

**W**hen you are lying on a bed in the intensive care unit of a hospital, so sick that you are no longer able to interact with anyone, what would you choose?

Do you want to have a tube placed into your windpipe to help you breathe, through a procedure called endotracheal intubation?

If your condition worsens, do you want to be cared for in a hospital or elsewhere, such as in a nursing home, hospice or at home?

It may seem unthinkable that someone in such dire straits can still make choices. However, he can, if his preferences have already been made known to the health-care team and his loved ones, in what is known as advance care planning (ACP).

Drafting an ACP document involves a series of conversations with the patient, substitute decision-makers and an ACP facilitator – usually a doctor, nurse or medical social worker.

Several public health institutions here started offering ACP since 2010. So far, their efforts appear to have helped patients to fulfil their final wishes, statistics show.

Since 2012, of the 28 patients who did an ACP and subsequently died at National University Hospital, 15 died in their chosen places, 22 received their preferred treatment and 12 had both wishes met.

In all, 78 patients, including those from National University Cancer Institute, Singapore (NCIS) and National University Heart Centre Singapore, made ACPs during this period, said Dr Noreen Chan, a senior consultant at the department of haematology-oncology at NCIS.

At Tan Tock Seng Hospital (TTSH), more than 95 per cent of patients who signed an ACP and died at the hospital between October 2011 and June this year received their preferred medical treatment, said Dr Raymond Ng, a consultant at the hospital's department of palliative medicine. For example, some did not wish to proceed with cardiopulmonary resuscitation (CPR).

Another 23 per cent died in their chosen places, added Dr Ng. The findings came from an audit of 172 patients. In all, 741 patients did an ACP at TTSH and 348 have since died.

Similarly, most of the patients at Khoo Teck Puat Hospital (KTPH) who had done an ACP had their wishes honoured.

The hospital helped 312 patients with their plans, of whom 137 have died. About 80 per cent of them were treated in their preferred places and 64 per cent died in their chosen places.

#### WHY WISHES WERE NOT MET

However, all three hospitals did not analyse why some patients' wishes, as outlined in their ACPs, were not met.

Doctors say reasons may include a lack of caregivers at home, while some caregivers may find it challenging to care for the patient at home. The rapid deterioration of a patient's condition can also prevent him from being sent home in time to die – if that was what he wanted.

Dr Siew Chee Weng, a locum principal resident physician at KTPH's department of geriatric medicine, noted that reasons as to why wishes are not met are "usually medical rather than social".

At KTPH, one patient received CPR when she did not want it. Her family, although aware of the ACP, had called for an ambulance when she vomited blood and the paramedics applied CPR as they were not aware of the details.

#### PLUGGING THE GAPS

This is a problem which Singapore Hospice Council



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Doctors say one reason why some patients' last wishes were not met could be because caregivers find it difficult to care for the patient at home.

chairman R. Akhileswaran wants to solve, by getting paramedics to check ACP documents before they proceed with CPR.

This is because anxious family members may still call for an ambulance, even after they have been told not to do so in order to honour the patient's wishes, added Dr Akhileswaran, who is also the chief executive of HCA Hospice Care, the largest home palliative care provider here.

Members of the Singapore Hospice Council are now in talks with the Singapore Civil Defence Force to plug this gap.

Serious illnesses can also strike the young, which is why his colleague, Dr Chong Poh Heng, is offering ACP to children and young adults with life-limiting or life-threatening conditions, under the Star Pals (Paediatric Advanced Life Support) home-care service by HCA Hospice Care.

Since the programme started in April 2012, it has served 110 patients, of whom 50 have completed ACP. However, fewer than 10 were done with input from a child.

Besides the fact that some young patients are cognitively impaired, others chose to let their parents decide their treatment. Other parents

chose not to "burden the child with such decisions", said Dr Chong, programme director of Star Pals.

Sixteen-year-old Nina Adriana, who suffers from advanced chronic lung disease, took part in the ACP process with her housewife mother and cab-driver father last September.

In the event that she collapses suddenly due to respiratory or cardiac arrest, she has opted to have endotracheal intubation and ventilation for no longer than five days. In addition, she has declined external cardiac compressions and advanced life support measures.

Dr Chong wants to help more patients like her through the Paediatric and Young Adults ACP Taskforce, which he co-chairs.

The taskforce – set up last year with eight health-care professionals, including paediatricians, social workers, counsellors, and nurses and doctors trained in palliative care – is looking to introduce workbooks for children and parents to prompt discussions about ACP.

They are also looking to roll out the ACP forms used by his Star Pals team to other institutions that treat children with life-threatening conditions, as well as train other health-care professionals on how to offer ACP to their young charges.

Despite their young age, such conversations can help parents and doctors to understand the child's mentality towards medical treatments and uncover his fears about dying.

Dr Chong has had some children express their anxiety that their parents will forget about them when they die, or worry that their toys may be given to people they do not approve of.

"If the odds of dying are so high, it may be more important for a child to go to school to stay connected with his friends than to receive aggressive treatment in the hospital," he said.

Currently, Nina needs to be connected to oxygen devices around the clock to help her breathe, but she still attends school regularly.

She has told her parents and Dr Chong that the only thing she fears is that she cannot breathe.

"It is not all about what we want for her," said her mother, Madam Suriani Saini, 39.

"It's also about what she wants for herself."

Joan Chew

