



The Vision

June 2007

A Children's Hospital for Hong Kong

A Children's Cancer Foundation Initiative



As well as becoming the centre of excellence for paediatric care for Hong Kong, the proposed Children's Specialist Hospital can also play a significant role as a paediatric research centre for the Pearl River Delta region, according to Statistician and Senior Lecturer at the University of Hong Kong, Dr. Paul Yip Siu-fai.

“Recent research shows that in 2006, more than 20,000 babies were born to non-local parents in Hong Kong, and as a regional referral centre, a children's specialist hospital based here would be in the best position to take up the responsibility for the future medical needs of this group of children. This would create an efficient database for paediatric research in the Pearl River Delta, and by assuming a consultancy role the hospital would become the paediatric information and leading research centre for the whole region.”

“A centralized and accessible children's specialist hospital will not only provide much-needed support for patients' families, but also, with the best medical skills and technologies all under one roof, patients and parents will no longer need to go to different hospitals around Hong Kong to seek out the best treatment,” Dr. Yip said, emphasizing that

the proposed Children's Specialist Hospital will be an important component in the overall healthcare infrastructure for Hong Kong's children. “In addition, such a facility - which centralizes medical care and treatment for children requiring tertiary care - will create a sizeable critical mass for population study as well as medical research.”



medical service for teenagers, providing the right mix between counselling services, psychological treatment, medication and clinical back up.”

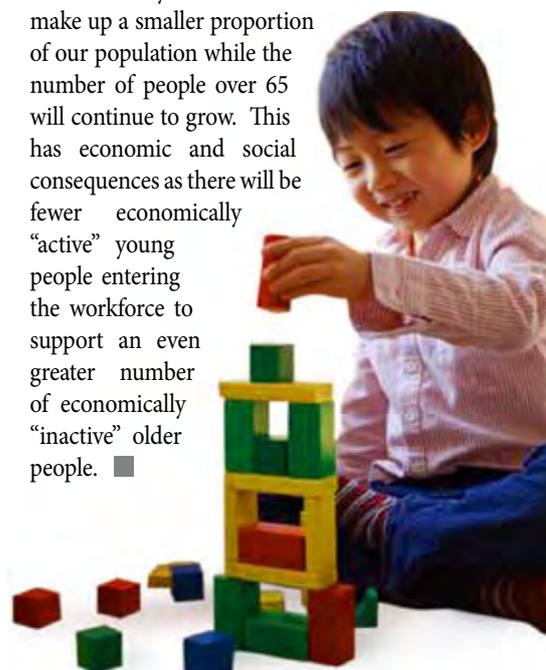
“ The proposed Children's Specialist Hospital will be an important component in the overall healthcare infrastructure for Hong Kong's children ”

More resources should be allocated to children, focusing on improving their quality of life and healthcare. According to Dr. Yip, this is the trend in many other developed countries and cities.

Dr. Yip is also the Director of The Hong Kong Jockey Club Centre for Suicide Research and Prevention, and believes that children are the most precious resource in any society faced with an ageing population, and they are our

future. “The government should not only focus on the clinical needs of children while ignoring their mental health,” Dr Yip said. “In most youth suicide cases, teenagers have inadequate coping skills when facing obstacles in their life course, and have very low self-esteem. The proposed Children's Specialist Hospital should be a centre of mental health education and a holistic

Healthy ageing is an important issue for Hong Kong's medical development and Dr. Yip reiterated that the best way to promote healthy ageing is to focus on the source of the ageing population – our children. Like many developed economies, Hong Kong faces the challenge of dealing with a combination of a low birth rate and a rapidly ageing population. With one of the lowest fertility rates in the world, children will make up a smaller proportion of our population while the number of people over 65 will continue to grow. This has economic and social consequences as there will be fewer economically “active” young people entering the workforce to support an even greater number of economically “inactive” older people. ■





PALLIATIVE CARE

A HOSPITAL'S LAST GIFT OF LOVE TO TERMINALLY-ILL CHILDREN

The Vision talks with Professor Godfrey Chan Chi-fung

Professor Godfrey Chan Chi-fung is a renowned paediatrician specializing in haematology, oncology, and haematopoietic stem cell transplantation. He is Associate Professor, Paediatrics and Adolescent Medicine at the University of Hong Kong.

The subject that is closest to Dr. Chan's heart is palliative care for children with terminal illness. He strongly believes that the provision of outstanding paediatric palliative care requires two important factors - a devoted team of doctors and nurses well-trained in paediatric palliation; and a warm and loving environment in which terminally-ill children can pass away in peace and with dignity. "A children's specialist hospital must at least be able to live up to that kind of standard," Dr. Chan stressed.

Dr. Chan's ideal palliative ward comprises 20 spacious beds equipped with inter-active computer technology that connects the child to other patients as well as with the rest of the world. The beds are separated by movable and curtained glass partitions so that the child has a choice in opening up or closing down. Contrary to general parental wishes, Dr. Chan believes that children do not necessarily like single rooms - they need to interact with other

children instead of being overwhelmed by a feeling of loneliness.

Dr. Chan pointed out that while presently about 20-30% of palliative cases involve cancer patients looked after by the Children's Cancer Foundation, palliation in other paediatric subspecialties such as neurology, metabolic disorders, etc. is a large missing piece that desperately needs to be addressed. "If the service can be reasonably expanded to involve all subspecialties in the proposed Children's Specialist Hospital, where there will also be a hostel for parents and a centre for respite care to look after patients when parents take extended breaks to rejuvenate from physical and mental exhaustion, then my prayer is answered," Dr. Chan continued with much hope and enthusiasm.

“Children need to interact with other children instead of being overwhelmed by a feeling of loneliness”

Advocating the importance of involving medical students throughout the process of palliation to provide the necessary training in this area, Dr. Chan cited examples from other countries where it is not unusual for a patient to donate organs for research after death.

"Assigned medical students befriend the patients through their last days and attend their funerals in a non-denominational chapel in the hospital. They wear a suit when autopsy is performed and show the greatest respect to the body, which is how it should be," Dr. Chan reflected, still visibly moved by the recollection. After cremation, a small jar of the patient's ashes is placed with an epitaph in a special library at the hospital built for such donors.

"If we are going to have a children's specialist hospital, I really hope we can place greater prominence on



teaching facilities and research, as it is so very important to train up new blood," Dr. Chan emphasized.

Although the trend is to encourage more planned deaths at home because children actually do not like dying in hospitals, it is unfortunate that parental anxiety or fear often prevails and, more often than not, these children spend their last days in the hospital. Thus, on the one hand, while doctors try their best to educate parents in preparing for deaths at home, on the other, palliative care remains an extremely important hospital-based service to terminally-ill children. "It is the hospital's last gift to the patient, so it should be wrapped up beautifully - with love, care and dignity," Dr. Chan concluded, with a note of tenderness in his voice. ■



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Respecting the special needs of children

How a hospital manages pain is a benchmark for how it manages all forms of distress in suffering children.

The Children's Specialist Hospital will be a place where all children are happy to come for treatment. Children will be actively involved in their treatment, and parents will be included in the health care team as "experts" in understanding their children's pain and helping them to deal with it.



HELPFUL SUGGESTIONS FROM A SURVIVOR AND HER MOTHER...

Mrs. Tai is very optimistic, although she still does not understand why her daughter, Annie, needs to have suffered from a brain tumour.

Three years ago, Mrs. Tai discovered that Annie had to urinate many times a day, and needed to drink a considerable amount of water. Worried about Annie's abnormal symptoms, Mrs. Tai took her daughter to Shenzhen Hospital for a check-up. Doctors in the Neurology Unit diagnosed Annie with polyuria, caused by a one-centimetre diameter tumour on her brain. Mrs. Tai was shocked by the news, and took Annie to the Guangzhou Air Force Hospital for further medication and treatment.

"I don't know if it was wrong to take Annie to Guangzhou for treatment, but the environment in Hong Kong just made me feel helpless," said Mrs. Tai, adding that she hopes the new Children's Specialist Hospital in Hong Kong will play the role of a children's health information centre for the public.

In March, 2006, Annie had influenza symptoms for more than a month, and her left eye was red and swollen. Mrs. Tai took Annie to Tuen Mun Hospital where it was discovered that her brain tumour had grown to a diameter of three centimetres. Annie was sent to the Neurology Unit for a tumour resection operation, following which she underwent chemotherapy for more than six months. She is now fully recovered.

"I understand that doctors and nurses are very busy, and they have no time to explain the patient's condition in detail," Mrs. Tai remarked. "I would like to suggest that the proposed Children's Specialist Hospital should have a library on children's illnesses, so that parents and the public can understand more about what's wrong with their children and what to expect."

Annie is a cheerful and pleasant girl who shares her mother's optimistic outlook on life. After staying in Tuen Mun Hospital for six months of chemotherapy, Annie shared with The Vision her view of an ideal children's hospital.

Annie's first suggestion is that the proposed Children's Specialist Hospital should provide living space for parents so that they can stay with their children overnight. "Parents' support is very important to us. I was very depressed every night when mamma had to go back home," said Annie.

Next, Annie suggested that the Children's Specialist Hospital should avoid putting children of different age groups together in the same ward. "I want to make

friends with my roommates, and do not want to be disturbed by babies crying."

As with most children, food is also a very important issue for Annie. "I love to eat, but the food in hospital is too boring. Adding dessert and different kinds of fruit to the menu would definitely be a good choice!" she concluded. ■



Vision Facts

CARE COORDINATION

Effective care coordination helps families and children enjoy the highest quality of life throughout the continuum of care. It also reduces the cost of care by minimising hospital visits, absence from school and parents' absence from work.

At the proposed Children's Specialist Hospital, care management and planning will commence before admission or treatment, and will be undertaken in conjunction with admitting teams, ward areas, medical subspecialties, referral sources, allied health workers, patients' own family doctors, parents and carers, and other providers involved in on-going care. Designated Care Coordinators will assist in:

- removing barriers to care and discharge, including referrals to health care providers in the private sector
- ensuring continuity of care and consistency of information
- providing a central point of information for all stakeholders
- promoting patient and family education
- providing linkage to community services and schools
- providing phone support to families and community providers
- facilitating review and re-admission, if required
- developing clinical pathways that outline care to be provided, outcomes to be achieved, and timeframes in which to achieve them
- coordinating the clinical team, including nurses, doctors and allied health team members
- planning transition to adult health care services, whether to primary, secondary or tertiary, public or private



A PLACE TO CARE FOR THE WHOLE FAMILY

Chun-kit's smile, like that of his mother Ms. Ng, is so positive that it is hard to imagine that they were abandoned by Chun-kit's father during their hardest time. It's also hard to imagine that Chun-kit has become a talented football player since he was confined to a wheelchair!

In 2002 when he was only six, Chun-kit suffered from serious pelvic pains which kept him awake night after night. During Chinese New Year in 2003, his mother took Chun-kit to Xiamen for an MRI scan. He was diagnosed with lymphoma, and was admitted to Tuen Mun Hospital immediately after returning to Hong Kong.

After a further MRI scan in Tuen Mun, Ms. Ng was given the heartbreaking news that Chun-kit was also a victim of neuroblastoma and would likely survive for only three months. Obviously

“With his mother's support and his own strong will, Chun-kit won his battle against cancer”

Ms. Ng was very sad, but she did not give up. With his mother's support and his own strong will, Chun-kit won his battle against cancer after being hospitalized for more than one year to undergo chemotherapy, and he is now studying at the Hong Kong Christian Service Pui Oi School, where he can receive physiotherapy regularly.

Ms. Ng feels strongly that there is a great need for the proposed Children's Specialist Hospital in Hong Kong, so that all resources and professionals can be centralized in one place. “People like me have undergone many traumatic experiences during their children's illness and treatment,” said Chun-kit's mother, who, despite her

courageous smile and positive attitude, explained that she needs to see a psychologist herself twice a month.

“My wish is that the proposed Children's Specialist Hospital will not only take better care of patients, but that it will also provide a comprehensive follow-up service for the whole family after the patient has been discharged,” she concluded. ■

What should a Children's Hospital for Hong Kong be called?

We invite you to send us your ideas on a suitable name for a children's hospital in Hong Kong.

Providing specialist care for infants, children and adolescents from birth to 19 years old, the proposed hospital could be named after a person, a place, or a fun idea. Children and parents want it to be a place of happiness and healing.

What do you think? Let us know your ideas, and we'll print some of the best in future editions of this newsletter and on our website - www.hkchildren.org.

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Respecting the special needs of children

Wherever possible, patients at the Children's Specialist Hospital will be grouped in inpatient units according to their age and condition. That way, teenagers can be surrounded by those their own age, and likewise for younger children, toddlers and infants. It also allows for easier contact between the multi-disciplinary teams at the hospital when a variety of specialists and health care experts may be treating infants, children and adolescents with similar conditions.

The hospital will be a nurturing and gentle environment for young patients and their families – a place where art, colour and open space are more common than white hospital coats.

Contact Us:

c/o **Children's Cancer Foundation**

Room 702, Tung Ning Building, 125 Connaught Road Central, Hong Kong. Tel: (852) 2815 2525 Fax: (852) 2815 5511

E-mail: myviews@hkchildren.org Website: www.hkchildren.org

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