

A Publication for Staff & Volunteers of HCA Hospice Care

You Are Always Here, All The Time

~ By O Thiam Chin

The following is a short story inspired by one of our patients, Mr Edgar Lu, who was struck with amyotrophic lateral sclerosis. It is told from the perspective of his wife and caregiver, Ms Gina Ho, who had kindly allowed Mr O and hospice staff to gain insight into their lives at home. This was written as a part of a programme at the Singapore Writers Festival 2011. Mr Lu passed away in August this year.



Above: Edgar communicates with Thiam Chin via the computer, with an eyeball-tracking device that allows him to type.

You don't need a lot of things after what happened, always telling me to put them away. You don't say this, of course, not in words or nods or gestures; all this is lost to you now. Every time I bring you an old book or a CD, you would reject it. You only have to close your eyes, and it is enough to tell me what to do with them. The dust has settled over the shelves of books in the study room; some of them have been there since we moved in, and some have yellowed, crumbling. You have no need for them anymore.

These days, you seem to be contented with the computer and the cats. They circle round your bed in the living room all the time; there are six of them, picked up from the streets in the neighbourhood. They have gotten used to the life in the apartment, and we have come to depend on them. You like it when they jump onto the bed and lie beside you. You don't like the touch of anything rough – the corners of a pillow, the edges of freshly-laundered pajamas, the tubes around your face – but these cats, you like their caresses, the brush of their short-cropped fur against your skin. Your eyes say it all; you close them, and your pleasure is evident across your facial features.

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Yes, pleasure. It is hard to tell sometimes whether you can still feel it, but when the cats are with you, it is hard to refute this fact. The cats have found the right spots to rest their bodies against yours – the small of your back, your ankles, near the stomach, the bay of your arms. You let them lie next to you for hours at a stretch as they nap and yawn and curl themselves in. Even as they wander round the flat, there is always one or two close to you, within touch or sight, even at night when everyone has retreated to their rooms.

Words – you had so little of them before what happened; and now, you have none. You were always so quiet, back in the days when everything was taken for what it was, always the same for as long as we live. The words were there one day, and then, they were not. Now you open your mouth, and there are only grunts, soft or loud, incomprehensible. Do you think about your voice, how it was like? Do you still remember how you pronounced certain words, leaving out the 's' or 'ed'? Maybe you have forgotten, or perhaps thought it was best not to remember. The words you used now are the words displayed on the computer screen, words you blink into existence, with a special visual-communication programme the people of the hospice had set up on your computer. It was not easy, at your age, but you were determined and resolute, as ever. In you, some things never change. You blink, and the words appear on the screen. A letter, a short word or two, and then, much later, a simple sentence. Yes. No. Thanks. How Are You? I'm Good. I Like To Have Some. OK. You take a long time to blink a reply; you work out the words slowly, patiently, always eager to give a full answer. You move your eyes across the word pad on the computer and the cursor follows the movements. You blink, the letter appears, and then you blink again. Over time, you got used to using your eyes to talk, to master this painstaking language of blinks, to build your life around unspoken words.

Most of the time, you work on the computer, between your milk-and-morphine meals and short periods of sleep. You update your blog, upload the photographs, design greeting cards for different festive days – Easter, Christmas, Lunar New Year – and even write programme software, something you had enjoyed doing in your last job, in a different life, eleven years ago, as an IT specialist. You would spend days on a programme and when it finally worked, you would put it on your blog, for anyone to use. You reply to emails and keep up-to-date with the latest news online, *The Straits Times* or *The New York Times*. You have joined different support groups for people with the same condition as

you. You read their stories and were inspired, touched by their lives, by their strength and resilience, by their courage to recreate new lives out of old ones. You couldn't see that your life is just as good and inspiring as theirs. You read the latest developments in the field of medicine for your condition, and would cut out the hopeful parts and put them on your blog, hoping others would take comfort in them, just like you had.

Locked-in, locked away in a body that has failed you, your life lived only on the inside, hidden from the world,

filled with so many things, as real and vital and vivid, as anything outside.

In your mind, in that intensely

private world, you are more alive than anything, even though you can't move a finger or turn your head without any assistance. You would lie there, motionless, and the next day, on your blog, there would be an update on your life, where you would talk about how you had spent your day, yesterday, with so much details, so many ideas, full of plans and hope, that it is impossible not to think about the different paths and journeys you take every day, inwardly, towards the heart of your being, towards something invisible but real. You are not locked in, not then, not now. You can never be.

“locked away in a body that has failed you, your life lived only on the inside ...”

Yes, it took a long time to get to this point, to be where you are now. Back then, you were angry, at your condition, at the inability to move or talk or do anything with your hands, at me, at our sons, and when you finally came round to it, at God. You raged against what he had done, what you had done, his silence, your helplessness, your undeserved fate. Your eyes went crazy with derision, with a wildness, primal and restless, and the tears stayed pooled in the deep eye-sockets where your flesh had hollowed out. They streamed down your face when they finally overflowed. You couldn't wipe them away, and so, your grief and rage were open for all to see. You couldn't turn your face away, to hide or pretend otherwise, and your helplessness was all the more hard to bear for all of us. Everything was done to relieve the pain, to bring some comfort, to make it bearable, and to a great extent, you found solace in them. What couldn't be done – your anger at God – was left alone.

But then – and this was after some years – something happened. Something broke in you. Your eyes softened,

became almost at ease. The mention of God started appearing again in your writings, in the words you used. The tone of your words had calmed, becoming less urgent, softer and more accepting, and they were no longer about fate or pain or grievance, but about grace and love and looking to the future, but mostly it is about grace.

Sometimes when the boys come to sit beside you, on the bed, you would brighten up and start to blink at the screen, trying to make conversation. The words would come slowly. How was your day? What did you do? Have you eaten? You would listen to their replies and ramblings, and then you would ask some more. Nothing in their lives seems un-interesting to you, or insignificant. Sometimes even before the words appear on the screen, they would have gotten bored, or distracted, ready to move away, to slip into their rooms, to their own worlds. You would let them go and they would leave quietly. You would then close your eyes, not to sleep, no, but to think, to hold still against the changes in the boys that you could do nothing about. You have watched them grow over the years – nineteen and twenty-one now – and they are not the young boys they used to be, who were contented to be by your side, attentive to what you had to say, stretching their heads to your face, their faces stricken with awe. It's a truth of life: Sons will always outgrow their fathers. Knowing what you know now, you would close your eyes for a long time.



City at twilight. Photo by: Jane Steinbeck

Some nights, you stirred in your sleep and your eyelids would flutter with the movements of your dream. What did you dream about? You used to share these dreams with me, in the early days of our life together. Dreams about your childhood in the kampong, your student days in the university, and your trips overseas, to Egypt, China or Tokyo, the days and weeks spent in these countries, moving and leaving and arriving. The sights,

you exclaimed, the sights, they simply filled you up, these holy cities and derelict towns taking site in you, be-

coming part of you. Are these cities what you were dreaming about during those nights, your endless journey through them, walking on solid ground, breathing in the raw dusty air? You gave no indication the next day, nothing about what you had dreamt or where you had been. You have always been a solo traveller, a quiet observer.

You like to flip through the albums, all the photographs scanned and saved on your computer. You would take hours to peruse them, sometimes going through an entire album very slowly, sometimes in random, leaping from one particular photograph to another, like the skipping of memories, one leading to another, in a loose thread of hidden meanings. Photographs of the boys when they were toddlers, the cats, the picture of us at East Coast Park, backlit by the setting sun, our faces straining with an untested happiness. Sometimes you would look at the old photographs of your younger self – at the park, behind a desk, standing, sitting, smiling, laughing, as a boy, a young man, a husband, a father – staring at them as if you wanted to make contact with the man in these photographs, to see into him, and to fathom the long distance that had separated both of you since then. You would have stared at these photographs for hours if you could hold up. But the effort exhausts you completely, this act of remembrance, of forgetting. You would switch off the screen, but still, your eyes would linger on the darkness of its surface that reflected back a distorted image of you lying on the bed.

You were hopeful, once, in the early years of your condition, of a recovery, a miracle. You attended a special service in church, sitting among the walking and the afflicted, listening to the message roaring from the pulpit, of healing and deliverance and the promises of God. The blind shall see, and the lame walk. Ask and you shall be given. Ask. It is as simple as that, to utter the words, and you would be given. You must have asked, quietly and fervently, immobile in the wheelchair, hardly able to lift your eyes above the pulpit, drips of saliva dribbling into the napkin under your chin. You must have hoped against every single ache of hope, for the words to be true, for His will to be done, because you finally did get what you hoped for. You

“... about grace and love and looking to the future, but mostly it is about grace.”

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managed to move your head to the side and clasp your hands together as if in prayer. Your eyes brimmed with tears and fire.

But hope, sometimes, makes a fool of us all. You moved one day, and then the next day, you were where you had begun, and it seemed like nothing had, and would ever, changed. You had hoped, and you had been given, very briefly, and now it was taken, and that was all that was. Even after this, you still went back to church and still attended the healing services. You went to church and you hoped, and when you couldn't go anymore – you couldn't keep your body upright anymore, your limbs have weakened considerably, your health failing – you kept the hope to yourself, tiny and manageable. Hope, as they said, is always the last thing to die.

Eleven years. A long decade and a year. How the years have worn you down with their passing. You have become weaker, more fragile, and your skin paler and lighter, milk-white, almost luminous. Your hair has

turned grey, thinning in patches, but your eyebrows are still black, caterpillar-like. Your fingers no longer possessed the strength they used to have; now they hold a different kind of strength, one that is gentle and soft, pliant and quiet. The years took away some, but still, you are still you, and you are always here, all the time.

But more, more than just being here, you are – and I know this is true, I know – becoming more of yourself, the true nature of who you are, what you are really meant to be. The silence surrounding you, in you, has a way of refining and sharpening you, making you into a man that is taking shape, growing and transforming within, inside you, inside this second womb. How much have you changed? How much would never change, no matter what you do?

Would you, one day, emerge from it, like a newborn, like a young man, screaming, hoarse with hope, blue with life and blood and hunger? Would you then live a second life, a life you truly desire?



Bringing GPs into the Palliative Care Framework

*~By Christine Van der Ven
and Emma Goh*

Left: Dr Chong gives an introductory speech to GPs.

Forty family physicians attended a Symposium for General Practitioners (GPs) titled “Doctor! ... The hospital said the condition is terminal” – A Hospice and Palliative Care Primer for Family Physicians.

It was held in conjunction with the Hospice Awareness Week, which falls in the month of October every year. Altogether, everyone involved whether it was the organisers or the participants, had a rich and fruitful Saturday afternoon on 15 October 2011. This project is spearheaded by Dr Chong Poh Heng, Deputy Medical Director, HCA Hospice Care. The objective is to build connections by reaching out to GPs in the community.

The family practitioners have always been curious about the work that we do in palliative care. They have previously indicated that they would like to learn more about how to support their own patients who face life limiting illnesses. However several barriers thwart their efforts to provide what they describe as meaningful and rewarding work. The lack of knowledge and experience are some of them. Resource constraints in terms of time and concerns regarding financial burdens on the families are others.

In Dr Chong’s view, the GPs’ proximity to patients, and the longstanding relationships they have with their pa-

tients as a family doctor, make them natural partners in delivering quality, multi-disciplinary palliative care.

“Excellent communication skills, a particularly important asset in palliative care, have been honed through their specific training for and on the job. Besides, the typical GP would have known the patient and his/her family for a number of years. This rapport that is built before our patients become ill is something we will never attain ourselves despite the best of intentions and skills,” says Dr Chong.

It is in this spirit that we conceptualised the first and hopefully many more exchange programmes between GPs and specialised Palliative Care providers.

After treating our invited guests to a sumptuous lunch, Dr Akhileswaran, CEO and Medical Director of HCA Hospice Care, opened the symposium by first introducing HCA Hospice Care and its services. He then passed the podium over to Dr Richard Yap and Nurse Amy Lim. They used a case study to impart the principles and practical aspects of rendering supportive care. The accurate assessment and appropriate management of pain was highlighted by Dr Yap.

He introduced the concept of the WHO Pain Ladder to guide initial therapy and expounded on how one titrates and brings in adjuvant drugs to augment the treatment regimen. On a more humanistic note, Amy shared with everyone the finer points of nursing a dying patient and the intricacies of sensitive communication at this difficult time. The latter was poignantly illustrated by screening a short film that portrayed her interviewing that particular patient discussed in the case study, days before he died.

Questions came hard and fast during a forum thereafter, with physicians clearing their doubts and seeking advice on how to deal with various situations including that of collusion and euthanasia. After short tea break, Dr Chong presented a

survey of the palliative landscape in Singapore to help the audience understand the existing network of services available locally. Following that, he rolled out the HCA ‘GP buddy’ system. He explained how HCA and family physicians can work together, with intrinsic benefits to all parties involved, most of all the patients and their families.

For the GP, they get regular updates from the hospice team, experientially learn the skills in delivering end of life care, and ultimately derive satisfaction in being able to provide holistic care to their own clinic patients. Our patients stand to gain in continuity of care, and the additional advocate in the GP at a critical point in their lives. Bereavement care could also be enhanced with the GP’s involvement, at a time when the hospice team withdraws its service upon the death of the index patient.

The day ended on a high note with physicians lingering after the symposium to talk to some of our staff who were present. Many participants provided feedback that they had found the symposium relevant and helpful. Some had even requested for more seminars or similar talks to be conducted on a regular basis.



Above: GPs go through their notes.

Coffee with . . . Dr Adrian Kan

In this issue, HCA's Emma Goh sits down with Medical Officer Dr Adrian Kan, who hails from Tasmania, Australia. He came to Singapore in 2009 and talks about his learning experience in palliative care.

Why did you come to Singapore?

After completing my internship at the Royal Hobart Hospital in Australia, my father suggested coming to Singapore for a couple of years in order to experience working in a different healthcare system. My father had worked as senior consultant anaesthetist at Singapore General Hospital (SGH) for many years and he thought that it would be very educational and enlightening. My first year was spent with the Department of Anaesthesia and Surgical Intensive Care at SGH. After that, I did a six-month attachment with the Toa Payoh Polyclinic, and then for my last six-month attachment, I chose HCA Hospice Care.

Why does palliative medicine appeal to you?

Most doctors entering medicine do not contemplate spending any large amount of time in a palliative setting simply because they feel that treating and curing patients is the main goal of the health care system and that working in such a setting would be too depressing. In fact for most doctors, their only experience with palliative care is as a medical student and even then, it is only usually for a handful of days. As such, most of my colleagues were surprised by my choice to do a six-month attachment with here, especially since it was my last attachment in Singapore before I returned to Australia. I chose HCA Hospice Care as my last six-month attachment for a variety of reasons.

The first reason was that I had always felt that even in cases where the prognosis was grim and no curable treatments were available, it was still important to make the patients feel as comfortable as possible in their final days. The second reason was that since my palliative care experience was limited and given that I only had a short amount of time left, I thought that home hospice care would be a more interesting undertaking than working in an in-patient hospice setting. I was also curious as to what was exactly involved with home visits since my medical career had, up to that point, been predominantly hospital/polyclinic based.

Did your expectations meet with reality?

I am very pleased with my experience. I was always amazed at how much people appreciate it when you visit them to find out how they are keeping and to make them just a little bit more comfortable.

I am very thankful that the patients and their families gave me the great privilege to see them in their own homes. Seeing a patient in a clinic or in a hospital setting often does not give you a true picture of a patient's situation. When you see



Above: Dr Adrian Kan at his work desk in the HCA—Ci Yuan (Hougang) satellite centre.

a patient in their own home, you can see firsthand how the patient's health issues affect not just their own activities of daily living, but also how the patient's disease impact the rest of the family and their caregivers. It is often very easy to forget these aspects when you are working in an environment focused on seeing as many patients as possible.

Can you give a few examples on how a patient's health affects their daily living?

For example, a patient with lung cancer may initially be relatively symptom-free, but as their disease progresses, their condition may deteriorate. They may become increasingly short of breath and find even simple activities such as bathing too tiring to perform by themselves, or they may find that their disease causes them to experience significant amounts of pain which requires high doses of analgesia [painkillers] to control. If the disease spreads to their brain or to their spine, they can also develop weakness, seizures or even become paralysed. All of this puts increasing pressure on their caregivers physically, emotionally and even financially, as the patient lose the ability to care for themselves.

As a doctor, do you feel if there is a difference between looking after end-of-life patients in their own homes and in a hospital or in-patient hospice environment?

At the very final stages of a patient's disease, there isn't much difference in terms of the level of treatment they receive. In both settings, once a patient is placed on the Care of the Dying Pathway, the treating medical team will focus on making the patient as comfortable as possible. All unnecessary or irrelevant treatments will be stopped in favour of this goal. I personally feel that there is no right or wrong answer when it comes to where a patient chooses to die, all that matters is that they be able to do so with dignity.

Overall, I felt my time in HCA Hospice Care was highly enjoyable and very fulfilling. I would like to thank HCA Hospice Care for allowing me to experience it and given the choice, I would definitely do it again. I would strongly encourage others to spend some time working within a palliative care setting, even simply on a voluntary basis.

Reflecting on the Light from Within ~ By Lim Yuan Kang

Many paths lead us to volunteer at HCA Hospice Care. I came here three months ago on a grant awarded by Middlebury College in the green mountain state of Vermont, to research hospice volunteerism and public education. Moreover, I hoped to kickstart a mini loan library of hospice books and DVDs to aid in that process.



Above: Yuan Kang (extreme right) with students from NUS at the HCA Day Hospice as they prepare for a programme.

Over time, it has come to me that volunteerism and awareness within hospice in Singapore differs as much as it agrees with my limited observations in Vermont. While the stigma associated with hospice remains high in both societies, many underlying cultural and social reasons contrast. Just as the local hospice in Addison County (where my college is located) depends on the retired and mature to volunteer, a younger profile aids Singapore. Similarly, both public awareness efforts are promising – except that it radiates outwards among the mature in Vermont while the Singapore young remains the most receptive to issues of illness and death. However, reminders of one's mortality stills the tongue and quietens conversations. Therefore, personal conversations may most effectively disseminate the basic concept of hospice, the Latin root which is associated with hospitality.

In spite of my findings, I have learnt as much, if not more, from the patients. Writing on volunteerism merited a stint in the daycare section, where one is privileged to share in the lives of the patients and be amazed at the trust they offer us to enter their lives, however briefly. The 30 or so patients that come to daycare present a window into the lives of not just 900 home hospice patients whom HCA cares for, but innumerable others who face such daily struggles.

I have glimpsed that which Dr. Elisabeth Kübler-Ross, pioneer of hospice care, saw when she said *"People are like stained-glass windows. They sparkle and shine when the sun is out, but when darkness sets in, their true beauty is revealed only if there is a light from within."* Credit goes to numerous volunteers and staff that allow this glow to surface occasionally. For some, bright eyes light up, some find a hidden reserve of energy to dance to a

song, for others, loud singing in a rousing voice. Nonetheless, the remaining prefers to sit in silence – being in the moment – the only sign a serene visage and a solemn thank you at the end of the day.

I have learnt practical skills such as moving patients safely, communicating in the face of language barriers, patience, bringing energy to an otherwise

dull afternoon, listening skills – all represent different facets of my experience. Yet beyond these, the central aspect that unfolded during these three months was not the professional (or volunteer) extent one can accomplish in caregiving, but the importance of one's presence that

One surprising lesson came unexpectedly – that patients who receive care desire to care for others as well. Care came in the form of constant reminders to take my lunch, to share in their tea break, or to rest – seemingly trivial concerns that, on the contrary, show us their ability and desire to care for others have not diminished at all. In this way, I believe we can form a bridge to the patients, not as caregivers to patients, but as companions and friends who can walk, even so briefly, on the same journey. The words expressed so far will not convey the sense of loss at leaving. Truly, they might have lost a volunteer, but I will miss these 30 friends at HCA Hospice Care.



Yuan Kang (pictured right) volunteered from June 6 to August 29 during his summer vacation this year and brought smiles to staff and patients alike. Thank you Yuan Kang for your energy and enthusiasm!

PasSAGES Unwound ~ HCA Patients Inspire Writers

Singapore authors teamed up to breathe life into the untold tales of those battling terminal illness and the aged sick.

The writers Ms Heng Siok Tian, Mr Aaron Lee, Ms Jayanthi Sankar, Ms Noor Hasnah Adam, Ms Stephanie Ye, Ms Yeo Wei Wei and Mr O Thiam Chin, whose story appears in this issue, visited HCA Hospice Care and SWAMI Home for inspiration.

From his unique perspective, Mr O was able to recount that interviewee Mr Edgar Lu was “a dynamic man, very alive and thoughtful; forceful at times within his body” before he passed away in August.

Their intimate conversations with patients and caregivers formed the basis of seven short stories, excerpts of which were presented at the PasSAGES Unwound event on Oct 30 in conjunction with the Singapore Writers Festival.

For an hour, the audience was transported into the hearts and minds of patients, whose inner strength rendered the room into complete silence, especially following Ms Noor Hasnah Adam’s gripping delivery



Above: O Thiam Chin presents a piece from his short story “You are Always Here, All the Time” during PasSAGES Unwound.

from her story *Tales of Rabiah*. The spoken words were in Malay but the intensity of the emotion needed no translation.

Then Ms Heng had the crowd almost seeing the white-walled gallery change colours before their eyes as they listened to her story *Whose Song is it Anyway?* - “Are his eyes yellowing? Is the ceiling turning yellowish? . . . When one stares long enough, hard enough at something white, like a ceiling, does it yellow?”

PasSAGES Unwound is a project organised by the Quarterly Literary Review Singapore. The event was curated and moderated by author Yong Shu Hoong.

~ Jane Steinbeck

Upcoming Programmes:

- ◆ Palliative Caregivers’ Training for November and December.

Each session is from 12.30pm to 5.30pm.

- HCA-Loving Heart (Jurong) Centre || 5 Nov and 3 Dec
- HCA (Bedok) Centre || 12 Nov and 10 Dec
- HCA-Ci Yuan (Hougang) Centre || 19 Nov and 10 Dec
- HCA (Woodlands) Centre || 19 Nov and 17 Dec
- HCA Hospice Care Headquarters || 26 Nov and 17 Dec

To register, please call 6251-2561.

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