

THE HOSPICE LINK

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A hand is shown with each finger having a small, smiling face drawn on it. Several colorful speech bubbles (red, orange, yellow, blue) are floating around the hand, some containing small text or symbols. The background is a solid blue color.

**GURMIT
SINGH:**
Hospice
Care is a
Wise Choice

THE POWER OF CONVERSATION

HOW TO TALK
ABOUT END-
OF-LIFE ISSUES

PLUS
Caregiving
Tips



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

12 Jalan Tan Tock Seng, S(308437) T: 6251 2561 F: 6352 2030
www.hca.org.sg info@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 MWSshh@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: 6563 2281 F: 6561 8205
www.slh.org.sg/wp/ general@slh.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.ktph.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 graduate Medical School Singapore
8 College Road Level 4, S(169857)
T: 6516 4233 www.duke-nus.edu.sg/lcpc

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Start your conversations today. Plan your future.

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Discussing these difficult issues in advance is a loving act. We do not want to leave our loved ones clueless and burdened to make decisions for us.

When we plan for our future, we make provisions not only for ourselves, but also for the people close to us. We plan for our children's education, a roof over our family, insurance policies as protection, a will, and perhaps even our own funeral. But such plans may still not be sufficient. People live longer these days and they could live with multiple chronic diseases over a prolonged period of time. Not many planned to live with life threatening illnesses and gradual decline.

“Talk = Love + Respect” was the theme of Singapore Hospice Council's community event held in October 2017 to encourage Singaporeans to initiate conversations about end-of-life issues with their loved ones.

Discussing these difficult issues in advance is a loving act. We do not want to leave our loved ones clueless and burdened to make decisions for us. Starting such conversations may not be easy at first. In this issue of *Hospice Link*, we bring you stories of how others have done it and the topics that they spoke about. We hope these valuable experiences will encourage and help you to start your own conversations.

We would love to hear from your own journey. You may email your stories to story@singaporehospice.org.sg.

Ms Yeo Tan Tan
Chief Executive
Singapore Hospice Council

Talk = Love + Respect

The Singapore Hospice Council leads the way in initiating frank conversations about end-of-life issues.

On 28 – 29 October 2017, the Singapore Hospice Council (SHC), together with its member organisations and partners, celebrated the World Hospice and Palliative Care Day (WHPCD 2017). The two-day celebrations were held as a community event at Ang Mo Kio Central Stage. Mr Tan Chuan-Jin, Speaker of Parliament, was the Guest-of-Honour, gracing the event with special VIP Dr Amy Khor, Senior Minister of State, Ministry of Health.

Usually, death and end-of-life issues are met with hushed tones. But at the event, themed “Talk = Love + Respect”, these issues were in the spotlight. The event highlighted that having frank conversations about one’s preferred end-of-life care choices is a way to demonstrate love and respect to all involved. It is a way to show our love by caring and knowing what our loved ones’ desires, and that honouring our loved ones’ wishes at the end-of-life is a way of showing respect.

Having frank discussions about the issue is important so that there are no misunderstandings or dilemmas when the time comes.

The opening ceremony featured a short interview with Mr Tan and Dr Khor on what mattered most to them at the end-of-life. The two-day event covered a range of topics including Advance Care Planning, What is Palliative Care?, and Tips for Caregivers. mm2 Entertainment artists Michelle Tay and Chan Tian Wen were among the celebrities who graced the





① Dr Angel Lee, Chairperson, SHC; Mr Tan Chuan-Jin, Speaker of Parliament; Dr Amy Khor, Senior Minister of State, Ministry of Health; and Dr Chong Poh Heng, Honorary Secretary, SHC (from left to right); ② more than 1,300 people turned up for the two-day event; ③ many messages of love were pinned by the participants on MWS Home Hospice's board; ④ mm2 Entertainment artist Chan Tian Wen entertained audiences with singing and shared what matters most to them at the end-of-life; ⑤ speaking in front of a live audience, Singapore Cancer Society's patient, Mdm Lok Chwee Har, spoke about her experiences in battling with cancer; ⑥ exchanging and sharing of information between St Luke's Hospital staff and HCA Hospice Care staff.




7 Sharing from her perspective as both a daughter and a parent, Dr Amy Khor highlighted that it was important for parents to initiate end-of-life conversations with their children, lest they are accused of being unfilial; 8 emcee Ken Low (left), interacting with the audience in a question and answer segment; 9 HCA Hospice Care put up a skit on practical tips on caregiving for the caregivers.

“Palliative care is more than just the arrangement over monetary or funeral arrangements. It is also about focusing on immediate, concrete goals that improve a person’s quality of life and fulfil his desires as far as possible.”

event, and encouraged audiences to talk about end-of-life issues with their loved ones.

Mr Tan wrote on his social media after the event: “Palliative care is more than just the arrangement over monetary or funeral arrangements. It is also about focusing on immediate, concrete goals that improve a person’s quality of life and fulfil his desires as far as possible.”

After all, the goals in palliative care is to live a fulfilled life before leaving with a legacy.

In line with the three-year partnership with the Ministry of Health, SHC hopes to educate more Singaporeans on palliative care and equip members of the public with the tools to start having end-of-life conversations with our loved ones. This community event only marks the beginning of the many other outreach campaigns to come. 



WORDS: SINGAPORE HOSPICE COUNCIL
PHOTOS: KOH SHU JUN, VICTORIA TAN YUE NI
AND YEO TAN TAN/ SINGAPORE HOSPICE COUNCIL

Where death is no longer taboo

“Death” and “dying” are not easy subjects to broach. Sister Geraldine Tan, executive director of St Joseph’s Home shares her tips for communicating with those who are dying.

In November 2017, St Joseph’s Home resumed its hospice service with the same care model but in a completely different setting. Our goal remains to regard every visitor as a person, not patient. This means being concerned not just about their physical health, but also their psychological, emotional and social well-being. We took the opportunity to rethink the concept for our hospice wing when we redeveloped the Home.

We thought of designing it to look like the “Street of Verona” in remembrance of our Foundress St Magdalene of Canossa, who started her mission work in 1808 in Verona, Italy. Her charity work included education and pastoral care of the sick and the dying. Here at St Joseph’s Home, more than two centuries since our foundress started her mission and almost 40 years since St Joseph’s Home began operations, we try to continue living her legacy in the work we do every day. We hope that with the way our hospice wing is designed, we will not only be reminded of our core duty but also inspire visiting family members to live well and to enable their loved ones to do so right until the very end of life.

HOW THE CONVERSATION HAS CHANGED OVER THE YEARS

When the Catholic Welfare Services first started St Joseph’s Home in 1978 with the help of the Canossian Sisters, death used to be spoken of in hushed tones, if the topic was even spoken about. Either that, or it was referred to only implicitly. For instance, “Mum is going, so you better come see her.”

At least today, people are more open to using the words ‘dying’ and ‘death’. This is partly the result of education, partly the erosion of the cultural fear of the last moments of one’s life. But it remains a difficult topic for most people, perhaps except children.

How can one go about talking about such sensitive issues? Here are some tips I’ve found to work in my experiences.

1. Ask the dying person: ‘now that you’re going, can you imagine your family without you? What difference would you have made to your family?’ (what is your legacy?)
2. Try listening and observing first instead of talking. Is the person
3. Offer concrete support/action rather than vague words of concern e.g. If it’s easier for you, shall I get dinner for you every Friday since I go past your place that day? OR Is there anyone you would like me to contact/inform on your behalf?
4. Recognise the fear of not starting the conversation. Is it you or the dying person? Why is the fear there? How can it be addressed?
5. Never say ‘I understand’ because you never will. You are not them and never will be. 🙏



The new St Joseph’s Home is designed to inspire patients and family members.

A wedding at a wake

A son was committed to fulfil his mother's final wish of seeing him get married, even if it meant it was at her wake.

Madam Chew (not real name) is married with a son, worked as an administrative staff for many years before she quit due to her medical condition. In 2016, she was diagnosed with gastric cancer metastases in the lymph nodes, liver and oesophagus. Her main caregiver was a helper, assisted by family members. She was referred to Singapore Cancer Society's Psychosocial Services (PSS) to provide emotional support to the patient and family in coping with this terminal illness.

Communication between Madam Chew and family had never been easy. She did not talk much due to phlegm, nausea and other side effects caused by the chemotherapy. Her communication challenge was also attributed partly by the cancer metastasis in the lymph node that suppressed the vocal cord. At times it was difficult for her to process and retain information.

Every patient has different ways of communicating their illness and end-of-life issues. Mdm Chew preferred to discuss and make her decisions on such matters with her family instead of with the medical team. Her husband had not been very forthcoming in talking about her condition. Her son, on the other hand, discussed about his mother's condition and the care plan with us.

In fact, Mdm Chew had clear instructions to her son about her care preferences: she preferred to be cared for and to spend her end of life at home. She also indicated that she did not want to be resuscitated in the event that she stops breathing or has no pulse. I worked closely with her family to best support patient's care.

Despite of her pain and symptoms, Mdm Chew was very much focused on her "final" responsibility which



is her son's wedding. This seemed more important to her than anything else. She felt that this could possibly be the very last thing she could do to express her love for her son.

It had always been Mdm Chew's wish to see her son get married. He promised her that he will start with the wedding plans. At that time, he had no definite plans for a wedding, and the solemnisation date was not even set.

Mdm Chew knew her days were numbered since she stopped her chemotherapy. She then urged the son to marry during her hospitalisation. The son started planning for the wedding.

During her last days, Mdm Chew busied herself with helping her son in the wedding arrangements. She took on the responsibility to pen down the guest list and other ceremony procedures although she was in pain.


Unfortunately, Mdm Chew passed away before her son's wedding. Nonetheless, he decided to proceed with the solemnisation

and wedding luncheon as planned. It was important for him to fulfil his mother's last wish. The couple decided to go ahead with the wedding despite knowing that there will be negative comments from relatives.

I affirmed her son and family about their decision despite the pressure from relatives and society. Furthermore, it was a closure for couple as the wedding was an unfinished wish and responsibility of Mdm Chew's.

The couple and family discussed about the possible consequences that may result from their decisions, but they decided to go ahead. The couple was mentally prepared.

At Mdm Chew's wake, the couple dressed up in their wedding outfits and completed the ceremony with the blessing from the late Mdm Chew and their family.

In facing the loss, the couple started a new chapter in their lives. They left no regrets behind. I believe that the couple can live their lives better with the love and blessing from the late Mdm Chew. 

The legacy of a mother

Bright Vision Hospital's patient Madam Hajjah Khamisah was cheerful till the end, and her memory lives on, in the name of the granddaughter.

The loss of a mother may remind people more of pain and sadness. But for Mohd Safri bin Baba, his late mother's kindness and cheerfulness is what he remembers the most about her.

THE JAUNTY MOTHER

Madam Hajjah Khamisah's condition was complicated as she suffered from pneumonia, tuberculosis, lung infection, kidney failure and diabetes, all at the same time. She went through an arduous medical journey, and was in and out of several hospitals and various polyclinics for over two years before she was admitted to Bright Vision Hospital (BVH).

Throughout her stay at BVH, Mdm Hajjah Khamisah remained cheerful and did her best not to affect others with her pain.

"My mother would always say "thank you", and a few kind words to anyone who tended to her. She was grateful to the doctors, nurses and physiotherapists, and the warmth

shown by fellow patients," Safri said.

Safri and his father visited Mdm Hajjah Khamisah every day at the hospital, and she would always tell them about her day, the treatments she received, the tests and physical exercises she did, the food she tried, and the patients, nurses and doctors she met. She rarely complained about her pain. Though some things were left unsaid, Safri always knew that his mother went through a lot.

THE BVH JOURNEY

At BVH, the doctors, therapists and nurses worked together to help Mdm Hajjah Khamisah manage her condition and relieve some of the pain, while the social worker comforted her family members and provided them with the information that they needed.

The hospital provided caregiver's training to the family's domestic helper on the appropriate ways to clean, bathe and change Mdm Hajjah Khamisah, as well as how to safely carry and transfer her from the bed to the wheelchair.

"I learned a lot from those sessions too. That was also when I realised that I took some things for granted previously," said Safri. "The things we learned from the caregiver's training were very helpful."

THE TRIP TO MALACCA

Madam Hajjah Khamisah used to live in Malaysia where many of her relatives and friends still live. To fulfil her wishes to see them again, Safri drove her to Malacca twice last year.

The first trip, in May 2016, was for Safri's wedding reception in Malacca, following the ceremony in Singapore a week earlier.


To make sure that the trip would be safe enough, BVH Physiotherapist, Shelby Tan, guided Madam Hajjah Khamisah on how to walk while Occupational Therapist, Lim Zi Le, advised Safri on the safety aspects of the car ride.

Despite the challenges, the drive provided a mother-and-son moment for Safri and his mother outside of the hospital setting.

"It was not all that comfortable for my mother during the long drive, but she did not complain even a bit. She was determined to make the trip, as was I. She was joyful and excited throughout the journey, which was quite amazing," Safri added.

Madam Hajjah Khamisah passed away on 27 November 2016. Three months later, on 23 February 2017, Safri's daughter was born.

Safri and his wife named their daughter Khadijah binte Mohd Safri, which means trustworthy and most revered in Arabic. It bears resemblance to the name of Safri's mother, Hajjah Khamisah binte Abdul Majid.

"My hope is that my daughter will be as kind, respectful and grateful as her grandmother, whom sadly, she would never get to meet," Safri said. 



Safri, his parents and wife at the wedding reception in Singapore.

Hospice care is a wise choice

Television personality Gurmit Singh talks about the importance of hospice care.



Gurmit at one Dover Park Hospice's 25th Anniversary Roadshow.

On August 2017, Dover Park Hospice (DPH) appointed local celebrity Gurmit Singh as Ambassador for its 25th Anniversary outreach campaign, "Hospice care is a wise choice".

He is the first celebrity ambassador for DPH, a secular charity hospice. Gurmit has been helping to bust myths about hospice care and spread awareness on how hospice care can help terminally-ill patients live life meaningfully and with purpose, making every moment matter.

Q: Why did you decide to be an ambassador for DPH and hospice care?

A: When I had the initial meeting with DPH, I was astounded and

touched by the work being done. Like most people, I was of the impression that hospice care was the place for unfilial children to drop off their ill parents and wash their hands off their duty and obligation. But nothing could be further from the truth. So after hearing the work they do here for the patients and their families and caregivers, it was a no brainer for me when DPH asked me to be their goodwill ambassador.

Q: What is your personal experience as a caregiver?

A: My Mom and Dad passed away in 2001 and 2003, respectively, from cancer. It was a trying time, a stressful time. It was a continuous challenge to make sure that their needs were met. I remember having

to drive at full speed, ignoring all traffic rules, to get to my Dad who was in excruciating pain to the hospital in the wee hours of the morning. The constant worry of having to make sure they had the right medicine and dosage and at the right time was just one of many everyday challenges. Had I known about hospice care then, I would have chosen it without hesitation.

Q: What is your personal experience and views about end-of-life care?

A: I have seen both my parents at their end-of-life stages. I have seen how that process can affect not only them but also their loved ones and caregivers. The end-of-life stage should be one of peace, embrace, and acceptance, so that one is able to do the necessary things like

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We have different therapy sessions like music, massage, occupational and other forms of therapy to keep the patients alert and involved.”

settling of home affairs, saying the goodbyes and enjoying what precious time and life there is left. The last thing you need is stress or anger or all the other negative feelings.

Q: Why do you think hospice care is a wise choice?

A: I don't think it is a wise choice. I KNOW it is a wise choice. If you could take an hour to just come down to DPH and talk to someone from the staff and/or volunteers, you will easily come to the same decision. All our misconceptions and prejudged biasness will be eradicated and you will have new found respect and gratitude for the hospice care as a whole. A care that is total, holistic and nurturing. The hospice not only tackles the symptoms of the patient but they also provide psychosocial aid to the patients and their caregivers. And even after the patient has passed on, the hospice follows up with the bereaving family to ensure that they are not alone but instead are given both emotional and psychological support.

Q: Why do public have these misperceptions about hospice care? What are these misperceptions?

A: I guess what you don't know, you make up. I mean I was one of them thinking the place is dingy and dark and gloomy. I thought that this was the place to “dump” your dying family member. I thought very little of hospice, if any at all!

But DPH is a place that is well lit and aired, run by professionals and specialists, and is never a place to “dump” your loved one.

Another misperception is that

once the patient comes in, they can never leave unless they pass on. That is not true. We have patients who go home for festive occasions and come back again feeling so glad that they were able to make one more joyous occasion like a birthday and so on. Their loved ones are also allowed to visit any time of the day. There are no “visiting hours”.


Another misperception is that the patients are left on their beds to “kill time”. So untrue! We have different therapy sessions like music, massage, occupational and other forms of therapy to keep the patients alert and involved. These sessions are not compulsory but they provide patients with the option to mingle with other patients in these activities.

Q: Many people find it difficult to broach this topic, especially with their loved ones. How does having an earlier conversation help?

A: Actually, what we found through some of our outreach efforts was that it was the younger generation that was afraid to broach the subject.

That's interesting because it was thought that the older generation would get offended if the subject was brought up. So

hopefully with more awareness from platforms like this interview, social media and so on, the younger generation will be encouraged to take up this conversation with their elders.

And having an earlier conversation helps to prevent any confusion or even disagreements between siblings or relatives because the pertinent decisions would have been made when the patient was still of sound mind and without anxiety. 



Conversations worth having

Many people think about how they want to live, but how many think of what they want their end-of-life care to be like?

If you suffer from an irreversible brain injury, leaving you unable to express your wishes for medical care, who would make the decisions for you? For many of us, these may be hypothetical questions, but such difficult questions about medical care should be addressed while you are still healthy and able to communicate your wishes. This will give you some control over any treatment and care you want should you be affected by a sudden and unexpected illness later. Difficult as it may be, end-of-life care is worth talking about.

ADVANCE CARE PLANNING DISCUSSIONS

There are three types of advance care planning discussions.

1. General: This discussion is focused on helping patients reflect and understand their goals, values and beliefs, exploring what the patients might or might not want in certain medical situations, and choosing a spokesperson in the event that the patients cannot make their own decisions.
2. Disease specific: Such discussions focus on helping organ failure patients with recurrent hospital admissions and declining functions to understand and select treatment preferences in various clinical scenarios based on their goals, values and beliefs.
3. Preferred Priority of Care (PPC): PPC is focused on helping patients with a short and limited prognosis identify their healthcare spokesperson(s), discuss care options on CPR and care goals when one suffer a

potentially life threatening crisis. In addition, preference on place of care in event on deterioration and death will be explored.

Patients and their families do not need to make a decision during the first ACP contact with the trained facilitator after the discussion. The facilitator will provide an ACP brochure or a workbook to them and pace with them after the session. ACP is not legal binding. Patient and his family can make changes to their preference anytime.

A CASE OF ADVANCED DEMENTIA

89-year old Madam G has had advanced dementia for several years, and has been attending the hospital's geriatric clinic. In the past two years, she had been frequently admitted

due to chest infection, functional decline and impaired swallowing. We initiated an ACP discussion with Mdm G's daughter, Candy. During that conversation, I got to know many interesting details about Mdm G's younger days as well as her preferred plan of care. That was because Mdm G had had the foresight, while she was still lucid, to discuss with Candy the kind of care and interventions she wanted.

A CASE OF ADVANCED BREAST CANCER

I was referred to talk to Melonie (not her real name) about ACP when she was diagnosed with breast cancer. Despite going through several sessions of chemotherapy, tumors has spread to various parts of her body.

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Difficult questions about medical care should be addressed while you are still healthy and able to communicate your wishes. This will give you some control over any treatment and care you want should you be affected by a sudden and unexpected illness later.

Changi General Hospital palliative care nurse Wang Liyun speaking to a member of the public.

During the ACP session, Melonie was very engaging and appeared cheerful. I suggested that we have the 2nd ACP session with her husband to confirm the discussion and documentation which she agreed. During the second session, Melonie's husband did not agree with Melonie's decision and asked for more time to discuss with her. The next day, Melonie called and informed me that she will be transferring to private hospital for more chemotherapy and would not be continuing with ACP as her husband could not accept the end-of-life topic.


ACP: A TOUGH TOPIC

The above two patient cases illustrate the different responses patients and their families to ACP. Several years ago, a street-poll survey done by Lien Foundation on 800 respondents found about 60% of those surveyed were comfortable to talk about their own death or dying. As it is perceived to be a taboo to discuss about death and dying in Asian countries, initiating such conversations can be difficult.

It is never too early to start talking about these conversations. Starting ACP conversation is never easy for both patient and family

members. There is no right time to initiate it, it is only through frequent communication and engagements of patient and family then these discussions will be a success one.

HOW CAN I MAKE AN ACP APPOINTMENT IF I AM INTERESTED FOR IT?

If you are a patient at any hospital, your doctor can make an online referral to the ACP office. 

FREQUENTLY ASKED QUESTIONS

1. Why do I need to have a preference about life-sustaining treatments?

Medical technology allows people to be kept alive even when cure is no longer possible. Decisions about the use of machines and emergency treatments to keep you in that state need to be made. The ACP process allows your preferences on such matters to be made known to others when you can no longer speak for yourself.

2. Does having an ACP means that doctor won't treat me?

No. An ACP helps your doctor understand who you are and what matters to you, when you can no longer tell them yourself. Your doctor will always provide care that is in your medical best interest. This includes considering your views on matters like life-sustaining treatment.

3. How will my doctors know what my wishes are?

If you are seriously ill and cannot make your own healthcare decisions, the doctors may consult with your loved ones about care options. Having discussed your wishes with you in advance, your loved ones can share your plan with doctors.

4. When will my doctors act on the decisions in my ACP?

Your preferences may be used to guide your healthcare team if you are no longer able to make decisions for yourself. As long as you have the mental capacity to make decisions, you will be consulted upon for your consent on receiving or ending treatment.

How do you tell a child about death?

Medical practitioners learnt how best to broach on the topic at a workshop organised by Star PALS.

We speak an average of 15,000 words a day, 105,000 words per week, 460,000 words a month. But how often do we talk about death, be it ours, or that of a loved one?

In our Asian culture, talking about death is almost always deemed taboo. A plug is placed on the conversation about dying even before it begins, with a “choi ah!” or “don’t say die!”

What’s even more difficult is to broach the topic with a child whose life has barely begun to blossom.

Dr Chong Poh Heng, HCA Hospice Care’s (HCA) Medical Director emphasises the need to relate to children who are on this journey: “There is a need to be in sync with these children, to meet them where they are at, to be able to speak to them at their level.”

Many of the medical practitioners present at a workshop hosted by Star PALS, a paediatric palliative care service provided by HCA, admittedly felt nervous about broaching the topic of Advanced Care Planning (ACP) with parents of terminally ill children.

Why the need to talk about ACP? “ACP serves as a guide for the child’s future medical treatment which specifies what treatment will or will not be provided to the child. In so doing, it avoids delays in decision

making when the child is critically ill,” explains Dr Richard Yap, a Senior Resident Physician with HCA.

ACP involves discussing one’s beliefs and goals for end of life care. How does one start a conversation with a child about a topic that is difficult even for adults to handle? Here are some steps medical practitioners can take:

- 1. Establish** an agreement with parents, children and caregivers early on in the relationship concerning open communication.
- 2. Engage** the child at an opportune time.
- 3. Explore** what the child already knows and wants to know about the illness.
- 4. Explain** medical information according to the child’s needs and age. Children often have many questions about what is happening and what is going to happen to them. Children may want some specific information, but not all. Asking questions such as “What would you like to

know?” and “What have you been worrying about?” will allow you to address specific information needs.

- 5. Empathise** with the child’s emotional reactions with “I can see that you’ve really been worried about this”, validating their reactions with statements such as “We’ve been wondering why you’ve been upset” and clarifying the situation with “Can you tell me what you’ve been thinking about?” These will help you understand the child better.
- 6. Encourage** the child by reassuring him or her that you will be there to listen and to be supportive.

Dr Yap shares that it is difficult when parents do not acknowledge that their child is ill and are not open to discussing about ACP while the child is still in a stable condition. However, parents become distressed when the child

Opposite page:
Dr Richard Yap shares
about the importance
of ACP for children;
Dr Chong facilitates a
group sharing.





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ACP is more than just care planning — it is walking the journey with the child and their parents in the midst of uncertainty, with patience and an open heart.”


encounters his or her first medical crisis. He encourages parents to have these five important conversations with their terminally ill child:

- 1. Talk to your child about their sickness** - Explaining the disease in a clear and simple language appropriate to the child's age should help the child understand what they are having and what they are going through. This can be helpful as the child goes through numerous procedures and treatment in the course of their illness.
- 2. Find out your child's treatment preference** - Asking children in terms of their choice of treatment may even help parents make decisions for them. Sometimes a difficult decision may become “easier” on hearing their child's viewpoint.
- 3. Elicit hope even if there is no more cure** - Maintain hope up until the end, but do not provide false hopes. Hope for cure can

be translated into a hope for peace and comfort when one is approaching the end of life.

- 4. Find out about their unfulfilled wishes** - Simply asking their child what they want or what they might like to do can add joy into their lives. It could be going for their dream Disneyland trip or simply having a new pet!

- 5. Talk about death and dying** - Discuss in a gentle and time-appropriate manner and in their own terms. Children with terminal prognosis often have understanding and concerns regarding the terminal nature of their illness. Expressing through art or play can help bring out some of their concerns.

ACP is more than just care planning — it is walking the journey with the child and their parents in the midst of uncertainty, with patience and an open heart. 



Walk with me, till the end

A patient's last wish to declare his love for his supportive wife was fulfilled with the help of Tan Tock Seng Hospital's Palliative Medical team.

Mr A was a Chinese gentleman in his late 40s. He had end-stage cancer and his prognosis was short. He was admitted to TTSH earlier this year (2017) with severe abdominal and lower limb swelling, as well as deteriorating liver function.

He shared with me his desire to have a candlelight dinner with his wife as their wedding anniversary was approaching. Being homebound due to his illness, he had not brought his wife out for a long time. He recounted how he used to bring his wife for meals after work. He was then the sole breadwinner. Since his illness, he lost his job, and his role as a protector and provider for his wife. Thus, he requested to have a meal with his wife to reminisce the times they had together.

Unfortunately, he was too ill to be discharged, and it was difficult for him to have a meal with his wife in a nice restaurant.

When our team learnt of his last wish, we decided to "make it happen". In preparation for the day, Mr A chose a series of songs that the couple enjoyed, and also a song to dedicate to his wife and started to practise before the actual day. Mrs A chose photos that brought back fond memories to be developed.

“

Mr A taught me what love meant in a marriage and what “in sickness and in health” was.

Our Palliative Medicine team (nurses, medical social worker, doctor and ward nurses) decorated a room in the ward with candles and romantic lighting, accented by the couple's pictures and favourite music played in the background.

We prepared a Western-style meal and gave the couple a memorable time together. Mr A requested for a bouquet of flowers and he got to sing his favorite song as a pledge of love to his wife. Mrs A was caught by surprise.

With soothing, sentimental music in the background, Mr A was able to declare his love for his dear wife one last time. This moment was captured in photos and a short video clip, which was later presented to his wife as a lasting memory of her beloved husband.

Mr A was later transferred to the hospice and had passed on peacefully with Mrs A by his side.

I have been privileged to be able to play a part in organising this candlelight meal. Mr A taught me what love meant in a marriage and what “in sickness and in health” was.

Even as he was deteriorating, he was loving towards his wife. One could not help but to tear when the song was played. As the lyrics aptly put, “life happens, it comes and goes, you were with me the longest”. Mrs A had been very supportive and loved her husband unconditionally. She stood by him when friends deserted him and when the illness seemed so grim.

I will remember Mr A for a long time. 

A home care patient's journey

Assisi's homecare service lets patients live out their last days in the comfort of their homes.

Seventy-one year old Mr Temian Bin Sakiran has been living with rheumatic heart disease since he was 12 after he suffered a bout of rheumatic fever hit him. Although he was on long-term medication throughout his adult life, Mr Temian married and raised three children on his income as a barber with the Sri Nada barber shop at Parkway Parade. He retired in 2015, after which his second daughter Ms Tiayah assume his HDB loan payments and became the main breadwinner of the family.

In June 2017, when his medication was no longer having any effects, Mr Temian quietly refused further procedures. He asked to be discharged so he could spend his remaining days at home to avoid incurring further hospital charges, which would be strenuous on his daughter.

When Mr Temian was referred to Homecare Nurse Joseph Tan, he was told that Mr Temian had only two days to live. Settling him down at home was an important priority.


The frequency of homecare visits is always based on the needs of the patient. Joseph and our doctor checked in on Mr Temian daily to provide extensive symptom management. When Mr Temian outlived his two-day prognosis, Ms Tiayah, who is a flight attendant, struggled with the dilemma: should she working or stay by her father's side? In the end, financial needs made her choose the former.

To help Ms Tiayah during her two-week home absence because of work, Joseph visited Mr Temian more often to check on him, ensuring that his family could cope with caring for Mr



Temian. With increasing symptom management demands, the hospice supported Mr Temian with free medications as the family could not afford them.

Mr Temian lived for more than a month and his family became familiar with his care needs, but his symptoms increased. To honor his wish of passing away at home, Joseph and Mr Temian's family kept him comfortable at home. Mr Temian passed away on 22 July 2017.

Assisi Hospice's homecare visit service is free so that needy patients like Mr Temian are not denied medical help because of their financial circumstances. About 50 percent of our patients come from the poorest of poor families in Singapore. We are able to provide free homecare services only with the help of our donors, with whose generosity can patients Mr Tamian live with dignity and comfort in their remaining days. 

“

With increasing symptom management demands, the hospice supported Mr Temian with free medications as the family could not afford them.

More than words

MWS Home Hospice staff nurse Melissa Fong shares about the importance of using the right approach when broaching the topics of death and dying.



Nobody likes to talk about dying. For many Singaporeans, death is a taboo topic that is seldom discussed. But for those in palliative care, talking about death is not a choice but a responsibility.

For MWS Home Hospice staff who provide palliative care in the patients' homes, the relationship is especially intricate and deep. Beyond attending to medical and nursing demands, they are drawn into the patients' private sphere where they get to know and understand more about the lives of patients and their families. As the relationship matures, it opens conversations that are otherwise sensitive and difficult to broach.

Ms Melissa Fong, staff nurse at MWS Home Hospice, shares her experiences on the difficult conversations that she had to do to prepare the patients and their families for the end-of-life journeys.

THE RIGHT WORDS

One of the most common questions that patients and their families ask is: "How long more do I have?"

"Nurses at MWS Home Hospice have to choose their words very carefully. Sometimes, the patient who asks such a question may not really want to know the answer. And neither do we have the answer. More often than not, the patient is acutely aware of his deteriorating health condition, and the truth can be hard to bear," adds Ms Fong.

She says she would encourage them to ponder their feelings and come to terms with the end-of-life.

Sometimes, a reassuring pat is all that is needed. Ms Fong shares the case of an elderly lady who simply refused to discuss matters related to her last days. Whenever the topic came up, she was silent. However, the tears welling in her eyes betrayed her feelings. In moments like this, Ms Fong offers her comfort in silence.

BEFORE IT'S TOO LATE

Watching their physical body deteriorate day by day, palliative care patients commonly exhibit volatile emotions, and vent their frustrations on those closest to them, and these are often their caregivers.

Caregivers have the gargantuan task of caring for their loved one 24/7. They have to bite their tongue, take in the negative outbursts and still provide emotional support. This aspect of care is especially challenging, since they too are grappling with the eventual loss.

Despite the love and appreciation that patients feel for their caregivers, they may not know how or when to express it.

Ms Fong recounts the story of a wheelchair-bound patient who suffered from a brain tumour that impaired his speech. Every day, his wife worked tirelessly to care for him. One day, Ms Fong probed him to think of one thing he would like

to say to his wife. When he mouthed the words “I love you”, she broke into tears. The magical and touching moment for the old couple was also a timely one, as the patient became unconscious a week later and subsequently passed on.

THE RIGHT TIME

While patients or their families may not be ready to talk about end of life, it does not mean that they never will. Ms Fong explains that for patients who are not ready to talk, she will focus on building a rapport with them first.


Asking mundane questions, she says, may help to lead into the main conversation. “What did you eat?” or “How has your day been?” are just as important as “How would you like

MWS Home Hospice nurse Melissa Fong with her patient and his wife.



your funeral to be?” These routine questions may help the patient to open up and feel more at ease to discuss deeper, more thought-provoking subjects.

Ms Fong shares the case of an elderly lady who seemed indifferent about her mortality. It all changed when she read a birthday card that her grand-daughter wrote her. It moved her so deeply that she

decided to write cards to those who mattered to her. With the help of MWS Home Hospice nurses who penned her wishes and thoughts down for her, she was able to leave behind last important words for her loved ones. 

If you are keen to volunteer with MWS Home Hospice, please find out more at www.mws.sg or email ce@mws.sg.

Tips for Caregivers

DR JAMIE ZHOU

Palliative Care Physician

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.

This issue will welcome many special occasions including Christmas, New Year and Chinese New Year. There will be many opportunities to come together as a family, and many tend to use these occasions to reflect on the past year. For some, it may be their last.

One thing I have noticed as a palliative care physician is the importance for families to find closure, and the impact it has on the future. Here are some tips for finding closure:

Tip #1: The 4 important tasks

According to American palliative care physician, Ira Byock, the four important tasks to finding closure are :

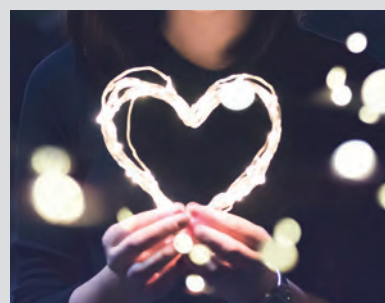
I) To express gratitude;

- II) To forgive (this is 2 ways: ‘I forgive you’ and ‘Please forgive me’);
- III) To express love (see Tip #2); and
- IV) To say goodbye in order to give permission and peace to go.

Each task calls for reflection, preparation and sensitive delivery. Remember that you know your loved one best, including whether they are ready to have such a conversation. Some tasks are more difficult than others so you might want to do it in parts and ensure it is done in a comfortable setting.

Tip #2: There are many expressions of love

Being aware that there are five love



languages (described in Gary Chapman’s book, “The 5 Love Languages”) helps us to express love in more ways than one. The five love languages are: words of affirmation, spending quality time, physical touch, receiving gifts and acts of service. Many of us, especially in the Asian context, feed our loved ones as a loving act. However, when our loved ones are very ill, they often reject food. Sometimes it even feels like they are rejecting our love! Understanding the normal body changes during this time, and knowing that there are other ways of expressing love help our relationships to grow stronger and closer.

Upcoming Events

6 JAN, 13 JAN & 27 JAN 2018

Mini Medical School

Come and join us at our Mini Medical School where you can learn in a fun and interactive way on how to care for yourself and age gracefully! The three Saturday morning sessions are designed to be fun, casual and informative. No background in science required!

Topic: Good Life, Good Will, Good End

Venue: Khoo Teck Puat Hospital Auditorium

Time: 9.00am – 11.30am

Registration: www.ktph.com.sg/main/home (will be up in mid-December)

30 JAN 2018

SHC-LCPC Multidisciplinary Palliative Care Forum

Exploring the Complicated Decisions Around End of Life Care: Research at the Lien Centre for Palliative Care, Singapore

Venue: HCA Hospice Care Auditorium

Time: 1.00pm – 2.00pm

Registration: www.duke-nus.edu.sg/lcpc/shc-lcpc-multidisciplinary-forum (will be up in mid-December)

3 MAR 2018

Dover Park Hospice 25th Anniversary Charity Concert

Venue: Lee Kong Chian School of Medicine, Main Auditorium

Time: 6.30pm – 10.00pm

Tickets: michelle_too@doverpark.sg or yijing_tan@doverpark.sg

10 MAR 2018

Bright Vision Hospital Flag Day 2018

Time: 9.00am – 6.00pm

Website: <http://www.bvh.org.sg/bvh-flag-day-2018.html>

To volunteer, email: community@bvh.org.sg

13 MAR 2018

St Luke's Hospital Palliative Care Awareness Day - Serving with Love to Bring Hope

Venue: St Luke's Hospital, Multipurpose Hall

Contact: general@stluke.org.sg

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Editor
Associate Editor

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Koh Shu Mei

Designer
Printer

Christian Subrata
Yung Shung Printrade Pte Ltd



133 New Bridge Road, #04-06 Chinatown Point
Singapore 059413

T: 6538 2231

E: secretariat@singaporehospice.org.sg

www.singaporehospice.org.sg



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ANNOUNCEMENT

St Luke's Hospital new palliative care wards will be opening in December 2017.