

# HONGKONG CANCER PATIENTS LEFT ALONE AND IN FEAR

By WENDY KAY

**A** SHORTAGE of funds, archaic superstitions, beliefs and the lack of foresight among some hospital administrators are forcing many thousands of Hongkong's terminally ill to die lonely and frightened in cramped wards of general hospitals.

More than two decades ago in England, Dame Cicely Saunders founded the contemporary idea of hospice care which has since snowballed to provide enormous support to millions of terminally ill patients throughout the world.

"You matter because you are you. You matter to the last moment of your life and we will do all we can to help you die peacefully, but also to live until you die," she said as she opened St Christopher's Hospice in London.

However, it wasn't until six months ago that her words finally reached the ears of Hongkong and became the inspiration of a selected few dedicated, alleviating a little of the anguish suffered by those living on borrowed time.

Called the Society for the Promotion of Hospice Care, a handful of doctors, nurses and social workers have laid the foundation for a mammoth project aimed at providing moral support for the terminally ill and their families.

"There is no special care for the dying in Hongkong," co-ordinator Lucy Chung said simply. "At the moment they are treated as any other patient, with no specialised counselling, comfort or care."

Until the society was formed, and despite the fact that Hongkong's biggest killer, cancer, was responsible for more than 7,500 deaths in 1985, hospice care was limited to a small team of doctors, nurses and social workers operating from the Maryknoll Hospital at the institution of Ms Chung.

A continual shortage of hospital beds left terminal patients with no alternative but to return home. Shortly before their death they would be readmitted to hospital in overcrowded conditions to spend their remaining time surrounded by those often too busy to care.

Now, based at the Ruttonjee Sanatorium, a sparsely furnished tiny office boasting one bookcase housing her society's small library, Ms Chung is determined to put Hongkong in

league with other developed countries in providing modern day hospice care.

Already the society has set up a small team at the Ruttonjee Sanatorium itself but further progress is hindered mainly through the shortage of funds and lack of education.

"We have to make people aware that terminally ill patients need a special service to help them die more comfortably and with dignity," Ms Chung said.

The Government has refused requests for help and the majority of financial support is provided by grants from the Keswick Foundation, with the rest coming from donations from churches and independent fundraising activities carried out by the society itself.

Ms Chung, who graduated as a general nurse in Hongkong, turned her attentions to hospice care after seeing the suffering of dying patients who were spending their last moments crammed in overcrowded general wards or sleeping on uncomfortable camp beds in corridors.

"There was nobody to tell them it was alright to be afraid, nobody to let them know there was no shame in showing emotion," she said.

In 1982 she left for England to train in hospice care at St Luke's Hospice in Sheffield. She returned to Hongkong brimming over with ideas and enthusiasm and a firm conviction that Hongkong's dying were to be ignored no longer.

Soon after her return she set up the team at Maryknoll and then began campaigning for the

foundation of a society to promote hospice care.

All of Ms Chung's time is taken up by educating both the medical profession and the families involved with the terminally ill and eradicating many of the misconceptions surrounding terminal disease.

The practical side of the program is carried out by the two mobile teams at Ruttonjee and Maryknoll.

Although the words of Dame Saunders sum up the goals of the society, putting them into practice is far more complex.

Basically, hospice care is a non-profit and non-denominational organisation. The objective is to eliminate active treatment and concentration instead on enhancing the quality of the patient's last months of life.

It aims to preserve mental alertness, promote the prevention and management of pain and other distressing symptoms associated with terminal illness and to give both the patient and the family members physical, emotional and spiritual support which continues into the bereavement period.

The hospice concept emphasises home care with family members encouraged to participate in caring for the patient while supported by hospice staff members and community agencies with regular visits to the home and a 24-hour emergency call service.

The team will also provide assistance in regular household

duties such as meal preparation, laundry, or shopping.

For patients who need hospitalisation there is a sophisticated in-patient service in either a specific hospice centre or a hospice unit where specially trained medical staff and social workers deal with the terminally ill.

No matter which program the patient follows, whether it be at home or in hospital, all are accepted on the basis of health needs, not according to their ability to pay.

According to Ms Chung, Hongkong is a long way from receiving a special centre for the dying, and she says that is her ultimate dream.

"Right now we would be happy just to have a house to which about 10 terminal patients can be admitted and receive special care and attention. The most important thing is to help them appreciate the time left to them and to preserve their dignity."

The mobile team provides a consultant service and will visit the patient either at home or in a hospital ward. It comprises three full-time nurses especially trained to deal with terminal patients, two volunteer doctors and social workers.

"Unfortunately, however, our services are limited to only the patients of these two hospitals. We are helpless when other hospitals pick up and ask our assistance as we simply do not have the manpower or resources to extend the service to patients of other hospitals," Ms Chung said.

Ms Chung said that is her ultimate dream.

# A death with dignity

"All our patients are Chinese simply because they are by far the majority. We do whatever we can to help Europeans suffering from terminal illness but often they are more comfortable talking with someone of their own culture."

Most of the hospice patients are terminal cancer victims who are given oral treatment enabling them to stay at home. However, this situation, although preferable to most, can often result in added trauma as patients are faced with possible isolation from friends and family because of superstitious ideas that cancer is contagious.

"Amongst the Chinese the attitude towards incurable disease such as cancer is distorted by the fear that it is contagious or is a death taboo for the whole family," she said.

"I am often asked if the rest of the family can eat with the same chopsticks as the patient or sit at the same table," she said. "Support both for and from the family is very, very important. Although patients who already have a strong bond with their family never face abandonment, there can be an enormous

feeling of isolation which, coupled with the patient's own fear of dying, can prove to be even more devastating."

"Religious support of any denomination is also available if requested," Ms Chung added. Lack of education within the medical profession itself is also a major problem.

"The education of doctors and nurses themselves is just as important as making the family aware," Ms Chung said. "Medical staff have to be taught how to deal with a patient's emotions. At the moment there is no back-up support system within the hospitals and the common nurse cannot be responsible for the total care of a terminal patient."

"So far we have found that the staff are willing to learn but are finding it harder to generate interest amongst the administrators. I think this is because it is the nurse and doctors who have the direct contact with the patients and see for themselves what goes on."

The society is doing all it can, but hard-hearted Hongkong still has a lot to learn in the tender art of dealing with the dying.