

THE

HOSPICE

LINK

MARCH – MAY 2019 • MCI (P) 108/12/2018

The course of respite

A father's 27-year caregiving journey

REACHING OUT TO THE NEGLECTED CAREGIVER



PLUS
Views from
the pros



SINGAPORE
HOSPICE
COUNCIL

Members' Contact

Assisi Hospice
832 Thomson Road, S(574627) T: 6832 2650 F: 6253 5312
www.assisihospice.org.sg assisi@assisihospice.org.sg

Bright Vision Hospital
5 Lorong Napiri, S(547530) T: 6248 5755 F: 6881 3872
www.bvh.org.sg enquiries@bvh.org.sg

Dover Park Hospice
10 Jalan Tan Tock Seng, S(308436) T: 6500 7272 F: 6254 7650
www.doverpark.org.sg info@doverpark.org.sg

HCA Hospice Care
705 Serangoon Road, Block A #03-01 @Kwong Wai Shiu
Hospital, S(328127) T: 6251 2561 F: 6291 1076
www.hca.org.sg contactus@hcahospicecare.org.sg

Metta Hospice Care
32 Simei Street 1, Metta Building, S(529950)
T: 6580 4695 F: 6787 7542
www.metta.org.sg hhospice@metta.org.sg

MWS Home Hospice
2 Kallang Avenue, CT Hub #08-14, S(339407)
T: 6435 0270 F: 6435 0274 www.mws.sg MWShh@mws.sg

Singapore Cancer Society
15 Enggor Street, #04-01, Realty Centre, S(079716)
T: 6221 9578 F: 6221 9575
www.singaporecancersociety.org.sg
hospice@singaporecancersociety.org.sg

St Andrew's Community Hospital
8 Simei Street 3, S(529895) T: 6586 1000 F: 6586 1100
www.sach.org.sg general@sach.org.sg

St Joseph's Home
36 Jurong West St 24, S(648141) T: 6268 0482 F: 6268 4787
www.stjh.org.sg general@stjh.org.sg

St Luke's Hospital
2 Bukit Batok Street 11, S(659674) T: 6895 3216 F: 6561 3625
www.slh.org.sg referral@stluke.org.sg

Changi General Hospital
2 Simei Street 3, S(529889)
T: 6788 8833 F: 6788 0933 www.cgh.com.sg

Khoo Teck Puat Hospital
90 Yishun Central, S(768828)
T: 6555 8000 F: 6602 3700 www.ktp.com.sg

KK Women's and Children's Hospital
100 Bukit Timah Road, S(229899)
T: 6394 8008 F: 6291 7923 www.kkh.com.sg

Ng Teng Fong General Hospital
1 Jurong East Street 21, S(609606)
T: 6716 2000 F: 6716 5500
www.ntfgh.com.sg enquiries@juronghealth.com.sg

National Cancer Centre Singapore
11 Hospital Drive, S(169610)
T: 6436 8183 F: 6220 7490 www.nccs.com.sg

Tan Tock Seng Hospital
11 Jalan Tan Tock Seng, S(308433)
T: 6359 6477 F: 6359 6294 www.ttsh.com.sg

Lien Centre for Palliative Care
Duke-NUS Medical School Singapore
8 College Road Level 4, S(169857)
T: 6516 4233 www.duke-nus.edu.sg/lcpc

Contents



- 2 Members' Contact
- 3 Chief Executive's Note
- 4 Reaching out to the neglected caregiver
- 6 A father's 27-year caregiving journey
- 8 The course of respite
- 10 Caring for caregivers – a physiotherapist's view
- 11 Empowering caregivers through training and more
- 12 Gearing up for the final stretch
- 14 Views from the Pros
- 15 Tips for Caregivers
- 16 Upcoming Events & Announcements

Supporting caregivers

An elderly man once shared that his wife has been suffering from dementia for many years and how he, as her sole caregiver, wished that he could swap places with her. When I asked what he meant, he went on to say, "All my wife does is eat and sleep whereas I have to care for her day and night." It dawned on me just how many caregivers in Singapore are like this elderly man – lonely, fatigued and weighed down by negativity.

It is estimated that there are approximately 210,000 caregivers in Singapore caring for seniors, children with special needs, the disabled, and the mentally and terminally ill (The Straits Times, 27 September 2013). The number is likely to have increased, given that Singapore is experiencing an ageing population with elderly persons aged 65 years and above who require support and care. Caregiving can be stressful. However, we hope that the burden of caregiving can be mitigated through caregiver education, support and enablement.

In this issue, you will find compelling stories about caregivers' experiences, the various programmes and support available as well as caregiving tips. We will be organising a two-day "Live Well. Leave Well." community event at Westgate (shopping mall in Jurong East) on 11 and 12 May 2019 to reach out to caregivers and the elderly. Come on down, bring your family and friends, and spend the weekend with us. There will be various booths set up to spread awareness about the service care and support available and provided by our community partners, educational talks by subject experts, entertainment, goodies and more.

So, do mark your calendars and "like" our Facebook page to get the latest updates.

See you in May!

Ms Yeo Tan Tan
Chief Executive
Singapore Hospice Council

We hope that the burden of caregiving can be mitigated through caregiver education, support and enablement.



Reaching out to the neglected caregiver

Caregivers also need support as they face upheaval in their lives. Compassion and practical help will go a long way towards easing their burden.

It is almost inherently human to feel compassion for a person diagnosed with cancer. Yet, compassion towards the patients' caregivers may not come as naturally.

With each cancer diagnosis, there is a systemic impact on the person with cancer and those in that person's social network. In addition to the one with cancer, the impact is felt most deeply by the caregivers. Yet, caregivers' needs tend to be overlooked, as the needs of the patients are usually more visible and immediate.


As those with cancer face multiple losses and grief, and adjustments to a different life routine, so do caregivers. Caregivers may face losses such as loss of job, relationships, and having to learn to adjust to new caregiving routines and skills. They also deal with more profound losses such as the changes to their loved one's personality and involvement in their lives due to cancer progression. For example, a caregiver may have to learn how to accept and relate to their loved one who is more easily irritable or depressed and who may no

longer seem to be the spouse or offspring they knew before.

It is common for caregivers to put their physical, emotional and social needs aside so that they can continue to meet the needs of their loved ones with cancer. As such, caregivers may also be less open to getting support for themselves. Yet being human, their needs are no less important. Hence, it is crucial for members in their social networks to develop compassion for them and to make the effort to reach out to them in ways that they perceive as supportive.

WORDS: AMANDA TAY, SENIOR SOCIAL WORKER, PSYCHO SOCIAL SERVICES, SINGAPORE CANCER SOCIETY PHOTOS: SINGAPORE CANCER SOCIETY

It is common for caregivers to put their physical, emotional and social needs aside so that they can continue to meet the needs of their loved ones with cancer.

The Singapore Cancer Society (SCS) Home Hospice team of medical professionals and social workers provide counselling services and explore caregiving options that take into account the needs and resources of patients and caregivers. Some case-by-case options include involving home personal care nurses and interim care services to provide respite care for caregivers. Medical escort and transport services for hospital appointments are also explored. SCS also provides caregiver support training periodically. 

Below and opposite page: With support from their social network, caregivers will be able to continue their work



SIGNS AND SYMPTOMS OF A CAREGIVER WHO MAY BE NEGLECTED:

- Feeling overwhelmed and inadequate in caregiving
- Having no personal time and social interactions
- Deterioration of mental and physical health
- Feeling like one is indispensable in providing care

SUGGESTIONS TO REACH OUT TO CAREGIVERS:

- Start conversations with caregivers on issues that they are most concerned with
- Provide a listening ear and a nonjudgmental attitude towards caregivers to share their struggles and anxieties
- Give permission to caregivers to have respite and to participate in activities they enjoy
- Provide practical support such as helping with errands, medical appointments or medication collection
- Engage social services that can provide respite care and counseling for caregivers

A father's 27-year caregiving journey

To Mr Phillip Tan, caring for his son, Harold, was a bittersweet experience filled with much love and faith, despite the many challenges.

For 27 years, 66-year-old Mr Phillip Tan was the sole caregiver for his only son, Harold. Harold was diagnosed with Williams Syndrome at five years old and passed away at 32 years old. In recognition of his dedication as an exemplary caregiver to Harold, Mr Tan received the Healthcare Humanity Awards 2018 under the Caregiver category.

Williams Syndrome is a developmental disorder that affects many parts of the body. Due to his condition, Harold had mild intellectual disability, developmental and physical issues like stunted growth, limited sight, speech difficulties and abnormalities in his jaw. He was unable to walk on his own.

Harold's father cared for him with great patience and love, helping him with all his daily activities. Harold could not open his mouth fully due to his jaw abnormalities, but he was a foodie. Mr Tan would patiently crush all the food that Harold wanted to eat and feed him using a teaspoon, allowing him to enjoy the taste while preventing

him from choking. Harold was also at high risk of bleeding from his gums and tongue; his father would gently clean the insides of his mouth after eating, to remove all food residue to prevent infection or potential bleeding.

When Harold had bleeding episodes, which could possibly be fatal, his father would reassure him. Mr Tan also carried Harold wherever he needed to go, including visiting the hospital twice a week for his life-sustaining dialysis. As there was limited support from other family members, Mr Tan had to manage the housework in addition to caring for Harold. Despite his tiredness, Phillip would do bible study with Harold and they would watch their favourite drama together.

As Mr Tan aged and Harold grew bigger, caregiving became increasingly challenging for the father, especially when Mr Tan had to carry and transfer Harold to his wheelchair. Because of Harold's jaw abnormalities, his speech was extremely slurred, and he would lose his temper at his father when he was not understood. As Mr

Harold wanted to celebrate his 32nd birthday with family and friends who were important to him.

Tan was no longer working and was devoting all his time to caring for Harold, he did not have a social life besides his family.

To Mr Tan, the greatest challenges were the unpredictability of Harold's symptoms as well as his eventual mortality. He said, "Everything was too hard for me to understand and bear; I grew tired and became fearful." His religion gave him strength. He said, "Harold and I put our trust in our all-knowing God to give us strength for each day. Although it was very difficult, we continued believing in Him and His purpose, and He gave us the strength to go forward doing His will and letting Him do the impossible for us."

In 2016, Mr Tan found comfort on his caregiving journey from the Assisi Hospice Home Care team, which provided home palliative care, and psychosocial and spiritual support for Harold and himself. Assisi Hospice's nurses and doctors visited regularly, and readily responded to Mr Tan's calls whenever Harold's bleeding occurred. Assisi Hospice's Medical Social Workers (MSW) offered Mr Tan emotional support and helped him cope with his anticipatory grief.

Mr Tan declined assistance for the practical day-to-day care tasks for Harold as he felt that he could cope on his own. However, he wanted to prepare for Harold's funeral in advance, to enable him to focus his time and attention on Harold when he became more ill. Assisi Hospice's MSW went through the process of planning the funeral with Mr Tan, including helping him with the printing and framing of Harold's photo for use during the funeral.

Assisi Hospice's MSW also had conversations with Harold about his end-of-life care preferences and wishes. Harold requested for a caricature drawing of himself as a keepsake for his family. The Assisi Hospice team sponsored a caricaturist to do the drawing, and presented it to Harold as a gift.

Harold wanted to celebrate his 32nd birthday with family and friends who were important to him. He invited the Assisi Hospice Home



Care team to his birthday celebration which was arranged in September 2017, as he saw them as significant people in his life who were there for him and his father during challenging times. It was his last birthday and he passed away peacefully in November 2017.

Ms Sandra Lim, Assisi Hospice's Senior MWS, shared, "In their quest to provide the best care for their loved ones, it's inevitable that caregivers experience varying degrees of physical and emotional responses to the stress. They may neglect their own basic needs and health. Many of them do not have someone to share their most genuine feelings and thoughts with, hence they experience a build-up of emotions in addition to the physical stress that they go through as caregivers. They may also lack practical support and have financial concerns. Due to the lack of time to find support for these issues, which is actually available, they may continue to suffer alone for extended periods of time."

To prevent burnout, she encourages caregivers to have conversations about caregiving experiences with others through their informal support network or with healthcare professionals. This helps to prevent them from developing feelings of isolation and helplessness on the caregiving journey. She said, "When challenges get too overwhelming, it is also easier for them to acknowledge that they will benefit from support to enhance their well-being."



From left:
The Assisi Hospice's Home Care team celebrated Harold's birthday with his family at the hospital; Mr Phillip Tan with his son, Harold.
Opposite page:
Assisi Hospice's gift to Harold – a caricature of him with his favourite food

WORDS: ANGELA YEO, MANAGER, CORPORATE COMMUNICATIONS, ASSISI HOSPICE. PHOTOS: MR PHILLIP TAN AND ASSISI HOSPICE

The course of respite

Medi Minders, such as Kay Thompson, elevate their time with their charges beyond clinical care with fun activities.



“**S**hall I read a story to you now?” Kay Thompson asks. Her charge, 11-year-old Danielle Seah, mumbles a muffled “yes” in response. At an age when most of her peers spend their days in school, making friends and trying out new activities, Danielle, a HCA Star PALS beneficiary, is confined to her bed.

She has spinal muscular atrophy, a neuromuscular disorder that leads to muscle wasting and impaired mobility. Unable to move at all, Danielle requires round-the-clock care, a role largely taken on by Vivian*, her family’s helper. Each day, Vivian follows a meticulous routine of diaper changing,

milk feeding, suctioning and physiotherapy.

The weight of responsibility on the caregivers of children with high nursing needs such as Danielle is undoubtedly heavy. This is where HCA’s Medi Minders come into the picture – they are a special group of trained volunteers who help to provide respite care for the caregivers of Star PALS patients.

SERVICE FROM THE HEART

Thompson spends four hours each week with Danielle, attending to her nursing needs and engaging in different activities with her. “We usually start with joint exercises,” she says. “For the rest of the afternoon, we will make

cards together for Mummy, read storybooks or simply just hang out together.”

There is always time for beauty and pampering in these sessions as well. “Danielle loves getting her nails painted and having facial massages,” Thompson says with a smile. These personal touches elevate the Medi Minder service beyond mere clinical care. Thompson’s sincerity is evident in her thorough understanding of Danielle’s medical and emotional needs; she devotes much care to each art-and-craft project the duo does together.

The young girl’s favourite pastime is to watch cartoons on autoplay on YouTube and Thompson is ever

Therein lies a common motivation that unites HCA’s Medi Minders – the drive to bring life into the days of these children and to be a source of support for their families.

observant to Danielle’s responses to the stimuli around her. “Sometimes, she finds certain cartoon characters scary and she’ll make protesting sounds,” Thompson says. “I’ll then look quickly for a different video for her to watch.”

Thompson’s attention to detail is also apparent in her record-keeping. In the course of each session, she jots down numerous details relating to Danielle’s routine, such as the time of her feeds and

medication, the amount of output in the form of urine and vomit, if any. On the flip side of the chart is where she usually includes a personal note for the patient’s family. “Sometimes, I will write, ‘She was a very good girl today,’” Thompson shares.

MOTIVATING DRIVE


Thompson first stepped foot on our sunny island in 2012, when her husband took on a job in

Singapore. “We didn’t know anyone here at all,” the Scottish native shares.

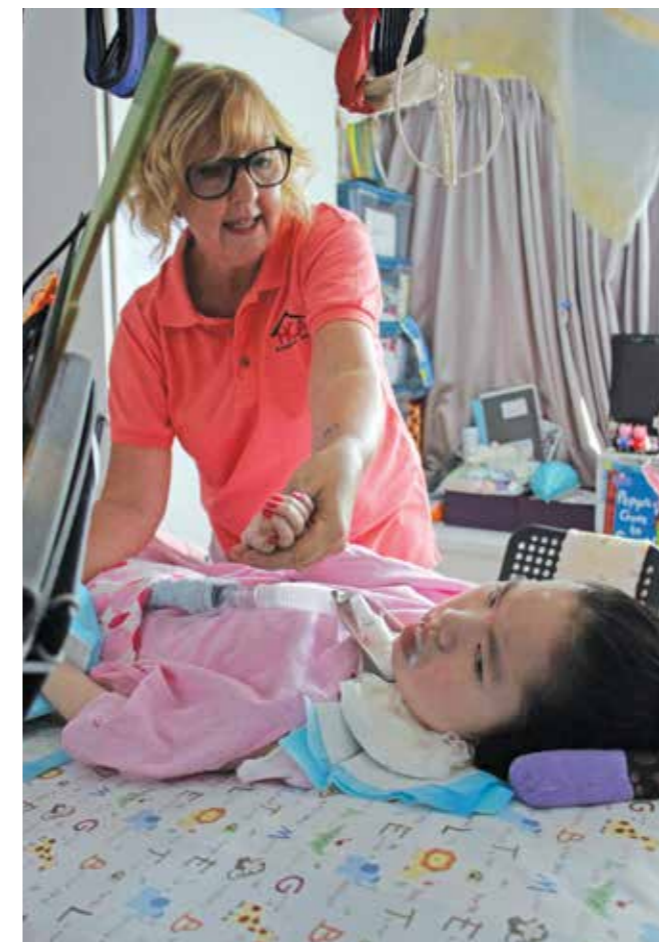
A nurse by profession, she learned about HCA through her husband’s colleague, whose friend was a volunteer. “I was getting used to life in Singapore and didn’t want to stay at home all day,” she explains. “I was really interested to find out more about volunteering at HCA, so I decided to give it a try.”

Thompson first started volunteering at HCA’s Day Hospice and soon ventured into the Medi Minder programme after a conversation with HCA Medical Director, Dr Chong Poh Heng. Like the pieces of a jigsaw puzzle, things fell into place quickly and she took on the role immediately. “I love being a Medi Minder,” she says. “Whenever I am in Singapore and they need my help, I will make myself available.”

There is no doubt that the emotional rewards of being a Medi Minder have been bountiful. “It has been really lovely to be accepted into people’s homes,” Thompson says humbly. “The Star PALS team is very supportive of each other and open to feedback.”

Facing death is never easy, especially when it happens to a child whose time is cut short abruptly. But therein lies a common motivation that unites HCA’s Medi Minders – the drive to bring life into the days of these children and to be a source of support for their families. 

**not her real name*



Opposite page and left: Medi Minder, Kay Thompson, takes copious notes about her time on duty but also makes sure to inject fun and games

Caring for caregivers – a physiotherapist's view

Sometimes intervention is needed with palliative patients so that their caregivers get time to recharge for the long haul.



For 32-year-old Muhammad Firdaus Bin Mohamed Zin, working as a physiotherapist in the palliative ward at Bright Vision Hospital (BVH) for the past year has been an eye-opener. Compared to his four years' experience caring for rehab or sub-acute patients, palliative care requires him to be more resilient, extra compassionate and empathising on the job.

Other than caring for patients, Firdaus works closely with caregivers. "A palliative caregiver's role is to provide companionship and to assist patients with their physical and emotional needs," he explained.

LESSENING CAREGIVERS' BURDEN

Palliative patients' caregivers may suffer more emotional and physical distress, especially when seeing their loved ones suffer as the cause is irreversible. To help ease caregivers' stress, BVH provides training to

caregivers in performing a range of motion exercises, bathing and even injection procedures. BVH also educates caregivers on the disease their loved ones are going through and what to expect in due course. Social workers also provide emotional support and link them to financial aid.

"Caregivers must also be able to take care of their own health," advised Firdaus. The stress of caregiving can lead to depression, anxiety or burnout. To prevent this, caregivers need to occasionally take time off to recharge by having enough rest or some 'me' time. Emotionally, they can share their feelings with close friends, family members or social workers..

SUPPORTING CAREGIVERS

Firdaus used to care for a patient who suffered from weak lower limbs and was unable to move his legs despite feeling discomfort from lying in one position for too long. "The patient had a supportive wife,

and he would want his wife to stay by him constantly which made her weary," shared Firdaus.

His care team then stepped in to inform the patient that his wife needed to adhere to visiting hours. Following the intervention, his wife was able to go home to rest and was refreshed when she came back the next morning. The team also taught her some range-of-motion exercises to help lessen her husband's discomfort. With the support, the caregiver was able to take care of herself, as well as her husband.

"At BVH, there is always plenty of support to ease caregiver stress, and for them to feel positive and hopeful again. Caring for a loved one who is dying is not easy. Though you may not feel like you are doing much, every little thing that you do means a lot, even if it's just being around them," said Firdaus. 🗣️

BVH INPATIENT PALLIATIVE CARE

Weekly Group Therapy

Occupational therapists and physiotherapists lead patients in exercises and games.

Daily Living Kitchen

Weekly Cooking Sessions have patients assigned simple tasks.

Relaxation Therapy

Patients enjoy an hour's nap time in a comfortable room with music and scent of their choice.

Mental Wellness Support

Patients and their caregivers are given counselling.

WORDS & PHOTO: BRIGHT VISION HOSPITAL

WORDS: DOMINIQUE ASHLEY WANG, EXECUTIVE, COMMUNICATIONS & ENGAGEMENT, METHODIST WELFARE SERVICES. PHOTO: METHODIST WELFARE SERVICES

Empowering caregivers through training and more

Caregivers need to be equipped with the skills required to manage their care recipients at home which will increase confidence and ease stress.

The full-time demands of caregiving can be physically, mentally and emotionally draining. Caregiver stress arises from dealing with a host of daily duties, and is worsened when the care recipient is also depressed or uncooperative. Unfortunately, the rigour of caregiving increases as the patient's condition deteriorates. Many caregivers feel that the duties take a toll on their own health and finances, and some face burnout when they cannot cope adequately. According to a survey done by the Ministry of Social and Family Development (MSF) in 2013, 15-20 per cent of caregivers in Singapore reported symptoms of depression, and 21.6 per cent said that caring for their spouse worsened their own well-being.

Thankfully, the many support functions available now not only ease caregiver stress, but enable caregivers to be more adept at managing their patients' illnesses. Methodist Welfare Services (MWS) Home Hospice is one such place that equips caregivers with the skills needed to manage their care recipients' medical and nursing issues at home.

Six years ago, Ms Tan Kah Hong stopped work to be a full-time caregiver for her mother, Madam Yeo Ah Cheng, who had a bad fall at home. After frequent hospital admissions in the following years, Madam Yeo was referred to MWS Home Hospice in September 2016.

MWS Home Hospice's nursing staff provides guidance to caregivers on

managing symptoms of illnesses through frequent and regular home visitations, and a 24-hour nursing hotline. MWS Home Hospice staff trained Ms Tan to manage Madam Yeo's symptoms, which included breathlessness, swallowing impairment, chronic bronchitis and recurrent pneumonia. Being equipped with caregiving techniques, Ms Tan is now more confident of managing her mother's chronic illnesses at home.

Having emerged convinced of the assistance MWS Home Hospice can offer, she encourages others to seek such support services as well. "MWS Home Hospice actually empowered me to take better care of my mother. I want people to know this service exists and they need not be afraid of it," she said.

In addition to caregiver training

and support, MWS Home Hospice medical social workers also help families explore financial subsidies on nursing home fees, and attend to bereavement needs in the event of the demise of their loved ones. Medical / nursing services, counselling, case management, information and resource referral, psychosocial and spiritual support are also available for the care recipient which help alleviate the demands on the caregiver.

With the complex burden of care, caregivers have to grapple with a host of ever-evolving needs. Institutions are working to continually enhance and integrate their services for beneficiaries and their caregivers. For caregivers, utilising the various formal services available can greatly ease their responsibilities in giving care. 🗣️



Madam Yeo with her daughter Ms Tan benefit from home visitations and a nursing hotline

Gearing up for the final stretch

While many palliative patients' last wish may be to complete their life's journey at home, caregivers and families need to be prepared to handle this physically and emotionally.

“It is something that Mama would have wanted – to pass on at home.”

Palliative Care Service (PCS) in Changi General Hospital has been activated many times to facilitate a smooth transition from hospital to the comfort of patients' preferred place of demise, usually their own home. Terminal discharge, as it's called, refers to the last 48 to 72 hours or less of a patient's life.

During this fragile time, PCS will inform the family of the risk of death en route and the ambulance paramedic will continue to send the patient home and lay the patient at the designated place prepared by the family. The family will also be informed of potential symptoms that may arise at home.

Terminal discharge by non-emergency ambulances is more costly than a routine transfer to a patient's home. The oxygen and monitoring requirements of the patient and the risk taken by the ambulance service to transport the critically ill patient account for the high fee of the ambulance service, which could run to a few hundred dollars, to be paid in cash at the end of service rendered.

In the family's enthusiasm to fulfil what some may call “final filial piety” to respect their loved one's last wish, often the needs of the immediate caregivers, such as the

foreign domestic worker (FDW) or live-in family member caring for the patient prior to hospital admission, are not taken into consideration.

Are the immediate caregivers ready for this final journey? Families can request for terminal discharge, but the immediate caregivers are the ones who will have to manage the end-of-life care at home. The reasons for the decision to send your loved one back to the hospital needs to be reviewed – was there some form of caregiver stress relating to care or the difficulty in managing the symptoms; or did your loved one request to be sent back to the hospital due to agonising symptoms?

No one death is the same – even when people are dying from the same condition. Some may be burdened with a rocky road full of symptoms at the end of life while others may not even have any. So even if families have had prior experience with having their loved ones pass on at home, they should be mindful of the current situation and, as much as possible, help to ease the caregivers in caring for the terminally ill.

The anticipation of symptoms that may arise at home and yet having to keep composed cannot be overemphasised. Caregivers

may have to administer injections at home as their loved one can no longer take medication orally.

Family members have to support each other at this time of need, be it emotionally or physically, or both. Should immediate caregivers have little support from the family, they need to speak up instead of bowing to the pressure of this idealistic vision of presumed “good death”. Over the years, I have noticed that the experience of your loved ones' death will influence the care you will opt for in the future. As the saying goes, the dying will eventually die but the living are the ones that will carry on. It is important to look after yourselves during this trying time and not get burnt out.

Being Asians, most of us do not talk openly about the taboo topic of death. From my multiple experiences of exploring advance care planning (read more about ACP on page 14), and as expected, most people would opt for home as a preferred place of demise.

However, upon further exploration of care – should the family be unable to cope at home, the patients are usually agreeable for terminal care to be done in an institution such as a hospice, community hospital or nursing home where they will live their final days in dignity. ☺

WORDS RASIDAH BTE ALIAS, PALLIATIVE CARE NURSE, CHANGI GENERAL HOSPITAL

As the saying goes, the dying will eventually die but the living are the ones that will carry on. It is important to look after yourselves during this trying time and not get burnt out.

Making sense of advance directives in Singapore

DR EUNICE CHUA SHUMIN

Associate Consultant, General Medicine, Clinical Co-Lead for Advance Care Planning, Tan Tock Seng Hospital

Advance directives are instruments that enable people to make decisions about their healthcare ahead of time. They can be used in situations when decision-making capacity is lost, for example in the case of severe dementia. These instruments are especially helpful in relation to healthcare decisions on end-of-life care, when a person is usually too ill or incapacitated to decide if they would want certain treatments.

In Singapore, there are three types of advance directives that can be used to communicate one's healthcare preferences and decisions.

Advance Medical Directive

The Advance Medical Directive Act was enacted in 1996, allowing for an Advance

Medical Directive (AMD) signed in advance to inform his/her doctor that he/she does not want the use of any extraordinary life-sustaining treatment to prolong his/her life, in the event he/she becomes terminally ill. Extraordinary life-sustaining treatment usually refers to the use of machines to artificially take over the work of keeping the human body alive.

A completed AMD form has to be registered with the Registrar of Advance Medical Directives, under the Ministry of Health.

Lasting Power of Attorney

In 2008, Singapore enacted the Mental Capacity Act. This Act came into

effect in 2010 when the Office of the Public Guardian was set up. Under this Act, a person can make a Lasting Power of Attorney (LPA). The LPA is a legal document that allows a person (the donor) to voluntarily appoint one or more persons (donee/s) to make decisions and act on his/her behalf in the event he/she becomes incapacitated.

The LPA only comes into effect when the donor loses decision-making capacity. The form is submitted to the Office of the Public Guardian.

Advance Care Planning

In 2012, the Agency for Integrated Care (AIC) distributed funds to various regional health systems to train

a pool of Advance Care Planning (ACP) facilitators. ACP is a series of discussions between patients, their loved ones and healthcare professionals. It involves the sharing of preferences and values a person has in making his healthcare decisions. In an ACP discussion, the use of extraordinary life-sustaining treatment is discussed, as well as a range of other treatment and care options. For example, the preferences regarding dialysis, use of artificial nutrition or even blood transfusions can be discussed to elucidate a person's goals of care.


The ACP discussion also aims to explore a person's definition of living

well, quality of life and a good death. Part of the ACP discussion also involves nominating a healthcare spokesperson, someone who will speak on the person's behalf in the event he/she loses capacity. A person's ACP acts as his/her own voice, to reflect what his/her treatment goals and preferences are, in the event he/she becomes incapacitated.

The ACP 'document', submitted to the AIC and stored online in the individual's electronic health record, can be retrieved by healthcare staff through the National Electronic Health Record (NEHR).

These various advance directives all play a role to help convey a person's

healthcare preferences ahead of time, in the event he/she cannot speak for himself/herself. ACP has greater advantages compared to the others as it explores a person's values and preferences, providing greater guidance for a wider range of healthcare decisions at different stages of disease.

ACP can be done by anyone, regardless of their age or health status. It is widely incorporated as part of standard healthcare and has greater benefit when done at an early stage as part of ongoing care. More information about ACP can be found at www.livingmatters.sg/. 

Tips for Caregivers

DR JAMIE ZHOU

Consultant, Division of Supportive and Palliative Care
National Cancer Centre, Singapore

There is no single definition for caregiving, but for the purpose of this article, a caregiver is any relative or friend, who provides a wide range of (unpaid) care to a person with a chronic or serious illness.



Being a caregiver is a huge commitment with much sacrifice of personal time and space. It is important to care for yourself so you can continue providing care for the long haul.

Here are some tips to take care of your mind, body and soul.

#1: Mind – Stay in the present

If you are too preoccupied with the future, you might feel anxious. If you dwell too much in the past, you might get depressed. Staying in the present means you focus on what you have to deal with for that day.


#2. Body – Do not neglect your own physical needs

Your body needs to be well taken care of in order to carry out caregiving tasks. Besides ensuring a balanced

diet, adequate hydration, good sleep and regular exercise, you should also try to prevent injuries that may be sustained during caregiving, such as falls and strained backs.

#3. Soul – Nourish yourself spiritually

This can be in the form of connecting with nature (eg. gardening), connecting with a higher being or connecting with yourself (eg. keeping a journal). There are many mobile apps that now support these such as "Calm" (a meditation app) or a religious app to listen to sermons or prayers.

This new year, I hope you will take good care of your mind, body and soul. Not only for your sake, but also for your loved ones. 

Advance Directives	What it is	When to arrange	Witnesses required	Bodies concerned	Revocations
Advance Medical Directive (AMD)	A legal document to inform the doctor that no extraordinary life-sustaining treatments should be given in the case of terminal illness	Above 21 years old, of sound mind	Signed in the presence of a doctor and another witness above 21 years old; attending doctor and two specialists to decide to discontinue life-sustaining treatments upon AMD confirmation	Registrar of Advance Medical Directives at Ministry of Health	Any time in writing or verbally
Lasting Power of Attorney (LPA)	A legal document whereby up to two donees can be appointed to handle the donor's personal welfare, and property and affairs	Above 21 years old, of sound mind	LPA certificate issuers can be a doctor accredited by Office of the Public Guardian, registered physician or practising lawyer	Office of the Public Guardian	Automatic under certain scenarios set out by the Mental Capacity Act; any time by the donor in person while of sound mind
Advance Care Planning (ACP)	A written document, video or verbal directive arising from a series of discussions about his/her treatment goals and living preferences	Above 21 years old, of sound mind	Documentation requires trained ACP facilitators	Agency for Integrated Care, retrievable through the National Electronic Health Records	Ongoing process where changes can be made with the assistance of ACP facilitators

Upcoming Events & Announcements

15 MAR 2019 (FRIDAY)

HCA 30th Anniversary Gala Dinner

HCA Hospice Care (HCA) turns 30! Celebrate this momentous milestone with HCA as they commemorate 30 years of compassionate care of patients with life-limiting illnesses at the HCA 30th Anniversary Gala Dinner.

Venue: Island Ballroom, Shangri-La Hotel Singapore

Time: 7.30pm – 9.30pm (Cocktail starts at 6.30pm)

Contact: Ms Mel Basuki, Fundraising Manager at melb@hcahospicecare.org.sg / 6891 9508

24 MAR 2019 (SUNDAY)

Metta Charity Carnival 2019

Have your passport to inclusivity ready when you join the Metta Charity Carnival where all 'travellers' meet at this melting pot for games, delicious food and entertainment for the whole family!

Venue: Metta Welfare Association @ 32 Simei Street 1, Singapore 529950

Time: 9.00am – 4.00pm

Contact: Mr Andy Chua, andychua@metta.org.sg / 6580 4614

26 MAR 2019 (TUESDAY)

Multidisciplinary Approach to Deal with Bone Metastases

Venue: Yishun Community Hospital

Time: 1.00pm – 2.00pm

Contact: secretariat@singaporehospice.org.sg / 6538 2231

30 APR 2019 (TUESDAY)

SHC Multidisciplinary Palliative Care Forum

Non-Cancer Palliative Care: Lessons learnt 18 months into Programme IMPACT

Venue: Tan Tock Seng Hospital, Theatre, 11 Jalan Tan Tock Seng, Singapore 308433

Time: 1.00pm – 2.00pm

Contact: secretariat@singaporehospice.org.sg / 6538 2231

11 & 12 MAY 2019 (SATURDAY & SUNDAY)

"Live Well. Leave Well."

Community Engagement Event by Singapore Hospice Council (SHC) Learn more about the palliative care, support and services available for the elderly and their caregivers in Singapore. There will be interactive booths, talks by healthcare experts and live performances.

Venue: The Courtyard@ Westgate, 3 Gateway Drive, Singapore 608532

Time: 10.00am – 5.00pm

Contact: secretariat@singaporehospice.org.sg / 6538 2231

28 MAY 2019 (TUESDAY)

SHC Multidisciplinary Palliative Care Forum

Management of delirium in patients approaching the end of life

Venue: TBC (do check out SHC's website or facebook for updates)

Time: 1.00pm – 2.00pm

Contact: secretariat@singaporehospice.org.sg / 6538 2231

16 JUN 2019 (SUNDAY)

Assisi Fun Day 2019

Assisi Fun Day 2019 is Assisi Hospice's biggest fundraising event of the year and is expected to attract 10,000 visitors. It hopes to raise at least \$1 million to provide palliative care to patients. The mega fair is a community event put together by staff and volunteers from all walks of life, including corporate organisations, church groups, schools and family-run businesses. There will be established F&B names, retro treats, games, lots of activities and live entertainment!

Venue: St Joseph's Institution International, 490 Thomson Road, Singapore 298191

Time: 10.00am – 4.30pm

Contact: Ms Lilian Lee, lilian.lee@assisihospice.org.sg / 68322880

EDITORIAL COMMITTEE

Editor
Associate Editor

Assisi Hospice
Bright Vision Hospital

Changi General Hospital
Dover Park Hospice
HCA Hospice Care
Khoo Teck Puat Hospital
Lien Centre for Palliative Care
Metta Hospice Care
MWS Home Hospice
Singapore Cancer Society
St Andrew's Community Hospital
St Joseph's Home
St Luke's Hospital
Tan Tock Seng Hospital
Singapore Hospice Council

Design
Printer

Christina Wee
Anne Loh

Angela Yeo
Muhammad Azhar bin
Abdul Rahim
Rasidah Bte Alias
Jenny Goo
Toh Wei Shi
Ong Min Li
Madhurima Bagchi
Souriyasack Sinnie Julie Anne
Nicole Andrea Tan
Kumudha Panneerchelvam
Peh Lay Koon
Shereen Ng
Chua Hwee Leng
Dr Ho Si Yin
Leo Wan Ling

Christian Subrata
Yung Shung Printrade Pte Ltd



1 Lorong 2 Toa Payoh #07-00
Braddell House
Singapore 319637
T: 6538 2231

E: secretariat@singaporehospice.org.sg
www.singaporehospice.org.sg



Contents are not to be quoted or reproduced without the prior written permission of the Singapore Hospice Council.