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23 June 2014

The Hon Mr. Fernando Chiu Hung Cheung,
Chairman, Joint Subcommittee on Long Term Care Policy
Legislative Council, Government of HKSAR

Via Email: mchiu@legco.gov.hk

c.c. lillianlamling@gmail.com (Ms Lam, Assistant to Mr F Cheung)

Dear Mr. Cheung,

Hospice Care Services

Thank you for your letter to us via fax on 9 June 2014.

At this stage we do not have any corporate submissions to make to the Joint Subcommittee on the development of hospice care services in Hong Kong, and we will not send any representative to attend your forthcoming meeting on 24 June 2014. We may however share with the Joint Subcommittee our philosophy and some experiences in providing hospice care services in Hong Kong.

Founded in 1963, The Hong Kong Anti-Cancer Society is the oldest non-profit making organisation in Hong Kong conducting all kinds of activities to fight against cancer, encompassing cancer educations (to both the public & medical professionals), charity programmes to assist cancer patients & families, as well as provision of residential rehabilitation and hospice care. We have for many years since 1967 until 2003 provided hospice care services through the operation of Nam Long Hospital. After the closure of Nam Long Hospital, we have secured funding from the Hong Kong Jockey Club, and re-built on the same site The HKACS Jockey Club Cancer Rehabilitation Centre [JCCRC], which began operation in 2008 to provide residential care services to meet the diverse needs of patients, many of which are undergoing their last legs of life.



We believe that terminally ill patients should be allowed to spend their last days on earth with optimal comfort provided and dignity preserved; in peace and surrounded by their loved ones. A holistic and multi-disciplinary approach should be adopted in the provision of hospice care services to patients facing the last legs of life. Our philosophy basically follows what the National Institute for Clinical Excellence of UK sets out as the Essence of Good End of Life Care, which includes:

- (i) Treat the patients as individual
- (ii) Show patients respect and preserve their dignity
- (iii) Help with control of symptoms particularly pain
- (iv) Offer psychological, social and spiritual support
- (v) Reassure patients that their families and carers will receive support during their illnesses.

Our experience shows that apart from the need for quality medical and nursing care to the terminally ill patients, the provision of comprehensive collateral services can be most helpful in providing optimal quality of life to them and comfort to their families. For example, at the JCCRC, we provide the following collateral services:

- (i) **Recreational & Diversional Therapy Unit.** We conduct activities every afternoon for patients who feel well enough to participate. These activities include handicraft, flower arrangement & cooking classes, mahjong games, Wi-Games and movie watching etc. Patients can also enjoy other free/low charge services on site such as hair-dressing, festival parties; outings etc. Our Betterment Fund can provide certain “last wish” fulfilling activities as well.
- (ii) **Unrestricted visiting hours.** Family members are welcomed to stay for as long as they wish to keep the patients company. Overnight staying for accompanying person(s) can be arranged. Patients in their last hours may be transferred to a single room if one is available, for the family members to spend private time together with the patient.
- (iii) **Home leaves with assistance & advice.** Weekend home leaves are encouraged if patients & families wish so alike. Our Physiotherapist provides advice and assistance with minor home modification/ adaptation. Our nursing home minibus can provide wheelchair transfer between JCCRC & patient’s home for a fee.
- (iv) **Spiritual Care.** In addition to a full time staff spiritual carer, we have arrangement in place for spiritual carers of 5 major religions to come to provide spiritual care & support should any patients have such specific needs; namely, ones of Catholic, Protestant, Buddhism, Taoism & Muslim.
- (v) **Farewell viewing room.** We have a viewing room set up like a normal bedroom for family member(s) to identify patient’s body, instead of having to do it in the mortuary out of a stainless steel body refrigerator trolley, which is an emotionally traumatic experience to the surviving love ones.

- (vi) **The Last Rites.** Patient's families preferring a simple farewell are welcomed to utilise our Spiritual Centre adjacent to the Mortuary and the Farewell Viewing Room, free of charge, to hold prayer meetings or a simple funeral service and then proceeding to cremation or the burial site. (Families can get funeral service provider to change clothes and place body in coffin on site). This is always much appreciated by families having used our service.

In essence, we aim to provide our patients with a full spectrum of care covering medical, nursing, psycho-social & spiritual aspects. It is a genuine "one-stop" place for terminally ill patients to spend their last days in dignity with peace of mind for both the patients & their families. In addition to doctors, palliative care nurse specialist, other supporting nursing staff, social workers, physiotherapists, dietician, spiritual care workers etc are also important members of the palliative care team. Often, traditional/conservative Chinese culture makes it difficult for many terminally ill patients to express their true final wishes, thinking that they have already been burdening their families by being ill. On the other hand, families feel it may upset the dying patient if they mention the subject. Hence, many patients and families would have missed out on death with fewer regrets if the process could be facilitated with a professionally trained medical/nursing/spiritual care team. End-of-life care aims at maximizing comfort for the dying, while bereavement care begins before death, and will be continued for family members after the death of the patient.

We note however that the provision of structured and high quality hospice care services is very resource-intensive. Average price for operating a palliative/end-of-life care bed costs up to \$60,000 per month. Due to the self-financing nature of JCCRC, we have been getting feedbacks frequently from patients & families from the "sandwiched class" that while they feel that JCCRC can definitely serve their palliative care needs very well, they could not readily afford the costs we need to charge them, even on a not-for-profit, cost-recovery basis. We have been fortunate to have supports from some charitable foundations and benevolent individuals by means of monetary donations in order to operate our beds in a subsidised manner, enabling families to pay a lower & more affordable charge. For families with poor financial means, they could be qualified for fully subsidised "charity beds".

We hope the above background information may assist the Joint Subcommittee to work together with the Government to develop a satisfactory and comprehensive government policy on hospice care services (including educating the public) in Hong Kong, without which adequate and appropriate resources allocation to the area is not likely. With increasing ageing population in Hong Kong, the incidence of cancer and other illnesses requiring end of life care is expected to keep rising.

The Hong Kong Anti-Cancer Society

-4-

For your further information, we understand that the UK has a well structured End-of-Life Care Programme commenced by its Nation Health Service since 2004, while Australia Government Department of Health has developed *Guidelines for a palliative approach in residential aged care* in the same year. WHO had published 5 different lengthy papers on Better Practices on Palliative Care since 1998.

We would be more than happy to supply more details/information on our hospice care services experience, or to clarify any queries you might have on the subject matter. Please feel free to contact me or our CEO Ms. Iris Leung at 3921-3821.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'P. Chu'.

Patricia Chu, Mrs.

Chairman

The Hong Kong Anti-Cancer Society