives in a two-storey property, the progression of life-limiting disease may lead to a discussion between patient, carers and the primary healthcare team about whether a bed should be placed downstairs. This issue is loaded with emotion and has implications that go well beyond simply rearranging the furniture.

The discussion has to be raised sensitively and handled as though it were a 'breaking bad news' scenario. 'The bed downstairs' is a metaphor for a patient's deteriorating situation.

'Having a bed downstairs' or acquiring a hospital bed can mean a number of things to patients and

their family. Disruption of the layout of the home can be difficult in a small property; it reinforces that all is not well and is possibly a warning shot that things may get worse. That sense of privacy that a 'proper' bedroom offers is lost.

Third, if a patient does have the opportunity to die at home, in whose bed will they be?

Health and safety policies/risk assessments require that many patients being cared for at home be nursed in 'hospital' design beds acquired through their PCT home loans department or similar. No longer should district nurses struggle with low divans or high springy beds.

But patients think they will die in their own beds.

If this was the one they shared with their partner, or have perhaps given birth in, should we deprive patients of that last wish?

Beds that are loaned to patients tend to be of a modern type; while they do not appear quite as clinical

as traditional hospital-style beds, they and the accompanying pressure-relieving mattress tend to be single. And what does a single bed say to a couple who, despite illness, have enjoyed intimacy? Are we inflicting yet another loss at a time when patients feel they are already losing so much?

Those involved in procuring equipment for patients to use at home need to think outside the framework of the single bed, and start delivering real choice for end-of-life care. ●

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### REFERENCE

National End of Life Care Programme et al (2009) *Common Core Competences and Principles for Health and Social Care Workers Working with Adults at the End of Life*. Leicester: NEO-LCP. [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)

**'Placing a bed downstairs has implications that go well beyond simply rearranging furniture'**

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