

The Power of Advocacy

By Dr Tan Poh Kiang, Editorial Board Member

“...compassionate care does affirm and honour the individual’s humanity...provides healing on the other levels than the physical.”

Editorial note:

All names have been changed to protect the identities of patients.

For the longest time, I have associated the term “advocates” with lawyers – that is, they represent and defend their clients. With each year of medical practice among people who consult doctors for more than physical symptoms, I am beginning to appreciate that it is an underrated role that doctors ought to assume.

LISTENING TO HER WOES

My awakening to this role was very recent. *Hannah*, who is in her early 50s, dropped by my clinic to tell me that her tremors and palpitations have improved. Although I have been aware of her sensitivity to stimulatory effects of caffeine, pseudoephedrine and salbutamol, her recent spate of relapses coupled with loss of weight pushed me to do a thyroid function test. It turned out normal. We eliminated most of the possible factors but could not arrive at any conclusion regarding the cause. The conversation turned to her recent Genting Highlands trip and just as I was winding it up, she dropped a bombshell almost casually.

“I can’t take this any more. I have got to tell someone. Dr Tan, my husband has AIDS.”

This shocking revelation explained the cachexic look of *Hannah’s* husband who had seen me a few times for acute infections. I had no clue. She went on to share her agony over her spouse’s refusal to disclose the diagnosis to their four children and his mother. She worried about how to handle the family’s confusion when he eventually dies and has to be cremated immediately. She speculated about the blame that her children and mother-in-law would heap on her for not informing them before his death. She was anxious about her ability to see her last two kids through school.

“You are the only one I can think of to talk to. I’m going mad having to shoulder this all by myself.”

Whatever words I had to offer did not seem appropriate or comforting. I clumsily assured her that I could sit down with her husband to persuade him to help his loved ones cope with the stigma of HIV. She wiped off her tears, nodded her head and left. I was left with the stinging question – how does a family doctor fit into this situation in terms of help and

service? At the very least, I was available to let her ventilate. But what else can I do?

BELIEVING IN HIS TROUBLES

I learned from the Oxford Dictionary that an “advocate” is also one who pleads for another. This reminds me of a phone call several months ago when I was chided by an irate wife for prescribing her husband, *Soon Leong*, ten tablets of sleeping medication. I tried to explain the rationale of giving him sedatives even though I am fully aware of his past history of drug dependency. (I was the one who helped him wean off his dependency over an extended period of four years.)

Soon Leong is a man familiar with misfortune. Five years ago when his Chinese antique business failed, he was also diagnosed with gout, hypertension and hyperthyroidism. He was already being followed up by a urologist for malignant seminoma that was removed, and a neurologist for paroxysmal syncopic spells. He could no longer afford consulting his specialist doctors at Mount Elizabeth Medical Centre. His greatest pain was that he ran out of money to support his dependency on sleeping medicines and thus suffered major withdrawal symptoms. I was very hesitant to take him on as I am generally wary of handling drug dependency and would rather refer to my colleagues in psycho-medicine practice. However, we made a contractual agreement that I would help him wean off gradually, provided he followed the rules I had set. It was extremely difficult to handle his bargaining and denials but I persisted only because it was also his effort to stave off a divorce. His wife had agreed to reconciliation only if he could demonstrate his recovery from drug dependency.

Why did I break my own rule four years later? *Soon Leong* had not been able to hold on to a job since he was made bankrupt. His lack of necessary knowledge and skills compounded by his multiple medical conditions hindered his access to a job that could bring him more than a thousand dollars a month. His medical treatment at the National University Hospital was heavily subsidised and he knew that if he were employed, the medical social worker would take him off the subsidy scheme. That meant he would not be able to afford his follow-up and treatment at the oncology,

endocrinology, and urology clinics. His wife had labelled him a “good-for-nothing bum” and most of his relatives ostracised him. His adopted son is now old enough to ask his dad why he does not work regular hours like his friends’ dads. So his days are spent wandering shopping malls and hanging around coffee shops to kill time, to convince his son that he had a job. When *Soon Leong* told me his troubles, his tears flowed freely and his eyes burned with shame. He confessed that he had thought of suicide as a way out. He laid awake at night wondering what future hope he had. In desperation, he asked for a few sleeping tablets for relief. I gave in. I chose to believe him and thus alienated his wife.

ACTING ON HER BEHALF

I am also learning that advocacy involves acts of kindness and practical help for those whom we serve. *Ah Huay* is a school drop-out but has impressed me as a highly intelligent and capable woman. Her husband “inherited” his elderly mother to live with him because he is the youngest of six children. *Ah Huay* is the one who cooks for the family (including a sister-in-law who lives three doors away in the same HDB block) everyday, does all the domestic chores, runs errands for everyone, and is devoted to caring for her mother-in-law. So, when she called and asked me to make a house-call, her desperate voice told me that this was urgent and her usual efficiency did not suffice.

“My back is killing me from cleaning up her watery stools for the third time today!”

Her mother-in-law looked lethargic but was glad to see me when I arrived. Her bowel incontinence was one of several signs that she was suffering something serious. A temperature of 38.6 degrees, a blood pressure of 90/60 mmHg, and the inability to eat or drink convinced me of the need to admit her into the hospital. The diagnostic part was a no-brainer even for *Ah Huay*, but she had not hitherto been able to convince her husband or her siblings-in-law that the old lady could not be cared for at home. I had to call her husband and told him firmly that I had

decided to call the ambulance for his mother unless he wanted to be responsible for her fatality.

Ah Huay called often to ask for help in other aspects of domiciliary care. I had connected the family to Nightingale Medical Services for them to change the in-dwelling urinary catheter periodically. In order to save cost, I had to source for cheaper versions of disposable body wipes (wet paper towels used to clean bed-bound patients). She would bring the huge bag of medications from the hospital to discuss with me how to rationalise and minimise poly-pharmacy.

HOLISTIC HEALING

A patient (who has become a good personal friend) returned on home leave from a PhD programme, and came by the clinic to give me a book that he predicted I would enjoy. “Sometimes my heart goes numb – love and caregiving in a time of AIDS” by Charles Garfield (Jossey-Bass Inc., Publishers, 1995) is a collection of essays portraying the challenges faced by those who care for AIDS victims. A trenchant observation made by Tom Schiller, M.D. spoke deeply to me about the whole concept of advocacy. He said:

“Many stories of caregiving relationships demonstrate for me that the biggest difference of all is the difference between zero and one, zero being the absence of a compassionate caregiver who is there for the patient as a partner in the healing process, and one being the presence of such a person. The absence contributes to the painful reduction of the patient to the status of an object or a problem. The presence of a caregiver does not necessarily elevate the patient, but compassionate care does affirm and honour the individual’s humanity. Such care provides healing on the other levels than the physical.”

Advocacy can potently transform the cutting-edge life sciences into the art of holistic care. Patients need accurate diagnosis and cost-effective treatment, no doubt. More often than not, they are hoping to have somebody to listen to their woes, to believe in them and to act on their behalf. I am learning to be that advocate for those who seek my help. ■