

By Dr EDNIN HAMZAH

It was January 2020 and another New Year had begun.

For Hospis Malaysia, we were looking forward to further improving palliative care for our patients while ensuring that the doctors and nurses that we are training acquire the necessary skills, and enhancing the public awareness of palliative care.

However, there was news of an emergence of a viral illness in China.

Within a few months, Malaysia and many other countries were affected and each nation enforced its own version of a lockdown.

Since then, life has not been the same again.

Although Malaysia is in its "recovery" phase, many other countries are still struggling with this global pandemic.

Throughout this pandemic, experts in public health and infectious diseases have been at the forefront of each nation's response, aiding and sometimes being undermined by other "experts".

Who is hearing us?

Amidst all this, is there a voice for palliative care?

Covid-19 brought the spectre of an incurable illness that is pivoted between being asymptomatic and fatal.

Most governments rushed to shutter the country and mobilised the healthcare system to confront the viral enemy. Personal protective equipment (PPE) became the "must have" for everyone.

For palliative care services, some were reduced, others redeployed and some continued.

Yet, palliative care which is defined as the care of patients and families faced with the suffering from a life-threatening illness, should be well suited in dealing with this Covid-19 pandemic.

After all, palliative care has ample experience in dealing with HIV, Ebola and SARS.

Palliative care deals with:

- > Uncertainties in facing illness, providing hope though not neglecting the possibility of end of life care
- > Management of physical symptoms such as breathing difficulties and pain
- > Dealing with social, psychological and spiritual issues
- > Communication issues such as breaking bad news and helping

Times of uncertainty

While healthy individuals are dealing with the fear of contracting Covid-19, thousands of palliative care patients are trying to have the best quality of life that they can.



The goal of palliative care is to improve the quality of life for patients and their families. — AFP

patients and families make complex decisions

- > Managing complex medical issues in the home
- > Grief and loss.

During the past few months, society as a whole has experienced:

- > Physical and social isolation
- > Poor quality of life due to restrictions to movement and other activities
- > Economic deprivation
- > Uncertainties in work and social relationships
- > Psychological concerns due to fear and anxiety, and
- > Spiritual and religious concerns as places of worship are shuttered.

Throughout this pandemic, healthy members of the public are dealing with the fear of contracting the virus.

In the meantime, thousands of Malaysians with cancer, organ failures and other illnesses, which are

for the most part life-threatening, are trying to have the best quality of life that they can. For them, they have already come to terms with an uncertain future.

Care for the terminally ill

Whilst others grappled with changes in day-to-day routines of staying at home, many patients had a different reality.

Hospital services were reorganised for the pandemic and services such as cancer treatment, surgery, investigations and outpatients were all affected.

In hospitals, seriously ill patients were isolated in intensive care units and often required ventilators; their physical contact with loved ones no longer possible.

For those who succumbed to the disease, their end of life were shared only with hospital staff; the comfort of being with loved ones

was no longer possible.

Unable to bid farewell

Dying was a lonely process.

In some countries, where healthcare workers were able to discuss with their patients their mortality, and what was important to them at that stage of their lives, technology was utilised for families to share their final moments through a virtual experience.

For many unfortunately, the inability to say goodbye in the way they wanted led to exacerbated grief for the surviving family.

The national response to the pandemic requires that the greater good of the public overrides personal priorities.

Within the global narrative, the work of palliative care continued in the background to support the stretched healthcare services struggling to deal with the acute situa-

tion of infected patients. Increasing community palliative care in some countries for example, enabled more hospital beds to be utilised for Covid-19 patients.

Palliative care expertise and guidelines helped deal with breathlessness and pain. Advance care planning and guidelines in communications supported care in intensive care units and helped staff, patients and their families live through this pandemic.

Basic human right

For Hospis Malaysia, our palliative care services continue during the course of lockdown and the pandemic. Following both national and international guidelines, our care was modified to incorporate identification of people at risk, use of PPE and physical distancing.

In some cases, some guidance and discussions were done through telephone or occasionally a virtual interface. But many aspects of care cannot be done virtually such as wound dressing or change of catheters.

For patients in pain, a physical assessment helped to ensure the right medication was prescribed, and proper bedside guidance for the caregiver to dispense the medication was important.

In these times, there is the delicate balance of ensuring good care continues to be delivered to patients with a serious illness such as advanced cancer, and subjecting the patient, their family, and the healthcare worker and their families to the potential risk of Covid-19 infection.

Palliative care is a basic human right and should be seen as part of universal health care. It is the foundation of decent values in medical care and should be available to all who need it, whether in normal times or in the midst of a viral pandemic.

Dr Ednin Hamzah is the CEO of Hospis Malaysia, a charitable organisation that offers professional palliative care to patients living in the Klang Valley.