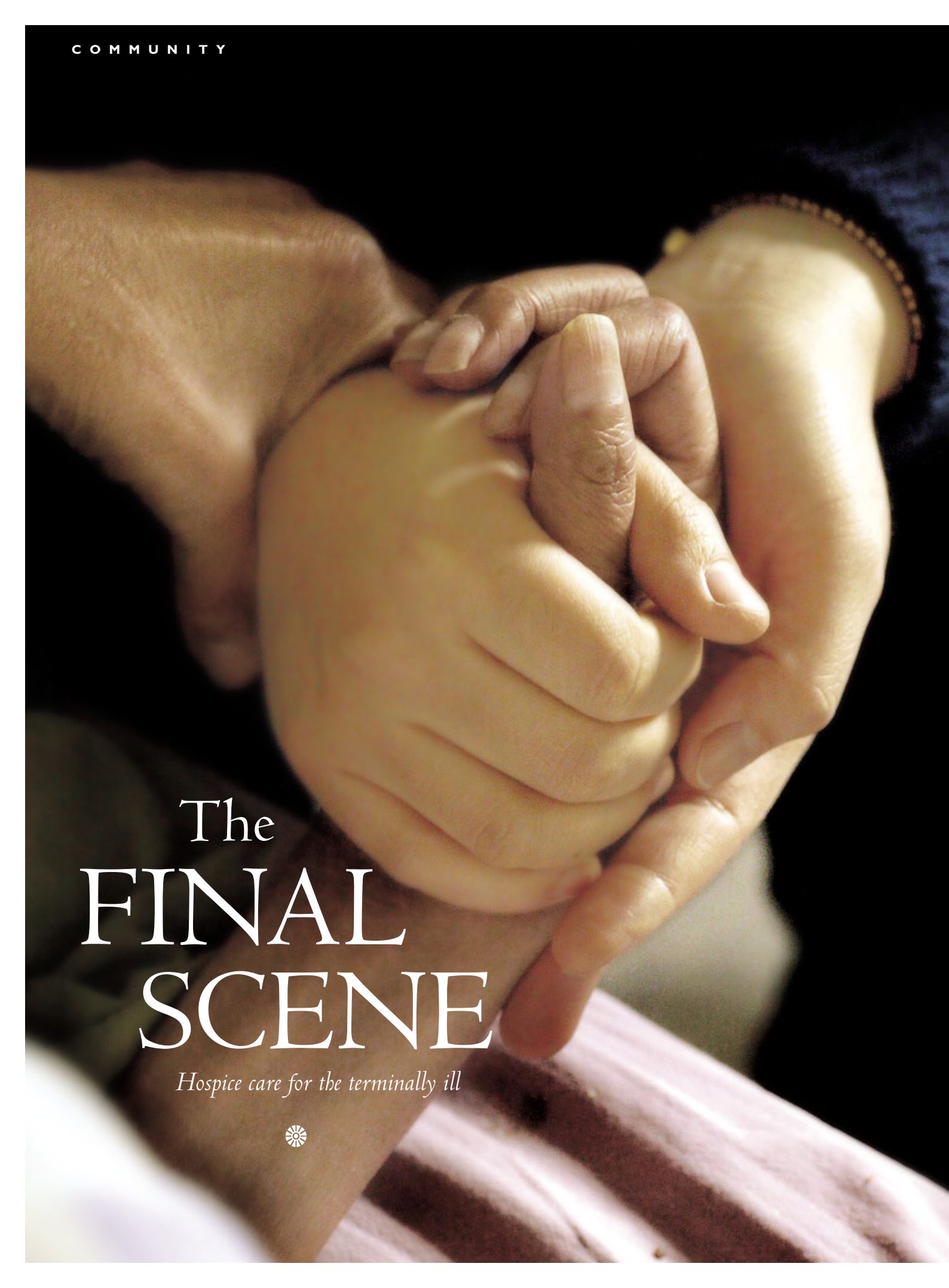


COMMUNITY



The  
**FINAL  
SCENE**

*Hospice care for the terminally ill*



“I wish to work with you hand in hand because we are all dedicated to helping people who have nowhere else to turn to. This programme will be in place for not just a year; it will go on until the Mainland becomes more affluent and more capable of *taking care* of its *terminally ill patients*. My commitment to the advancement of education and medical care will go on *beyond my lifetime*.”

Cancer patients have made contributions to society. I hope to help *alleviate their suffering* as much as possible so that they can *live out their remaining days with dignity*.”

— Li Ka-shing

IN NOVEMBER 1998 MR LI KA-SHING set up, with a personal donation, the first hospice in Mainland China at the First Affiliated Hospital of the Shantou University Medical College. Before then, hospice services and palliative care – virtually unexplored territory in Chinese medical history – were unavailable in Mainland China. At the time, the facility was the only provider of free hospice care for impoverished cancer patients at home, offering pain alleviation, psychological counselling, life ethics and other forms of terminal care. Falling within the realm of social work, hospice services go beyond the confines of purely medical care. Although patients can not be cured, hospice care allows them to live their remaining days in serenity and love.

As defined by the World Health Organisation, palliative care “affirms life and regards dying as a normal process, intends neither to hasten nor postpone death, provides relief from pain and other distressing symptoms, integrates the psychological and spiritual aspects of patient care, offers a support system to help patients live as actively as possible until death, and offers a support system to help the family cope during the patient’s illness and their own bereavement.”

### One man’s compassion

The programme was inspired by personal experience. Mr Li went to a hospital one day to visit a friend suffering from cancer. Despite receiving the best possible care at this leading hospital in Hong Kong, his friend was still tormented by his

illness and Mr Li was deeply moved as he watched his friend suffer. There are people on the Mainland who suffer from the same illness, he thought. If these patients are poor, their pain would be much harder to bear. He then started discussions with the Shantou University Medical College about setting up the first hospice on the Mainland.

The vast majority of terminal-stage cancer patients on the Mainland suffer tremendous physical pain and psychological torment during the final stages of their lives. Most cancer patients with financial difficulties cannot afford basic analgesic medication and die in excruciating pain.

“Terminal-stage cancer patients are people who have once made a contribution to society, but now they are suffering agonising pain,” said Mr Li. “Easing their pain, filling their thoughts with the best memories of their lives and allowing them to complete their final journeys in peace and with dignity is the best reward that we, the living, can give them.” This is the guiding principle behind the beginning of hospice care on the Mainland.

The Chinese name for the hospice, Ning Yang Yuan (literally “Peace and Care Hospital”), was Mr Li’s idea. He found it a more acceptable name for a hospice in a society where death remains a taboo.

### Into a new era

The Ning Yang Yuan created a practical model for hospice care on the Mainland by integrating home and outpatient services. Patients and their families are given analgesic treatment, psychological counselling and information on palliative care through the Home, Consultation and Outpatient Services provided by the hospice. To reach out to a larger number of terminal-stage cancer patients, Mr Li made a further donation in January 2001 to set up the National Hospice Care Programme. The programme receives HKD26 million from Mr Li every year, with total donations now exceeding HKD130 million. Today, 19 other major hospitals in Mainland China have set up hospices through the National Hospice Care Programme. As the only provider of free terminal care for impoverished cancer patients and their families, the



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## NEW FREEDOM FOR THE NEEDY

**O**NE OF THE most common problems of terminal-stage cancer is pain. Pain must first be alleviated before one can even begin to talk about improving the patient's physical and psychological well-being.

World Health Organisation (WHO) studies have shown that 70 per cent of cancer patients suffer pain, of whom 40-50 per cent suffer moderate and severe pain. In the 1980s the WHO launched a campaign, Freedom from Cancer Pain by 2000, which proposed using non-traumatic drug therapy to treat cancer patients individually according to a scale known as the pain ladder.

Freedom from Cancer Pain, however, remains a distant ideal for most cancer patients on the Mainland. The majority of terminal-stage cancer patients suffer excruciating pain. Painkillers can provide total pain relief for most cancer patients, but because many impoverished patients cannot afford basic analgesic treatment, they end their final days in misery, their bodies wrecked, their spirit broken. Pain and poverty deny them peace and dignity in their last days.

The 20 hospices set up by the Li Ka Shing Foundation on the Mainland provide free standardised treatments for cancer pain and complications arising from terminal-stage cancer. Not only are they a soothing balm to the destitute patients, they also alleviate the mental anguish suffered by patients and their families. They allow patients to reclaim their dignity and live each day of their remaining lives in peace.

At the hospice in Shantou, for example, each patient on average receives a free seven-day course of painkillers that costs around RMB300. The patient who underwent the longest treatment period was a breast cancer sufferer who, over four years, received free analgesic drugs that cost around RMB23,000. Two other cancer patients with bone lesions were each given painkillers that cost around RMB12,000 over a period of two years. For poor families, such medical expenses are astronomical and completely out of their reach.

To improve the use of resources and lower drug costs, the Office of the National Hospice Care Programme obtained permission from the State Food and Drug Administration to reduce the number of links in the drug supply chain on the Mainland. In a trial run, six hospices purchased specially approved analgesics at factory prices, saving up to 38 per cent in costs. Based on the result of this trial, all 20 hospices on the Mainland would save RMB7.33 million a year if they used specially approved drugs.

Where the average cost incurred by each patient is RMB1,900, it would mean that the hospices would be able to serve an additional 3,800 patients, or improve the quality of their services. At the moment, the Office of the National Hospice Care Programme is actively seeking approval for the expansion of this special drug distribution scheme to all 20 hospices by 2007.

At present, the hospices are already providing total pain relief for 40 per cent of terminal-stage cancer patients under their care, a figure that is on a par with international standards. The free analgesic treatment given to cancer patients by the hospices follows the WHO's three-step pain ladder.

After a doctor has conducted an evaluation, the pain is classified as mild, moderate or severe. Different medication is prescribed for each class of pain. Non-opioid +/- Adjuvants are used for patients with mild pain, while mild opioids +/- anti-inflammatory drugs and Adjuvants are prescribed to patients suffering from moderate pain. For patients in severe pain, strong opioids +/- anti-inflammatory drugs and Adjuvants are administered.



The 20 hospices set up by the Li Ka Shing Foundation provide free standardised treatments.

programme is leading China into a new era of hospice care.

The 20 hospices employ 140 medical professionals and are spread across 19 cities in 13 provinces. To date, the programme has served more than 47,000 patients.

The launch of the National Hospice Care Programme has attracted extensive media coverage, arousing greater awareness and interest among the Chinese public, which in turn has generated more public concern for the physical pain and psychological trauma suffered by terminal-stage cancer patients.

### Embracing the sunset together

"The work on the hospices will go on beyond my lifetime," said Mr Li. "I hope members of the hospice staff will always offer their love and kindness to cancer patients." Describing his dedication to the service of impoverished cancer patients as "timeless", Mr Li expressed the hope that the hospice staff would share his enthusiasm and carry the torch for this worthy cause.

Despite his hectic work schedule, Mr Li tries to find time to visit hospice staff members and often writes letters to encourage them.

"Please remember that you never work alone. We are of the same mind with the same genuine desire to offer hospice care," he wrote in one letter. "How noble your work is, to offer a dose of painkillers, a touch of human warmth and kindness to a person suffering from illness and pain, so that the physical torment is immediately assuaged and the soul becalmed.

"It is said that after people die, they either ascend to heaven or descend into hell. However, to terminal-stage cancer patients in their last days, the immeasurable pain and torment that they suffer already feels like hell on earth. To all the medical personnel in the hospices who



*“While serving over 14,000 cancer patients every year, I hope my programme will considerably raise the public’s attention on hospice.”*



volunteer their love and kindness to these patients without expecting any reward, in the hope of lessening their pain, allowing them to regain their dignity and alleviating the mental anguish of their families; to all of them I say: You are the greatest.”

### **Physical and psychological needs**

Mr Li pays close attention to the details of the services the hospices provide. His instructions state that they must use the most effective anaesthetics. “If there is a drug that

### **■ Case Study 1**

Both my wife and I are disabled in our lower limbs, and we depend on social security assistance for our livelihood. After my wife Chen Weizhen developed breast cancer, her mounting medical bills added further to our already severe financial hardship. During the terminal stage of her cancer, when she had brain lesions, her whole body went into spasms. When I saw her excruciating pain and thought of the prohibitive medical expenses, I felt so desperate and helpless. It was then that you came and helped us by conscientiously making house calls and dispensing free medication. I am so grateful to you for the professionalism and care you showed us. You came just when we needed you.

— Chen Weizhen’s husband

#### *Patient details*

*Chen Weizhen, female, Guangzhou, Guangdong  
Aged 41, deceased, breast cancer and brain lesion  
She was disabled and so is her husband*

### **■ Case Study 2**

...After that, I underwent one medical treatment after another. Radiotherapy, chemotherapy, Traditional Chinese Medicine, western medicine...I tried everything, but they did not stop my condition from getting worse. The illness itself was nothing to be afraid of; what scared me was the pain. I was in so much pain that I wanted to die. It was only when I was prescribed the drug MS Contin that I became free from the pain. It really took away my pain.

— Zhang Meng

#### *Patient details*

*Zhang Meng, female, Lanzhou, Gansu  
Aged 35, deceased, breast cancer patient from a financially distressed family*

### **■ Case Study 3**

...Just when I thought my situation was beyond hope, when all I wished for was a quick death, angels in white gowns came to my aid. Professor Cui, the head of the hospice at your hospital, led a medical team all the way from Shenyang to my house and treated me free of charge. They gave me free doses of MS Contin and I was amazed at the immediate effectiveness of this strong painkiller. My pain was significantly reduced.

— Cui Hongwen

#### *Patient details*

*Cui Hongwen, male, Faku, Liaoning  
Aged 56, deceased, bladder cancer*

### **■ Case Study 4**

...The first one to receive me was Dr Shen. She listened patiently to the patient’s symptoms and prescribed medication according to each patient’s condition. We were thrilled that our father’s condition was brought under control and he could sleep peacefully. The excruciating pain that he had suffered was lessened considerably. Our family’s greatest wish was for our father to suffer less pain during his final days. The hospice was a godsend to our family.

— Daughter of Wang Shuangqing

#### *Patient details*

*Wang Shuangqing, male, Shanghai  
Aged 52, deceased, retrenched worker with terminal-stage lung cancer*

relieves 90 per cent of the pain and costs \$50, and another one that relieves 99 per cent but costs \$100, I would rather buy the one that costs \$100,” he said. “The most important thing is to ease the patient’s pain as much as possible.”

He also makes it very clear that vehicles used to make house calls must be washed regularly and medical personnel making house calls must project a lively, professional image when serving their patients. His concern for patients has had a profound effect on medical staff. Instead of lab coats, a number of doctors and nurses now take casual wear when making house calls because many families with terminally ill relatives do not want the neighbourhood to know that there is an impending death in the family.

Management of the hospices also reflects Mr Li’s entrepreneurial qualities. All daily expenditures are logged into Hospice Eye, an online monitoring system, giving a clear picture of where the money is spent. The system also includes other statistical data, such as records of medication consumed by each patient, helping in the research and development of palliative care.



### More like-minded associates needed

Every year more than two million people in China develop cancer, leading to more than 1.4 million deaths. Mr Li believes that 20 hospices definitely are not enough. He knows he cannot do this alone, but he hopes that he has started the ball rolling and more people in the community will be encouraged to get involved. “If all of us do this together, we can achieve a lot. Nothing great will be achieved if I do this alone,” he said.

A pressing concern is the severe shortage of hospice medical staff. Palliative care has yet to develop into a full-fledged discipline on the Mainland and getting the Ministry of Public Health to recognise it as a legitimate field of study is the most important task at hand.

With the support of the Li Ka Shing Foundation, the National Hospice Care Programme has benefited an increasing number of patients since its launch five years ago. However, demand still far outstrips supply. If the programme can be incorporated into the existing medical service network, more policy and financial support will be forthcoming. The programme will then gain greater influence in society and help the development of hospice care on the Mainland.



## A LESSON IN MEDICAL ETHICS FOR HOSPICE VOLUNTEERS

**D**UE TO THE unique spirit of service it embodies, hospice care has attracted not just professional medical personnel, but also a growing number of volunteers. Among their main tasks, the volunteers accompany patients on visits to doctors, help patients make medical appointments, and provide timely feedback regarding patients' conditions to the doctors in the hospices.

They also collect medicines from the hospices for patients or their family members, and help with invalid patients' domestic chores and the homework of patients' young children. In addition, the volunteers make occasional home visits to patients, during which they read the newspapers to them, take them out for walks and provide counseling. The patients' family members are not neglected. The volunteers assist them in finding solutions to their difficulties, for example, by obtaining information on job vacancies.

There are approximately 5,000 hospice volunteers nationwide, of whom 70 per cent are undergraduates. Although most of the medical personnel involved in palliative care are experienced clinical physicians and nurses, there are far too few of them to meet the demand. More participation from the community is desperately needed. As future doctors, medical students are the most obvious source of volunteers, and the first hospice volunteer team comprised of undergraduates on the Mainland was formed in the Shantou University Medical College.

Volunteer recruitment campaigns at the Shantou University Medical College invariably meet with a very positive response. When asked about their reason for applying, most

students cite a desire to gain experience and exposure in hospice care. However, as hospice volunteers, these students stand to benefit from much more than work experience.

There was a student from out of town who, after losing the map showing the way to his patient's home, cycled several hours on the streets looking for the house. Another student who was delivering medicine on a rainy day became upset, not because he was drenched from head to toe but because the knapsack containing analgesic medication had become wet. Then there was the student who spent the night surfing the Net to collect information on job vacancies for his patient's family members. Another did all he could to borrow books for a patient's despondent little girl, and was rewarded with a delighted smile. These examples indicate the degree of responsibility and care that the current batch of undergraduates have for their community.

As they are giving, the volunteers are also receiving a lesson in professional ethics. Each time they follow a doctor to a patient's home, they will be moved by what they see and will come to recognise the value of hospice care, as well as the importance of their future vocations as caregivers and lifesavers.

The patient bedside manner of palliative care doctors, and the obvious love they have for their jobs, show the volunteers how doctors should conduct themselves. Given the prevailing ethical issues such as bribes and favouritism in Chinese medical circles today, volunteering in hospices is an uplifting lesson in medical ethics, which cannot be taught in the classrooms.



**Hospice care is a new type of medical service on the Mainland, and more needs to be done in a society where death is still a taboo subject.**

