

病危幼少将可预订预先护理配套

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身患绝症的少年儿童不久后有望在家长和医护人员帮助下,制定一套符合自己喜好的预先护理计划,借此减轻紧急危病时所承受的不必要痛楚。

本地HCA慈怀护理副医药总监张保贤医生向本报透露,卫生部属下全国预先护理计划(advance care planning)工作小组,特别针对19岁以下青少儿病患成立指导委员会,探讨推广面向年幼病童的预先护理计划,而设有儿科的国大医院和竹脚妇幼医院医护人员将从明年开展试验。

张保贤是指导委员会主席之一,他昨天受访时说,本地成人预先护理计划开展已有一段时间,目的是让患者提出临终时的护理要求。相对来说,年幼病童生病去世的过程比较让家长难接受。

“我们觉得有必要为病童制定预先护理计划,一旦出现突发状况,孩子是否去加护病房、做心肺复苏术,家长希望医生做什么或不做什么,双方都能有所参照。如果小孩最终过世,但已按照这份计划尽了力,也可在一定程度上减轻遗憾。”

他指出,家长和病童都有各自的喜好和期望,但这个了解的过程并不像闲聊这么简单,医护人员需要有一定技巧和经验,接下来也将通过培训,协助医生护士,甚至社工和辅导员掌握沟通技巧。

HCA慈怀护理是目前本地规模最大的住家临终护理机构,去年专为19岁以下绝症儿童提供“星光友伴”(Star PALS)临终护理试验服务,目前有40多名病童加入计划。他们也积极培训儿童临终护理义工,使得人数从最初4人增加到现在的16人。

昨天,在HCA慈怀护理和民间公益组织“肖像援梦队”(Help-Portrait)的策划下,20个临终护理病童家庭在裕廊飞禽公园拍摄了全家福,留下温馨感人的画面。



在HCA慈怀护理和“肖像援梦队”的协助下,卢玟祺(右)和丈夫吴建南带着大女儿和患病的小女儿在裕廊飞禽公园度过了快乐的一天,拍下了全家福。(温树良摄)

卢玟祺(38岁)的小女儿两岁时被诊断为脑退化,过去五年来健康每况愈下,卢玟祺总是担心女儿随时会在睡梦中离开。“我们很珍惜与她在一起的每分每秒。我曾经尝试找专业摄影师拍全家福,但他们看到小女儿便手足无措,不知道如何摆弄,这次终于能有一张全家福照片为我们一家人留下最美好回忆。”

“肖像援梦队”负责人陈冠中(27岁)说:“了解这些家庭的经历后,真的觉得他们很了不起,在镜头前看到一家人笑得开心,其实也让人觉得心酸,幸好我们能为他们留下一幅永恒的画面。”

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Critically ill youngsters will be able to set up advance care plans

Reported by Yang Yang

Terminally ill youngsters and children will soon be able to make advance care planning according to their own preferences with the help of their parents and medical workers, so as to reduce any unnecessary pain that they may have to undergo in times of medical emergencies.

Dr Chong Poh Heng, Deputy Medical Director of Singapore HCA Hospice Care told this paper that the National Advance Care Planning Taskforce under the Ministry of Health has set up a steering committee to specifically look into advance care planning for patients below 19 years old and medical personnel from NUH paediatric clinic and KK Women and Children Hospital will be conducting relevant trials early next year.

When interviewed yesterday, Dr Chong, one of the Chairmen of the steering committee, said that advance care planning program for adults has been in force for quite some time. The objective of the program is to let patients convey their wishes with regards to medical care during their last days. It is relatively more difficult for parents of a young patient to come to terms with his or her passing.

“We feel that there is a need to formulate advance care planning for young patients. In emergency situations, should the child be admitted to intensive care unit? Should he/she be resuscitated? What do the parents want the doctors to do or not do? There will be some grounds that both parties can make references to. If the child eventually passes on, at least we have done all we can based on the advance care plan and this will leave fewer regrets to some extent.”

He also pointed out that the parents and the young patient will have their own preferences and expectations. The process of reaching a common understanding is not as simple as a casual chit-chat session. The medical personnel have to be equipped with specific skills and experiences. Training will be conducted to help doctors, nurses and even social workers and counsellors master the relevant communication skills.

HCA Hospice Care is currently the largest home based palliative care centre in Singapore. Last year, it launched “Star PALS”, a trial palliative program for terminally ill patients below 19 years old. There are presently more than 40 children in the program. HCA also actively conduct training for children palliative care volunteers and the number of volunteers has increased to 16 from 4 when the program first started.

Twenty families with young patients under palliative care shared warm and touching moments as they took family portraits at the Jurong Bird Park yesterday in an event organised by HCA Hospice Care and Help-Portrait, a non-profit community organisation.

Lu Wen Qi (38)’s younger daughter was diagnosed with Alzheimer’s disease when she was two. Her condition has deteriorated over the last five years and Lu Wen Qi is constantly worried that her daughter will leave them anytime in her sleep. “We cherish every moment we have with her. I have tried to get professional photographers to take a family portrait but they were at a loss when they saw my daughter and would not know how to pose her. This time, we can finally have a family portrait to leave our happiest moments as a family in print.”

Chen Guan Zhong, 27, person-in-charge of “Help-Portrait” remarked that, “After understanding what these families have gone through, I really feel that they are great people. To see them smiling happily in front of the camera can in fact be quite heart-wrenching. Fortunately, we could help them capture a permanent image of their unflinching love for one another.”

Photo caption:

With the help of HCA Hospice Care and Help-Portrait, Lu Wen Qi (right) and husband Wu Jian Nan brought their elder daughter and younger daughter who is ill to the Jurong Bird Park to spent happy moments together and took a family portrait.