No one has to die alone: Palliative care lends a helping hand

Susi opens up the door to her home with a big smile on her face. At first glance, it is hard to know that she has less than a year to live.

The 65-year-old Singaporean was diagnosed with heart failure.

“My doctor told me and my family that [I have less than a year to live]. Thank God, I’m still alive today. He gave me more time,” said the mother of three, who now lives with her eldest daughter and her family in Jurong West flat.

Following her diagnosis, she was referred by her doctor to enter HCA Hospice Care — a registered charity in Singapore that provides comfort and support to patients with life expectancies of one year or less.

Under the free-of-charge program, she is one of the patients who receives regular visits from
the hospice care’s multi-disciplinary team, which includes doctors, nurses, social workers, counselors and trained volunteers, in her own home, depending on her needs.

The services are provided to all terminally ill patients in need — regardless of their religions, ethnicities, income levels and nationalities.

That day, she welcomed nurse Kahvidah Nathan, who, without hesitation, gave the woman she called auntie Susi a hug and soon, like two friends, they were chatting in the living room.

Auntie Susi revealed how the swelling on her leg was getting better and she did not suffer much pain anymore. She did, however, experience mild pain in her stomach, just under her chest area, but it came and went.

“But I watch my diet,” Susi said, explaining the swelling was likely caused by her high uric acid.

The nurse then asked more about her eating habits and other daily routines before checking her medication. Nathan later opened up her suitcase and took auntie Susi into another room for physical examination.

“She’s more than just a best friend to me,” Susi said after the examination, referring to nurse Nathan. “She’s more like a daughter, a family [member]. I call and she will come.”

When the patients are being referred by their doctors to enter hospice care it means they have a limited life expectancy — one year or less.
Into details: Nurse Esther from HCA’s Jurong center trains caregivers on palliative care. (Courtesy of HCA Hospice Care)

“All hospice care is palliative care, but not all palliative care is hospice care. In palliative care you can stop or continue — but hospice care continues until the patient passes away,” said HCA Hospice Care’s CEO and Medical Director R. Akhileswaran.

Since it was set up in 1989, HCA has cared for over 55,500 patients or over 3,700 annually, with team members on call around the clock to prevent patients from making unnecessary trips to the hospital to get help. They make around 40,000 home visits annually.

Fifty one percent of the patients are elderly, aged 61 to 80. Many of them, 41.3 percent, were taken care of for 1 to 30 days before they passed away.

Akhileswaran said for most patients, whether they are advanced cancer patients or non-advanced cancer patients, there would be some point when their doctor would say: “we can’t give you more treatments to cure your disease” — meaning the treatments are no longer effective and there is nothing more to do.

Such a statement, he said, could be very shocking to the patients and their caregivers, meaning that they have to look after themselves and take care of what is happening in their lives.

“It’s at such a time that palliative care comes in and says there’s always something that we can do for the patients and their families. This is where palliative care has become an important aspect of healthcare,” said the radiation oncologist.
“It’s the philosophy of caring for the patients — not just curing the patients. When you can’t
cure, you still care. It’s something that people should understand. It’s not all about curing the
patients.

“If a patient comes with advanced disease, does it mean you can’t care for the patient? I think
that’s not right. No matter what, no matter how advanced a disease is we can still care for the
patients and the families.”

Apart from home service, HCA also sets up five hospice care centers across the city state and
day hospice care where the patients are engaged in social and physical activities to make
them stronger.

“Sixty percent of our day hospice patients can do three out of six activities for daily living,
such as bathing, dressing, eating, using the toilet and transferring [from one room to another].
We train them and give them enough strength to continue doing these activities that we often
take for granted but are very difficult for them to do,” Akhileswaran said.

Palliative care, he said, was so important since it took care of patients and their families, the
main caregivers of the patients.

“It does not mean, however, palliative care is given only when patients were having advanced
disease, but it can be given when patients are undergoing active treatments, like when
patients are undergoing chemotherapy or dialysis,” he said.
He said it is important for a patient to die peacefully at home, with dignity and not in pain,
since it would affect the caregivers and make them depressed, having to live with the image
forever.

“They would remember those who they knew so well die of such terrible deaths even years
later. The image still keeps coming back to them. We do not wish this to happen to the
majority of our caregivers,” he said.

“Fifty five percent of our patients passed away at home and 97 percent of them were
symptom free [from pain to breathlessness] at the time of death.”

Back in her office, nurse Nathan said a nurse usually has 30 to 35 patients under her or his
care, making five to six home visits in a day.

“We play a lot of roles, not just nursing. We teach the patients, and their caregivers, the
basics,” said the advanced practice nurse with 15 years of experience, including 10 years in
palliative care.

“We help them deal with their swollen legs and even things like choosing the makeup and the
clothes they want to wear when they die,” said the nurse, who holds a master’s degree in
nursing from the National University of Singapore.

The hardest thing for her was tending to young patients.

“To see them going through cancer at such young age is tough. But somebody has to take
care of them. I’m trying to help them go through all that. You’re there to help. I find it
challenging,” she said.

“A patient teaches you values, at the end of their lives. It changes you. As a nurse, I give. As a person I grow. They give me strength. It keeps me going.”

- See more at: http://m.thejakartapost.com/news/2015/06/10/no-one-has-die-alone-palliative-care-lends-a-helping-hand.html#sthash.O0D1KOxD.dpuf