



Better Early Than Late

By Dr Tan Poh Kiang, Editorial Board Member

There are two recurring questions that are at the core of the predicament I observe in the area of palliative care today. The first question was asked by a patient whose father was recently diagnosed with metastatic oesophageal cancer, “Doc, isn’t it too early for us to broach the idea of hospice services when my dad is still relatively well?” Edward’s father, Mr Lee had difficulty swallowing not long after he had complained of hoarseness of voice. The bad news at the point of diagnosis was that the disease had already spread to the lungs and liver. He was put through an extensive investigative process and the conclusion was that due to the cancer’s local spread, he would lose his speech if he chose to have the tumour removed surgically. Amidst the confusion, Mr Lee was clear about one thing – he was not prepared to sacrifice his ability to communicate. The ensuing days were packed with a dizzying combination of chemotherapy, traditional Chinese medical treatments and attending miraculous healing rallies (as he was a Christian). Hospice service or palliative care was not on his priority list.

The second question is, “Why didn’t we get the hospice service in earlier? It would have prevented so much unnecessary suffering from some of the medical treatment that did not make any difference to my mom.” Gerard’s mother, Mrs Fong had stage two breast carcinoma two years before her recurrence. Radical mastectomy was followed by both chemo and radiotherapies as well as Tamoxifen. Unfortunately the bad news was announced after she had a minor fall and fractured her humerus. The doctors found that it was a pathological fracture due to metastatic disease. A bone scan revealed that the secondary malignant deposits had gone to the spine, ribs and the skull. The family was thrown into a distressing period of confusion where they were offered a myriad of false hopes including an expensive concoction of “natural herbal supplements” sold by a specialist. It was when I sensed that Gerard and his siblings were at their wits’ end and emotionally drained that I managed to persuade them to call Hospice Care Association (HCA) for assistance. Quality of life was immediately better for both Gerard’s

mother and her care-givers the moment the HCA team stepped in to render their guidance and help. The pain control was managed to the point she was able to enjoy her Korean drama in the afternoons. A special bed was brought in together with an oxygen concentrator and a commode. She was able to sleep better with less gasping and she no longer had to walk to her home toilet. Gerard’s sisters and domestic worker were taught how to rationalise her medications as well as to prepare an appropriate diet. And the best part was they had a hospice person to call in any situation, any time of the day.

This common struggle of terminal patients and their families not wanting to engage palliative/hospice care early when they would benefit the most, and regretting after the sufferer had died that they had not engaged the essential end-of-life help early enough is complex. I have pondered much and read around to better understand the dilemma that I know I will have to face if my loved ones or I come to the end of life. No one is spared in this era of modern interventional medicine.

Atul Gawande puts it eloquently: Our responsibility, in medicine, is to deal with human beings as they are. People die only once. They have no experience to draw upon. They need doctors and nurses who are willing to have the hard discussions and say what they have seen, who will help people prepare for what is to come – and to escape a warehoused oblivion that few really want.

I was thus delighted to chance upon Dr Atul Gawande's recent piece in *The New Yorker* (Letting Go, 2 August 2010). Gawande is an American surgeon and also an award-winning author. In the article, Gawande offered a few insights that brilliantly describes our problem with end-of-life care.

The first insight is that swift, catastrophic death is the exception rather than the rule. Gawande observed: For all but our most recent history, dying was typically a brief process. Whether the cause was childhood infection, difficult childbirth, heart attack, or pneumonia, the interval between recognising

us are trained to fight the common enemy – death and this training somehow causes us to be unrealistic. A Harvard researcher asked doctors of almost 500 terminally-ill patients to estimate how long they thought their patient would survive, and then followed the patients. 63 per cent of doctors overestimated survival time. Just 17 per cent underestimated it. The average estimate was 530 per cent too high. And the better the doctors knew their patients, the more likely they were to err.

Our unrealism is compounded by a tendency to worry more about being overly pessimistic than being overly optimistic. As

or the marketplace – to limit them. But that doesn't mean we are eager to make the choices ourselves. Instead, most often, we make no choice at all. We fall back on the default, and the default is: Do Something. Is there any way out of this?

Good news is breaking on the horizon, or at least the evidence is mounting so that perhaps the tide will slowly turn. In late 2004, executives at Aetna, a large American insurance company, started an experiment. They knew that only a small percentage of the terminally-ill ever halted efforts at curative treatment and enrolled in hospice, and that when they did,



3 Insights:

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that you had a life-threatening ailment and death was often just a matter of days or weeks. Consider how our Presidents died before the modern era. George Washington developed a throat infection at home on 13 December, 1799, that killed him by the next evening. John Quincy Adams, Millard Fillmore, and Andrew Johnson all succumbed to strokes, and died within two days. Rutherford Hayes had a heart attack and died three days later.

The reality now is that for most people today, because of advanced medical knowledge and technology, death comes only after a long struggle with an incurable condition – advanced cancer, progressive organ failure (usually the heart, kidney, or liver), or the multiple debilities of very old age. In all such cases, death is certain, but the timing isn't. So everyone struggles with this uncertainty – with how, and when, to accept that the battle is lost.

The second important insight has to do with doctors and our “unrealism”. Many of

such, there is a universal reluctance to bring up the subject of death with our patients. Studies find that although doctors usually tell patients when a cancer is not curable, most are reluctant to give a specific prognosis, even when pressed. More than 40 per cent of oncologists report offering treatments that they believe are unlikely to work. In an era in which the relationship between patient and doctor is increasingly miscast in retail terms – “the customer is always right” – doctors are especially hesitant to trample on a patient's expectations.

The third insight is the tragedy of the “default” that is played out over and over again. Dr Gawande describes it as such: ... rarely is there nothing more that doctors can do. They can give toxic drugs of unknown efficacy, operate to try to remove part of the tumor, put in a feeding tube if a person can't eat: there's always something. We want these choices. We don't want anyone – certainly not bureaucrats

it was usually not until the very end. So Aetna decided to let a group of policyholders with a life expectancy of less than a year receive hospice services without forgoing other treatments. A two-year study of this “concurrent care” programme found that enrolled patients were much more likely to use hospice: the figure leaped from 26 per cent to 70 per cent. That was no surprise, since they weren't forced to give up anything. The surprising result was that they did give up things. They visited the emergency room almost half as often as the control patients did. Their use of hospitals and ICUs dropped by more than two-thirds. Overall costs fell by almost a quarter.

More recently, in a landmark study published in the *New England Journal of Medicine* (N Engl J Med 2010; 363:733-42), Jennifer S. Temel et al randomised 151 newly-diagnosed metastatic non-small-cell lung cancer patients into two groups to receive either early palliative care integrated with

standard oncologic care or standard oncologic care alone. In the past, it was what Jim Collins and Jerry Porras (Built to Last: 1994; HarperCollins Publisher Inc) would describe as “Tyranny of the OR”, that is, patients with this terminal diagnosis had a choice. They could undergo aggressive treatment and put up with the associated significant side effects. Or, they could be referred for palliative care – a clinical specialty that focuses on managing of symptoms, improving psychosocial support, discussing long-term treatment options, and aiming to improve a patient’s quality of life. Essentially, there was a tradeoff between aggressive treatment and palliative care.

Temel’s study demonstrates that it is a false dichotomy that patients had to choose between palliative care and aggressive treatment. Instead the outcome is a clear demonstration of the “Genius of the AND”. The paper illustrates that palliative care can go a long way towards reducing patients’ suffering in their last year of life and also allow patients to live longer. Those patients getting early palliative care had a lower incidence of depression, less pain and nausea, and more mobility. What’s more, they also lived nearly three months longer, on average,

than patients who did not have early access to palliative care.

I realised that with all the obstacles stacked against us, the onus is on us medical practitioners to provide the sorely-needed leadership when it comes to the crunch. Sometime back, an old schoolmate called me in desperation, “PK, may I meet you? My father-in-law is dying of advanced stomach cancer.” I sat with Ivan and his wife Nancy and listened with much agony to their account of the family’s struggle through the confusion of options when a loved one is faced with impending death. With each round of chemotherapy, their father was filled with more false hope but looked less likely to improve. I shared with them my own philosophy of engaging the hospice service early. Our strong friendship had built sufficient trust for them to follow up on my suggestion; they began to work with a palliative team right away. Ivan and Nancy were determined to follow the guidance offered by their compassionate friends from the hospice while allowing their dad to try out different modalities of therapy so long they did not cause him to feel worse. The journey was brief. He died barely three months after our first discussion. Shortly after the funeral, I received

a text message from Ivan, “Thank you, PK. Your wise advice to bring in the hospice team cleared our confusion at that time. With proper help, the last few weeks were peaceful and the family had precious moments with my father-in-law. He died with minimal pain in the presence of all his loved ones at home.”

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My advice to my patients facing end-of-life illnesses with regards to palliative care? Better early than late. **SMA**



Dr Tan Poh Kiang (MBBS, 1990) is a family physician who practices in a public housing estate in the heartland of Singapore.

He is privileged to practise the art of healing and enjoys writing in his free time. He can be contacted at email: liejoan@singnet.com.sg

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SMA News

Singapore Medical Association

Alumni Medical Centre, Level 2

2 College Road, S 169850

Fax: 6224 7827

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