

# THE HOSPICE

LINK

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**HELPFUL  
TIPS!**

**Constantly  
out of breath**

**7 things to note  
when caring for  
a person with  
dementia at the  
end of life**

**CARING FOR  
PATIENTS  
WITH SERIOUS  
ILLNESSES**



SINGAPORE  
**HOSPICE  
COUNCIL**



# Members' Contacts

## 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

## Buddhist Compassion Relief Tzu Chi Foundation (Singapore)

9 Elias Road, S(519937)  
T: 6582 9958 F: 6582 9952  
www.tzuchi.org.sg/en

## Dover Park Hospice

10 Jalan Tan Tock Seng, S(308436)  
T: 6500 7272 F: 6258 9007  
www.doverpark.org.sg  
info@doverpark.org.sg

## HCA Hospice Care

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

## Metta Hospice Care

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

## MWS Home Hospice

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

## Singapore Cancer Society

15 Enggor Street, #04-01,  
Realty Centre, S(079716)  
T: 1800 727 3333  
www.singaporecancersociety.org.sg  
hospice@singaporecancersociety.org.sg

## St Andrew's Community Hospital

8 Simei Street 3, S(529895)  
T: 6586 1000  
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  
referral@stluke.org.sg

## Tsao Foundation

298 Tiong Bahru Road  
Central Plaza, #15-01/06,  
S(168730)  
T: 6593 9500 F: 6593 9505  
tsaofoundation.org  
info@tsaofoundation.org

## 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: 6225 5554 F: 6293 7933  
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 8000 F: 6225 6283  
www.nccs.com.sg

## Tan Tock Seng Hospital

11 Jalan Tan Tock Seng, S(308433)  
T: 6256 6011  
www.ttsh.com.sg

## Woodlands Health Campus

9 Maxwell Road,  
MND Complex Annex A,  
#03-01A, S(069112)  
T: 6681 5999  
www.whc.sg

## Lien Centre for Palliative Care

Duke-NUS  
Medical School Singapore  
8 College Road  
Level 4, S(169857)  
T: 6601 2034 / 6601 7424 [Education]  
T: 6601 5113 [Research]  
www.duke-nus.edu.sg/lcpc

# Contents



- 2 Members' Contacts
- 3 Chief Executive's Note
- 4 7 things to note when caring for a person with dementia at the end of life
- 6 Constantly out of breath
- 8 Losing muscle control of the body
- 10 Holistic cancer care
- 12 Not just on the surface
- 14 Singapore Palliative Care Conference 2020
- 16 An unexpected journey
- 18 Where are you now?
- 20 Prevent cancer caregiver burnout
- 22 Improving nutrition and the mealtime experience
- 24 Upcoming Events & Lend Your Voice to Palliative Care

# Caring for patients with serious illnesses

**A**merican actor Michael J Fox said: "Family is not only an important thing. It's everything."

I am sure all of us concur but often ask: then how could care be better extended?

The care quality of patients with serious illnesses can be enhanced through using a systematic approach. Most individuals, when faced with the loss of independence or control to their health, will tend to have mixed feelings of denial about the situation or extreme concern about the future and worry about their loved ones.

Indeed, depression and anxiety can be common issues for people dealing with illness, and sometimes, even for their caregivers. Often, a person dealing with chronic illness may grieve or feel a sense of loss. If you or someone you are caring for are not coping well, talk to the people who care about you.

With appropriate support, especially from the multidisciplinary team and caregivers, patients with chronic illness can learn to adjust and realign their

lifestyle to enjoy quality of life by adopting good care tips, a balanced diet and caring regime.

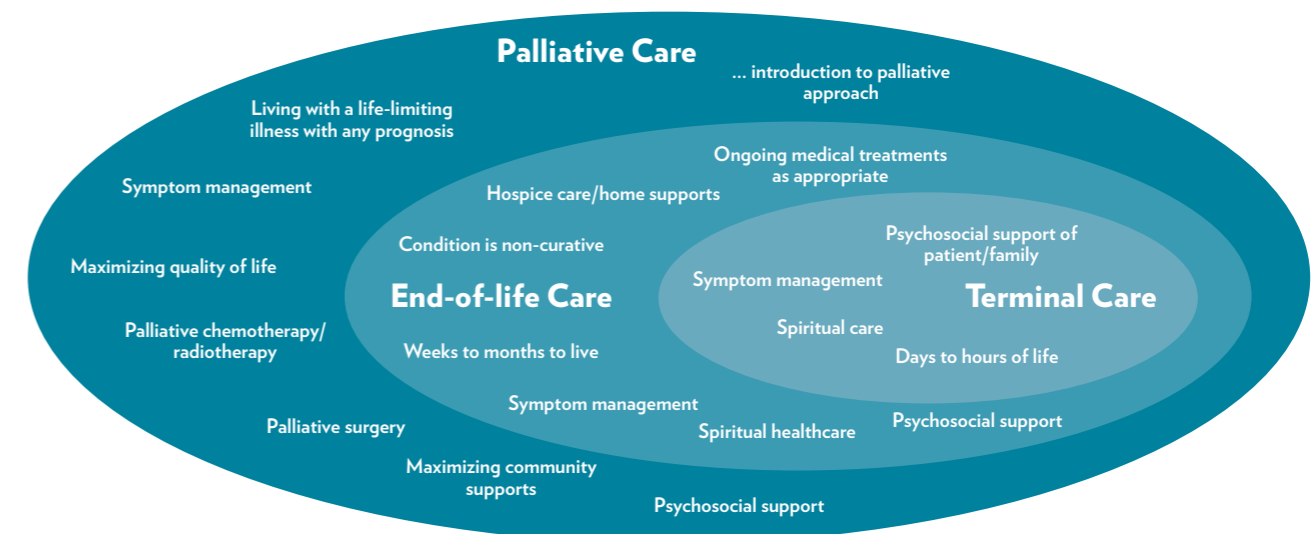
The multidisciplinary and care support group will be there to:

- Reduce unwanted variations in care and improve the patient experience
  - Improve efficiencies and outcomes at a potential lower cost
  - Align communication and collaboration among all healthcare disciplines
  - Enable one to effectively face new challenges
- Learning more about your or your loved one's disease and condition can help ease concerns and anxieties. Hence, it is important to educate yourself from the best sources of information so as to be able to mitigate issues relating to you or your loved one's condition.

Ms Evelyn Leong

**Chief Executive  
Singapore Hospice Council**

## The phases and layers of care



“

The way to get started is to quit talking and begin doing.”

**WALT DISNEY**

# 7 things to note when caring for a person with dementia at the end of life

Caring for a person with dementia, especially at the end of life, can be very challenging and tiring for the caregiver. The Principal Resident Physician of Assisi Hospice, Dr Rina Nga, who is from the Assisi Dementia Palliative Work Group, shares the following tips which can make the entire journey a little less bewildering for the caregiver.

**TIP #1**

**RECOGNISE WHEN YOUR LOVED ONE IS AT THE END OF LIFE**

According to research, it has been found that persons with dementia who are in their last year of life generally experience more frequent admissions to hospital for complications like pneumonia and urinary tract infections\*; and another life-limiting illness such as advanced cancer or end-stage organ failure.

As the entire dementia illness trajectory is usually very long and protracted, family caregivers often find it difficult to come to a point of realisation that the journey may be coming to an end.

During this time, good palliative care support is available both for the person with dementia as well as the family caregivers. Do speak with your loved ones' primary doctor to discuss a referral to either a Hospice Home Care, Day Care or Inpatient service.



Dr Rina Nga interacting with a patient at the Dementia Palliative ward in Assisi Hospice

**TIP #2**

**FOCUS ON WHAT IS POSSIBLE, NOT THE IMPOSSIBLE**

Although we would all hope that our loved ones would remain with us forever, we know deep inside that this is not possible.

However, what is important and possible to achieve in this phase of a person's life is to provide comfort and maintain as best a quality of life as possible. If we can focus on and work towards these goals, caring for a person with dementia at the end of life can indeed be a positive and fulfilling experience.



**TIP #3**

**RECOGNISE THE PERSON WITHIN**

Throughout the illness trajectory of persons with dementia, their personhood remains. It is no different at the end of life. They are still the same person with the same likes and dislikes, personalities and values. We can still help them recall pleasant past memories that trigger positive responses. We can also stimulate their senses with their favourite tastes, sounds and fragrances.

**TIP #4**

**HAVE AN ADVANCE CARE PLAN DISCUSSION WITH YOUR HEALTHCARE PROFESSIONAL**

If not already done, do ask your healthcare professional for an Advance Care Plan (ACP) discussion. You may have to stand in as proxy decision-maker for your loved one. It is important to keep in mind that decisions should be made based on what your loved one would have wanted for him/herself, not what you would want for him/her.

Nevertheless, the final decision will also take into consideration the practical aspects of whether the preferences stated can indeed be honoured.

**TIP #5**

**RECOGNISE SIGNS OF DISCOMFORT OR PAIN**

Towards the end of life, pain, breathlessness, nausea and vomiting may be experienced more. Healthcare workers may use different non-verbal pain assessment tools such as PAINAD to help them assess the level of discomfort your loved one has. If you know of any particular sign that your loved one exhibits which indicates some discomfort (e.g. tightly shutting the eyes, shouting, tapping the bed, becoming very quiet, frowning etc.), do inform the healthcare workers who are attending to him/her.

**TIP #6**

**LEARN TO MANAGE AND CONTROL SYMPTOMS**

The Hospice team will be working with you to manage the symptoms that may be troubling your loved one.

Prevention is best, but picking up the symptoms early is as important. Problems such as constipation are notorious for causing abdominal cramps, and can be easily resolved through laxatives and good bowel clearance. Skin care is a must, through applying moisturising agents and regular turning to prevent skin breakdown and pressure sores. Mouth care is another important area. Your loved one may be on tube feeding, or may have very poor oral intake. Dry mouths can lead to cracks in the oral cavity and painful mouth ulcers.

Your loved one may experience other unpleasant symptoms like pain, breathlessness, nausea or vomiting. In addition to the medications that your healthcare workers prescribe, do also create a comforting reassuring environment through dim lighting and calm sounds. Aromatherapy and gentle massage may also help.



**TIP #7**

**HONOURING THE PERSON WITHIN**

Don't get caught up in tasks for your loved one. Set time aside to also reminisce with the rest of your family and appreciate the life of your loved one. You may want to set aside items and memorabilia that highlight the significant moments of his/her life. These may include pictures, favourite soundtracks, craftwork and other items.

One suggestion is also to start envisioning the type of funeral you may want to have, to honour the life of your loved one.

*These tips are not exhaustive. There are many resources available from organisations like Agency for Integrated Care, Alzheimer's Disease Association, Health Promotion Board, Monfort Care, Yishun Health and Tsao Foundation.*

\*Source: Schonwetter, R. S., Han, B., Small, B. J., Martin, B., Tope, K., & Haley, W. E., 2003: "Predictors of six-month survival among patients with dementia: An evaluation of hospice Medicare guidelines" in American Journal of Hospice and Palliative Medicine

WORDS: DR RINA NGA, ASSISI DEMENTIA PALLIATIVE WORK GROUP DR RINA NGA PHOTO ASSISI HOSPICE

# Constantly out of breath

*Tan Tock Seng Hospital senior occupational therapist Stella Liew gives her perspective on how to manage breathlessness so as to allow continued participation in valued tasks.*

**M**r X has been living with chronic obstructive lung disease for the past five years and he is now at the last stage of this chronic illness. He is constantly bothered by breathlessness. Everyday activities like showering and wearing his pants can take a toll on him. Therefore, he prefers to stay at home, instead of going out to have coffee with friends. An occupational therapist was referred to him during a visit by a community nurse to coach him on breathlessness management so he can continue to participate in the activities he values.

## WORKING WITH PATIENTS WITH END-STAGE LUNG DISEASE

As an occupational therapist in Tan Tock Seng Hospital for the past six years, I have developed a strong interest in working with patients with end-stage lung disease. Many whom I know are plagued by breathlessness and started to stay home, which eventually led to social isolation. Most of these patients lack the knowledge about energy conservation and activity pacing which

are useful skills. These skills, once mastered, coupled with compliance to a medication regimen, allow them to continue to engage in valued tasks and manage daily activities.

During the initial assessment of each patient, I conduct an interview to understand their daily routine, the activities they like to do but have difficulty engaging in, and those they are currently doing but are having difficulty with due to breathlessness. I will also check on their emotional well-being, cognitive ability and physical ability regularly. With the information obtained, collaborative goals will be set with the patient. Therapy sessions will focus on energy conservation and activity pacing. Practical application of the skills taught will follow to allow knowledge assimilation. For patients with difficulty in community mobility, they will be introduced to powered mobility aids such as motorised wheelchairs or motorised scooters. I will conduct assessment and practice sessions for them to achieve basic skills needed to drive the device safely. Home visits will be conducted to ensure they are able to utilise the device in their familiar environment.

## TIPS FOR PATIENTS WITH BREATHLESSNESS ISSUE

### 1 SHOWERING

- sit down to shower
- use warm water (avoid water that is too hot or too cold)
- shower when weather is not cold
- use long-handled sponge to wash back and legs
- ensure toilet is well-ventilated; for example, open toilet window, leave gap at door
- break down steps to shower: wash upper body, take a break, then wash lower body



### 2 DRESSING

- consider wearing loose clothing
- sit on a chair to put on your pants
- use long-handled reacher to reach for clothing



### 3 TOILETING

- use urinal or commode if you have difficulty in walking to toilet at night
- pace your breathing when defecating



### 4 COOKING

- sit down to prepare the ingredients e.g. washing of vegetables, cutting of ingredients
- take a break during cooking by placing chair nearby
- serve food in small portions instead of carrying pots and pans loaded with cooked food
- push or slide objects across tabletop



### 5 GROCERY SHOPPING

- plan a shopping list to buy only what you need
- use a shopping trolley
- take a few breaks if distance to travel is long



### 6 MOPPING

- use a spin mop or a mop with a handle to drain water
- take a break after cleaning each room

### 7 SWEEPING

- use dry wiper sheet or vacuum cleaner instead of broom
- use the momentum of the body while cleaning the floor
- take a break after cleaning each room

WORDS AND PHOTOS: STELLA LIEW CHUAN HUI, SENIOR OCCUPATIONAL THERAPIST, TAN TOCK SENG HOSPITAL

# Losing muscle control of the body

*Spinal Muscular Atrophy (SMA) and Duchenne Muscular Dystrophy (DMD) are two neuromuscular conditions commonly encountered by the HCA Hospice Care Star PALS team. Palliative care nurses Serene Wong and Ren Hui elaborate on challenges and care tips for these conditions.*



**F**or the parents of HCA Star PALS (Paediatric Advanced Life Support) patients, the journey of caring for their children is often fraught with varying challenges and mixed emotions. Patients often experience great challenges with activities of daily life.

## **What are some common physical symptoms of SMA and DMD and their accompanying challenges?**

Patients afflicted with SMA are often dependent on machines to maintain their bodily functions (such as breathing, eating and removing secretions). This reliance increases as the condition progresses and patients gradually lose muscle control of the body. As a result, they become completely dependent on their caregivers for all activities of daily living (ADL).

For patients with DMD, the condition is often detected in early childhood, as they experience muscle weakness and falls more often than their peers. Scoliosis, contractures and poor heart function are common in DMD patients. Similarly, as the condition advances, they gradually lose their physical functions and require assistance for ADL.

## **What are some of the challenges that caregivers of patients with SMA and DMD might face?**

Caregiving is a round-the-clock responsibility, which can be both emotionally and physically draining. In the advanced stages of both SMA and DMD, patients who are bedridden will need to be turned very frequently, in order to minimise the risk of bedsores. Patients with DMD often lose a lot of weight in the advanced stages of the condition, which makes it difficult for them to find a comfortable resting position. As they steadily lose fat and muscle mass, caregivers have to be especially careful during transferring, to prevent fractures and dislocations.

There are many care routines to go through on a periodic basis, especially for patients with SMA. These include insertion of feeding and tracheostomy tubes, stoma care and passive exercise (may also apply to patients with DMD).

Emotional guilt is common as well, especially for the mothers of patients with DMD, as the condition can be passed on from the mother, who is a carrier of the genetic trait. The diagnosis often affects the entire family, as the female siblings could also be carriers, which might impact family-planning decisions.

In addition, financial difficulties may arise, given the chronic nature of SMA and DMD and need for specialised medical equipment to support ongoing care. For patients with milder forms of SMA and DMD, they might be able to attend school and go outdoors, but transportation options are often limited and expensive.

## **What are some tips to strengthen muscle and joint function?**

Maintenance is key to slowing the deterioration of SMA and DMD, and improving quality of life through passive exercise, supplements and sun exposure. Passive exercise can minimise contractures and facilitate secretion movement. For patients with DMD, supplements to boost muscle function can be given. Using the cough assist machine, incentive spirometer and peak flow meter can also help to maintain lung function.

Most importantly, caregivers should try to maintain existing functions through play,

exercises and activities (e.g. getting patients to grasp a ball with his/her hands).

## **As the condition advances, what physical and psychological changes should patients and their loved ones expect?**

There are ups and downs while caring for patients with SMA and DMD. Patients and their loved ones may experience low moods at the start, but grow to accept reality over time, and even embrace the new norm and focus on the remaining abilities.

As patients with SMA and DMD gradually lose all their physical functions and become completely bedridden, risks of mucus blockage and aspiration pneumonia can occur.

Some parents might experience anticipatory grief as their child's condition deteriorates, but the child's positivity and acceptance often brings them much comfort.

## **How does the HCA Star PALS team prepare patients and their loved ones for the eventuality of death?**

The HCA Star PALS team builds rapport with patients and their loved ones over time and encourages open discussions of what is important to the patients' lives, and to live life fully. If the family does not want to broach the subject of Advance Care Planning (ACP), the team will respect that. Maintaining normalcy in the family's routines, such as playing games and having meals together, can also be beneficial to all. 🌟

Opposite page: Patients with SMA often require numerous medical equipment to assist in basic physical functions, such as breathing and eating; Below: HCA volunteer Kay Thomson assists with lung exercises for a Star PALS patient, who has SMA. This helps to dislodge the secretions that build up in the lungs



WORDS AND PHOTOS: HCA HOSPICE CARE

Maintenance is key to slowing the deterioration of SMA and DMD, and improving quality of life.

# Holistic cancer care

*Cancer is a chronic disease and can be disabling, physically and emotionally, for a long time. Here are some tips that can help patients and those caring for a loved one with cancer.*

**M**adam Lee (not her real name) was diagnosed with cancer and underwent surgery to remove the tumour in her brain. After surgery, she was admitted to St Luke's Hospital. She had difficulty performing daily activities like walking. She also experienced hearing and vision loss. Besides her physical impairments, Madam Lee struggled emotionally and mentally. She grieved over her condition and loss of independence, and frequently broke down during her rehabilitation sessions.

After two months of rehabilitation at St Luke's Hospital, Madam Lee was able to walk with a walking frame with minimal assistance. The journey was not easy but she persevered despite many setbacks. Madam Lee was also cared for by a multidisciplinary team of doctors, nurses, therapists, dieticians, social workers and counsellors.

**What are some common physical symptoms a person with cancer may face and what are some ways to help them cope?**

**Fatigue**

Patients may experience fatigue that may not be proportionate to their activity. For example, taking a bath can be very tiring. A simple helpful strategy is to design a daily timetable

**Cancer rehabilitation at St Luke's Hospital**

St Luke's Hospital provides services to meet the needs of cancer patients. The cancer rehabilitation team provides care during pre-rehabilitation stage (before cancer surgery / treatment), treatment stage (during chemotherapy / radiation therapy) and post-treatment stage (post-operation). The team includes therapists trained in lymphoedema management for chronic swelling in the lower limbs. For more information, email [general@stluke.org.sg](mailto:general@stluke.org.sg)

Caring for cancer requires strong medical and social support. Your quiet acts of service and journeying alongside will be of great comfort.

that includes medication time, shower time, meal times, and time for recreational activities and exercise. Spread out the higher and lower energy activities. Scheduling can help patients better pace themselves and make the daily activities more achievable.

**Memory loss**

Some patients may face memory loss such as forgetting tasks, where they place things and important appointments and events. This can be upsetting and frustrating. Use a to-do list. Put personal items at the same place instead of scattering them so that it is easier to look for them. Set calendar reminders for important events. This would allow patients to feel that they still have control over certain aspects of their daily lives; it will be a great encouragement to them.

**Joint stiffness and muscle tightness**

Due to pain and fatigue, patients may wish to lie in bed more often. To help reduce joint stiffness and muscle tightness, and to promote blood circulation, here are some stretches that can be done safely on the bed daily, together with a caregiver. Helping with these exercises also promotes therapeutic touch, and is a practical way to show you care.



Hip-knee flexion



Inner thigh stretch



Calf stretch

Consult your healthcare professional or physiotherapist, and do not attempt these stretches without a caregiver.

**1. Hip-knee flexion**

Patient lies flat, face up, in bed. Caregiver supports patient's heel and back of knee. Bend the hip and knee toward the chest and straighten the leg out. Repeat 10 times.

**2. Inner thigh stretch**

Patient lies flat in bed. Caregiver supports the patient's heel and back of knee. Move the leg away to the side. Hold the stretch for 10 seconds when you feel slight resistance. Return the leg to neutral. Repeat 10 times.

**3. Calf stretch**

Patient lies flat in bed. Keeping the patient's knee straight, toes facing upwards, caregiver bends patient's ankle towards the head. Hold the stretch for 30 seconds. Repeat five times.

**How can I help my loved one feel more comfortable?**

Coping with cancer requires strong medical and social support. Your quiet acts of service and journeying alongside will be of great comfort. For example, accompany patients for appointments, get their favourite food, and share good books and music.

**Are caregivers expected to put up a strong front all the time?**

Caregiver stress is real. Take time to pause and reflect. Do acknowledge your feelings regularly. You are allowed to feel sad or inadequate. You are not expected to know everything. You are definitely allowed to rest.

**How can I approach end-of-life topics with my loved one?**

Listen actively and observe if there are underlying fears, anxiety and worries. It is important to address these emotions and issues earlier, for instance, to complete unfinished business, encourage reconciliation or forgiveness in relationships.

If the patient wishes, you may ask for Advance Care Planning, which is a platform for individuals to make plans about their future healthcare and record their preferences if they lack the mental capacity to make decisions in the future. For more information, visit [livingmatters.sg](http://livingmatters.sg)

WORDS AND PHOTOS: JOLYN KHOO, PHYSIOTHERAPIST, ST. LUKE'S HOSPITAL



# Not just on the surface

*From using diapers and scarves to cover the neck, to placing tea leaves under a patient's bed to mask the smells, Bright Vision Hospital's wound nurse Sister Liew Lee Fong teaches us a thing or two about caring from the heart.*

**N**urses at Bright Vision Hospital (BVH) look after both the body and soul of patients who receive an extended period of stay after their transfer from a general hospital or nursing home.

With more than 15 years of nursing experience, Sister Liew Lee Fong takes a special interest in her patients' wounds. As the only wound care nurse in BVH, she helps to assess, treat and care for patients with simple or complex wounds.

Because wounds need frequent attention, Sister Liew will also help to educate patients and their

loved ones on how to clean and dress a wound, as well as what to look out for in order to prevent any complications.

"Most of our patients are elderly, who tend to have low immune systems, and red blood cell levels that are dynamically unstable. Some of them also suffer from low blood pressure or are sometimes anaemic," explained Sister Liew. "This is why wound nurses need to work with other healthcare professionals such as dietitians to make sure the patient has enough nutrients so that the wound does not deteriorate."

Opposite page:  
Bright Vision  
Hospital's wound  
care nurse Sister  
Liew Lee Fong  
tends to wounds  
directly and  
through nutrition

WORDS AND PHOTOS: BRIGHT VISION HOSPITAL

## Wound care nurses will need to do their homework well so that they are able to communicate and care for their patients.

Her vast experience has also taught her that wound care is an area that requires lots of teamwork involving nurses, doctors, dietitians and even therapists to ensure patients are well taken care of. Networking with other healthcare institutions is also very important.

In addition, therapists will advise their patients on the suitable positions to be when they are resting or moving around.

### WOUND CARE FOR PALLIATIVE PATIENTS

Palliative patients will need support physically and psychologically for their quality of life.

For this, Sister Liew works with the BVH rehabilitation team to provide for patients' social well-being with activities like playing mahjong with other patients or going for refreshing trips outside of the hospital.

To ensure that patients receive the best comfort during these activities, Sister Liew and the rehab team do what they can so that patients can be active and enjoy themselves.

"The challenge comes when patients have tumors on obvious areas such as the cheek, face or neck. They can be embarrassed because of how they look and the unpleasant odour that exudes

from the wound," shared Sister Liew.

She once had a patient with a tumor on his neck and was unable to turn his head. Due to its size, the nurses decided to use baby diapers and a scarf to cover it so that the patient will still be able to enjoy his life outside the ward.

To reduce the odour, Sister Liew and her team placed an antibiotic powder in between the gauze. They even placed green tea leaves under his bed.

"We have to be innovative and think out of the box when attending to such wounds," she said.

### A JOURNEY IN WOUND CARE

Sister Liew started caring for chronically ill patients on a part-time basis in 2005 before venturing into rehab and sub-acute wards and eventually specialising in wound care at BVH in 2012.

During her many years of work, Sister Liew encountered numerous patients who suffered from pressure injury wounds. Those experiences built up her skills and interest in wound care.

"I get to know my patients first even before they are being transferred to BVH," she said.

Essentially, wound care nurses will need to do their homework well so that they are able to communicate and care for their patients - understanding the patient and their care, being constantly updated on the latest wound care products, attending conferences to keep abreast of the latest news, as well as having a good network of healthcare colleagues.

Although the healing process for her patients may be extensive - some as long as six years - it does not stop Sister Liew from loving her job.

"You can see the progress of the wound healing, which can be fulfilling!" shared Sister Liew. 🌟

### Tips on wound care

1. Ensure that you have sufficient knowledge about the wound.
2. Nutrition is very important when it comes to wound care.  
Approach dietitians to ask how to improve the nutrition hydration.
3. Be mindful of blood glucose and diet.
4. Reduce or avoid smoking.
5. Have emergency contacts ready at all times.
6. Visit the doctor on time and regularly as a follow up.

# Singapore Palliative Care Conference 2020

## - Embrace • Engage • Envision

The Singapore Hospice Council marks its 25th anniversary this year with a conference that will engage professionals beyond the palliative care community.

This year marks the 25th anniversary of the founding of the Singapore Hospice Council. It is therefore timely, that the 7th Singapore Palliative Care Conference (SPCC 2020) held from 8 to 11 July 2020 at the Sands Expo & Convention Centre invites everyone to embrace our rich history and discover for ourselves the core values of compassion, strength and resilience that lie deep within our roots. It is pertinent that we reach out beyond our traditional boundaries to engage professionals outside the fraternity, as well as community services and industrial partners in relevant fields. It is only through bridging the divide amongst specialities, services and interest groups that we may extend holistic and comprehensive care to patients and their families. As we celebrate who we are and what we have achieved together, we continue to reach out with open hearts and minds, fixing our eyes on the future. Thus, the theme of the conference: "Embrace • Engage • Envision".

This four-day conference will feature plenaries by esteemed local and international speakers, pertinent updates on clinical practice, as well as presentations on recent scientific developments. Building on the community's shared knowledge, skills and insight, SPCC 2020 aspires to provide our participants with an inspirational vision into the future of hospice and palliative care.

Thirteen overseas and more than 50 local eminent palliative care professionals have been invited to share their expertise across a



diverse range of topics, that include management of pain and breathlessness, serious illness conversations, end-of-life care ethics as well as holistic care for paediatric patients. As we continue to improve access to palliative care beyond cancer patients, we are discovering an increasing awareness of the palliative care needs of non-cancer patients of healthcare professionals. This resulted in increasing interdisciplinary collaborations in the last few years. Many of our speakers at SPCC 2020 are involved in these collaborations across different settings and we are excited to be able to learn from their experience.

SPCC 2020 starts with eight pre-conference workshops and a pre-conference symposium over two days, covering a breadth of topics, from management of breathlessness, neuropalliative care, to psychosocial interventions, serious illness conversations and

music therapy. The workshops offer opportunities for speakers to engage a smaller group of participants and also allow participants to meet and connect with others of similar interests.

Our pre-conference symposium on Dignified and Compassionate End-of-Life Care is one of the highlights of SPCC 2020. This one-day international symposium brings together four world-renowned scholars and clinicians in the fields of thanatology, palliative, hospice and bereavement care to share their knowledge in rendering holistic, dignified and compassionate care to better support patients and families facing death, dying and bereavement.

All in all, SPCC 2020 promises great opportunities for learning, rediscovering our inspiration for holistic clinical practice, and reconnecting with old friends as well as making new ones in the ever-widening palliative care community. On behalf of the Organising Committee, we welcome you to SPCC 2020. We are certain it will be a rich learning and networking experience!

WORDS: DR NEO HAN YEE, CHAIR OF SPCC 2020 ORGANISING COMMITTEE; DR HO SHIRLYNN, VICE-CHAIR OF SPCC 2020 ORGANISING COMMITTEE. PHOTO: SINGAPORE HOSPICE COUNCIL



### PRE-CONFERENCE WORKSHOPS

**Breathlessness Management**  
Dr Sara BOOTH

**Communication, Law, Ethics and Professional Regulations (CLEaR)**  
Dr Han Yee NEO

**Neuropalliative Care Made Easy**  
Dr Mavis ANG

**Use of Music and Imagery (MI) in Palliative and End-of-life Care**  
Prof Nicki COHEN, Ms Tammy LIM

**Paediatric Palliative Care**  
Dr Poh Heng CHONG

**Psychological Interventions and Techniques in Palliative and End-of-life Care**  
Dr Irene TEO, Ms Yee Pin TAN, Dr Carolyn NG

**Palliative Care Nursing: Management of Complex Palliative Care Issues in The Community**  
Dr Jo HOCKLEY, APN Sylvia LEE, APN Wan Ru NG, APN Wei Ting CHEN, A/Prof Edward POON

**Serious Illness Conversations**  
Asst Prof Rachelle BERNACKI, Dr Joshua LAKIN, Dr Alethea YEE

**International Symposium on Dignified and Compassionate End-of-life Care**  
Asst Prof Andy HO, Prof Robert NEIMEYER, Prof Elizabeth LOBB, A/Prof Darcy HARRIS

### PLENARY HIGHLIGHTS

**Long Term Use of Opioids In Cancer And Non-Cancer**  
Prof Anthony DICKENSON

**National Strategy for Palliative Care - 9 Years On and What's Next?**  
Dr Angel LEE

**Being Human in the Era of Medical Advances**  
Sister Geraldine TAN

**Holistic Management of Breathlessness**  
Dr Sara BOOTH

**Fireside Chat: Core Values, Dreams and Aspirations for Palliative Care**  
A/Prof Cynthia GOH, APN Sylvia LEE, NE Amy LIM

**Communication Strategies in Challenging Clinical Situations**  
Asst Prof Rachelle BERNACKI and Dr Joshua LAKIN

Organised by:



Supported by:



Held in:



8 - 11 July 2020  
Singapore



**PRE CONFERENCE:**  
8 - 9 July 2020  
Lee Kong Chian School of Medicine  
Novena Campus

**CONFERENCE:**  
10 - 11 July 2020  
Sands Expo and Convention Centre  
Marina Bay Sands, Singapore.

### International Speakers



### IMPORTANT DATES

	1 SEP'19	31 MAR'20	30 APR'20	30 APR'20	8-9 JUL'20	10-11 JUL'20
Registration/ Call for Abstracts						
Abstract Submission Deadline						
Notification of Acceptance of Abstract						
Early Bird Registration Deadline						
Pre-conference Workshops						
Main Conference						



# An unexpected journey

*A patient suffering from renal failure at Khoo Teck Puat Hospital shares his journey thus far.*

**T**he usual reaction people will have when they are first diagnosed with kidney failure is shock and denial. However, I was not surprised as I was expecting the news. Having had diabetes for more than 20 years, I knew it was a matter of time before my kidneys fail. To make matters worse, despite having hypertension and diabetes, I did not adhere to my dietary restrictions. I ate a lot of salty and junk food too. I thought to myself, I was lucky to avoid other complications from diabetes such as blindness and amputation but I was not able to avoid kidney failure. I told my wife and children about the news. They too accepted it. Like me, they did not want to worry too much. I have friends who are on dialysis but they seem to look normal and are still active in the community. Thus, we decided to take each day at a time and try to adhere to the dietary restriction that we were told.

Prior to the dialysis initiation, I had multiple hospitalisations due to my leg wound and leg swelling. Despite having multiple doctors telling me that my leg swelling was due to my worsening renal function, I still hesitated to create the vascular access. During the pre-dialysis counseling, the renal coordinator had mentioned to create the vascular access instead of wasting money and creating pain for myself with the catheter insertion. My children were convinced and persuaded me to create the vascular access but despite having accepted my condition, I wasn't ready to create one. I thought my kidney condition was not too serious. I wouldn't need dialysis so soon.



Eventually, during one of the consultations with my nephrologist, I was given the ultimatum to initiate haemodialysis either via vascular access, or a temporary dialysis catheter while waiting for the vascular access. I finally agreed to create the vascular access.

On 10 September 2019, I was admitted for fluid overload. Prior to admission, I had difficulty sleeping as I was unable to lie flat on my bed. I was feeling very breathless and my legs were badly swollen, with blisters. Many doctors advised me to initiate hemodialysis but I refused.

Once I start dialysis, there is no turning back as I would need it for life. Also, I'm retired and I worry about the financial impact on my family just to support me on dialysis. I wanted to try alternative treatment overseas which was recommended by my friend. My son was against that as he was worried that something unexpected might happen. Furthermore, it will be difficult for my family to oversee the treatment as they are here.



Opposite and this page: KTPH renal coordinator Sri Fairuz Baizuri counsels the patient and his caregiver

When I was first introduced to the Disease Specific Advance Care Plan (DSACP), I thought it was a good idea as I will be able to express my thoughts and preferences in case anything unexpected happens to me and I am unable to choose my preferred medical treatment. I feel ACP really benefits my family as they do not have to carry the burden or guilt in making medical decisions for me in the event that I am unable to speak for myself. ACP also helps to prevent conflict among my four children.

Some of the scenarios asked during the ACP discussion were about my decision in the event I am faced with low chance of survival, loss of ability to move around or communicate, or mental incapacity. I prefer a good quality of life and do not want to be cared for 24 hours a day as I do not want to be a burden to my family. It is very important to me that I do not become a burden to them physically and financially. 🗣️

Two years after I first saw my nephrologist, I finally initiated hemodialysis via vascular access. My first session took two hours. I remembered feeling mentally and emotionally down as I was still unable to accept my condition. I was worried about the expense and complications of dialysis, and the unexpected. My family visited me every day and I was discharged on 2 October.

My life has definitely changed after starting dialysis. Physically, I am free of the breathlessness and swollen legs. My leg wound is also recovering well. I am able to sleep and lie flat on my bed now.

However, I still feel less than perfect. To me, hemodialysis is just a way to survive. My freedom is restricted as I have to adjust to the strict thrice-a-week dialysis schedule. I can no longer go for long holidays nor meet my friends outside like I used to, as I will feel very tired and weak after dialysis. Due to my heart condition, my physical activities are limited and I experience occasional chest pain. I can only hope my chest pain does not occur before or during my dialysis as I will be asked to seek treatment at A&E. I am unable to walk long distances and have difficulty with steps and kerbs. On dialysis days, my whole day

is wasted away even though my dialysis schedule is in the morning. I rely on a wheelchair to get around.

I cook my own low-salt meals. I no longer consume sweetened drinks. Despite my nephrologist telling me my fluid restriction is 800ml, I limit myself to 500ml per day. I no longer eat my favourite food - nasi briyani.

On 26 December, I had my Advance Care Plan (ACP) done.

## Patient's perspective

Don't give up hope. If you decide on hemodialysis, prepare your vascular access early to avoid the need for a dialysis catheter. A friend of mine, who is also undergoing hemodialysis, did not manage to have his vascular access created on time and went through at least three dialysis catheter insertions and multiple hospitalisations until he started using his vascular access for dialysis. Lastly, always give due consideration to your doctor's advice, over and above your friends and family.

## Caregiver's perspective

Ever since my father started dialysis, we have become more attentive to his needs and always plan and discuss my father's transportation to and from the dialysis centre. We even make time, despite our busy schedule, to accompany him for his medical check-up. It is normal to develop emotional stress from caring for the patient. Thus, it is also important to have good social support from family members, close friends, and colleagues. I shared with my colleagues and they understand when I need to take leave. Do not over-think your problems and always heed your doctor's advice.

WORDS AND PHOTOS: SRIFAIRUZ BAIZURI, RENAL COORDINATOR, KHOO TECK PUAT HOSPITAL

# Where are you now?

*Pastoral care volunteer, Martina Ho, at St Joseph's Home talks about the joys of caring for dementia patients, and the importance of meeting them on their own terms.*

“Please lah, please lah. Give me two dollars.” Mary looked at me earnestly. She had attempted to ask for money from the nurses, but without success. She now turned her attention to me. Thinking fast, I asked her in return, “Why do you need two dollars? Everything here is free.” “Oh, good.” She considered, gave a slight nod and relaxed into the chair. Less than five minutes later, Mary prodded my arm. She whipped an empty lipstick case from her handbag. “Come, I sell you this lipstick case. It’s three dollars.” Caring for residents with dementia is such a joy. I laugh at their witty replies and reminiscence at their childhood stories.

Most touching of all, they care about me. I recall an encounter with another resident named Rita. “I see that you’re here every day,” Rita commented. Then, in hushed tones, she asked, “Do you get paid?” I shook my head, “No, no, I’m a volunteer. They don’t pay me.” Almost shocked, Rita quietly pushed her plate full of food towards me. “Come, eat this.” She insisted. “The food here is free. Eat before you leave.” My friends often ask how I manage to converse with residents with dementia. To my friends, they are either repeating stories of old or making impossible demands. While residents with dementia can appear to go back and forth on their timelines, the present remains

very real and rich to them. To be compassionate caregivers, we need to meet them where they are.

**MEETING THEM WHERE THEY ARE** Jasmine is a gentle and soft-spoken lady. When she is invited to join in activities, she mostly keeps to herself. Hoping to get to know her better, I introduced myself. Eventually, she opened up with a story from her childhood. It was during the Japanese occupation. She was only 11 years old. The radio broadcaster had announced that all males are to be whisked away in a truck and killed. She was distraught and especially worried for her father. She looked me straight in the eyes and emphasised, “I prayed and

Opposite page: Pastoral care volunteer Martina Ho having a conversation with a St Joseph's Home resident; Right: Residents with dementia live in the now



As she considered that, things fell into place. She brightened and replied, “You’re right!”

**LET THE PAIN OF GOODBYE GUIDE YOUR MINISTRY OF NOW**

The pain of caring for a loved one with dementia is that we will witness parts of them disappear before the death occurs. Their personalities change. Their memory seems distorted. Every day, we fear that we might have lost another part of them.

So, we scramble to regain who they are.

During residents’ birthdays, some families would prepare a party.

I have been to one such birthday celebration. The children would encourage their mother to don her favourite blouse. Old songs played. Decorations were put up. Family members sat around to talk about old times. Then, the celebration would end with a group photo.

The truth is, most of the residents with dementia do not remember their birthdays. They are simply living their current moment. What I

have learnt in my years volunteering at St Joseph’s Home is that the window of time we have with them is all that matters now.

I would like to share a final story about Rita. I hope it quells the panic you have when your loved ones dwell in the past or when they talk about dying.

I found her enjoying the windy morning after her daily Mass on one of my visits.

While waiting for lunch, we casually chatted. We somehow got on the topic of death. She commented, “I come naked and I go naked. When my time has come, I will become a bird and fly to heaven.”

I panicked. “Don’t fly!” I anxiously replied, “If you fly away, I’d have no one to talk to.” Hearing that, Rita burst out laughing.

Catching myself reacting to her hints about death, I added in a more serious note, “But Rita, if you feel like it is time to fly away, go ahead.”

She nodded at me, a gentle, peaceful smile on her face.

To be compassionate caregivers, we need to meet them where they are.



WORDS: MARTINA HO, PASTORAL CARE VOLUNTEER PHOTOS: ST JOSEPH'S HOME RESIDENTS' NAMES ARE CHANGED

# Prevent cancer caregiver burnout

*Taking on the care of a cancer patient, especially during end-of-life, could see the caregiver's whole life consumed by this one task. Here are the signs of caregiver fatigue and ways to prevent burnout.*

**T**aking care of a cancer patient, especially during end-of-life, can often be emotionally and mentally exhausting. It involves adopting new responsibilities, juggling various work- and family-related roles and navigating the healthcare system.

The demands of caregiving can be relentless, and your life may even seem to revolve around caring for your loved ones with cancer at home. Sometimes you might be so focused on your loved ones that you do not realise that your own health and well-being are affected.

Caregivers have been found to be more stressed and depressed and have lower levels of physical health and general subjective well-being than non-caregivers (Pinquart & Sörensen, 2003). If left unchecked, prolonged exposure to caregiver stress can lead to burnout. Caregiver burnout is a state of emotional, mental and physical exhaustion, where one becomes overpowered by caregiver stress over time. Often, feeling a sense of powerlessness can lead to burnout and depression. It is important to be aware of

the emotional signs and symptoms of burnout. You may become increasingly irritable, often feel helpless and hopeless, and frequently feel fatigued and exhausted.

Your emotional state can also affect your physical state and behaviour, which could also be indicators of burnout. For instance, you may find yourself falling sick easily, using alcohol or stimulants more often, losing interest in previously enjoyable activities and isolating yourself from social events.

Being aware of these signs will enable you to take active steps to prevent a major breakdown. By paying attention to your own self-care, you avoid reaching the stage of learned helplessness, where you believe that you cannot do anything to improve your situation.

How then can you better take care of yourself? Firstly, it is important to change your attitude towards your cancer caregiving experience and yourself. Let go of thoughts and feelings that are unhelpful, such as blaming yourself for your loved ones' illness, and feeling bitter and resentful over handling your caregiving tasks.

You may feel a sense of loss at having to give up your lifestyle, plans or dreams. You may even feel unhappy at having to make certain sacrifices. Remind yourself of opportunities on the caregiving journey to make meaningful memories and build deeper connection with your care recipient.

Secondly, having a self-care boundary is important, so that you will not feel overwhelmed by your caregiving tasks. This means knowing when to say "no". Know your own limitations so that you do not take on more responsibilities than you can handle.

Do not be afraid to ask for help. Sometimes you may feel helpless because you think that you lack the money, resources or skills to manage your caregiving role. Seek and accept support from trusted family, friends and healthcare professionals. Various financial assistance schemes are available for needy patients as well as caregiver workshops to increase your effectiveness as a caregiver. There are also respite care services that can allow you to take a temporary break from your caregiving roles. Do alert your healthcare professional if you need help to cope with your caregiving roles.

Caring for someone who is sick, taking on new responsibilities, and worrying about the future can be exhausting. At moments like this, do not be too hard on yourself but affirm yourself and even celebrate the successes, however big or small.

Another way of taking care of yourself is to set aside time to recharge and give yourself

breathing space. Give yourself permission to take breaks away from your caregiving tasks. This may involve making a commitment to allow yourself to participate in activities or hobbies that will re-energise your spirit. You will build up your capacity to handle stress and be better able to care for your loved ones.

It is important to be assertive in communicating your needs to others. Be willing to share your worries and concerns with trusted individuals. Advocate for yourself by being clear and specific about the type of help you need to better cope with your caregiving roles and responsibilities.

When things go wrong, express your feelings honestly to others who are supportive, and find out how you can improve on managing your caregiving tasks. Part of the caregiving journey is also learning to communicate well with friends and family. Sometimes it may be hard to talk to them about cancer, especially when breaking bad news. It is important to be clear on how much you and your care recipient are prepared to share, as well as how much information your loved one, family and friends are comfortable to receive. When in doubt, do not hesitate to seek help.

Caregivers very often play a crucial role in supporting the cancer survivors' cancer journey. Yet, the needs of caregivers are often overlooked.

The Singapore Cancer Society (SCS) strives to meet the needs of family caregivers of cancer patients through its services and programmes. The

team of social workers at SCS provides casework and counselling services to help caregivers cope better in their caregiving roles. *Find out more about our cancer caregivers training workshops (conducted periodically) by emailing us at [scs\\_pss@singaporecancersociety.org.sg](mailto:scs_pss@singaporecancersociety.org.sg)*

## Tips to help yourself prevent caregiving burnout:

1. Caregiving is not a sprint but a marathon. To help yourself manage your caregiving roles for the long haul, pace yourself and be aware of your strengths and limitations. Know when to say "no".
2. Seek practical support from others to help you to run errands, collect medications and go for medical appointments.
3. Seek emotional support from trusted individuals who can provide you with a listening ear and encouragement.
4. Continue to participate in activities that you enjoy and give yourself permission to take breaks when necessary.
5. Seek respite care services that allow you to have a temporary break from your caregiving duties.
6. If you find yourself unable to manage, seek professional help from professionals such as social workers and counsellors to help you better cope with your caregiving roles and responsibilities.

**Reference:**  
Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging, 18*(2), 250-267. doi:<http://dx.doi.org/epoxy.lib.hku.hk/10.1037/0882-7974.18.2.250>



WORDS: DR JOAN KHNG, SENIOR SOCIAL WORKER, SINGAPORE CANCER SOCIETY  
PHOTO: SINGAPORE CANCER SOCIETY

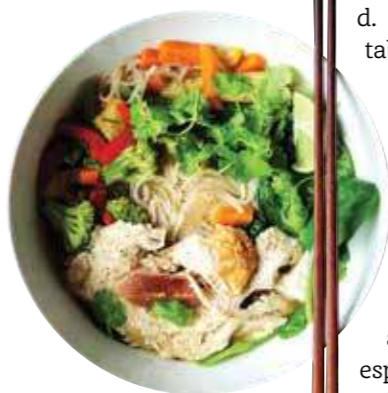


# Improving nutrition and the mealtime experience

*Tips to maximise your loved ones' nutrition, comfort and quality of life when faced with advanced illnesses.*

## 1. UNDERSTAND FOOD PREFERENCES

- a. Your loved one may have enjoyed certain types of food in the past, but their preferences can change – a sambal belacan lover in the past may now prefer plain porridge with simple bland side dishes.
- b. Be brave and experiment with different herbs and seasonings to enhance flavour and aroma.
- c. Different temperatures can make the meal more interesting, e.g., hot main meal followed by cold ice cream for dessert.
- d. Listen to your loved one, observe their responses to food and drinks, and be open to your loved one's changing feedback.



## 2. MAKE MEALTIMES MORE ENJOYABLE AND EASIER FOR YOUR LOVED ONE

- a. Have meals in a well-lit environment and help put on your loved one's spectacles if needed to help them appreciate what they are eating.

- b. Create a relaxing environment to allow enjoyment of food, e.g., in the company of family or friends or play some soft background music.
- c. Place dishes and cutlery within easy reach.
- d. Encourage your loved one to eat at the table, or at least out of bed.
- e. A good upright sitting posture on a chair or being propped up well on a bed helps to prevent regurgitation. It is good to remain upright at least 30 minutes after each meal or snack to prevent gastric reflux.

## 3. ASSIST AND PACE AS NECESSARY

- a. Eating can be tiring for your loved one especially if they are breathless or tire easily to begin with. Take frequent breaks during the meal.
- b. Ensure your loved one has swallowed the food before feeding the next spoonful.
- c. Provide small sips of fluid between mouthfuls of food to help clear the food in the mouth.

WORDS AND PHOTOS: SINGAPORE HOSPICE COUNCIL

## 4. SERVE SMALL MEALS OR SNACKS THROUGHOUT THE DAY

- a. Encourage your loved one to decide when or what they would like to eat.
- b. He or she may tolerate 5 to 6 small meals a day better than 3 large meals.
- c. Small servings may look less intimidating. You can always top up with more food if they are still hungry.
- d. If nausea is present, remember to serve the nausea medication at least 30 minutes before a meal, or as advised by the doctor.



## 5. MAKE EVERY MOUTHFUL OF FOOD COUNT

- a. Increase calories and protein content in meals, e.g., add sesame oil, egg, fish or tofu into porridge; add peanut butter or tuna to biscuits; add oral nutritional supplements to milkshakes.
- b. Provide high calorie, high protein snacks, e.g., red or green bean soup, sesame paste, bubur cha cha, bao, beancurd.
- c. Provide nourishing fluids, e.g., soya milk; full cream or flavoured milk; oral nutritional supplements; fruit smoothies; yoghurt drinks; adding milk, ice cream or honey to beverages.



*(Abstracted from Singapore Hospice Council's 'Nutrition in Advanced Illnesses' resource booklet. For more tips and recipes, download the booklet here: <https://singaporehospice.org.sg/caregiver/>)*



# Upcoming Events

**8 - 11 JUL 2020, WED - SAT\***

## **7th Singapore Palliative Care Conference (SPCC 2020)**

SPCC 2020 is a highly anticipated biennial conference organised by Singapore Hospice Council, featuring an excellent programme of distinguished local and international speakers. We look forward to welcoming you at SPCC 2020!

**Venue:** Lee Kong Chian School of Medicine, Novena Campus (8 & 9 Jul) & Sands Expo and Convention Centre, Marina Bay Sands (10 & 11 Jul)

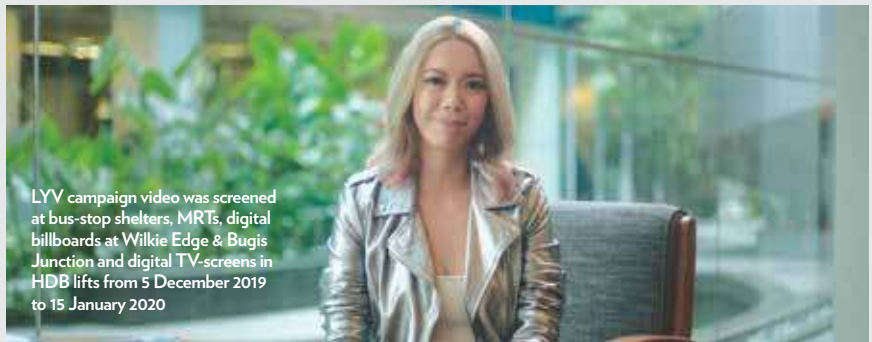
**Target Audience:** Healthcare professionals from all fields

**Contact:** secretariat@singaporepalliativecare.com

**Registration:**

<https://singaporepalliativecare.com>  
(early bird rate closes on 30 Apr 2020)

**\*In view of the COVID-19 situation, please refer to <https://singaporepalliativecare.com> for the latest updates.**



## **Lend Your Voice to Palliative Care**

Hot on the heels of our very well-received viral campaign #LendYourInstagram, the Singapore Hospice Council has launched a sequel initiative, titled 'Lend Your Voice to Palliative Care' (LYV), a nationwide social movement urging brands and individuals to help spread the message of hospice and palliative care, and dying with dignity.

Many Singaporeans are still unaware of or have little understanding about palliative care and how it aims to maximise the quality of life of those with life-threatening illnesses, by caring for the "whole person" physically, emotionally, psychologically, socially and spiritually, and alleviating suffering for both the patients and their loved ones. Because ultimately, hospice and palliative care empowers these patients to #LiveWellLeaveWell during their final days.

No matter who you are or where your talents lie, find out how you can help bring hospice and palliative care to those who are most in need. Whether it's offering a service / product / promotion, donating advertising space or creating beautiful works of art, anybody is welcome to lend a helping hand.

Find out how you can help at <https://singaporehospice.org.sg/lendyourvoice/>

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Chua Hwee Leng  
Candice Tan  
Desiree Lim

Design  
Printer

Christian Subrata  
Yung Shung Printrade Pte Ltd



1 Lorong 2 Toa Payoh #07-00

Braddell House

Singapore 319637

T: 6538 2231

E: [secretariat@singaporehospice.org.sg](mailto:secretariat@singaporehospice.org.sg)

[www.singaporehospice.org.sg](http://www.singaporehospice.org.sg)



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