

THE HOSPICE

LINK

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I THINK I
KNOW WHAT
PALLIATIVE
CARE IS

MISCONCEPTIONS IN PALLIATIVE CARE

PLUS
Views from
the pros



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Contents



- 2 Members' Contact
- 3 Editor's Note
- 4 Common misconceptions of palliative care
- 6 H = Hospice. H = Hope
- 7 Before-I-Die SG
- 8 To cry or not to cry?
- 10 Of coffee, snacks and chit-chats
- 11 A recipe for love and legacy
- 12 Living the last lap well
- 14 From healing to helping patients say farewell with dignity
- 16 The journey, yours sincerely
- 17 Caring for patients in their last days
- 18 Views from the Pros
- 19 Tips for Caregivers
- 20 Upcoming events

Busting myths on palliative care

Singapore Hospice Council's 17th member, St Luke's Hospital, will officially open its new palliative care ward in March 2018. Its services are starting to meet the growing needs for palliative care in an aging population.

While the wealth of knowledge of palliative care has advanced over the decades with research and studies, ignorance and old beliefs die hard, and continue to plague the general public. In fact, a 2014 survey showed that the as much as half the population may not have heard of palliative care.

In this issue of Hospice Link, healthcare professionals, social workers, volunteers and patients' families share their hearts and thoughts on some of these common misperceptions and misconceptions of palliative care.

We need to get the word out. You can help us. As explained by one of the medical social workers, Ms Dawn Khoo: "Good palliative care is not just about effective pain management and symptom relief, but also offers emotional, spiritual and practical support to improve the well-being of patients and their families".

Palliative care is about quality of life. It is not abandonment or giving up. We hope that these stories will help refresh our perspectives.

Ms Yeo Tan Tan
Chief Executive
Singapore Hospice Council

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Palliative care is about quality of life. It is not abandonment or giving up. We hope that these stories will help refresh our perspectives.”

Common misconceptions of palliative care

Methodist Welfare Services' Dr Andy Lee debunks the taboos surrounding death and palliative care.

With death being a taboo subject in Singapore, conversations about palliative care for the terminally ill tend to remain off-limits until they are absolutely necessary. This makes discussing home-based care even more sensitive and challenging.

Getting around deep misconceptions and myths about palliative care involves addressing a patient and his family's concerns individually and tactfully, instead of bombarding them with medical facts and figures, says MWS Home Hospice acting head Dr Andy Lee.

"It is important to always explore the underlying ideas and previous experiences that may have given shape to their current concerns. It is often a knee-jerk response to react to the families' concerns by giving them scientific facts and numbers," Dr Lee says.

"But, this approach may not work because there may be deep-seated beliefs that have been built up over many years based on what they have seen or heard from trusted friends or family members. Unless we address these erroneous beliefs and misconceptions, it may well be a one-sided provision of medical jargon that does little to engage and educate our patients."

Dr Lee debunks seven common misconceptions his team encounters:

1. A hospice is a medical facility to care for patients at the end of their lives.

Contrary to popular belief, hospice is not just a medical facility for patients to receive care at the final stage of their lives. The term "hospice" actually refers to a concept of care that focuses on improving the quality of life for terminally-ill patients and their loved ones. This care can be delivered at home or in long-term care facilities such as nursing homes, or inpatient hospices.

2. Palliative care only starts when the patient is dying, or when all other curative treatments have been exhausted.

Palliative care is appropriate at any stage of a serious medical condition. A patient can still receive curative treatment while undergoing palliative care. The aim of palliative care is to provide a better quality of life for patients by helping them with their physical, psychological and spiritual needs. In fact, starting palliative care as early as possible after diagnosis has proven to be beneficial to patients in offering a higher quality of life.

3. Palliative home care is not useful because nothing much can be done at home.

Although there are limitations to the investigative work that can be done at home, palliative home care is still beneficial for patients, especially those who are home-bound and are unable to travel to the hospital for their regular follow-ups. With good clinicians tending to patients, diagnosis and medication can still be administered effectively.

4. The end is near because the doctor and nurses are coming to my home.

Many patients and their families lose all hope and fighting spirit at the sight of doctors and nurses visiting them at their homes. They assume this means that the patients can no longer receive treatment and are merely waiting out their days. Sadly, this has resulted in the rejection of home care services for some patients. In fact, on many occasions, the support from home care doctors and nurses help to allay a lot of anxieties of home-bound patients, especially if they are no longer able to visit the hospital for their usual follow-ups. Many of



Dr Andy Lee (right) believes in engaging with and educating his patients and their families.

our patients actually look forward to the visits even when they are well because of the companionship and camaraderie.

5. The administering of morphine should only be started when the patient is about to pass on and the drug will make the patient drowsy.

Morphine belongs to the opioid class of medications and is very effective in the management of severe pain and breathlessness. But because of the bad press related to diamorphine (heroin), many patients and their family members are very hesitant about morphine. Morphine, when used at the correct dose, can help to relieve pain and breathlessness effectively without causing undue drowsiness and side effects.

6. A patient may get addicted to pain medications, which will lose effectiveness after a while.

Controlling symptoms as a condition progresses often involves increasing doses of pain medications. For example, a growing tumour may cause increasing pain and require much higher doses of medications as the condition worsens. This does not mean the patient is addicted to the medication, or that the medication is no longer working.

7. An unconscious patient may feel hungry because he cannot eat.

This misconception is especially important in the local context, as our cultures view feeding our loved ones and having meals together as acts of love. There is often a lot of guilt within the family as they watch their loved ones deteriorate with decreasing oral intake. As the patient gets sicker, the organs start to shut down and are no longer able to process and regulate food and fluids. As such, patient loses his

appetite and do not experience hunger pangs. In fact, force feeding fluids or food when the patient is unconscious may cause unwanted side effects, such as choking and accumulation of fluid in the peripheries or even lungs. 🚫

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

REAL-LIFE CASE:

The family of a female patient diagnosed with terminal cancer was initially unreceptive towards the services of MWS Home Hospice after being referred by the hospital.

Her son was upset that the hospital had prematurely referred her to palliative care when management plans in terms of curative treatment were still unclear. In fact, the family felt that the hospital was shirking its responsibility by giving up on the patient.

After a few visits and much involvement from the MWS Home Hospice team and the hospital's palliative care team, the family's hard-line attitude started to change. They realised the importance of having some guidance as they tread along this difficult path, and appreciated our help in alleviating her symptoms, which needed extensive reviews even as she began receiving curative treatment.

Eventually, the patient passed on peacefully at home, surrounded by all her loved ones. Her family was so grateful for the services of MWS Home Hospice that the entire extended family attended the memorial service to thank the team.

H = Hospice. H = Hope

Hospice can provide hope, comfort and care to those in need.



HCA's home hospice care allows patients to retain dignity and peace of mind in a familiar environment.

As a patient's illness progresses, it can take a toll on their ability to even conduct daily life, the act of simple chores can now seem insurmountable. By providing them a safe environment for them to cope with the illness allows them to live as independently and 'normally' as possible. This, in turn, is a way to affirm the patients' personal dignity, to assure them that their individuality and freedom are intact.

Home hospice care also involves bringing cheer to the homes from people other than the medical teams. With the family's consent, volunteers bring food and fun during their visits to the patients' homes. Festive activities are a distraction away from the daily grind of caregiving, providing respite for patient, family members and caregivers. All these little sparks not only warms the heart, but lights the embers of hope.

Not all outcomes in the medical field are measured by quantifiable data. Death is real, but so is hope. When a patient struggles with constant pain from a progressive disease, this can only take a toll on the will to live on. With medical support and care at hand, this will to strive on can be strengthened. Our staff are there to pace with the family at every step of the journey.

Mindful outreach to start an open conversation can lead to embracing change, and eventually overcoming fears. Compassionate care, coupled with a patient-centred approach will serve to uphold dignity in the process.

The perception of hospice need not be foreboding – it can be one of hope, courage and comfort. We should train our sights not on the final destination, but on every optimistic step that we take. 🍏

they will somehow go on to live out their supposed terminal illness for much longer. Some may even outlive their prognosis for years.

AFFIRMING HOPE

For some of these 'miracle' cases, we noticed that home hospice care does make a contribution to their mental well-being. For the patient, being in a familiar, loving environment, surrounded by their nearest and dearest can underpin their sense of security and safety. The routine of home is also welcome, as the patient can go about their daily activities to which they have been accustomed.

Home care offers patients who are already struggling with a devastating prognosis peace of mind and dignity in coping with debilitating illnesses by letting them be cared for in the privacy of their own homes instead of being surrounded by strangers and the unfamiliar setting of an external facility.

Death. The end. Terminal. These are the stigmas that often surround the term "hospice".

At HCA Hospice Care (HCA), we find inspiration in our approach to caring for those with life-limiting illnesses. Our multidisciplinary teams see an average of 800 patients at any one time, with over 3,700 admissions per year. Typically, our service to our patients lasts about only three months.

Yet, within this bleak landscape there are pockets of hope and inspiration – miracles of life seem to defy the odds. Of the 3,700 admissions, about 2,000 of our patients eventually pass on. But some 700 do relatively well enough to be cleared for being cared for at home. That means out of five patients we do treat at home, at least one patient's condition will stabilise enough to be discharged to their own primary care physician.

There is no exact determination as to what contributes to this astonishing outcome. Many come to us with an initial prognosis of a few months, but

Before-I-Die SG

The project that aims to get people talking about end-of-life returns for a third time.

Death is inevitable. We all have to come to terms with it, some day, and contemplate about everything that has been and will be. Yet, it is difficult to think about and discuss crucial end-of-life options until we are faced with a life-threatening situation.

Before-I-Die is directed to encourage people to discuss death with their family, as well as to improve their awareness about palliative care options. Through our efforts to reduce taboo about death, help people better understand and utilise the options when needed.

2017 marked the third instalment of Project Before-I-Die Sg. During our month-long exhibition in October, we installed large wooden chalkboards in public areas and invited people to write their answers to some questions, or simply pen their thoughts on end-of-life care and reflections on life.

We also rolled out new initiatives such as posters and postcards to dispel myths people have about palliative care. Some people thought

it only encompasses specific therapeutic procedures, such as cancer treatment. Others believed it is expensive and did not include family support services such as bereavement service.

We gained valuable and refreshing insights, especially through the Life Stories' Exhibition (LSE).

An uncle who saw our LSE said he believed in living each day as it came rather than planning for the future as there were already so much uncertainty. Although he remained ardent in his belief, he said he was glad to have broadened his perspectives on end-of-life issues. More importantly, it prompted him to reflect on his life and to live every moment fully.

The uncle's perspective on end-of-life care is not uncommon among Singaporeans. Yet, it is this unpredictability about life that shaped the focus of our project. We believe it is never too early to talk about end-of-life issues because it is more reassuring to know that we are fulfilling our loved ones' wishes.

We believe palliative care is about

improving the quality of life for patients. This is why we hope to raise more awareness on the issue.

We are privileged to have embarked on this meaningful project and learned more about palliative care. Granted, it is still a heavy topic, but we believe the importance of having these conversations with our closed ones so that we are assured that we can help them live out their days meaningfully.

It is our wish that Singaporeans will be more comfortable in discussing end-of-life issues with their loved ones and be part of the decision-making process eventually. 🍏

THANK YOU!

We would like to express our gratitude towards a special group of people without whom our exhibitions would not have been possible. We would like to thank our project sponsor, Singapore Hospice Council, for being such an ardent supporter, without whom we will not have the means to carry out our exhibitions.

We are also very thankful to Ultra Supplies for sponsoring the printing of our postcards.

We are very grateful to our project mentor, Dr Noreen Chan, for her guidance as well as our project seniors for their valuable advice.

We would also like to thank our friends from Project Happy Apples for allowing us to showcase our boards at LSE.

Lastly, we would definitely want to thank our volunteers for their dedication and hard work.



Our volunteer presenting our project to a member of the public.

WORDS AND PHOTO: HCA HOSPICE CARE

WORDS BEFORE I DIE COMMITTEE 2017
PHOTO: PROJECT HAPPY APPLES

To cry or not to cry?

A reflection on expressing grief and tears in palliative care.

In palliative care, the expression of grief, of which crying is the most overt, is often a challenging aspect to deal with amongst patients, caregivers, and healthcare workers (HCWs). It is invariably caused by the possibility of, or the reality of death, itself a major taboo in modern societies.

FEARS OF CRYING

There are socially and culturally acceptable ways of expressing one's grief during the bereavement period. This could involve certain rituals and overt expressions like crying, in order to facilitate the processing and eventual release of grief. But, expressing grief and crying due to the possibility of death before it has even happened, often brings about conflicting reactions and fear among many.

Patients and caregivers may fear that the tears could burden each other emotionally, diminish each other's positivity, open a floodgate of emotions both sides are unable to control and deal with, expose each other's emotional vulnerability, and have them face imminent death when neither side are prepared to do so.

HCWs may have concerns over their own tears. They fear that expressing grief and tears in front of their clients would make them appear unprofessional and incompetent, thus losing the trust of and rapport with their clients. They also fear losing control of their emotions such that they would be unable to steer the clinical consult effectively. They may also fear exposing their own emotional vulnerability in front of their clients.

If patients and their caregivers cry, HCWs may worry about being unable to navigate the clinical consult if the emotions are out of control. They worry about whether they have "over-dosed" on the "bad news" or clinical information given, overwhelming the patients and caregivers to tears. Sometimes, HCWs may also be uncomfortable with handling the emotional vulnerabilities of their clients.



CRYING AS THERAPY

In clinical palliative care, the expression of strong emotions such as anger and grief, including crying, are common. The act of crying can be cathartic and therapeutic. The HCW is often encouraged to react appropriately when such emotions are expressed, using them as a bridge to a deeper rapport with their clients, and a route to their healing by being present, showing empathy, affirming, offering a chance to talk, and showing respect for their clients' individual needs and the different ways they may cry.

The greater challenge is deciding when we as HCWs can and should express our grief together with our clients. Psychotherapists have reported having better rapport with their patients through therapist crying in therapy (TCIT). This could mean that crying with the client helps create empathy and normalises the act of crying in facing anticipated death and loss, thus building meaningful connections and rapport between the HCW and their clients.

But Professor Amy Chow from Hong Kong University, in a seminar on grief and bereavement held by Hospis Malaysia in December 2017 cautioned against the HCW having an excessive emotional response. For example crying louder and longer than the client could mean the HCW was reacting to his/her own internal personal grief rather than being present with their client's grief, thus potentially eroding the trust and rapport with the client.

EMOTIONAL SINCERITY

Our clinical training in healthcare, in particular that of doctors, has molded us into technically capable professionals, but somewhat lacking in

The palliative care journey should be a meaningful and humanising experience for the medical team, patients and caregivers.

“

Should medical staff cry with the patients? The simplest answer is that if crying fits for you and for the situation, it can be positive in its ability to strengthen existing bonds.”

communication skills or ability to make emotional connections with our clients.

Local medical schools in recent years have devoted more teaching resources to the teaching of communication skills (to the benefit of future doctors and their patients).

One paper wrote on the need to reverse the depersonalisation of the patient-doctor relationship, and to offer patients a sound blend of rationality and compassion with an attitude of humility. The pervasive "manly attitude" that keeps us from expressing our grief, as it is seen as a sign of weakness or vulnerability, may also need to be deconstructed.

Palliative physician Christian T Sinclair believes in emotional sincerity. On whether to cry with the patient or not, he wrote: "The simplest answer is that

if crying fits for you and for the situation, it can be positive in its ability to strengthen existing bonds. If tearing up in public is not your thing, don't go there."

I have teared on many occasions. I do not suppress my emotions but remind myself that I am there for my patients and their families, to feel for them, but not to indulge in my own personal emotionality.

Do I make mistakes on either side of being too emotional or being too insensitive? Yes. Do I have a set recipe for getting it right all the time? Unfortunately, no. Would I encourage fellow palliative care colleagues to express their empathy through tears if they want to? Certainly yes.

And it is my sincere hope that the palliative care journey becomes a deeply humanising meaningful experience for all of us, the HCW, client, and caregivers. 🙏



WORDS DR TEOH REN SHANG, SINGAPORE CANCER SOCIETY PHOTOS SINGAPORE CANCER SOCIETY

Of coffee, snacks and chit-chats

At Yishun Community Hospital, patient assessments and rehabilitation are no longer confined to the wards.

It is 2pm and almost time for tea and snacks. Packets of cookies are opened, the coffee is made, and music starts playing in the background. Patients are wheeled to a communal table, where they get to meet others from the ward. Everyone wams up to one another and chat away softly as the palliative multidisciplinary team (MDT) feeds, talks and assess them. Occasionally, family members join in too, and this simple hour becomes a little gathering.

This meal-time intervention is an initiative, known as HOPE and CARE (Holistic Patient Evaluation through Communal Activities and Rehabilitative Engagement). It was

redesigned by the MDT in an effort to create a more engaging and fun way of assessing patients and to improve the quality of patient-care in the palliative ward.


With this initiative, check-ups are no longer confined at the patient's beds, but have evolved into weaved-in table-top activities and conversations over a meal. Instead of working in silos, the MDT come together to check on their patients. This strengthens the team as they get to learn from one other. Such instances include dietitians assisting the physiotherapists in wheeling patients out of their beds, and medical social workers supporting the speech therapists observe swallowing patterns. This synergy

rubbed off both the MDT and the patients, making it enjoyable yet productive.

"The key mindset here is that we are working in a palliative ward, so we want to debunk the mindset that in palliation, everybody is confined to the bed. This is not essentially true," says Clement Liew, a physiotherapist in the MDT. "In palliative care, where the prognosis can look a little bleaker, engaging the patients in a meaningful way can still happen."

To ensure that the entire assessment is holistic, the MDT also holds meetings at the end of each HOPE & CARE session to highlight issues relating to the patients or how the team can better work together.

This initiative may be a simple idea, but its results have proved otherwise. The majority of patients have requested for more of such gatherings as they shared how much this small change has added some light into their life. Positive feedback was validated by quantitative tools that track improvements in trust within the palliative MDT and satisfaction levels of patients.

Clement adds: "We want patients to benefit from this, so when we see them chatting and interacting with one another, it encourages us to continue our efforts in serving our patients. Productivity of the MDT also improved as patients received more interventions from the MDT with Hope & Care." 

Left: Patients like Mary take turns to do simple exercises at the communal table.



WORDS HANNAH WONG, EXECUTIVE, CORPORATE COMMUNICATIONS, KHOO TECK PUAT HOSPITAL PHOTO KHOO TECK PUAT HOSPITAL

WORDS KAITLYN NG, DOVER PARK HOSPICE PHOTO DOVER PARK HOSPICE

A recipe for love and legacy

Dover Park Hospice MSWs help families grieve by creating special projects that become the patients' legacies.

In 2013, Dover Park Hospice launched the *Make It Happen* project which aims to help support patients and loved ones through the grieving process. Through this project, the Medical Social Workers (MSWs) endeavour to honour the wishes, talents and values of the Hospice's patients.

As an MSW focusing on providing psychosocial support for end-of-life care, Dawn Khoo's role include observing and understanding the patient and their relationship with their family members. She also explores avenues to help the family in their journey through death and grief as part of what she calls "Life and Legacy work" and the *Make It Happen* project.

"Good palliative care is not just about effective pain management and symptom relief, but also offers emotional, spiritual and practical support to improve the well-being of patients and their families," Dawn explains. The project aims to provide life-affirming opportunities for patients and families to nurture their relationships and enhance their inner lives despite the deterioration of the physical body.

One such recent project was a recipe book for a patient's family. The book also included pictures of the patient, Mr Yeo Yam Huat, his favourite words of wisdom and his cherished Orange Skin Jam recipe.

In July 2015, the 78-year-old was admitted into Dover Park Hospice's Home Care. He was suffering from Stage 4 colon cancer. A few months later, in December, he was admitted to the Hospice's inpatient care when his condition worsened.

Dawn came up with the book idea as part of Mr Yeo's legacy for

his family. After spending time with him, Dawn learned that he was a good cook and was very creative in making up recipes. The day before he was admitted to inpatient care, Mr Yeo made his unique orange skin jam for his family, from scratch. Dawn also learned that Mr Yeo liked to share words of wisdom with his family whenever he could.

"My dad was a handy man, a homely man and a very supportive husband. He would cook when my mum was not free and when the children needed help, he was always there to do things for us," recounts Benjamin, Mr Yeo's youngest son.

The Yeo family loved Dawn's idea. They began to work on the book together while Mr Yeo was still able to tell them his thoughts and experiences. It was Mr Yeo's willingness to talk about end-of-life matters that fuelled his desire to create this book for his family.


Mr Yeo narrated the instructions on how to make the jam, his eldest daughter, Alice, provided photos to be included in the book, while Dawn

helped to facilitate the process and put the book together. "To be humble, to be thrifty, to do good deeds" was just a few of the many words of wisdom Mr Yeo included in the book.

Mr Yeo passed away in January 2016 in the company of his family members. He was survived by his wife, two daughters and five sons.

Benjamin is extremely grateful for Dawn's involvement. "She did an excellent job out of passion, going beyond her core duty. She has done so much for my dad, and up until today, we are still friends."

He says the book is deeply treasured by the family as a means of remembrance, a connection and continuing bond with Mr Yeo, and something to be passed on to future generations.

For Benjamin, his father's jam has become a symbol of how to love and care for his family. "The recipe book reminds me that even though my dad isn't here anymore, his passing wasn't the end of our relationship - it helps us know that we are loved." 



Medical Social Worker Dawn Khoo (left) and the late Mr Yeo's son, Benjamin.

Living the last lap well

A day out grocery shopping or lunch may be a mundane daily affair for most, but it was a precious experience for four palliative care patients.



Seated at the neighbourhood coffeshop, four wheelchair-bound seniors tucked into their plates of common hawker fare. Between slow bites, they watched passers-by and chit-chatted.

Most people would not have given the group a second look, except for the accompanying portable oxygen tank and a uniform-clad entourage. The seniors – Uncle Fong, Uncle Yam, Madam Jegapai and Madam Zainab – are our palliative patients. With them were seven Bright Vision Hospital (BVH) staff and volunteers.

The lunch and subsequent short grocery run on 5 December 2017 was one of the monthly community outings BVH organises for patients with life-limiting illnesses. What

may be a mundane daily affair for most was in fact a precious experience for those who spend their days in the hospital wards.

Contrary to common belief, palliative care is not only about relieving pain and physical symptoms. Instead, this specialised care aims to holistically address patients' psychosocial, emotional and spiritual needs.

Outings like this are an example of recreation therapy, an effective intervention that involves the search for life's meaning, confronting fears, and dealing with the loss of control among others. Bringing patients out of the hospital and into the community can help to build their self-esteem. Meeting fellow patients also allow them to socialise and draw support from each other.

From top left: BVH staff and volunteers brought four palliative patients on a short grocery run and lunch at the coffee shop; Providing a listening ear is a form of emotional support to palliative patients.

WORDS: DANIEL YANG, CORPORATE COMMUNICATIONS,
BRIGHT VISION HOSPITAL PHOTOS: BRIGHT VISION HOSPITAL

“End-of-life patients often have the feeling of ‘losing it all’, including the loss of self, which is a fundamental form of suffering. Bringing them out of a hospital setting and letting them do some social activities helps them regain the sense of self,” says Yumi Watanabe, our Occupational Therapist who joined the outing.

The outing not only brought cheer to our palliative patients, it was also a good day for our volunteers. Volunteer Caral Goh, who helped to push the patients' wheelchairs, says: “It is a simple act of kindness, but it brings me great joy to see them enjoy their favourite food and the outing. Their smiles (have) brightened my day.”

“

End-of-life patients often have the feeling of ‘losing it all’... Bringing them out of a hospital setting and letting them do some social activities helps them regain the sense of self.”

From healing to helping patients say farewell with dignity

A nurse's transition from bedside nurse to palliative care nurse.

My interest in palliative care started after watching a feature about palliative nurses. It gave me a peek into the daily working life of a palliative care nurse.

I was deeply touched by how the nurses were able to make a difference in the last phase of patients' lives. In particular, the part where the nurse spoke about how she was the focal point for her patients in terms of medical, psychosocial, caregiving or even financial issues, opened my eyes to an area which I was previously unaware of.

Having been a palliative nurse for the past two years, I have had my fair share of sadness and happiness. It can be heart-breaking when a patient passes away. But being able to help my patients pass on peacefully is a source of comfort for me and for their family members.

Each patient's medical condition and social background is unique and poses a different challenge for me each time.

I was not trained specifically in palliative care but I was able to learn on the job with the help of my seniors and doctors. I found that I was able to transfer my nursing knowledge to serve my palliative patients. I also attended a basic palliative course at Dover Park Hospice to prepare myself for the work.

As a home palliative nurse, my role is to provide palliative care for patients in the comfort of their homes. My colleagues and I have to constantly anticipate and work closely with our doctors. For instance, we have to be aware of the symptoms that patients may potentially develop and to prepare their caregivers on how best to deal with them.

We also try to address their psychosocial issues by working closely with our social worker. Patients should be allowed to reconcile any broken relationships and to say a proper farewell to their loved ones. It is important for our patients to maintain their sense of dignity by giving them a say in how they would want their end-of-life care treatment to be.

Perhaps, the biggest transition for me from the hospital to palliative home care was the fact

that we have to work closely with our patients' family. There are times when I found myself unable to handle complicated family issues. This is where we have to acknowledge that nurses are not miracle workers and we cannot work alone. We have to understand our own strengths and limitations. That is also when I will call for my social worker to iron out any serious psychosocial issues my patients may be having.

When I first joined Metta Hospice, my seniors told me that the goal for palliative nurses was to ensure our patients pass on with dignity. Initially, it was a difficult concept for me to grasp as my previous role as a bedside nurse in the hospital was to heal patients. Having to watch my patients pass on was especially difficult in the beginning.

"Good Death" is a term that have become close to my heart. Good

“

While it is true that staring death in the face is not a job for everyone, we should never be afraid to embrace this challenge.”



Metta home hospice nurse Batrisyia with her patient.

WORDS: BATRISYIA BINTE ABDUL WAHED (STAFF NURSE), ALICIA LUM (COMMUNITY ENGAGEMENT OFFICER) PHOTO: METTA HOSPICE CARE

death advocates early end-of-life planning, and abolishing the taboo of death. This is something that I have learned over the course of my two years with Metta Hospice. While my job may be emotionally draining at times, I have since learnt to embrace it as a part of my personal growth as a nurse.

Prior to joining Metta Hospice, the preconceived notion I had was that palliative nursing will not be as fulfilling as regular bedside nurses in the wards since nurses will not be able to see patients leave the hospital healthier.


Through my work, I got to meet many patients from different walks of life. In my first couple

of months at work, I met a cancer patient with a prognosis of less than four months. Despite her condition, she was full of positivity and zest for life. She inspired me to stay strong in times of adversity and appreciate the little things in life. These are the things that keeps me interested and passionate about palliative care. At the end of the day, palliative care can be a meaningful career option for nurses.

My advice to non-palliative nurses is really to embrace the challenges that comes with palliative care. My passion for nursing and to serve patients keeps me going, even on the hardest of days. Through my home visits, I have got to know my

patients on a deeper and more personal level.

Being a palliative nurse has helped me grow as an individual. We should not shy away from palliative care just because of our preconceived notions that we may have about death. While it is true that staring death in the face is not a job for everyone, we should never be afraid to embrace this challenge. It may require much compassion and courage but I think it is worth the while.

Ultimately, death is part and parcel of life's journey. I would definitely encourage more nurses to join palliative care. 

The journey, yours sincerely

Through its knowledge and expertise, Assisi Hospice strives to provide personalised hospice care which ensures that individuals are at the centre of their care.



Mr Tay Cheng Tian was a 54-year-old bachelor who led a carefree life, finding meaning in his work doing odd jobs including cargo driving, and celebrating the end of each work day with a few beers. His family included his late parents, siblings and their nuclear families.

In 2017, Mr Tay's life changed when he was diagnosed with oesophageal cancer. Our journey with him began when he was first referred to our home care service, and subsequently, admitted into our inpatient hospice unit where he had wanted to spend his final days.

Our Medical Social Workers (MSW) from Psychosocial Support Services (PSS) team, Ms Ivey Tee and Ms Samantha Soh, came on board the case. They ensured that the important but difficult conversations about Mr Tay's care took place between him, his loved ones and the hospice care team.

Through these conversations, we learnt what brought him comfort and dignity.

One of Mr Tay's most immediate concerns was the practical aspect of his care arrangement as he became more dependent. The thought of becoming a burden to his loved ones weighed him down, but he found himself unable to articulate it to his family without having a solution in place.

He was unsure of where to access information and the support that he was seeking. Ivey sensitively initiated discussions about his current state and also the future. She ensured Mr Tay's loved ones were involved in the discussions, and gathered support from other resources, including community agencies and other hospice team members.

Our MSWs often discuss the most challenging and intimate of topics with our patients and families such

as final day care arrangements, dying, making peace with one's life, and grieving, among many others. In Mr Tay's case, our MSWs had to navigate through these issues delicately as he was a quiet and stubborn who never opened up his heart to his loved ones.

Together at different points of the journey, Ivey and Samantha ensured he had the information he needed, dealt with practical issues, provided emotional, social, cultural and spiritual support. Very importantly, they focused on what quality of life meant to him, and ensured that he was not alone, because he did not want to be. He was immediately enrolled into our hospice No-One-Dies Alone Programme (NODA) where he was accompanied by volunteers even as he took his last breath.

As a hospice MSW, Samantha supported Mr Tay in articulating his final needs, desires and fears. She

was mindful to remember and remind others that Mr Tay was the best expert on himself, despite our team's vast and varied knowledge and experience. Samantha also empowered him with a voice to actively pursue his yet-to-be-fulfilled wishes. The power of decision-making was shifted back into him in the whole process.

During his stay with us, our team organised outings for Mr Tay, including a durian feast to taste the legendary "Mao Shan Wang" durians, a nostalgic cable car ride and a seafood meal in Chinatown, complete with Baron beers. All these were organised with Mr Tay's inputs, including a surprise birthday party that staff and volunteers planned for him and for themselves.

Mr Tay had never splurged on "branded" durians such as Mao Shan Wang, due to his social and economic circumstances. It was his desire to taste some. Samantha organised a durian feast featuring the famed durians, together with staff, volunteers and other hospice patients. It was a once-in-a-lifetime experience for Mr Tay to taste the famous durians and the love and support from the hospice family. The cable car ride was packed with reminiscence and new found peace. And, he did not forget to celebrate his life with Baron beer in the last days of his life.

One of the scariest things about the dying process can be fear of the unknown. Samantha prepared

Mr Tay and his loved ones with enough knowledge of what they can generally expect during the process. She shared with them the resources available and encouraged Mr Tay to embrace his emotions without guilt by normalising and validating his specific feelings about situations at different points in time. The same support was provided to his loved ones.

Through these interventions, Mr Tay remained active in planning his care at every stage of his final days. Opportunities were opened up for him and his loved ones to talk about dying and bereavement and make choices. Through this, he managed to express what was important to him and his family. 🗣️

Caring for patients in their last days

At St Luke's Hospital, a dedicated team of doctors, nurses, therapists, social workers and pastoral care staff work together in a dedicated palliative care ward to bring care, comfort and dignity to patients in their last days.

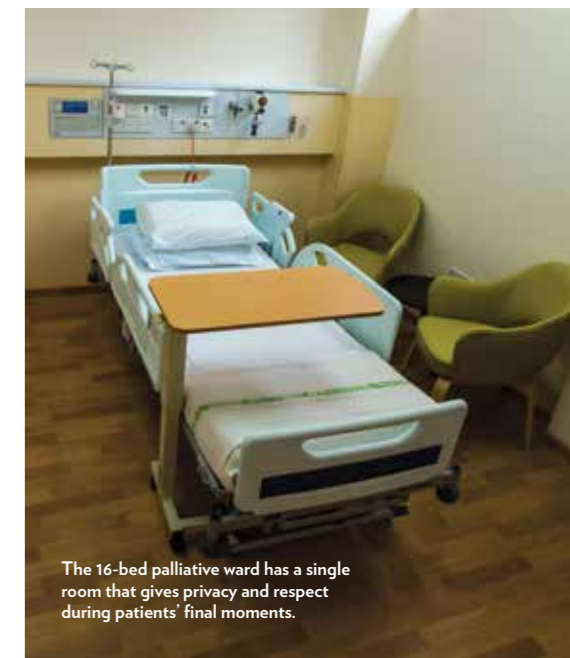
Madam Wong (not her real name) managed to cook a plate of fried rice for her husband at St Luke's Hospital kitchenette before she passed on. She had been cooking for her husband all these years, and she wanted to cook for him one last time. She did.

Another patient also wanted to cook, so her therapists organised cooking sessions for her. It brought her joy. Her recipes are being compiled into a book as part of her legacy.

When a patient's family was absent in his last moments, nurses took turns with his helper to hold his hand, assuring him he would not die alone.

It was not only patients who received support. Caregivers are not forgotten. In one case, a patient's daughter was grief-stricken after her father died. She still visited the hospital as her mother was also a patient. The daughter told the pastoral care staff who had cared for her father that she did not dare to enter the ward her late father had been in because of painful memories.

The staff encouraged and accompanied her to the ward. She saw that there were new patients there. The staff affirmed her observation and assured her she could close that chapter in her life and look forward to new things. The daughter cried and found the closure she needed to move on. 🗣️



The 16-bed palliative ward has a single room that gives privacy and respect during patients' final moments.

WORDS AND PHOTO ASSISI HOSPICE

WORDS & PHOTO ST LUKE'S HOSPITAL

Non-cancer palliative care

A/PROF WU HUEI YAW
Senior Consultant,
Palliative Medicine
Tan Tock Seng Hospital

We are pleased to introduce the latest column in Hospice Link, "Views from the Pros". In each issue, we will feature articles from the medical professionals on various issues relating to palliative care. We kick off our inaugural column with Associate Professor Wu Huei Yaw's discussion on palliative care for non-cancer patients.



Most people associate palliative care with care of advanced cancer patients. But there are many terminally-ill patients who suffer from non-cancer conditions such as end-organ failure and neurodegenerative diseases.

Like cancer patients, these patients struggle with symptoms such as pain and breathlessness in their terminal stages. In fact, the symptoms are often prolonged as these patients can remain unwell for several years. This long-drawn battle with the diseases may result in significant psychosocial and spiritual distress for both patients and caregivers.

The most unique feature of non-cancer terminal conditions is the

unpredictability of the disease trajectory. Unlike cancer patients, whose decline in function usually occurs in the last three to six months before death, the non-cancer trajectory is often a gradual decline punctuated by several episodes of acute deterioration. This makes accurate prognostication very difficult.

It is not unusual for these patients to bounce back from episodes of acute deterioration, which may reinforce the wrong perception that the condition is not too serious. As a result, they often postpone talking about death and dying.

Very often, clinicians are unsure

of the outcome of each acute exacerbation, making it difficult to advise the patients on the most appropriate care options.

It is therefore essential to introduce advance care planning early in the disease trajectory so that patients can be guided to make decisions on their preferred treatment choices in the event of future deterioration.

A recent encounter with a patient brings to mind these challenges.

Mr X has been suffering from end-stage chronic obstructive pulmonary disease (COPD) for about four years. Estranged from his family, the 56-year-old lives in a 1-room rental flat with an acquaintance. He was hospitalised multiple times, and on three occasions, he was mechanically ventilated in the intensive care unit (ICU) because of respiratory failure.

He once mentioned he wished he could just pass away in his sleep to end his suffering. He said terminal cancer would have been more tolerable than COPD. His mother died of cancer, and he felt she did not suffer much as she died relatively soon after prognosis.

Mr X still had flashbacks of those difficult moments in the ICU and found it hard to imagine going through such treatments again.

Yet, when asked if he would consider comfort care instead of life-prolonging measures which would be

uncomfortable and painful, his answer caught me by surprise: "If there is a chance of getting better, why would I want to refuse treatment?"


Mr X has consistently opted for trial of treatment in the event of deterioration and he managed to pull through each time. His decision on the extent of care has not changed in the last two years.

Mr X's case highlights one of the greatest struggles among hospice

care providers faced with a patient whose condition suddenly takes a turn for the worse: how sure is one that this is going to be a terminal event? Should the advice be to return to the hospital for a trial of acute treatment which could potentially be futile and compound the patient's suffering?

It is such difficult decisions that make non-cancer palliative care so challenging.

Hospice care focuses on improving the quality of life of the terminally-ill, not hastening or prolonging the dying process. But decision-making during crises as illustrated above is not always straightforward.

Ultimately, we still have to rely on the patient's preferred choices and deliver care that is in their best interests and most consistent with their values. 

Tips for Caregivers

DR JAMIE ZHOU
Resident Consultant (Palliative Care), St Joseph's Home

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.



"I wish the palliative care team was referred earlier" is a common comment I hear from caregivers once they experience what palliative care teams do.

Many, including medical practitioners, believe that palliative care teams can only get involved when there are no further treatment options. Delays in palliative care referrals may also occur due to refusal from patients or family members. The misconception that palliative care means giving up is, unfortunately, very common.

On the contrary, the philosophy and spirit of palliative care is a proactive one. The focus is on personhood, dignity and quality of life in the final journey. In fact, good palliative care makes you want to live more fully and enables you to do so through good symptom management, psychosocial and spiritual support.


Whenever I am asked "When is the right time for palliative care?", I reply, "When is the right

time for quality of life?". Quality of life should not be determined by treatment failure or disease progression, and neither should palliative care.

Basic palliative care can be provided by the treating doctor. Specialised palliative care teams can be referred to when there are more complex needs.

Tip #1: If the medical team talks to you about palliative care, be open. Find out more about how it might help with your loved one's care.

Tip #2: If you have concerns about your loved one's quality of life, ask the medical team about palliative care and if they think it will be appropriate.

Tip #3: Here are some online resources that provide more information about palliative care: <http://singaporehospice.org.sg/> <https://www.duke-nus.edu.sg/lcpc/content/about-palliative-care> 

Upcoming Events

10 MAR 2018

BVH Flag Day 2018

“Give With Passion, Spark Your Compassion” aims to raise funds for our needy patients through Flag Day street collections. This community event targets to ignite the public’s compassion by giving with passion through the generosity of individuals and organisations.

Venue: Island-wide

Time: 9.00am - 6.00pm, island-wide

Contact: community@bvh.org.sg

18 MAR 2018

Metta Charity Carnival 2018

A healthy annual family-bonding charity carnival for the young and old.

Venue: Metta Welfare Association

Time: 9.00am-4.00pm

Contact: Andy Chua 6580 4614

20 MAR 2018

SHC-LCPC Multidisciplinary Palliative Care Forum

Topic: Communications in End-of-life Care

Venue: HCA Hospice Care Auditorium

Time: 1.00 pm – 2.00 pm

Contact: secretariat@singaporehospice.org.sg

24 APR 2018

SHC-LCPC Multidisciplinary Palliative Care Forum

Topic: “Don’t tell me I’m dying!” - Maintaining hope in the face of death

Venue: St Andrew’s Community Hospital Auditorium

Time: 1.00 pm – 2.00 pm

Contact: secretariat@singaporehospice.org.sg

25 - 27 APR 2018

34th LCPC-SHC Postgraduate Course in Palliative Medicine

This is a foundational course in the principles and practice of palliative medicine applicable to all fields of medicine. Course participants have opportunities to assess patients and discuss the most appropriate management strategies with palliative care physicians and other specialists. Any doctor (medical officer/resident, family physician or specialist) who is interested to learn about palliative care is welcome to attend this course.

Venue: HCA Hospice Care, Level 3, Auditorium

Registration: www.duke-nus.edu.sg/lcpc/course-catalogue for online

registration from 14th February to 13th March 2018.

Cost: S\$ 800 (inclusive of GST)

MAY 2018

Dover Park Hospice Charity Concert

A charity concert to raise funds for Dover Park Hospice which will help more disadvantaged patients and their families.

Venue: Lee Kong Chian School of Medicine

Contact: info@doverpark.sg

22 MAY 2018

SHC-LCPC Multidisciplinary Palliative Care Forum

Topic: Can We Teach Compassion?

Venue: TTSH Theatre

Time: 1.00 pm – 2.00 pm

Contact: secretariat@singaporehospice.org.sg

9 - 10 JUN 2018

SHC Community Engagement Event

Join the Singapore Hospice Council and our member organisations in the second run of our Community Event on end-of-life conversations.

Venue: Bedok Town Square

Time: 10.00 am to 4.00 pm

Contact: secretariat@singaporehospice.org.sg

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