Dying the ‘good death’

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THE Ministry of Health’s pledge to review and improve the subsidy framework for home-based care is welcome.

Right now, a strange anomaly exists, where many people speak of wanting a “good death” at home, but with few actually doing so. As former health minister Khaw Boon Wan described it, a “good death” is one where the dying person is “treated with dignity and respect, without pain, in familiar surroundings and in the company of loved ones”.

A home death may sound like the most natural outcome of a long and steadily declining illness such as cancer or progressively worsening heart failure. But while two-thirds of terminally-ill patients want to die a good death at home, only one-quarter actually do so.

Why this paradox?

At least four factors contribute to this.

The first is the dearth of “die-logues”. This term, popularised by the Lien Foundation, describes conversations about death and dying. Death is too often a taboo topic whispered in hushed tones. Families are not prepared for the impending death because these die-logues have not occurred. The result: A confused scramble in the last days and the automatic resort to hospital admission.

Because we do not discuss death openly, we retreat to the hospital and the modern paraphernalia of life-prolonging devices when it comes. In fact, not many people understand that dying at home is not just a pipe dream but a viable option.

The second factor that leads to death in hospital, and not at home, is the view that disease and death are battles to be fought to the bitter end.

American author Sharon Kaufman describes how “death moved out of the home and into medical institutions” in the 20th century. In Singapore, too, deaths in hospitals have increased over the decades.

Once upon a time, death was seen as “natural”, a consequence of ageing and disease, to be ameliorated but not resisted. Today, far too many doctors (and families) still regard death as an admission of failure, and see in a death the powerlessness of modern medicine to combat disease. If illness is a battle, then the hospital becomes a bastion of resistance, and the Intensive Care Unit the last stand.

Seen in this light, it is thus “normal” that more Americans die in hospital than anywhere else, with up to a quarter dying in an intensive care setting.

Beyond these psychological factors, health-care financing is the third factor explaining why there are relative few deaths at home.

Although dying at home would be a cheaper proposition than dying hooked up to a complex array of tubes and wires in an expensive hospital, hospital care is heavily subsidised by the Government while home palliative care often needs to be privately funded.

Home hospice providers receive subsidies from the Government ranging from 25 per cent to 75 per cent of the cost of a visit from a doctor or nurse, based on individual patients’ means testing.

The pernicious effects of such a policy are two-fold: Firstly, hospices need to spend large amounts of time raising funds to cover the shortfall, detracting from clinical services. Secondly, the amount of time spent with any single patient is limited, requiring families to pay for a private round-the-clock nursing service. The charge is typically $380 per day, far higher than what public hospitals charge for hospital admissions.

The perverse outcome? It becomes cheaper for families to send their loved ones to hospital to die than to enjoy a good death at home.

Poor funding, coupled with the emotionally difficult working environment, make palliative care a somewhat unattractive proposition to doctors and nurses. This is the fourth factor behind why people end up dying in hospitals: The sheer shortage of medical personnel and resources that allow the dying to be cared for at home.

Home hospice staff ratios are typically one nurse to 35 or even 40 patients, higher than the more ideal 1:25 ratio. Only a smattering of physicians are prepared to make careers in palliative care. These collectively contribute to the near-impossibility of providing for all patients a good death in the home setting, forcing unwilling referrals to hospital.

Talking about death is still hard, but it is coming out of the shadows into the light of mainstream society. It will take time to overcome thousands of years of cultural taboo. But efforts by the Government and civic society are moving us in the right direction, and these will also help muster more numbers of doctors and nurses into palliative care services.

Resolving the financing incongruities may be more immediate as these really reflect a policy blind spot. We in Singapore pride ourselves on being pragmatic and efficient. Dying the good death at home needs close clinical supervision and support. It is true that this may not be more cost-effective than concentrating dying in hospitals where doctors and nurses can be deployed to tend to more patients.

However, the more important consideration is not only about technical efficiency. It is also about quality of dying and, ultimately, the moral position. The late Pope John Paul II once said: “A society will be judged on the basis of how it treats its weakest members and among the most vulnerable are surely... the dying.”

In death, as in life, quality matters.

And for those who see loved ones into the dark night, the last few moments and days are precious. Dame Cecily Saunders, founder of the modern hospice movement, once famously remarked: “How people die remains in the memories of those who live on.”

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