

Planning to leave well

Fulfilling last wishes

PLAN AHEAD TO SAFEGUARD YOUR INTERESTS

SINGAPORE HOSPICE COUNCIL

PLUS
Views from
the pros

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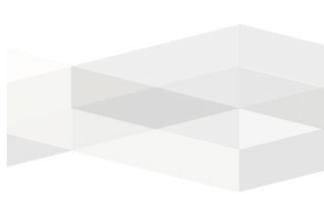
Contents



- 2 Members' Contact
- Editor's Note
- First SHC NLB collaboration
- Start talking about the end
- Our Collective Voices: The inaugural Grief and Bereavement Conference
- **12** Finance matters
- **13** Seize the moment
- **14** Planning to leave well
- **15** Plan ahead to safeguard your interests and attain peace of mind
- **18** Fulfilling their last wish
- **20** Planning ahead and how it has changed me
- 21 "I am the controller of my own life"
- 22 Views from the Pros
- 23 Tips for Caregivers
- 24 Upcoming Events & Announcements

Plan ahead







It is important that we start early planning for our end-of-life care and death.

ctober has been a busy and yet a fulfilling month for us at the Singapore Hospice Council. We collaborated with the National

Library Board and community organisations to host three exhibitions and 33 free programmes in nine public and regional libraries throughout Singapore. The aim is to promote and bring awareness on Palliative Care, Advance Care Planning and end-of-life matters to the general public. It is also to educate and encourage the public to "talk, plan and act" - to talk about endof-life care to their loved ones, to plan for suitable palliative care and finally, to act by talking and making plans.

We ended the month with the inaugural Grief and Bereavement Conference which attracted 402 delegates. Through this conference, we believe that we can create a greater synergy by forging meaningful partnerships and a community of support for the bereaved, which would positively impact the overall standards of grief and bereavement care in Singapore. You can read more about these two events in this issue.

People usually plan for happy occasions, or to celebrate an achievement or a new milestone in life: marriage, arrival of a newborn, birthdays, holiday trips and even retirement. But how many of us actually planned our wishes for our end-oflife care or death?

For many, death remains a scary, sad and a taboo topic.

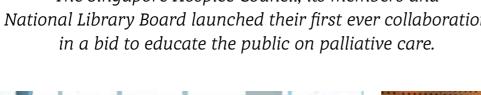
It is important that we start early planning for our end-of-life care and death. It not only leaves a priceless gift for our loved ones by leaving them better prepared for the eventuality, it also gives us the clarity to live a more purposeful life.

Let's leave a legacy.

Ms Yeo Tan Tan **Chief Executive** Singapore Hospice Council Life Book 1 - Lawrence of Arabia

First SHC - NLB collaboration

The Singapore Hospice Council, its members and National Library Board launched their first ever collaboration in a bid to educate the public on palliative care.









Singapore Hospice Council (SHC) organised a private launch to kick-start the "Live Well. Leave Well." exhibitions and programmes at

n 1 October 2018,

the Ang Mo Kio Public Library. This was held in conjunction with World Hospice and Palliative Care Day which fell on 13 October 2018. It marked the first time that SHC and 20 community partners collaborated with National Library Board (NLB) to raise awareness on palliative care and endof-life matters among Singaporeans.

For the month of October, SHC, our community partners and NLB jointly organised three exhibitions and 33 programmes at nine public and regional libraries island-wide. The free programmes included talks,

interactive workshops, sharing of life's experiences and many more, and they were hosted by doctors and other healthcare professionals. These programmes were wellreceived with over 450 participants in attendance.

Certificate of Appreciation was present to our community partners in recognition of their partnership and contribut

In support of greater understanding of palliative care and end-of-life matters, NLB had provided a list of recommended titles including eBooks which are currently available at public libraries for borrowing. The list can also be found in our website at www.singaporehospice.org.sg/books/.

Ms Catherine Lau, Assistant Chief Executive of NLB, said with 26 libraries spread across Singapore to encourage the appreciation and cultivation of knowledge sharing,

the collaboration with SHC was a welcome opportunity to spread the knowledge of palliative care.

In September 2018, 15,000 copies of SHC's special edition of its newsletter, Hospice Link, were bundled with NLB's quarterly magazine, Time of Your Life, and distributed to NLB's individual members and organisations.

At the launch, SHC proudly announced the publication of its first of the Life Book series called Lawrence of Arabia. The Life Book series is a SHC initiative that aims to raise awareness about palliative care by engaging the public with our community's rich repository of stories from many different perspectives - patients, caregivers, doctors, nurses, social workers, therapists and volunteers.

Ms Yeo Tan Tan, Chief Executive, SHC presenting a

"We want to get more Singaporeans comfortable to talk about end-of-life care by providing them with adequate and easily accessible information about palliative care. We hope the Life Book will help readers understand more about palliative care, celebrate the lives of palliative care patients and the legacies they leave behind," said Ms Yeo Tan Tan, Chief Executive of SHC.

The Life Book, published in both English and Chinese, are now available to the public for borrowing at all NLB libraries. An eBook version is also available at SHC's website at www.singaporehospice.org.sq

Start talking about the end

Talking about death is never easy. Hard as it may be, it is essential to set things in place to minimise confusion, conflict and chaos.

really do not know what his preference is as we never talked about it. I wish I had raised the matter with him ..."

Does this sound familiar? This is a common response which the healthcare team hears from the family of a dying person.

What does it mean to "live well, leave well"? Having had conversations with patients and their families, we realise that different people have different interpretations about "leaving well". Generally, most people agree that leaving well means leaving with as little pain and as few worries as possible.

The topic of death and dying are taboo for some people, especially those who feel that any discussion about the issue will bring bad luck. But death is inevitable and desired end-of-life truly begins with open, honest and loving conversation.

Death and dying are unique and intimate processes. We can support our loved ones to face it to the very end. This requires us to start end-

of-life conversations earlier. The process involves attentive listening to our loved ones, pacing them to make plans, exploring concerns, wishes and preferences, and giving them space to express their deepest feelings such as fear, anxiety, anger, helplessness and hopelessness.

WHO is involved in starting end-of-life discussions?

- You may be the best person to engage your loved one to plan ahead. You may be surprised; your loved one may be waiting for you to break the silence:
- Involve those whom your loved one would like to include. The plan not only affects your loved one; it also helps to ease the anxieties of family members when things take a turn for the worse and decisions have to be made.

WHY discuss?

 So you know your loved one's wishes and preferences and can provide support when situations arise;



Death and dying are unique and intimate processes. We can support our loved ones to face it to the very end."





- So your loved one can leave the world with dignity and with their wishes respected; and
- The family can avoid unnecessary disputes that may result in unpleasant consequences.

WHEN to discuss?

- Start thinking and planning earlier, when your loved one still has the state of mind to clearly indicate and communicate their wishes and preferences. Being clear minded gives them the edge to make more comprehensive plans without the pressure of time. Some decisions need a longer time to process and finalise, such as choosing nominated persons, and distributing assets and personal treasures; and
- When your loved one is diagnosed with an endof-life event, there is time pressure and distress, and decisions made may be less satisfactory.

WHAT to discuss?

- Legal and financial matters
- CPF nominations;
- Will making (assets distribution); and
- Lasting Power of Attorney appointing of legal donee(s) to make decisions on behalf of your loved one when the latter no longer has mental capacity to do so, for personal welfare and/or property and affairs.
- Non-financial matters
- Advance Care Planning a process of planning future health and personal care goals based on personal values, beliefs and preferences;

- Connection and reconciliation with family, friends and long lost friends (4 important tasks to find closure: thank you, forgive, express love, say goodbye); and
- Other unfulfilled wishes.

HOW to engage in conversation?

- Take the first small step to engage in conversation today;
- Use day-to-day events to begin a conversation on end-of-life issues in a less threatening atmosphere;
- $\bullet\,$ Pace your loved one; and
- Approach the care team such as doctors and medical social workers to guide you on facilitating the conversations if needed.

Having worked in a healthcare setting for over 10 years, I have seen missed opportunities in planning for end-of-life matters. Not wanting to miss the chance to know the wishes and preferences of my elderly mum, I started the conversation with her years ago. It is an ongoing process. She tends to brush things aside when sensitive topics are discussed and more so when decision-making is involved.

Despite the challenge, I will continue to persevere, being mindful of moving at her pace. I am finding out more from her each day, bit by bit, piecing the information together like a jigsaw puzzle. I hope that the day will come when she is ready to embrace death with grace.

7





Our Collective Voices

The inaugural Grief and Bereavement Conference

Over two days on 31 October and 1 November 2018, the conference – the first of its kind in Singapore – hosted practitioners to explore opportunities for collaboration to support the care of the bereaved.

he inaugural Grief and Bereavement Conference (GBC 2018), organised by the Singapore Hospice Council (SHC), was held on 31 October and 1 November 2018 at Furama RiverFront Hotel.

The conference, themed, "Our Collective Voices", brought together practitioners of various sectors to learn, network and explore opportunities for collaboration to support the care of the bereaved.

The conference also served as a platform for death-related service providers to forge meaningful partnerships and create greater synergy as a community of support for the bereaved.

Organising this conference was a natural extension of the work by the sub-committee that was formed under the auspices of SHC to improve the local standards of grief and bereavement care.

The four key objectives of the conference were:

- Consider the repertoire of appropriate responses to the needs of the grieving and bereaved;
- Build knowledge on grief and bereavement work;
- Increase participants' capability to deliver grief and bereavement care; and







From top left (clockwise): Booth exhibits by Association for Music Therapy (Singapore), Children's Cancer Foundation, Art Therapists' Association Seguitation booth for participants

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66

The aim of the conference is to work collectively towards a more healthy response and meaningful support of those who are grieving, that less may suffer the ravages of grief."













 Expand their network of service partners across the care continuum in delivering grief, bereavement and death-related services.

The pre- and post-conference workshops held at the Bone Marrow Donor Programme and Assisi Hospice respectively were well attended. The two-day preconference workshop, attended by 47 participants, presented an overview of how children and adolescents at various age and developmental stages experience and express grief. The other two-day post-conference workshop, with 61 participants, introduced the fundamentals of grief and bereavement care which are well-suited for beginning professionals, volunteers, grassroot and faith leaders.

At the opening ceremony on 31 October 2018, Guest-of-Honour,

Dr Amy Khor, Senior Minister of State, Ministry of Health and Ministry of the Environment and Water Resources, officially launched GBC 2018 and two of SHC's publications.

SMS Amy Khor said it was important to improve understanding about grief and to provide knowledge on how best to support grieving individuals. Dr Angel Lee, chairperson of SHC, added: "Grief is a reminder of what and who we have loved. The aim of the conference is to work collectively towards a more healthy response and meaningful support of those who are grieving, that less may suffer the ravages of grief."

The first book, *Caring For Yourself* and *Others After a Death*, serves to provide psychosocial information and suggestions for the bereaved to care for themselves and to support others with bereavement needs. The second

book, When a Death Occurs - A Guide to Practical Matters, offers guidance on managing hands-on issues such as funeral and estate matters. A self-help directory for those seeking professional help with bereavement is included in both books. An eBook version of these books can be downloaded from our website at www.singaporehospice.org.sg.

With over 402 local and overseas speakers, professional partners, sponsors and participants in attendance, the organisation of GBC 2018 represented a milestone in the development of grief and bereavement care in Singapore.

The GBC 2018 Organising
Committee thank SHC staff,
volunteers and everyone who
were involved for their valuable
contribution and relentless effort
in making this conference a
resounding success.

Finance matters

For hospice care patients, having financial certainty is as important as securing medical treatments. Despite the various assistance schemes available, some groups of patients are inevitably ineligible. What then can be done?

atients who are receiving hospice care often encounter financial difficulties as they have probably exhausted their personal financial resources on prior medical treatments.

It is also common to hear clients who have turned to alternative healing therapies in the hopes of getting better. With a medical condition as unpredictable as cancer, patients have to reprioritise their expenses while adjusting to major lifestyle changes - what used to be a lifestyle norm may now become a luxury that is good-to-have. Given a limited prognosis, it can be a challenge to live within one's own means and yet not feel shortchanged in life.

Subsidies and assistance schemes that cater to the elderly population render younger patients ineligible for assistance.

For example, younger patients who are diagnosed with cancer of the head or neck often have difficulty in swallowing and thus, develop malnutrition. They may be started on percutaneous endoscopic gastrostomy (PEG) feeding, where a tube (PEG tube) is passed into a patient's stomach through the abdominal wall, to provide a means of feeding.

Yet these patients would not be eligible for the assistance scheme catered for the elderly to purchase milk feeds at a subsidised rate. Over time, this could cause a financial strain on patients and their caregivers.

We often collaborate with community partners from the hospitals, government agencies and other voluntary welfare



organisations to gather resources for our patients.

At the Singapore Cancer Society, we have financial assistance schemes such as the Cancer Care Fund, Welfare Aid Fund and Education Financial Assistance Scheme to provide support for patients and their families.

On top of the financial assistance schemes provided by Singapore Cancer Society, the social workers in the SCS Home Hospice team also assist patients in identifying the available community resources for their needs and help to facilitate the application process.

One example is the Seniors Mobility and Enabling Fund (SMF)

which provides subsidies for assistive devices and home healthcare items for eligible patients.

Collectively, the SCS Home Hospice team assists patients to manage their physiological and psychological symptoms while providing a helping hand to navigate their way through the complex healthcare and social service landscape.

During this process, we forge relationships with the patients we serve. While we need money to survive in this world, the richness of interpersonal relationships is priceless and equally important.

MORDS JIA SEN TAY, SOCIAL WORKER, HOME HOSPICE CARE, SINGAPORE CANCER SOCIETY

Seize the moment

The devastating diagnosis of a terminal condition can crush the hopes and dreams of even the strongest and most optimistic. What, then, does one do with the time remaining?

fter the doctors told me I only had two years left, I learnt to let go," says 70-year old HCA patient Eric Ong Ah Ee.

For Eric, life was peaceful and happy before he first experienced ominous numbness in his limbs during a trip to Japan with his son in August 2016. The numbness quickly devolved into excruciating pain, and then Eric lost his ability

An MRI revealed a large tumour - measuring a whopping 6.6cm - pressing on the nerves in Eric's spine, resulting in the symptoms he was experiencing. The next blow came when the doctors told him it was inoperable. To curb the growth of the tumour, Eric underwent radiotherapy. But after 10 sessions, his condition remained bleak.

"The doctor told me I would never walk again," Eric shares. "I felt very helpless." It was crushing news for the avid traveller who loved exploring new places, and basking in the diverse sights and sounds of the world.

HOPES AND DREAMS

Determined to make the most of his remaining time and the curveballs life had so cruelly thrown his way, Eric decided to climb out of the helpless spiral into despair he had found himself in.

Eric began attending HCA's Day Hospice in October 2016 and commenced physiotherapy to improve his motor skills and strength. He quickly became a familiar face to staff and patients alike, always greeting everyone with a friendly smile and dutifully performing his physiotherapy exercises.

His hard work, alongside oral chemotherapy in a bid to shrink the tumour, paid off. Within a month, Eric was able to walk again. Always humble and grateful, he credits the staff of HCA and his loved ones for his miraculous progress.

Having regained his mobility, Eric decided to devote more time than ever to his family and cherished pursuits. "It is pointless to live in fear of the inevitable," he advises. "I want to live to the best of my efforts and hope to see my grandchildren grow up."

He's also back to his favourite pastime - travelling. "There are so many places I want to visit, like Korea, Taiwan and New Zealand," he laughs. "I will be going to Taiwan for 12 days with my wife soon and I have another trip to New Zealand planned after."

A BEACON OF OPTIMISM

There is an aura of peace that surrounds Eric as he strides briskly around HCA's Day Hospice,

participating in various ongoing activities, or simply having a chat with other patients and staff.

Finding peace within himself was something he achieved after learning of his diagnosis, when the realisation dawned on him that his days were numbered. "I was focused on material pursuits and money before I found out I was ill," Eric shares candidly. "There were times when I was bad-tempered too. But I have learnt to let go of conflicts and to be less focused on material pursuits."

The knowledge of finality sometimes affords greater clarity. It is the same wisdom he shares with other patients at HCA's Day Hospice. "There was another lady who, like me, was unable to walk," he says. "But she kept up with the physiotherapy exercises and is able to walk now!"

Eric remains sanguine. "There is nothing to fear when it comes to death - we just have to make the most out of the time we have left."



Planning to leave well

Nurse manager Moira Tan, who has more than 20 years' experience of working in hospices, explains the importance of Advanced Care Planning.



Q: What is Advanced Care Planning?

A: Advanced Care Planning has long existed before it was officially named as such. As nurses, we have always asked patients about their care plans and wishes early on. This is because we believe it is important to settle these things while they are still clear-headed and able to do so.

Advanced Care Planning discusses their current condition and what they want – be it comfort care, minimal intervention or resuscitation options.

Detailed Advanced Care Planning does not just take place in one session. It is a continuous process that is heavily dependent on the readiness of the patient to discuss such matters. It is extremely crucial for the patients to be clear about their plans because it makes decision-making easier for stressed family members during crucial periods.

Q: How important is Advanced Care Planning at MWS Home Hospice?

A: MWS Home Hospice provides comfort care in a place our patients are familiar with. But, their preferred place of care may change as their illnesses progress. Some choose to be admitted to hospices when their health deteriorates while others choose to live out their last days in their own homes.

I have patients who do not want to die at home because they are afraid of scaring their family with their dead bodies. Some just don't want to burden their families should they die at home. Of course, Advanced Care Planning is not legally binding, but it helps families to make the best and right decisions when the time comes.

There was a patient who did not want to be hospitalised because she wanted to die at home.
Unfortunately, her family just could

not cope with the amount of care required, nor the grief of watching her die in front of their very eyes. In this case, although they tried their best to honour her wishes, they had to make the best decision for all of them.

Q: How do your patients react or cope when discussing such matters?

A: I have observed that patients with religious beliefs handle the Advanced Care Planning process better. They are more accepting of what is coming because they leave it up to their faith. They also prefer comfort care and desire to pass away peacefully in their sleep. I remember a Buddhist patient who was exceptionally at peace with her condition. She knew her time was near. On my last home visit with her, she bade me farewell because she knew she was about to enter Nirvana. There was no pain and suffering on her face, and that really stuck with me.

Q: How has your work impacted the decisions in your personal

A: I sat down with my three sons to discuss my wishes regarding medical care should something untoward happen to me, and each son had a differing opinion. This is why communicating my wishes with my family had to take place while I am healthy and well - I need to make sure we are all on the same page. I recommend that everyone, regardless of how healthy they are, have this talk with their family. It may seem morbid, but things can change very quickly, and we never know what might happen next.

WORDS NICOLE ANDREA TAN, EXECUTIVE, COMMUNICATION ENGAGEMENT PHOTO METHODIST WELFARE SERVICES

Plan ahead to safeguard your interests and attain peace of mind

In March 2010, the Lasting Power of Attorney was introduced. This allows Singaporeans to appoint someone to make the decisions on their behalf should they become mentally incapacitated. Just what is an LPA and what does it entail?

s Lim* recalls speaking to her sister, Jane*, about making a Lasting Power of Attorney (LPA) just three months before the latter fainted. Jane has since been in a vegetative state. This was a shock to Jane's family and friends as she had no known pre-existing medical conditions. At a relatively young age of 54, Jane was open about end-of-life matters and had done up a will.

With Jane lying in the hospital bed, the Lim family referred to her will and sought permission from officials to unlock her assets to pay for her medical bills. Their request was rejected because an LPA was not done. A will only ensured that Jane's assets would be distributed according to her wishes upon her death but it did not allow her family to manage her assets when she is still alive but unable to make decisions and act for herself due to loss of mental capacity.

Ms Lim was told to apply to the courts to be Jane's deputy to make decisions on her behalf. Ms Lim eventually got the Deputyship order after a year. Had Jane made an LPA before her accident, Ms Lim would not have had to apply to the courts to be her deputy, a process which was costlier and more time-consuming.

The LPA allows anyone 21 years old and above to appoint persons they trust to be their donee(s) to make decisions and act on their

behalf in the event they lose their mental capacity. While many assume mental incapacity is either congenial or caused by agerelated complications, accidents can hinder our competencies to think and rationalise. Losing mental capacity can pose a real challenge to our physical and emotional well-being, create unnecessary stress for our family members, and is therefore something worth planning ahead for.

WHY IS IT IMPORTANT TO MAKE AN LPA EARLY?

Planning ahead with an LPA will give us peace of mind.

It can be difficult for loved ones to come to terms when something untoward happens to us. Having to make decisions or utilise our assets for our care may add to their emotional and financial stress. In the event we lose our mental capacity without making an LPA, our family members would have to apply to the Court to be our deputies. This Court process can be cumbersome and expensive, compared to making an LPA.

For the LPA, we have a choice and a say in appointing our donee(s) to make decisions and act on our behalf should we lose our mental capacity. We can carefully think through before appointing a reliable



Losing mental capacity can pose a real challenge to our physical and emotional well-being, create unnecessary stress for our family members, and is therefore something worth planning ahead for."



and competent next-of-kin or even a friend as the trusted proxy decision maker to act in our best interests should the situation arise. Those without suitable next-of-kin or individuals to appoint as donees can consider appointing a Professional Donee for a fee. (For more information on Professional Donees, visit bit.ly/AboutPDD).

It is not too early to start thinking and planning for ourselves and our loved ones.

WHAT TYPE OF DECISIONS CAN A DONEE MAKE?

We can appoint donees to act on two broad areas - personal

welfare matters and/or matters pertaining to our property & affairs.

A donee granted personal welfare powers is authorised to make decisions on matters relating to his/her accommodations and daily activities, such as:

- where the donor should live;
- who the donor should live with;
- day-to-day care decisions (e.g. what to wear and eat);
- what social activities to take part in;
- handling the donor's personal correspondence; and
- whom the donor may have contact with.

A donee granted property & affairs powers can make decisions such as:

- dealing with property buying, selling, renting and mortgaging;
- opening, closing and operating bank accounts;
- receiving dividends, income, or other financial entitlements on behalf of the donor:
- handling tax matters;
- paying the rent, mortgage repayments and household expenses;
- investing the donor's savings; and
- purchasing a vehicle or other equipment the donor needs.

Note: The list above only contains some examples of the types of decisions and actions that the donee(s) may make. •

HOW TO MAKE AN LPA?

For a step-by-step guide on how to make an LPA, visit www.publicguardian.gov.sg

| | LASTING POWER OF ATTORNEY (LPA) | ADVANCE CARE PLANNING (ACP) |
|---------------------------|---|--|
| Purpose | a) Plan ahead and appoint persons you trust to be your donees, to make decisions and act on your behalf should you lose mental capacity one day.b) Your donees can act in the two broad areas of personal welfare, and property & affairs matters. | a) Plan for future health and personal care. b) Share your wishes in advance so that doctor(s) and loved ones understand the treatment decision and preferences if you have a serious illness and are unable to express your wishes then (e.g. if you are unconscious). |
| Type of document | Legal | Non-legal |
| Who should do it | a) Anyone who is at least 21 years of age; and b) He/she must have mental capacity. | a) A person who is concerned about current or future treatment goals; or b) A person with a diagnosis of advanced cancer or end organ failure indicating a poor prognosis; or c) A person with diagnosis of early dementia or a disease which could result in a loss of decision-making ability; or d) A person with catastrophic illness or complex health condition. |
| Who do you need to see | When making an LPA, you will have to see an LPA certificate issuer. LPA certificate issuers can be: a) a medical practitioner accredited by the Office of the Public Guardian; b) a practising lawyer*; or c) a registered psychiatrist | A certified ACP facilitator |
| When to start | Start early. Plan ahead when you still can. Discuss these matters with your loved ones and have them documented for ease of accessibility and reference should the need arise. | |

start

WORDS SINGAPORE HOSPICE COUNCIL MAGE OFFICE OF THE PUBLIC GUARDIAN

*Note: This refers to a Singapore solicitor qualified to practice Singapore law in a Singapore law practice.

To find out more about LPA, the public can call the Office of the Public Guardian at 1800-226-6222 or visit their website at www.publicguardian.gov.sg *Names and identifying details have been changed to protect the privacy of the individuals.



Fulfilling their last wish

Every morning for the past five years, BVH Senior Therapy Assistant Jesline Leong will greet her patients before planning for their daily exercises or activities as she takes care of their needs in their final journey.

OVERCOMING THE STRESS

The Faith Ward in Bright Vision Hospital (BVH) is usually sterile. Aquariums and donated artwork make the environment homely; its hall typically quiet except for the faint voices of nurses and caregivers.

Among the staff is Jesline Leong, a Senior Therapy Assistant at BVH. She helps patients with their daily exercises and activities. "I have been working at BVH for eight years now," she shared. "During rotation five years ago I was transferred to the palliative ward to gain new exposure."

Her time in the palliative ward was not as smooth as she had expected. Time in this quiet ward was full of emotional and physical stress. For some time, Jesline struggled with her new

role but what kept her going was the advice from her supervisor.

"'Serving the death is an honor.'
Those words really touched me,"
she said.

As time went by, end-of-life care became second nature to her – all it took was perseverance and being able to provide empathy to her patients.

So Jesline gives pep talks to influence them positively, providing

RDS AND PHOTOS BRIGHT VISION HOSPITAL



Despite all the activities they can do, a sincere smile and cheerfulness are the things that can bring the most joy to a dying patient."

an intimacy to build a deeper bond between her and her patients. To them, she is a pair of warm hands to comfort them as they approach the final stage of life.

PLANNING FOR THEIR FINAL REQUESTS

Part of that comfort is to fulfill her patients' final requests. To find out what those requests are, Jesline and her Medical Social Worker (MSW) colleagues would first need to get to know the patients personally. This involved asking questions, sometimes through a legacy work interview.

From there, they get to know the patients' desires and how they would find fulfilment.
Jesline and her team would then start to plan on their requests.
"Whatever they want to do, we have to do it when their health is stable or else it will be too late," she said.

While some patients just want to be near to their family, others may have unique wishes. Still, Jesline and her team will try their best to help them.

"I had a patient who requested for a lot of recycled lunch boxes and medicine cups. We also provided him with tapes and scissors so that he can enjoy crafts work with the recycled materials. He was happy with it," she laughed at the memory.

The patient also requested to visit his wife – who was in a nursing home – regularly before he passed on. With her team's help, Jesline made the necessary arrangements to ensure the couple can spend time together weekly.

There was another patient who wanted to leave some artwork for her elderly parents, but wasn't very open to interacting with staff as she felt inferior because of her appearance.

Lucky for Jesline, they had something in common – both of them love to paint. It did not take long for Jesline to befriend her and start her legacy work. The patient managed to finish her project, and as an added bonus, Jesline has started to paint again, finding inner peace in the process.

PATIENTS' REGRET AND ADVICE

Fulfilling her patients' final wishes is only one aspect of her profession. Jesline is also privy to her patients' regrets, and in helping them resolve as much of it as possible

One of the most common regrets among palliative patients is not being able to cook for their family again.

To help them, the

before they pass on.

team organises cooking sessions just for the patients and their family. Be it cooking from a family recipe or preparing for their favourite dishes, the team will always be there to get the family involved and forge greater kinship in order to preserve the memory.

Despite all the activities they can do, a sincere smile and cheerfulness are the things that can bring the most joy to a dying patient. Serving in a palliative ward is tough but definitely rewarding.

Jesline has some advice for those who are interested in palliative care. "You must be a good listener and have compassion towards patients."

Opposite page: Jesline (right) with a patient during a morning exercise. Below: Jesline started to paint again and find her inner peace



Planning ahead and how it has changed me

When he saw how experienced facilitators are able to break down the barriers talking about death, and how community groups are working at making it less of a taboo, intern Justiin Easwarann was inspired to change his perspective.



n my diploma studies for gerontology, I interacted with seniors on a variety of lighthearted topics - health surveys, physical exercise, making terrariums and even how to use Whatsapp on their phones to communicate with their grandchildren. Planning ahead for end-of-life issues was never discussed. I had never intimately experienced death, nor did I see the importance of discussing what gave meaning to life. That changed, when I interned with the Advance Care Planning (ACP) Office at Khoo Teck Puat Hospital.

During my internship, I listened to many conversations where ACP facilitators broached the topic with patients and their family members. Some were uncomfortable. Difficult issues, such as strained relationships with spouses, cropped up.

The ACP facilitators had to navigate the complex family

dynamics and help them come to a common understanding of the care goals that needed to be discussed. Sometimes, emotions ran high.

On one occasion, I accompanied an ACP facilitator on a ward visit where she encouraged a patient, who had been admitted to the hospital for quite some time without much family support, to do ACP. Instead of jumping in with an agenda, I noticed that the facilitator got to know him as a person first. Once he felt understood, he opened up immediately. I saw that when someone embraces death, it frees him from fear, and that in turn opens himself up to plan for fuller days ahead.

These conversations are also happening in the community as well, among healthy uncles and aunties. I attended the launch of CLOSER, a public art installation encouraging people to get closer to the topic of death, as part of life. CLOSER was

organised by Both Sides, Now, a community arts project dedicated to engage seniors in the community on end-of-life conversations.

For six years, Both Sides, Now used the arts to raise awareness and interactions on the issue of death. For over a year, the artistes worked with seniors from Wellness Kampung, a community node of Yishun Health, to develop art pieces that expressed how they wished to live well and leave well. One of the exhibitions displayed wind blankets sewn by the seniors depicting their ideal place of death. Another exhibition presented photographs of seniors with items or loved ones that would be most dear to them when they near the end of their journey.

My experiences have changed my perspective on life and death. I am now more comfortable talking to people, such as my family members, about ACP and its importance. Death is often brushed off at first because it feels too heavy for daily conversation. But the work of passionate ACP facilitators showed me that barriers can be broken down if the individual trusts that you care and understand them as a person.

What I saw in the community taught me that it was possible to discuss end-of-life issues in a lighthearted and honest manner. This would allow more to embrace life and death, and see conversations about these topics in a positive light.

After all, the only person who knows you best is yourself. Death is inevitable for everyone, so instead of running away from it, why not plan for it?

"I am the controller of my own life"

Planning ahead can be a difficult issue for many patients and their families. But a family forged ahead, despite the problems they faced, because it was better to be in charge of one's life than to wait for things to happen.

iyah, why need to plan ahead before we are sick? If I fall sick with major condition, just come to hospital for treatment lor."

This is a common response during many of the Advance Care Planning (ACP) facilitation sessions I conduct with patients and their family members. For many of them, planning ahead is just too uncomfortable.

Mrs G* (name has been changed to protect confidentiality) was different. She is the main caregiver for her husband, who had been diagnosed with advanced liver cancer several years back. Mr G underwent multiple treatments, but none help in curing the disease. The cancer spread to his lungs and to the nearby blood vessels, making him frailer than before.

The family reached the end of the road when the oncologist, following assessment of Mr G's condition,

explained that he had run out of treatment options.

The disease and its progression not only took turmoil on Mr G's physical health but also affected the whole family, emotionally and financially. Mr G's sons had become quieter and were reluctant to visit him in the hospital.

Mrs G took all these in but told herself that she cannot give up, and hoped that her faith will give her strength to continue in her role as the caregiver until the very end.

The primary doctor in the hospital referred Mr G's case to the palliative team for symptom management and end-of-life placement. During one of the consult and review sessions, the palliative team introduced the concept of ACP to Mr and Mrs G and his wife.

Mr G has never verbalised his care preferences to the family and Mrs G thought it will be a good platform for the family to be aware of this,

Don't wait for things to happen, we are our own controller of life."

hence the discussion was initiated. It took several attempts for the family to complete the discussions as it was hard to make several decisions due to the family's reluctance to commit.

During one of the sessions, Mrs G told the palliative team that she has given good thoughts about her own ACP as she anticipated how her future care will be and seeing her family support system. She has arranged and done her ACP in another hospital with the presence of her two sons, and confidently told us: "I am my own controller of life". She felt strongly that if one did not plan ahead and let family aware of the preferences early, the emotional burden of family making decisions will be huge. Ever since ACP is done, she has become more confident in her living her life, even Mr. G has been influenced.

Mrs G's advice for anyone who wants to do ACP is that it is never too early to do one. "Don't wait for things to happen, we are our own controller of life."



MORDS AND PHOTO JUSTIIN EASWARANN, INTERN, ADVANCE CARE PLANNING KHOO TECK PUAT HOSPITAI

/ORDS GOH HWEE JIN, PALLIATIVE NURSE, CHANGI

Decisions in advance: Advance care planning -A gift to your loved ones

Dr Eunice Chua of Tan Tock Senq Hospital explains the importance of Advance Care Planning.

DR EUNICE CHUA SHUMIN.

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

The Last Lecture is a New York Times best-seller by Randy Pausch and Jeffrey Zaslow. The 2008 publication was based on an actual lecture delivered by Pausch, a professor of computer science at Carnegie Mellon University in Pennsylvania, USA.

Pausch had been diagnosed with pancreatic cancer in 2006. When his cancer became terminal, he wanted to record his delivery of a "last lecture" as a gift to his three young children. In a poignant statement, Pausch declared that he was "lucky to have had cancer rather than having been hit by the proverbial bus", because of the time and opportunity he had to have vital

conversations with his wife and to prepare his family for his death.

Nobody is able to predict the timing nor the way in which death will take us away from this world. Death may come suddenly or it may come at the end of a long, drawn-out illness. The opportunity to communicate with our loved ones before we pass on is not guaranteed either.

In certain situations, such as when a terrible illness strikes - massive stroke, brain damage or demential, a person may suddenly lose their ability to reason, communicate and make decisions. When a person loses his ability to think for himself, he often falls back on his family members to make decisions on his behalf. Most people feel that their family members know them well enough, and should be able to make good decisions for them. But studies have shown that the patient's family members, or designated decision-makers, are able to correctly predict what the patient would want in end-of-life decisions just 65% of the time.

Often, the surrogate decision-maker would make decisions based on what they would want for the patient instead of what the patient himself would have wanted. This is not surprising, given that these decisions are often made in stressful and emotional situations, where family members are more likely to tell the healthcare team to "do everything, whatever it takes".

Modern medicine has resulted in a paradox where although people are living longer, they are also living with more chronic illnesses, some of which are extremely debilitating. Medical technology has advanced and allowed many to be kept alive, with the trade-off of burdensome treatments, suffering and a poor quality of life.

In most of the developed world, the majority of the population will die in an acute hospital or in a nursing home, usually after many cycles of aggressive, painful and pointless medical treatments. Death rarely happens painlessly or quickly.

Advance Care Planning (ACP) is a continuous conversation between you, your loved ones and your healthcare providers. It is an opportunity for you to make healthcare choices for yourself in advance, should you lose the ability to communicate or make decisions in the future.

The ACP you make will guide your loved ones or designated spokesperson to make decisions for you that reflect your wishes and values. The ACP will also guide the healthcare team to ensure that your medical treatment

is in line with your preferences.

Other benefits of having your ACP done includes having greater understanding of your own medical conditions. A member of the healthcare team will facilitate the discussion of your healthcare preferences and assist in documenting them. During this process, you will gain better insight about your health.

Pausch decided to do a "last lecture" as a gift to his children, as a way to share with them about the values he stood for and the life lessons he had learnt. Doing an ACP parallels that same concept of giving a gift to your loved ones. Your ACP reflects your goals, beliefs and

values. It is an opportunity for your loved ones to know what a good life means to you. It allows you to communicate how you would like to be cared for near the end of life. Discussing these important questions with your loved ones is also a chance to communicate openly and strengthen relationships.

Your ACP is a gift to your loved ones – giving them a peace of mind and removing the potential burden they will feel in making difficult healthcare decisions on your behalf. Your ACP will guide them in ensuring your values and goals are always respected and honoured.

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.

It is often easy to forget that caregivers are humans too, and that they may also be affected by chronic illnesses and disabilities. A crisis may strike caregivers unexpectedly, leaving the caregiver no longer able to carry out the role. Hence, it is practical and wise for a caregiver to plan ahead, in case of crisis. Here are some questions to guide your planning:

#1: Who would take over your caregiving role if a crisis should strike?

The person(s) you have in mind should be aware that they are part of the crisis plan. While they might be a good replacement, it might not be feasible for them to take on the role. If you cannot think of anyone to replace you, it is all the more important to think of alternative options.



#2. Are you aware of the available options in Singapore?

If there is no feasible caregiver replacement, other options have to be explored. These include private nursing agencies, domestic help, daycare centre, community hospitals and inpatient hospices. The optimal option depends on various factors, including patient's priorities and preferences.

#3. Does your family know your wishes?

Advance Care Planning, Legal Power of Attorney and Advanced Medical Directive are not only for the patient; caregivers should also do it as part of crisis preparation. •



Upcoming Events & Announcements

19 JAN 2019

BRIGHT VISION HOSPITAL FLAG DAY

Venue: Islandwide **Time:** 8.00am - 6.00pm

2-3 MAR 2019

SINGAPORE CANCER SOCIETY **TALKMED RELAY FOR LIFE 2019**

Relay for Life is an inspiring overnight community event that offers everyone an opportunity to participate in the fight against cancer. Participants will walk or run around a track of path at their own pace during the event. Each team is asked to have at least a member on the track at all times to signify that the fight against cancer never sleeps. Taking place for the 3rd year, SCS Relay for Life gives everyone a chance to CELEBRATE cancer survivors and carers, REMEMBER loved ones lost to cancer, and FIGHT BACK by raising awareness and funds to support the work of Singapore Cancer Society.

Venue: National Stadium, Singapore Sports Hub **Time:** 6.00pm (2 March)

9.00am (3 March)

Admission: \$25 (early bird till 21 Dec 2018), \$30 (regular rate 22 Dec 2018 - 15 Feb 2019)

Information:

https://scsrelayforlife.sg/



HCA HOSPICE CARE WAIVES FEES FOR DAY HOSPICE SERVICES

HCA Hospice Care waives all fees for its Day Hospice services, effective from 1 November 2018. With this change, patients will be able to access HCA Hospice Care's Home Hospice, Star PALS (Paediatric Advanced Life Support) and Day Hospice at no charge.

Along with the fee waiver, HCA's headquarters and The Day Centre have moved to a new location on 5 November 2018. Their new address is:

705 Serangoon Road Block A #03-01 @Kwong Wai Shiu Hospital Singapore 328127

For more information, please visit www.hca.org.sg or call 6251 2561.



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