

*NOTE: No part of ANY text and material related to **Holding Space** can be used, copied, published or quoted without written permission from the author(s).*

**Word from the ‘Wart’<sup>1</sup>  
27<sup>th</sup> April 2019**

What is holding whatever? Is it a standstill? Is it waiting? Holding still, holding tight? Is it about bracing for some even bigger disaster? Is it coming to terms with the unknown? It is so uncomfortable.

Ngiap Heng’s *Holding Space* happened at a most opportune time for me personally, to reflect on my own experience. My 100-year-old mother passed away this March 11<sup>th</sup>, in the midst of this project. I knew that *that* call would come, but when it did, it was still disbelief. My mother had dementia for 20 years, mostly in fulltime care, in an elder care home in Taipei.<sup>2</sup> My mother lived in Taipei and I here in Singapore, so I outsourced her care. I have to constantly reason with myself that there is care and there is care. My siblings (both in North America) and I are *the* caregivers but the daily chores of *physical care* can be (and are) delivered by a hired professional, 24x7. I ask myself: why can’t I do everything, like a good daughter? Only obvious to me over time, I found that with time and immobile-ness, my petite mother expanded to 67 kilos; I am not strong enough to do the frequent lifting of her to/from bed and wheelchair, which was for nearly ten years. However, I convinced myself that despite her advanced dementia in the last decade, she did acknowledge my presence by flickering her eyelids and moving her lips. That was the entire extent of our communication for the last ten years. The *emotional care* of my mother is my job; the *physical* can be outsourced.

When my mother developed breathing difficulties late last year, she went into ICU and had to undergo a tracheostomy (cutting an opening in her neck, below her vocal cords to place a tube into her windpipe, allowing for air to enter directly into her lungs). The procedure is considered uncomplicated (normally takes 15-20 minutes), but she was in surgery for an hour; the last 30 minutes of not knowing what was going on was excruciating.

The big question from the medical staff was always: “do we resuscitate?” They said that she is so old, resuscitation is aggressive, so aggressive that it would damage her. So what’s our decision? I had to think very hard, consulting my two older siblings. We had mixed feelings as our mother did not leave any instructions. Death is a topic that our mother refused to talk about. We finally said “yes, resuscitate” and I added, “yes, at least once”. I thought very hard: *not* what I personally would have wanted, but what our mother would have wanted. I centered the decision on her character, what I remember of her. While growing up, our mother would go all out to preserve life, for herself and her loved ones. One sniffle and her aspirin tablet would show up. She had not gotten to 100, ignoring being sick. She would have wanted us to try to resuscitate her.

My mother was a devout Christian, daughter of a pastor, married to a pastor. She believed dying to is going home to heaven, to God. And yet, she had great discomfort about her journey getting there, the pain of ill health and treatment, the pain of loss, and the pain of not seeing her children, grandchildren and great grandchildren. I often wonder if she could change and take comfort in the possibility of seeing again the people she loved, who had passed on (her husband, her own family).

What do I believe? It is natural to live and natural to die. From the moment we are born, we are already expiring. Yet, there is so much living to do, so consuming that we don’t want to think about death. What I am and can still become are in God’s hands and I trust Him to put angels in my path. I admire my mother for her tenacity, stamina, love for food and just plain goodness. I want to be like my mother ... but I also don’t: I want to be better prepared. End-of-life preparation adds to faith and headspace to enjoy living. It also removes confusion, mystery and unwanted help for my son (who lives overseas); to minimize his fumbling around gives me peace of mind. Yet, I find Singapore social welfare policies lacking in options for individualized planning; the assumption is that immediate family is the primary port-of-call. What if one doesn’t have family in Singapore or live in private housing? Where is the licensed caregiver?

Anyone’s final end is easy to grasp (you are dead, done), it is what’s in-between that is so trying. Imagining God, He will throw me a surprise. I need more options. Today, at the end of each day for me, *Holding Space* is about holding on.

---

<sup>1</sup> ‘Wart is short for Stalwart, which Exactly Foundation’s first resident Kevin Lee suggested that for future residences, I should pen a statement as “Exactly Foundation Stalwart”. Thought “Stalwart” carried too much adult responsibility ... ‘Wart will do.

<sup>2</sup> Taiwan is so advanced in elder care options; my mother’s place offers assisted-living i.e. studio apartments with ensuite bathrooms and kitchenette for mobile individuals who can opt to eat in the canteen or cook and can take the shuttle bus to the MRT station ... or hospital-like ward for those in such need ... or a closed-off dementia unit of 6-8 mobile individuals where services come to them rather than them wandering around, getting confused finding places.