EDITOR’S NOTE

“A moral and ethical case for humane, expert care of those suffering at the end of life”

A personal reflection. In April this year, my mother died, aged 88, in her own home, in New Zealand, cared for by her children. It was her deep desire to die at home. She was blessed to have a caring, competent doctor, who had been her general practitioner for many years, to guide her along her way. She also had able-bodied family members, who struggled with the emotional and physical demands of caring for a loved parent whose independent spirit needed to be respected at all times. We had expert home-based palliative care, a caring community of neighbours and friends, spiritual/religious support and ceremony, ready access to needed medications, in short, all we needed to care for her with dignity. To know she died as she wished was my biggest comfort throughout the tensions and difficulties of her last weeks of life and continues to bring comfort in bereavement.

How few people in this world are given this opportunity.

I hope that, through the efforts of all of you who read this newsletter, many more people across the world, in all countries, will die with dignity, in their place of choice, with those who love them at hand, with as much control of the time, place and circumstance as possible within the limits of respect for the mystery of life and avoidance of intentional hastening of death.

Wishing you a very blessed Christmas and happy New Year 2016.

Odette Spruyt
In 2015 I was fortunate to have had the opportunity of travelling twice to India as part of Project Hamrahi activities. In June I spent a week with Anjum Joad at the Bhagwan Mahaveer Cancer Hospital and Research Centre (BMCHRC) in Jaipur, Rajasthan and then in October I had a week with Santanu Chakraborty at Ruma Abedona Hospice and the Chittaranjan National Cancer Institute. In this newsletter I would like to relate some of my experiences in Rajasthan.

Anjum Joad is a highly experienced palliative care specialist who established the palliative care service at BMCHRC 17 years ago. BMCHRC is a charitable trust cancer hospital with approximately 250 beds in a city of 6 million people. Over time the service has gradually developed to include two anaesthetic colleagues with palliative care experience who also provide medical input, two junior medical officers and two or three nurses. Apart from consultation liaison and direct care for inpatients, there is a busy outpatient clinic which operates on an open access basis six days a week.

For the last three years, Anjum has coordinated the Jaipur Certificate Course in Pain and Palliative Medicine which is a six week course for both doctors and nurses. Odette Spruyt and Mary Duffy attended the inaugural course in November 2013 and this year I was invited to help. The course is one of several six week courses available in India; currently these are also conducted in Ahmedabad, Hyderabad, Kolkata, Mumbai and of course Trivandrum. This year’s course was notable because it marked the commencement of input from the Indo-American Cancer Association, which is assisting to meet the growing demand for trained palliative care clinicians by partnering with Pallium India to write a clearly defined curriculum for these courses.

With the course being held in the peak of the Indian summer in the desert state of Rajasthan I was initially nervous to accept the invitation from Anjum, but eventually decided to accept this as a challenge to the cloistered life we lead in the air-conditioned homes, cars and hospitals of Australia. As it turned out, the challenge was raised a couple of bars along the way. Firstly, by virtue of the fact that the air-conditioning to the outpatient room which we used as our base had been disconnected for reasons unclear to all – so we had to manage with ceiling and table fans which seemed to do nothing other than blow our papers all over the place and just circulate the stiflingly hot air. Although it was hot - the maximum daily temperature tended to be around 42 to 43 degrees Celsius - the dry nature of the heat made it manageable.

The second additional challenge came with the invitation extended to join Anjum and a palliative care colleague from New Delhi, Sushma Bhatnagar, on a road trip to Jodhpur. Jodhpur is a major city in Rajasthan approximately 340 km from Jaipur – on Indian roads this translates to a five to six hour bumpy but entertaining ride. Anjum and Sushma had been invited to present a palliative care workshop for the medical community in Jodhpur and by luck this was scheduled for the day after my arrival in India. Once again, it was an opportunity too good to miss, and it was with great pleasure – and some amusement as I was obliged to be a recipient of assorted felicitations including not just a bouquet of flowers but also a commemorative trophy – that I assisted in the delivery of the three hour workshop to a very attentive audience of 80 or so doctors.

I joined the course in the fourth week and spent a week with a small group of four medical officers and three nurses. I was requested to deliver presentations on a number of topics including the pain management, anxiety and depression, prognostication, communication skills including not for CPR discussions, the management of ascites and brain tumours. As one would expect, this teaching was incorporated into the day-to-day provision of clinical care but this afforded many opportunities for bedside teaching. I was very interested to find out that two of the medical officers were in fact dental surgeons: it seems that in BMCHRC, and perhaps elsewhere in India, it is possible for dental surgeons to practice medicine under close supervision. If Anjum hadn’t told me about their qualifications I certainly wouldn’t have been any the wiser as they certainly demonstrated very good medical skills and knowledge.

On the final day of my Jaipur visit, Anjum had requested that I present at the hospital grand round. Based on my experiences in Jamshedpur, another Project Hamrahi site, I decided to talk about burnout as I had noticed that this was a problem for Indian oncologists. After several days of working together Anjum requested that I perhaps change the topic of my presentation to something of a more scientific nature, or in her words, ‘It would...’
be good if you didn’t talk about pet therapy but rather something to show my oncology colleagues that we in palliative care are real doctors also! So it was with that in mind that I chose to present the findings of the ketamine and octreotide studies conducted by the Palliative Care Clinical Studies Collaborative.

All in all I had a very enjoyable week in Jaipur. I was made to feel very welcome, it was a genuine privilege to witness the excellent work being done not only for individual patients but also to increase the palliative care workforce, I hope I was able to make a small contribution to the teaching being conducted and I was able to make a new friend with the dynamic and inspirational Anjum Joad.

Anil Tandon

TAKING APLI FORWARD – INTRODUCING ANIL TANDON

It is with pleasure and not a little sense of trepidation that I write to you as the incoming Chair of Australasian Palliative Link International. As some of you may be aware, at this year’s Annual General Meeting held on 31 August Odette Spruyt stepped down after 19 years at the helm of APLI. I’m sure that this wasn’t a decision she took lightly but I certainly knew she was looking forward to a few extra hours in her week and also that the time was right for her as she had steered the association into a position of security with the ongoing success of Project Hamrahi and a small but healthy number of members.

Perhaps in this first letter to you all it is appropriate that I tell you a little about myself. Although Australian born my heritage is strongly Indian with both of my parents coming from the city of Agra in the central north of the country. Famous for the Taj Mahal and numerous other monuments from the era of Mughal rule of India, Agra is otherwise a fairly non-descript Indian city. Growing up as a child I was fortunate to have been able to return to India on regular occasions for family holidays, which kept me well connected with the people and the culture. The strong bond that Aboriginals have to their country has always resonated strongly with me – I certainly feel a similarly strong bond with India even though I have never lived there. And so it was a happy circumstance that in 2009 I first heard of APLI and the nascent Project Hamrahi which I immediately saw as presenting a wonderful opportunity to combine my professional life with the strong force regularly pulling me back to India.

I was very grateful indeed for the recommendation from Odette that prospective mentors should take efforts to prepare themselves adequately for the work ahead. I attended an APLI Forum in January 2010 and also the Indian Association of Palliative Care national conference in February 2010 - both of these were extremely helpful in ensuring that I was undertaking the role of mentor with the right mix of cultural sensitivity, awareness of the Indian palliative care landscape and (hopefully) professional humility. My subsequent Project Hamrahi posting to Jamshepdur; which I visited four times over a five year period with Wendy Scott, was certainly personally and professionally rewarding for me and undoubtedly to the clinicians there, particularly our dear friend Urmila Patel. Since then I have accepted an invitation to Rajasthan, which I write about separately in this newsletter; and also Kolkata.

I have spent the last year in close contact with Odette in order to prepare for my new role with APLI. I am very pleased that not only has she remained on the Executive Committee but she will continue to oversee Project Hamrahi. In terms of the future, I do not anticipate any significant changes for APLI. The Executive Committee is made up of continuing members Odette Spruyt, Alan Hebb (outgoing Secretary), Suharsha Kanathigoda, Christine Drummond and Meera Agar to ensure stability together with new members Joan Ryan, Davinia Seah (incoming Secretary) and Chris Waples (Treasurer) to provide a new level of expertise and professionalism. We have already met a number of times since the AGM and initial work has focussed on strengthening our internal processes and expanding on the information provided to prospective mentors amongst other things. It would certainly be pleasing to see our membership base grow and so I encourage you to forward this newsletter to friends and colleagues. If anyone would like to join APLI, I can be contacted via chairman@apli.net.au or Davinia is available through secretary@apli.net.au

Thank you for your ongoing support and I wish you the best for Christmas and a safe start to the 2016 New Year.

Anil Tandon
The 2015 annual APLI forum took place on 31 August, at Peter MacCallum Cancer Centre. This year, the AGM was held in conjunction with the forum with some members able to participate by videoconference. The program included presentations about the Leadership Development Initiative, an initiative started by Charles Frank Ferris, Kathy Foley, Mary Calloway and Joe Hartford, USA. The LDI was developed to advance the understanding and practice of palliative care around the world. Dr Mark Boughey has been part of the international leadership mentoring group and spoke about the mutuality of learning that occurs through this program, with mentors extending their skills and understanding of leadership in palliative care, along with the nominated participants from diverse countries. In this capacity, Mark has visited Mongolia on a number of occasions to support the inspirational work of Dr Odontuya Davaasuren and her teams.

Anil Tandon reflected on his recent teaching in Jaipur, on the Pallium India Jaipur 6 week course. Brett Sutton spoke about the need for palliative care standards within humanitarian response guidelines and the work of PCHAS to influence the international organisations involved in providing frontline humanitarian aid in crises. Dr Suharsha Kanathigoda joined us on videoconference with news of the recent Train the Trainer workshop in Sri Lanka and the effective networking taking place across Sri Lanka.

Project Hamrahi was awarded the inaugural Palliative Care Australia Innovation in Palliative Care Project award, during the national PCA conference, 2015, held in Melbourne in September, 2015.
Prof. Margaret O’Connor collected over 20 Graseby syringe drivers from palliative care services around Australia who no longer use these devices. Margaret offered these to Prof. Rajagopal of Pallium India, who felt these would be of great benefit to patients in India. Odette was able to deliver these, plus palliative care books, donated by Peter MacCallum Cancer Centre, when she visited India in August.

Thanks to all those who kindly donated the Grasebys. We are happy to receive more if any services have any to donate.
Shanthi Foundation Australia- A response to Chronic Kidney Disease of unknown origin (CKDu) & Propagation of Palliative Care in Sri Lanka. - Dr. Suharsha Kanathigoda

What Shanthi Foundation Australia has done up to now in Sri Lanka:

- Introduced Home Based Palliative Care (Community Palliative Care) to Sri Lanka, deploying Shanthi Nurses to look after patients in their own homes.

- Introduced Renal Palliative Care to Sri Lanka (and India) through workshops in Colombo, Anuradhapura together with the Society of Nephrologists in Sri Lanka.

- Introduced a Patient & Family Sponsorship Program for patients with a life limiting illness in Sri Lanka such as Cancer & CKDu.

- Installed and maintains 40 Reverse Osmosis machines in 40 schools & villages in the Northern, Eastern, Uva and North Central Provinces of Sri Lanka to give clean drinking water to keep the next generation from getting affected with CKDu.

- Training of doctors, and nurses in Palliative care through courses conducted in Colombo, Anuradhapura, Kandy & Batticaloa with the College of General Practitioners Sri Lanka and in collaboration with the National Cancer Control Program of the Ministry of Health Sri Lanka. - July 2014

- Collaborating with the Lien Foundation Singapore & Asian Hospice and Palliative Care Network (AHPN) to conduct a Master Trainer Program in Palliative Care for 50 consultants including 18 Oncologists at the National Cancer Institute in Maharagama, Sri Lanka. (ongoing)-since 2013

- Provided 11 fully funded Shanthi Scholarships to send 11 Doctors & nurses to do 6 week Certificate Courses in Palliative Care in Kerala, India.

- Started a Kenda (porridge) Program in schools in the CKDu affected areas using Native Organic Rice to help children’s nutrition and promote Organic farming in Sri Lanka.

- Donated new & used equipment such as electric beds etc to rural hospitals in Sri Lanka worth over $ 300,000.
FIRST VISIT TO FIJI
- November, 2015

The team at the Colonial War Memorial Hospital welcomed me to visit them in November to meet and talk together about their efforts to develop palliative care in Fiji. Dr Fong, obstetrician gynaecologist and Chairperson of the National Oncology Clinical Service Network, is highly motivated to develop palliative care as part of his focus on ensuring primary care and health-promoting cancer care networks are in place across Fiji. The Ministry of Health is developing a new Fijian Cancer Action Plan and have palliative care within its sights as an integral part of this, but are looking for international support to determine best practice suited to the Fijian setting. Clearly, training needs are high on the agenda.

It was great to meet the team of hospital and community based nurses who are passionate about improving palliative care services.

We plan to continue our discussions in 2016 and collaborate on education initiatives, hopefully with the support of other international agencies already working with the Fijian MOH, universities and hospitals there.

Odette Spruyt
There is widespread recognition of the importance of palliative care, with major advances in policy and advocacy in recent years (1, 2). One of the most significant advances was achieved at the World Health Assembly in 2014. The Assembly voted in support of strengthening palliative care as a component of integrated treatment throughout the life course, in recognition of the essential nature of palliative care in health care (1). They recommended that evidence-based, cost-effective and equitable palliative care services be available within the continuum of care, across all levels.

Implementation of these advocacy advances now rests squarely on the shoulders of the international palliative care community working in partnership with key cancer and other organisations.

There is no time for complacency or perspectives limited to national borders, as we cannot avoid the evidence of unrelieved human suffering which is presented to us through the social and traditional media and other forms of information sharing.

For example, it is estimated that 42% of the world’s countries have no delivery system for palliative care services and that integration of palliative care is achieved in only 20 of the world’s 234 (8.5%) countries (3). In addition or perhaps, as a result, 80% of people are unable to access treatments for pain relief (4) and only 7.5% of the world’s population live in countries considered to have adequate opioid consumption (3). The needs of children in particular are often neglected (3, 5) but there are many other groups which remain hidden from view, such as people with dementia, the homeless and those living in remote and rural areas. The distribution of access is skewed toward economically more developed countries (6). When poverty is combined with political instability, war, populations on the move and humanitarian crises, introducing this essential component of health care requires strategic, creative, coordinated, policy and education-driven efforts on a scale as yet far from realised.

At the IAPC conference, Hyderabad, in February 2015, I listened to a plenary by Professor Simon Suctcliffe, in which he urged the palliative care community to present to change our conversation about palliative care and revitalise our efforts to drive development. He urged alignment with the efforts to achieve global cancer control, rather than distorting and engaging in a polarised or competing discourse, the either—or discourse between these two aspects of cancer care. He challenged us to recognise that the drivers of global cancer control - burden, mortality, morbidity, disability - also drive the need for palliative care, especially in countries where resources are least and cancer burden is greatest. We do not need to make a business case for palliative care so much as a moral and ethical case for humane, expert care of those suffering at the end of life, who have a right to expect relief of pain, distress, support for their caregivers and whole person care. Such relief is likely to result in an increased capacity for engagement with family and community, renewed independence and improvement in societal, not just personal, quality of life.

We need to be open to new collaborations and new thinking to address current global inequality.

An important change needed to improve palliative care for patients with advanced illness is finding ways to achieve better integration of palliative care into cancer or other speciality areas of health care. This change involves developing and testing new models of palliative care practice which foster integration (7, 8). There are encouraging reports of new models of palliative care service delivery within renal, respiratory, cardiac and intensive care medicine, to mention only a few (9-11). Features of integrated models include increasing palliative care services in the ambulatory care setting in acute medical centres (12), participation in specialist multidisciplinary team case conferencing, mutual sharing of expertise between palliative care and the respective other specialty area, research collaborations, and training opportunities across palliative and acute care specialties for trainees.

Looking at integration of palliative care into cancer care in particular, there has been a growing acceptance of the essential nature of palliative care in cancer care with key organisations such as ASCO, NICE, and ESMO promoting this for several years now (13-15). There is recognition of the range of benefits this brings, including better symptom control and quality of life (16), more caregiver satisfaction, fewer ICU deaths and fewer hospitalisations (17), and longer survival in metastatic lung cancer (18). Yet despite this, progress is slow and increased financial support for the development of palliative care, even in Europe and the USA, is lacking (19, 20).

In the recently published 2015 Quality of Death index (21), it is apparent that advances can be made despite scarce resources, when the triad of policy, education and access to essential medications is activated (22). In Panama, policy changes at primary care level have driven integration, in Mongolia, the focus on education by leading champions and the development of hospice facilities have been key and in Uganda, a significant increase in access to opioids has improved the quality of dying.

Identifying and supporting champions on the ground is critical to development. Finding ways to effectively grow that support in order to reduce the burden of unrelieved suffering related to health deterioration, is a critical challenge for all of us who enjoy a high level of health care development. We look forward to exciting developments ahead and challenge the next generation of palliative care specialists to use their innovativeness and energy to apply existing knowledge in new and creative ways.
3. WHPCA World hospice and palliative care day 10 October 2015 Hidden lives, hidden patients 2015 [cited 2015 October].

NEWS FROM EHOSPICE:
Report released on Palliative Care and the Global Goal for Health

The International Association for Hospice and Palliative Care, the International Children’s Palliative Care Network, and the Worldwide Hospice Palliative Care Alliance (WHPCA) have released a report ahead of Universal Health Coverage (UHC) Day (12 December), entitled ‘Palliative care and the Global Goal for Health’.

You can download the report from the WHPCA website.
Dr. Abhijit Dam, MD, FCCP, FPM, MSc Pall Med (Cardiff)

Working with the dying reveals two aspects of our nature…the first being our sense of compassion, which is bountiful and healing; not only for the patient and their family and friends, who too suffer, but also for our own self; for by practicing compassion, we are being kind to our self and fortifying our compassion. So in essence, by aiming to help others, we are healing ourselves as well. No wonder that the best palliative care professionals are persons who have undergone a lot of sorrow and suffering…and have evolved over the years to be better humans.

The second, and more primitive aspect of our nature, is the fear of death…it could be death in the sense of dissolution of our physical body or death of our ‘grasping nature’. We spend our whole lives acquiring relationships, money and fame…but little do we realize the fleeting nature of these acquisitions. Facing death in its raw and physical form while caring for patients, brings us face to face with our own ‘sense’ of mortality; And that is exactly where the confusion begins. For there are now no clear cut guidelines! What little scattered ‘evidence’ is there is refuted by science. Sadly, our minds have been programmed to ‘believe’ in science.

OK…now for a little task…you just have 10 seconds for this…name any three diseases of non-infective origin that has a cure.

Well you may now realize how ‘advanced’ our medical science has been over the last 300 years! What we have achieved by our ‘technology’ is to make the process of dying more prolonged, painful and undignified! No wonder, most health care professionals shudder at the prospect of having a ‘taste’ of their own medicine…and I yet to see a doctor or a nurse who would want to die in their own ICU!

I was in the same boat…a strong atheist. Working with the dying and for the reasons stated above, I started looking for answers…and I found them, which could satisfy an arrogant person like me. Little did I realize at that time that I was doing ‘Self care’!

The first step is re-learning to believe…with humility.

Remember, at least in our generation, how in our childhood we used to nestle in the laps of our parents and grandparents and listen wide-eyed to fairy-tales and other stories. Those are fond memories and I daresay that a part of our character too has been moulded by those experiences. Those experiences are ingrained in our memory as ‘good and soothing’…for we had believed!

I believe that death is comforting…blissful. You just have to be aware…being mindful!

I have ‘designed’ a ‘Retreat session’ on Self care based on these perspectives at our rural center in the tribal state of Jharkhand in India starting Jan. 30 2016, for a week. I intend to introduce you to your SELF in the retreat.

About KOSISH

I have been pioneering the cause of palliative care in a resource-poor and virgin community in the tribal state of Jharkhand in India since 2006. Illiteracy, poverty, ignorance are the rule of the day. Most people do not have access to basic health amenities. Care of the terminally ill remains a low-priority issue with them. Death means a mouth less to feed – economics simplified!

Faced with such challenges gave me an opportunity to innovate focusing on resources that are available, accessible, affordable and acceptable to the community. I put in my personal savings to buy a land and then construct the first and only ‘Long term care facility for the Elderly & terminally ill’ in a rural setting. I realized that the Elderly are the largest group requiring palliation and combining care of elderly with palliative care helped to remove the stigma associated with hospices which are often seen as places of dying. I also learnt to focus on spiritual, psychological and social aspects of care, which are often neglected…and I found that the use of medications came down!

Sadly now, we have no funding to support staffing and a vehicle for our ‘home-care’. Details can be found on www.kosishthehospice.webs.com and our page, www.facebook.com/kosishthehospice
KOSHISH THE HOSPICE SELF CARE RETREAT

Kosish-the hospice announces the first Retreat session on ‘Self care’ to be held at its residential ‘ashram’ in an idyllic rural setting in the tribal state of Jharkhand in India.

The retreat will start in the last week of January 2016 and will be held over one week.

It is open to all palliative care professionals, care givers, volunteers & others.

The program will include various aspects of self care along with sessions on mindfulness, Yoga nidra, and self realization, which will be discussed and practiced based on ancient Vedantic perspectives.

All basic facilities would be provided at the ‘ashram’ & the participants would be expected to follow a ‘monastic’ way of life during the retreat.

The ‘ashram’ is accessible by road & rail with nearest airports being Kolkata (300km) & Ranchi (260km).

Fees (inclusive of stay, food & teaching for seven days) 20,000 INR (approx. Aus$420)

Persons interested in attending the forthcoming palliative care conference in February, 2016 at Pune can proceed from here. Local tours can be arranged on prior request.

If you are interested in finding out more about this, please contact Dr Abhijit Dam on ratuldam@yahoo.com

http://kosishthehospice.webs.com

WELCOME TO IAPCON 2016

The 23rd International Conference of the Indian Association of Palliative Care (IAPCON 2016) will be held in Pune from February 12 to 14, 2016. This is being organised by Cipla Palliative Care and Training Centre and will be held at Hotel Hyatt Regency, Pune.

The theme of IAPCON 2016 is: engage, educate, empower and excel

- engage with the community, patients and their families, policy makers, opinion leaders, volunteers and the medical fraternity.
- education for all medical and paramedical personnel at all levels. This will help increase awareness about the important role of palliative care in ensuring quality of life, especially in the face of a life-limiting illness.
- empower every patient and the family to take informed decisions at the right time in partnership with the medical team.
- excel through interaction with experts and each other

We look forward to your presence at IAPCON 2016