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In praise of palliative care

OCT 8 marks 'World Hospice and Palliative Care Day'. Gail Featherstone, wife of the British High Commissioner to Malaysia, writes a very personal view of its benefits.

"My mother died in her local hospice just before midnight on Nov 11, 2005. Peacefully. Without pain. I was holding her hand. She knew she was dying and had written a letter for us to read after her death in which she told us all she loved us, expressed gratitude for a "happy life", and gave instructions for her funeral. Writing these words has made me cry. The grief of losing her is still there. But it is the fact of her death rather than the manner of it which saddens me. I am grateful for the way she died. For hers was what used to be called a "good death". And it's the kind of death I would wish for everyone, myself included. So why doesn't this happen more often? I would argue that it can, if we only paid more attention to and spent more money on hospices and palliative care.

What is palliative care? The World Health Organisation defines it as:

"An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual".

Terminal cancer is not the only such disease: the ageing populations of the world are seeing an increase in the incidence of Alzheimer's and dementia, for example. In all, they are estimated to be around 100 million people annually who would benefit from hospice and palliative care. Less than eight per cent of those in need actually have access to it. It's heartbreaking to think of the pain and grief those statistics represent. Yet it

doesn't have to be this way...

End-of-life care services are often, though not exclusively, centred in hospices. I'm proud to say that the modern hospice movement is at its most developed in my own country, the UK, spearheaded as it was by Dame Cecily Saunders, the founder, in 1967, of St Christopher's Hospice in south-east London. Her mantra was: "You matter because you are you, and you matter to the last moment of your life". Yet, even in the UK, the access to hospice care is patchy and mostly privately funded via charitable giving. Palliative care in general and hospices, in particular, remain taboo subjects for many.

Part of the problem lies in our own minds. We are frightened of death. But, let's face it, we all die. In the UK, we are fond of quoting Benjamin Franklin who famously stated that "In this world nothing can be said to be certain except death and taxes"! None of us like to think about death, especially our own, but perhaps it's time that we faced up to the elemental fact that, as one wit noted, "The global death rate remains constant at 100%". Death is a normal process in that it happens to us all. So it makes sense to prepare for it if we can.

But that is not to say that it is an easy subject to discuss. My mother was a remarkable woman and faced her final illness with great dignity and bravery, but even she was scared when the word "hospice" was first mentioned. She associated it, as many people do, solely with the end of life. As the months went by, however, and the treatment she received (to drain fluid from her stomach) was repeated many times, she came to regard her two-to-three-day stays in the hospice much as one would regard a stay in a nice hotel! As well as the medical attention, she enjoyed complementary therapies such as massages

and aromatherapy. There were daycare sessions to attend and counsellors and a chaplain on hand if she wanted to speak to them. But, in-between her visits to the hospice, my mother's life continued as normal, running the house, caring for my father and seeing family and friends.

In short, the care my mother received was *life-enhancing*; it enabled her to continue living *in the way she wished to do*. Indeed, she told me, some months before her death, that she was truly enjoying every minute of her life. Part at least of that enjoyment was due to the holistic care she received both at home from her lovely, caring palliative care nurse and in the hospice from the wonderful staff there. Just weeks before her death she was well enough to visit us for a few days in Switzerland. She walked a great deal, laughed a lot and generally exhausted us all! And, when the time came and she was told that death was likely to be very near, she was given constant emotional help and support as well as the medical intervention she needed to control her pain and keep her physically comfortable. We, her family, were offered support and counselling both before and after her death and encouraged to ask any questions we wanted.

Here in Malaysia, palliative care is impressively advanced given its relatively recent emergence as a recognised medical specialisation but, as Dr Ednin Hamzah, the visionary Chief Executive of Hospis Malaysia in Kuala Lumpur, is keen to point out, there are formidable challenges to be overcome if the huge and ever-increasing needs of local communities are to be met. He told me:

"Malaysian healthcare needs a paradigm shift both in terms of planning services as well as teaching doctors and nurses, all in the realisation that at the root of all illness, is a patient and a family that simply wants to have their fears

understood, their suffering to be empathised, their words listened to and their lives to have meaning. Palliative care can do this".

I was privileged and moved to see for myself the way that Dr Ednin and his nurse put these words into practice when I joined them recently to visit two hospice patients (from widely different socio-economic backgrounds) in their respective homes. As well as providing medication and advising on physical treatments, they spent a great deal of time just getting to know the gentlemen concerned. At no point did they appear to be in a rush. Dr Ednin gave the first patient plenty of time to ask questions but did not force him to say anything; he asked for permission of the second before leaving the room to speak to his family; when speaking to the families he was gentle but did not avoid "difficult" questions and was honest when he didn't know an answer.

In short, both patients and their families were treated with great respect; as "whole" people who were gravely afflicted and affected by illness but not defined by it.

Whether a person with a life-limiting illness dies in a hospice (as was the case with my mother) or at home, the aim remains the same: to give value and quality to that individual's life, however long or short it is, by controlling the symptoms of their illness — especially pain — in a way which neither hastens nor postpones death. By the time my mother died, she knew all the staff at the hospice well and thought of them as her friends.

What better way to die than peacefully, painlessly, and surrounded by friends and family? Such a death is possible for many more of us than we realise. But we need to think about it. Now.

Hospis Malaysia will be holding its biannual Voices for Hospices gala fundrais-

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ing event on Oct 9 at the JW Marriott Hotel for the fourth time since 2005. Themed 'Many Lives, Many Voices', the event will be held to help funds for the organisation as well as to raise awareness and understanding of the medical, social, practical and spiritual needs of people living with a life-limiting illness, and their families. Proceeds from the charity dinner will help Hospis Malaysia continue to support and develop hospice and palliative care services, to uphold the dignity and quality of life of those affected by a life-limiting illness.

HOSPIS MALAYSIA provides professional palliative care to those living with life-limiting illnesses which typically include cancers, Acquired Immune Deficiency Syndrome (AIDS), organ failure or progressive neurological conditions. Palliative care works alongside curative treatment, but it correspondingly increases as curative measures decline. The heart of its service lies in its philosophy — which is to offer palliative care that effectively addresses the various needs of patients and their families, and in the process, ensures comfort and dignity for those

living with the illness, as well as the best quality of life for them and for their loved ones.

Hospis Malaysia's services include a homecare programme, daycare for patients and loan of medical equipment. All the services and facilities are offered free-of-charge. The medical team of palliative care doctors and nurses make approximately 1,000 home visits a month. Hospis Malaysia needs about RM3 million to fund the operating expenses annually.

More information can be found on <http://www.hospis-malaysia.org>

About Hospis Malaysia



HOME CARE: A nurse from Hospis Malaysia with a patient at his home