Given the inevitability and importance of death, it may seem obvious that we, as individuals and societies, should all be planning for it. However, a laissez-faire approach is all too common. If this approach made no difference, or improved the outcome, such blithe nonchalance could be justified. But the end result is, all too often, death in an institutional setting.

There is no doubt that people prefer to die peacefully at home. This often requires sophisticated assistance, from family, and unpaid and paid carers. Patients approaching the final journey often experience an increased need for physical care and emotional support, which may fluctuate. The needs of carers are also significant. Given the unpredictability of the timing of death, being difficult to predict with much certainty even a few weeks or months in advance, a level of flexibility in the availability and intensity of such support is essential. Is it there? In this issue, Nanda et al have found that a perceived lack of home health care services before death resulted in a near doubling of the odds of dying in a nursing home.

Should home care services be expected to meet such need? Some may label a call for more home health care services as indicating an endless, insatiable appetite for home care. No matter how much is supplied, they may argue, people simply want more, and then the carers justify placing their loved one in a nursing home on the lack of home care. On this argument, no increase in funding will satisfy the need. But in fact, fewer than 10% of Nanda et al’s sample (144/1578) perceived a lack of home care, and fewer than 40% perceived any need for home health care at all.

This suggests that the need would not be difficult to satisfy, but providing home health care services to only 40% of the population hints at other problems. In many instances patients are reluctant to accept necessary and available home health care services, citing issues of price, convenience, and quality. Many carers exhibiting high levels of carer stress are using no or little home care. Some people are afraid of strangers coming into their home. Others fear that they will be judged and found wanting by the professionals, or looked down on by family or friends for not being able to do it themselves. Some carers say they do it better than the “professionals,” and sometimes they are right.

At the other extreme, even the most superstitious home health care services will not stop residents from dying in nursing homes, from a wide variety of reasons with the most common likely to remain dementia, in 36% of cases according to death certificates, although this may be an underestimate. Nursing home staff have particular skills to care for dying dementia patients, acquired by training and experience. They generally know better how to provide palliative care to dementia patients than staff in hospitals, yet many nursing home residents are transferred to hospital during their final illness. Advance care planning can help prevent the nonbeneficent last ambulance ride from nursing home to hospital.

Nanda et al’s study suggested that dementia was an unusual cause of death at home, accounting for 6% of deaths, which may also be an underestimate. But even with adequate home health care, only 38% of people died at home.

What is needed is timely, flexible, and high-quality home health care, with the ability to respond in a crisis, the knowledge to help patients maximize their quality of life, the links to institutional care to facilitate admission when it is needed and, especially for patients receiving post acute care after hospitalization who make up the majority of clients for home care, a rehabilitative focus to help regain independence when possible. Home health care needs to be multidisciplinary and coordinated within itself and externally with the patient’s existing and ongoing health care providers, particularly the family doctor. As well as providing excellent care, the patient must be educated and supported as a partner, not a subject.

Timeliness is a crucial aspect of providing an efficient service. When there is a long waiting list, patients will prefer to retain the service as long as possible, in case they need it in the future. When patients believe the service will be available for their future needs, they will more easily give it up if they improve. Therefore, cutting back on the service to the extent that waiting lists grow leads to inefficiency on many levels.

Unfortunately, the universal availability of high-quality home health care service provision remains unlikely. In times of financial stringency, it is politically easier for administrators and politicians to cut or underfund home care services than to close hospital beds. It is up to providers and patients to bring the issue to politicians and other decision makers, and an excellent way to do this is by demonstrating, as Nanda and colleagues have done, that a small deficit in home health care services leads to greater demand for higher cost care.

REFERENCES