

## Home is where her heart (and oven) is

### JENNIFER NAI

Patient

When we met Jennifer, she had just returned from her thrice-weekly dialysis treatment. If she was tired or feeling weak, she didn't show it. Jennifer, a petite 26-year old, sat cross-legged on the floor. She has Type 1 diabetes with end stage renal failure. Madam Ng, her mother and primary caregiver, sat beside her.

"When I was young, I wanted to be a nurse," says Jennifer. "Age 12, I was admitted to the hospital. Diabetes. Didn't know what was going on. So I decided to become a nurse." She giggles. "In the children's ward, I took the other kids around, brought them for injections and so on."

Jennifer has been in and out of hospital for many years. Her experiences in hospital were not always smooth. In 2016, her condition deteriorated. The constant readmissions to hospital caused substantial distress for her and the family. That was when she was referred to Hospis Malaysia by the palliative care unit at Selayang Hospital. She had discussed her goals of care with them, and wanted to be cared for at home as far as possible.

Jennifer's studies had to be put on hold. Her calm disposition did not betray any hint of regret or sadness. When her condition stabilises, she hopes to go back to college. What are you studying, I ask. "Nursing." Do you want to be a hospice nurse? "Yes, hopefully." "If Hospis was nearer to our place," her mother interrupts, "I want to volunteer there as well."

Both mother and daughter were complimentary about the support from the team from Hospis Malaysia. "Nurse Vicky is a very good nurse," says Madam Ng. "She calls and visits every week. Whenever she is here, she asks us about many things, and really listens to all our stories. She checks my daughter's blood sugar level, prepares the medication, and if she doesn't know anything, she will always refer to the doctor. We know that at the other end of the line, there is a doctor supporting her".

Throughout her illness, Jennifer has had frequent attacks of uncontrolled vomiting which had necessitated her being admitted to hospital. With the referral to Hospis Malaysia, she now has access to its medical team directly. A phone call to the hospice at any time of the day or night when she has had one of her frequent vomit attacks, has enabled her to be treated at home by the attending nurse. Often a sub-cutaneous line is inserted (she shows us the needle scars) to enable a quick injection of medication, and instructions left with mum for on-going dosages until her vomiting is controlled. Her hospital admissions have been reduced, and mum smiles when she recalls the number of times she has had to call on the hospice for help.



*Jennifer staying positive*

"I like Nurse Vicky," says Jennifer. "We have a lot in common. Food, mainly. Actually, if I'm well, I like to bake cookies. I bake for my family and friends and the staff at Hospis. I also like to watch Hokkien dramas. Mum, too. Mum will watch anything with a good story."

"We saved a lot with Hospis," says Madam Ng. "Nurse Vicky even got Hospis to lend us an oxygen tank, which would have cost me RM700 a month for rental." She beams again.



#### How Hospis Malaysia is supporting:

- Worked together with the palliative care team at Hospital Selayang, the patient and her family to determine the patient's goals of care
- Symptom management with 24-hour emergency support