England examines funding options for end-of-life care

Lack of clarity about how and what services should be funded as part of end-of-life care is a problem England “cannot afford to ignore,” according to a team of palliative care specialists undertaking a national funding review.

England’s current system for making that determination is a “postcode lottery,” where patients receive vastly different levels of service depending on their location or diagnosis, according to *Palliative Care Funding Review: The right care and support for everyone*, the interim report of a team commissioned to develop a new tariff-based funding mechanism for end-of-life care in England (<http://palliativecarefunding.org.uk/wp-content/uploads/2010/08/PCFR-Interim-Report-December-2010.pdf>).

England established national strategies for the provision of palliative care to both adults and children in 2007 and 2008, respectively. But the country has yet to develop a national tariff for end-of-life services, which remain poorly defined, unequally funded and difficult to navigate, says Dr. Sir Alan Craft, a member of the review team and emeritus professor of child health at Newcastle University in Newcastle upon Tyne, in the county of Tyne and Wear, United Kingdom. “There’s no real mechanism for funding the implementation of either strategy, so it’s been patchy, very patchy.”

The panel called for a new system of funding to enable:

- “24/7 access to community services
- Better integration of services across health and social care, and coordinated care packages
- An increased focus on outcomes and patient choice, and
- A reduction of inequities in the system; be they geographical, funding, or access to services for patients with different diagnoses.”

Central to the problem is defining the concept of end of life itself, Craft says. “Nobody quite understands what end of life is, when it starts, how long it

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England’s current system for determining what medical services are funded as part of end-of-life care is essentially a lottery, says a national review panel.

lasts or what supportive services should be covered under end-of-life care.”

Current services tend to be “cancer oriented,” mostly because there’s a clearer trajectory of death for cancer patients than for others at end of life, Craft explains. “However, there’s more to death than cancer, and we need to start looking across the whole spectrum of how people die. There’s some 500 000 people dying every year in England, many because they’re elderly, or have dementia or other chronic illnesses. They shouldn’t fall through the cracks because they don’t fit a profile.”

The report calls for a needs-based funding system that would recognize and provide patients access to different levels of care, regardless of their diagnosis.

Such tariffs have recently been developed in England to fund “an average year of care” for patients with chronic illnesses, such as diabetes, Craft says.

But developing such a mechanism for end-of-life care is no easy task, particularly as there is little robust information on how much those services currently cost.

As in many countries, England’s hospice and palliative care services

have evolved in an ad hoc way over time, leaving the statutory responsibility for such services unclear and their total cost to society difficult to quantify, Craft says. “There are some things it’s clear that the state should take responsibility for, such as pain relief and symptom management, but there’s also a slew of services on the periphery we’re still debating, such as bereavement care, or touchy-feely stuff like aromatherapy and massage that many hospices do provide.”

Spiritual care is a particularly “tricky” grey zone, because “if you happen to die in hospital your spiritual care is provided by a hospital chaplain, but if you die at home, it’s up to the local church to provide that care.”

England’s Department of Health estimates that across health and social care the overall cost of end-of-life care can be measured in billions of pounds. Much of that burden is borne by the voluntary sector, which manages and predominantly funds a large number of the country’s hospice and palliative care services.

On average, adult hospices in England received 34% of their running costs from government funds in 2009,

but the actual percentage of state funding for local charitable hospices across the country varies from 0% to 62% of their costs, depending on location. Government funding for children's hospices is typically much lower, averaging 15% of running costs.

The disparities are largely the result of a "lack of national direction as to how local health boards should spend their money," says Craft.

The report indicates some 97% of independent hospices are unable to cover the costs of providing National Health Service services with funding currently allocated by Primary Care Trusts.

Further disparities are created because providers of end-of-life care are currently funded through block grants or contracts, the vast majority of which are distributed and reassessed on a yearly basis.

"Many people who die in England will have access to a Marie Curie nurse — nurses specifically trained to provide end-of-life care — who are called in by a district nurse," says Craft. "The problem is the health board will commit to buying a certain number of nurses per year, so whether or not you get access to a Marie Curie nurse becomes dependent on what month of the year you end up dying."

Just over half of England's Primary Care Trusts cover full access to 24/7 community nursing. The rest provide 24/7 community care to some, but not all residents.

"Research consistently shows that people prefer to die at home, but about 60% end up in the hospital in their last 24 to 48 hours of life because there isn't sufficient support in their community to enable them to stay at home," Craft says.

The report indicates that about 40% of patients who died in hospital in October 2007 didn't have medical reasons to be there, and nearly a quarter of

those had been in hospital for more than a month.

Another part of the problem is that health and social services are funded separately but provide essential, and sometimes overlapping, supports for dying at home. "Social care, for example, might take care of any house adaptations needed for a person to stay at home," Craft explains. "But there are many grey areas and the question often becomes: Is this person a health care responsibility or a social care responsibility? And patients end up getting bounced back and forward, when there should be a single needs assessment and a single funding system for end of life."

A single system of funding would "improve services, streamline (and reduce) costs, reduce confusion and

improve outcomes for patients," the report states. But Craft says a difficulty in creating a single tariff for end-of-life care would be in ensuring that it doesn't "turn people dying in hospital into a revenue earning event for hospitals. We don't have the services available in the community to get people out now, so there's going to be a period of probably two years where we'll have to build up the capacity to move people out of hospitals and back into the community."

While the issue is being resolved, the review panel urged that immediate funding be provided to improve 24/7 access to community care. It is expected to make its final report in July. — Lauren Vogel, *CMAJ*

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Editor's note: Twelfth of a series on end-of-life care

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