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BERITA HOSPIS

The Year That Was

When you are busy, time seems to pass relatively quickly. And so it was that 2010 came to pass and we are fast going through 2011. So what went on at Hospis Malaysia in 2010?

The main event was the continuation of our building extension project that started in 2009. Providing an ongoing service amidst a combination of remodelling and construction was very challenging. It became obvious that some services simply couldn't carry on and needed to be modified. As the day care room needed to be renovated, this was reduced to a weekly service and held at the premises of our neighbours, Sri Seronok. This continued until we were able to come back to our own renovated day care in 2011.



Sue Marsden lecturing in Hospis Malaysia's Education Centre

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With no space for lectures, our workshops were held at various locations throughout Kuala Lumpur. Attachments for medical and nursing students needed to be continually adjusted to suit the construction schedule. As in previous years, hundreds of students from University Malaya, University Putra Malaysia, University Technology Malaysia, and several nursing colleges spent time seeing patients with us. We also hosted doctors and nurses from our neighbouring countries who were keen to know more.

Our palliative care workshops remain popular and 355 doctors, nurses and others attended our six regular workshops in 2010. These workshops have grown significantly since they were introduced in 1998. The workshops are supported by an enthusiastic teaching faculty drawn from palliative care consultants from Australia, New Zealand, the United Kingdom, Singapore and Hong Kong.

Hospis Malaysia Palliative Care Workshops 2010

		NO OF PARTICIPANTS			
NO	WORKSHOPS	Doctors	Nurses	Others	Total
1	PC1: Palliative Care Nursing: 6 - 7 February	3	49	2	54
2	PC2: Communication Skills: 10 - 11 April	5	43	1	49
3	Foundation Workshop in collaboration with APHN: 19 - 22 June	30	34	1	65
4	PC3: Suffering & Hope: 23 - 25 July	9	45	9	63
5	PC4: Pain & Symptom Management: 23 - 25 Oct	22	33	7	62
6	PC5: Grief & Bereavement Care: 18 - 19 Dec	9	37	16	62
		78	241	36	355

Note: Others: Refers to counsellors, psychologists, occupational therapists, pharmacists etc

Editorial

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Our palliative care professionals are also kept busy with frequent requests to speak at local, national and international meetings.

As in previous years, the number of patients being referred increased, 1,636 compared to 1,469 patients in 2009, an increase of 11%. At any point, we generally have between 370 to 400 under our care. All these patients have access to a 24 hour on-call service, even on the possibly world record number of public holidays that Malaysia has. We are mindful that for those who are ill, it is impossible to plan not to have an illness during public holidays! Our palliative care team of four doctors, eleven palliative care nurses and our occupational therapist conducted 12,122 home visits in 2010. This generally works out at about 1,000 visits each month. We certainly would like to do more but we do require more doctors and nurses to join us and would dearly love to improve the experience of driving and negotiating through traffic jams and flash floods in the Klang Valley. About 14,500 telephone calls were also made to patients and their families to provide further support.



Number of Patients Referred: 1992 - 2010

Council Members

Chairman Vice Chairman Secretary Members

Mr. Mok Yuen Lok Datin Kathleen Yeoh Dato' Dr. Sir Peter Mooney Tan Sri Lim Leong Seng Dr. Ednin Hamzah Dr. Azlina Firzah Abdul Aziz Dato' Brig. Gen. (R) Richard Robless Ms. Fairly Yap Swee Eng

Mr. James Armand Menezes



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Editorial

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MONTHS	JAN	FEB	MAR	APR	MAY	JUN	JUL	AUG	SEP	OCT	NOV	DEC	CUM
Patients carried over	425	421	402	391	407	351	364	389	404	406	406	402	
New referrals	140	103	156	146	129	131	148	145	133	145	130	130	
Re-admissions				1									
Total patients under care	565	524	558	537	536	482	512	534	537	551	536	532	
Referrals to date '10 (Cum)	140	243	399	545	674	805	953	1098	1231	1376	1506	1636	1636
Referrals to date '09 (Cum)	97	208	336	477	584	715	863	958	1091	1212	1325	1469	1469
Average no. of pts. per day	417	402	398	401	330	355	397	369	373	374	397	402	
Total visits (clinical team)	1042	797	1073	1016	937	938	939	921	817	997	994	956	11427
Visits after hours**	8	6	3	5	7	5	4	4	2	4	1	0	49
Telephone calls	1282	1057	1263	1288	1179	1075	1123	1214	1198	1242	1273	1149	14343
Bereavement visits	66	55	70	54	52	58	52	53	46	58	49	33	646

Statistics for Hospis Malaysia Home Care Year 2010

*Referrals to date (Cum) excludes readmissions.

** After hours defined as after 6pm Monday to Friday, weekends and public holidays.

These are done by either the doctor or nurse on call and are not included in the visits by nurses and visits by doctor figures.

In August 2010, Hospis Malaysia together with the Altarum Institute from the United States were awarded a world demonstration research project by the World Health Organisation to look into a new form of healthcare work organisation called Decent Care Values.



A visit from consultants from Altarum Institute to meet with the team working on the Decent Care Values Project

(L – R): Dr Felicia Chang, Antigone Dempsey, Dr Stephen Connor, Dr Sylvia McCarthy, Dr Ednin Hamzah, Assoc Prof Ng Chirk Jenn Yet for all this work and a patient care service provided at no charge, money needs to be sourced. In a period of economic challenges, this itself was a mountain to climb. The building project added to the burden and our public relations and fundraising team aided by our Council worked extra hard last year. We had our signature events, the annual Treasure Hunt and the Charity Bazaar and many others. We are indeed very grateful to those who feel that the cause we serve is worthy of their support. Over the years, we have come to realise that many that support us have been directly touched by our service.

As we traverse 2011, we shall continue our vocation in spite of the environment that we have to operate in. With a new building and hoping for a larger workforce, funding will continue to be challenging. We will practice the best palliative care that we can following evidence based guidelines and try and follow local legislation although negotiating a bureaucratic minefield can be immensely more difficult than patient care.

A Snapshot of Palliative Care

A man lies in a private room in a hospital. It is the evening and he is surrounded by his family. Over the years, he has fought against cancer. He has taken everything that modern and alternative medicine can offer, yet ultimately he is losing the battle. Weak, his breathing laboured and now bedbound, his previously strong will is slowly being challenged by the reality of his situation.

Oxygen and various infusions nourish his body and several charts adorn his bed. At regular intervals, nurses flutter around him, checking and measuring everything there is to measure. Every day for the past two weeks, the daily routine is repeated.

Up till three months ago, he was still king of all that he surveyed. A successful businessman and the head of his family. But now, his ability to control his immediate future is being challenged. From his diagnosis and all through his treatment, including his involvement in other forms of therapy, it was he who decided and had the final say.

Yet, now on his hospital bed, his wishes are being challenged or ignored.

'What's happening to me, doc? I want you to stop some of this. It's not helping me' 'It's ok. Not to worry' said the doctor.

'Please can I just go home? This is NOT home. I may not have that much time'

'But you are getting the best care in hospital. And anyway, it would be very difficult to look after you at home' said his family.

The sales mantra says 'The customer is always right!' But not always in many of our hospital settings. A strong patient is generally given the right to information and decision making powers and especially more so if he is intelligent and of high social standing. When he becomes older and weaker, his authority is often superseded by the doctor and more often by his family. This is not out of ill will but of a perceived sense of care and duty.

In palliative care, regardless of his debility, the care must still be patient centred and the patient has the right to information and to be involved in decision making. He also has the right to nominate others. Doctors and loved ones need to consider the best interest of the patient, not of themselves first.





World Hospice and Palliative Care Day 2011 will take place on the 8th October. The theme for this year is "Many diseases, many lives, many voices palliative care for non-communicable conditions". This year's theme will focus on how people living with conditions which are not contagious can benefit from palliative care, and is related to the UN High-Level Summit on Non-Communicable Diseases (NCDs) to be held in September 2011. WHO health statistics show that global health trends are shifting towards the main causes of death being attributed by NCDs, namely, cancer, diabetes, chronic respiratory diseases and cardiovascular diseases. The four common risk factors for these diseases are tobacco use, harmful use of alcohol, physical inactivity and poor diet.

These diseases contribute the highest rate of mortality in low - and middle - income countries, aggravating the economic stress of these countries. Hospice and palliative care could benefit people living with conditions which are not contagious yet more often than not, they have low or no access to such services.

World Palliative Care Day takes place on the second Saturday of October every year.

Measuring Vital Signs At The End Of Life

Walk into the domain of a doctor and before you could finish saying 'Hello', a thermometer may find its way into your mouth. Offer a hand to greet him and suddenly your forearm is wrapped and a stethoscope clasped against your skin. A finger reaches out for a pulse. In a minute, your temperature, pulse and blood pressure have been noted and hopefully, these will be pronounced as normal. The doctor may have also noted your breathing. You might well be anxious whilst waiting for the pronouncements!

The measurement of these 'vital' signs have been synonymous with the perception of 'good health' such that some patients feel that a medical consultation is incomplete without a doctor performing these 'rituals'. Yet, do doctors, patients and caregivers understand their significance? Especially when a patient nears the end of life?

These measurements are certainly very important in the assessment of a patient with certain conditions. Hypertension, heart problems, shock, infection and many others, where the aim is to treat the underlying problem and return the patient to his previous state of good health are some examples where these 'vital' signs are mandatory checks.

The purpose of any investigation is to weight the balance between benefit and harm and that any intervention will then be helpful. In performing a procedure such as surgery, most doctors will weigh up these conundrums. The measurement of these 'vital' signs is sometimes seen as 'routine' which means that a person stops thinking and functions within an automatic framework. It is an interesting experience if a patient asks a doctor the purpose of measuring the pulse, blood pressure etc. You might be surprised that some may not be able to give a reasonable explanation!

Patients and caregivers may 'learn' that since these procedures are repeated several times a day, they must be important. They may purchase machines to obtain these readings but at the same time have no idea as to their relevance and what would be normal given the patient's condition. Towards the end of life, these measurements may take on a rather insidious note. As life ebbs away, the body undergoes physiological There processes. are expected changes in the body's peripheral temperature, pulse, blood pressure and breathing rate. In accepting that a person is dying, measuring



these signs provides little meaningful information as there is no further intervention that can reverse the dying process. For both patients and caregivers, this can be a very distressing process and diverts their attention to measures that actually can do to comfort the dying.

Thus, when patients want to be comfortable in their final hours, the presence of anxious doctors and nurses measuring 'vital' signs repeatedly can only be a secondary source of distress. Unfortunately, some might err further by performing more 'heroic' but futile measures on the patient that lead to greater suffering.

Doctors are taught to diagnose death but not to diagnose dying. It is a clinical skill that is important in caring for patients at the end of life. At these moments, what is vital is no longer the measurement of pulse and blood pressure but rather to see whether patient and caregivers have all that they need to have a supportive environment at this important moment. In moments of distress, humanity often has a higher value than machines and technology.

What Do You Want From Your Doctors?

Recently, there has been much discussion in the media about the quality of the doctors that are being produced in Malaysia as well as those sent to seek a medical education abroad in somewhat dubious institutions. The terms quality and competency have been thrown around with a negative connotation associated with these newly graduated doctors. These issues have mainly been espoused by senior clinicians concerned at the inability of their erstwhile 'young' colleagues to deal with 'simple' medical issues.

We are all responsible for the state of our healthcare and a good and sensible system will enable each citizen to cope with illnesses well. Yet between parents who compel their children to pursue a medical degree in the hope of a better future, a government that seeks to achieve a doctor patient ratio of a developed country and a private healthcare approach that attempts to raise profits and impress the public with specialised treatment and machines with fancy acronyms, it is the vulnerable patients who suffer.

To some of us, the issue of vulnerable patients usually applies to someone else. It's not my problem. The system and the government know best so don't worry about it. Has one wondered why millions are spent in campaigns to stop smoking, yet at airports and on planes, pride of place is given to tobacco (and alcohol) products? Thus, do we really have an effective healthcare system that cares for us beyond the mere ringgits and sens? Ultimately, we are at the mercy of the system that govern us.

The fragility of the human body is such that most of us will require medical attention in our life. At some point, perhaps even tomorrow, it might be you. What do you want from your doctor?

Medical education is more than the mere repetition of factual data. In an education system that thrives on rote learning, new doctors whose brains serve as large hard disk drives may be able to regurgitate large amounts of facts which may or not be relevant to the situation at hand. This may be impressive. But knowledge without attitude and skills may leave the application of medicine seriously flawed.

When afflicted with a disease and a consultation with a doctor beckons, do ask yourself what are the important qualities that you wish to have in your doctor? A doctor filled to the brim with facts will not be very effective if he or she doesn't ask the right questions and or have the skills to examine you in a way that preserves your dignity.

And what if the right questions are asked? Are doctors trained to listen? Will they listen to all that you wish to say or merely to listen to what they want to hear? Will they only listen to the words, but not the emotions or the silence between the words? Will they be interested in your suffering or merely look for the symptoms that fit the description of the disease that they wish to label you with?

Will a doctor offer you the courtesy of their time, their attention, and their humanity as a person to truly convince you that he / she really cares for your wellbeing? Will a doctor ask for your permission, address you by name before an examination is made? Will clarification be given to why it is needed and what benefit or harm it could bring?

'To the typical physician, my illness is a routine incident in his rounds whilst for me it's the crisis



What Do You Want From Your Doctors?

in my life. I would feel better if I had a doctor who at least perceives this incongruity... I just wish he would... give me his whole mind just once, be bonded with me for a brief space, surveyed my soul as well as my flesh, to get at my illness, for each man is ill in his own way' – Anatole Broyard

Will the doctor in front of you, treat you in a way that makes you feel special and cared for?

Medicine, a hundred years ago, was still very much an apprenticeship. A young scholar learned the art through vocation, and wisdom coupled with knowledge created an empathetic understanding of suffering and illness. Though cure may be difficult, care was still the prerequisite.

In these modern times, the connection between patient and doctor appears no longer to be appreciated, unfortunately by doctors themselves. Various improvements in technology have reduced the demand for rigorous clinical skills and computers ... continued from page 6

and such like have made doctors feel that direct face to face consultations need not take place anymore.

Thus, back to 2011; what kind of doctor would you want to tend to you during your illness? A medical encyclopaedia linked to a barrage of technologies or an empathetic human being who cares and who happens to have studied medicine. I know who I want, do you?



A Response To Suffering



Image Credit: Associated Press

In recent years, the strength and fragility of the human spirit has been tested time and time again. Through acts of terrorism, the impoverishment of human rights and natural calamities, communities throughout the world are forced to

find the resolve to endure, to stand up and find the will to rebuild.

The tragedies that befell Japan on March 11, 2011 caused shock and horror across the globe. The incessant 24 hour media coverage creates a

voyeuristic climate where, glued to our television or computer screens, we are fed a constant diet of information and opinions. The images are shocking and there is a sense of helplessness to witness such a scale of human suffering.

For us working in palliative care in the Asia Pacific, the camaraderie of our work in dealing with human suffering has benefitted greatly from the leadership and generosity of our Japanese friends. Hospice and Palliative Care development in Japan has been truly remarkable and in the face of such great national loss, its services will be greatly needed.

Hospis Malaysia extends our condolences to the Japanese community and to all that have been affected by this tragedy that is still unfolding. We hope that with courage and resilience, even such tragedies could be overcome.

Tools of the Trade

Pulse Oximeter and Stethoscope



Pulse Oximeter

For most people who are suffering from a life-limiting illness, home is the place to be – surrounded by loving family and friends. Hospis Malaysia's home care service strives to provide the best support, attention and care to make this possible. With a palliative care team of eleven nurses and four doctors, we make approximately 1,000 home visits each month.

In order to meet our aim of providing the best possible palliative care, our team is equipped with the necessary mobile medical equipment such as stethoscopes, pulse oximeters, and blood pressure monitors, among others. To ensure our patients receive the best possible service, this equipment needs to be replaced approximately every two to three years. Among the items currently in need at Hospis Malaysia are **pulse oximeters** and **stethoscopes**.



A **pulse oximeter** is a non-invasive medical device designed to measure the oxygen saturation of the patient's blood. Assessing a patient's need for oxygen is the most essential element as respiratory problems is a common concern for a patient with a life-limiting condition. Breathlessness causes a great deal of discomfort and may lead to many other anxieties which affect not only the patient, but the carer as well. A pulse oximeter is typically clipped onto the end of the finger, over the nail, to measure the haemoglobin saturation. The results will facilitate the next course of action, such as the provision of an oxygen concentrator or, appropriate symptom management where necessary.

If you wish to donate these items, please contact the Public Relations department at 03-9133 3936.

Volunteer Recruitment Drive

Volunteers play an integral role in Hospis Malaysia, contributing their time, talents and energy to help to improve the quality of life for the patients and their carers. Without these unsung heroes, our organization would not be able to provide what we provide best, care for thousands of people each year. People choose to volunteer for different reasons, but all those who have done so will tell you that making a difference in peoples' lives can be extremely rewarding. If you would like to volunteer for Hospis Malaysia in any capacity, please get in touch with us on 03-9133 3936. We would be delighted to hear from you.

Hospis Malaysia Welcomes New Members

We first began our operations with a simple team of two nurses and two voluntary doctors. Now, Hospis Malaysia houses three core departments – clinical, public relations and finance and administration. The rapid increase in the number of referrals received by Hospis Malaysia each year has led to the expansion of staff. In the recent months, we saw the addition of new members.



From left to right:

Teresa Ng, Accounts Executive

A graduate in LCCI, Teresa has more than three years of experience in finance and accounting. She was previously from a valuation firm

Hoon Li Ping, Public Relations Executive

A graduate of Public Relations and Psychology from a local college, Li Ping had a brief stint in a local cancer organisation.

Yap Wai Mun,

Manager Palliative Care Services and Volunteer Coordinator Wai Mun was with Estee Lauder Group of Companies for 20 years and Himalaya Herbal Healthcare for four years, heading the Sales Department. A passionate runner, she is also an active member of the Pacesetters Athletics Club since 1992.

Ng I Miin, Public Relations Manager

I Miin holds a Bachelor's Degree in Communications from Monash University and has more than nine years

of experience in the advertising and communications industry. She helped develop and implement branding and tactical campaigns for accounts under her care, which included Nestle, HSBC, Prudential and Kraft. Her most recent appointment was Brand Director with McCann Erickson.

Belinda Lim, Receptionist

Belinda was a shopping and sales coordinator with a manufacturing company for more than ten years, dealing with clients from various fields.

Mary Frances, Operations Manager

Mary Frances has considerable management experience from working with corporations and social development organisations. Her most recent appointment was Technical Assistance Consultant with the American Cancer Society, covering Malaysia, Singapore and Thailand. Mary has an MBA in International Management.

In-house Happenings

Festive Celebrations in Hospis Malaysia



Christmas 2010 was a truly special event for everyone

in Hospis Malaysia. For the first time since 2008, it was held in the newly renovated day care room and activity room. When Hospis Malaysia was undergoing expansion works, the day care was temporarily relocated to its neighbour's premises.

In the spirit of Christmas cheer and goodwill, more than 40 people were invited for the party, many of them our current home care and day care patients.

The Oasis People's Church group sang carols followed by a musical performance by the Ti-Ratana Community Centre, Penchala.

Our grateful thanks to Cafe of Zang Toi, Chinoz on The Park, The Bee and The Bread Shop for sponsoring the wonderful buffet lunch spread.

Not long after, the Christmas tree and ginger bread was replaced with angpow packets and mandarin oranges!

With Chinese New Year around the corner, Hospis Malaysia threw another celebration. Patients, volunteers and staff came dressed for the occasion in various shades of red. Our dedicated volunteers prepared their signature dishes for the buffet lunch.

Patients were encouraged to try their hand at Chinese calligraphy. Some of the exquisite styles and strokes were admirable. Other than the traditional 'yee sang' tossing, patients were given cosmetic makeovers too.

A big round of applause to Hospis Malaysia's volunteers for organizing two successful and enjoyable celebrations.

Fundraising & Awareness

A Cut above Charity - A Fundraising Activity by TAR College

The students of Tunku Abdul Rahman (TAR) College did a stunning job by organising a fund raising event for Hospis Malaysia. The students' charity project named "A Cut above Charity" aimed to raise funds to create awareness of Hospis Malaysia and its services.

What started off as a classroom assignment ignited the students' interest to know how much further they could reach out to society, especially to understand the challenges faced by charity organizations and how they survive solely on public donations.

Their passion and enthusiasm paid off when they secured the opportunity to work with "A Cut Above" to perform charity hair cuts. Although charity hair cuts was the main activity, the supporting activity, Bald Challenge "Botak Wanted" received tremendous support. Even the TAR College Principal, Dr. Tan Chik Heok, accepted the challenge to go bald!

The event was officiated by Y.B Chua Tee Yong, Deputy Minister of Agriculture and Malaysia Agro-Based Technology. A big thank you to the entire management team and students of Tunku Abdul Rahman College for their tremendous effort that certainly made a significant contribution to our palliative care services.





The 10th Hospis Malaysia Charity Treasure Hunt is back. This time, we will be heading up north to Batu Ferringhi, Penang. Entry fee of RM150 per person is inclusive of two days and one night stay with BBQ dinner and breakfast at Hydro Hotel, Penang. A team shall comprise a minimum of two, to a maximum of four participants. Come support this annual event and help us to raise funds. You could support us as participants, or make contribution in the following areas. It would mean a great deal to us if you could do your bit towards making the 10th Hospis Malaysia Charity Treasure Hunt 2011 a successful event.

1.	Making a cash donation of RM								
	My / our	cheque No	for the said sum is	for the said sum is enclosed herewith.					
2.	Advertising in the Souvenir Pro	ogramme.							
	Type/Description	Position	RM	(🗸)					
	A5 Full page (colour)	Outside Back Cover	3,000.00						
	A5 Full page (colour)	Inside Front Cover	2,500.00						
	A5 Full page (colour)	Inside Back Cover	2,500.00						
	A5 Full page (colour)	Run of Page (R-O-P)	1,500.00						
3.	Providing the following items as a prize / prizes. Item type / name								
	<u> </u>								
	s:								
Tel:	(O)	(M) F	ax:						
Email:									

OFFICIAL ENTRY FORM 10[™]CHARITY TREASURE HUNT 2011 14 – 15 MAY 2011

Competition No.



Yes! We would like to enter the 10th Hospis Malaysia	a Charity Treasure Hunt 2011 Regular Novice
Team Name	Contact Person
Driver	Navigator
Name	Name I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I I
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Vehicle Particulars	
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ENTRY FEE Route : KL - Batu Ferringhi, Penang Venue: Hydro Hotel, Batu Ferringhi, Penang With 1 night accommodation + 1 prize-giving ceremony BBQ dinner + RM 150 per person x pax (please refer to attached copy for details of accommodation) Extra bed for child (3 – 12 years, incl meals, 1 extra bed per refer	: RM oom) : RM70.00 TOTAL : _ (cash/cheque*) no
We declare that the particulars stated herein are true and co and hereby agree to abide by them. We further indemnify the injury, accident, or death to ourselves, or damage or loss incu- taking part in this event. We further declare that the vehicle e the Motor Vehicle Rules (third party risks) 1959 (Malaya) white	te: 15 APRIL 2011 Implete. We have read the rules and regulations governing this event the organisers and those connected with the organisers against any urred to the vehicle hereby entered, however caused, arising out of our entered is covered by insurance and road tax duly paid as required by ich is valid for an event such as this.
Signature: Driver NRIC No:	Signature: Navigator NRIC No:

Signature: Passenger 1

ospis

PLEASE FAX THIS FORM TO 03-9133 3941 No. 2, Jalan 4/96, Off Jalan Sekuci, Taman Sri Bahtera, Jalan Cheras, 56100 Kuala Lumpur. Tel: 03-9133 3936 www.hospismalaysia.org

Signature: Passenger 2

NRIC No:

NRIC No: