The Seventeenth Sir Harry Annamunthodo Memorial Lecture
D Rajé

This is an emotional journey and a great honour for me to be invited to give this, the 17th Sir Harry Annamunthodo Memorial Lecture. As I tread gently along this well-trodden path, in the footsteps of 16 Caribbean giants of Jamaican Medicine, who preceded me in “apostolic succession”, I am conscious of my responsibility. I accept it with great trepidation but also with pleasure, gratitude and humility. Pleasure because I am returning home to Kingston on Tom Redcam’s “little Green Island, in far away seas”. And gratitude for being given the opportunity, though in my Second Life, to talk to my old friends and colleagues with whom I spent 25 years of my very happy working life. I feel humble as a stray sheep that wandered away all these years, and now returned to the fold with audacity, in colours of the opposition, The Royal College of Physicians, for whom I now work as a volunteer. I would like to thank the Association of Surgeons for their generosity and forgiveness.

In remembering Sir Harry, I am also thinking of my other colleagues in Jamaica and elsewhere in the Caribbean and Guyana who extended their friendship and support to me when I needed it. It all began at the Kingston Public Hospital where the likes of Henry Shaw, Mickey Roper, Gwyn McNeil-Smith, Sidney Williams and Ivan Parbhooingsh, were my guiding beacons in the alien waters of down-town medicine. Sir Harry wooed me away from that down-to-earth experience to the academic sanctuary of Mona. This Ascent to Mona, in words of my friend the late Sir John Golding, made me into a reluctant academic. But it had its rewards: I became a part of a team with a diverse skill-mix, led by a scholar, teacher and an astute surgeon who worked with the speed of lightning. I would like to thank Harry for those numerous early morning phone calls, which finally took me to his department. Here I met colleagues, who were to remain friends for ever. Amongst them were Bhasker Rao and Nigel Gibbs, whose untimely deaths sadly highlighted the urgent need for palliative care services at the University Hospital of the West Indies (UHWI).

Harry was a kind man, humble, honest, hard working and meticulous in keeping records in his own classic hand writing. This appetite for accumulating data and documenting observations reflected in his many publications and the life-long collection of West Indian stamps. His surgical skills were well known and the list of his publications bears the evidence of his all round interest in taking on the impossible challenges of medicine; from lachrymal duct to anal canal and from chromomycosis to lymphogranuloma venereum. His research in strictures due to lymphogranuloma venereum earned him the distinction of being the Hunterian Professor at the College of Surgeons of England in 1960.

When one looks at Harry’s collection of advanced tumours, including those of the penis, one realizes that he was, most of the time, operating for palliation in an attempt to relieve pain and suffering. He could turn his skilful knife to any part of the body. And, as he waded through those enormous stomach cancers, colorectal tumours and grotesque sarcomas, no one could see anything for a few minutes because of welling red fluid. Harry would then ask for his special extra large packs and then everything was over. When he returned from the surgeons’ room, his nerves now much calmer after a well-earned cigarette, Harry would look over his glasses and say to the shattered assistant, ‘let us take out the packs and close’. And lo and behold, by some miracle haemostasis was achieved and another monster was on its way to the laboratory and on to the teaching museum. Most of these tumours were incurable and, for the average surgeon, inoperable. Even the cancer of the penis that Harry saw in its advanced stage – foul smelling, large, fungating tumours with metastasis, there was no time for procrastination and Harry did not hesitate. Instant surgical palliation was the answer. He would have loved to have seen early lesions, eminently treatable by radiotherapy with little or no mutilation, and leave things as magnificent as the stately statue round the corner from this hotel.

I have no doubt that if Harry were practising today he would have referred a lot of his incurable patients to Palliative Care. My topic for this lecture today is based on this rapidly expanding speciality of healthcare and medicine, which seems to have a low priority in the Caribbean.

Palliative Care: the art of living
The origin of Palliative Care dates back to Biblical times when hospices were the places of temporary refuge and care for the battered pilgrims on their arduous journey. The travellers on these journeys, like to Lourdes today, for example, were very often the incurables and the terminally ill, many of whom did not make it to the “miracle cure”. This basic humanitarian principle of free care and respite for the weak and weary sufferers is still retained in the modern hospice.
The modern hospice movement really took off when Dr Cicely Saunders opened St Christopher’s Hospice on the outskirts of London in Sydenham, Kent, in 1967. Saunders had trained as a nurse during the Second World War, but due to a chronic back problem following an injury, she retrained as a social worker, and after the war, volunteered at St Luke’s Hospital, previously a home for the dying poor, for several years. Here, among many of her dying patients, she came across a young Polish refugee who was suffering a painful death from incurable cancer. This experience at St Luke’s inspired her to devote her life to improving the care of dying cancer patients. Interestingly, a consultant chest surgeon with whom she worked closely in caring for lung cancer patients had advised her to become a doctor so that her voice could be heard more clearly.

Armed with multidisciplinary training, a deeply religious conviction and a vast experience with the dying, Dr Saunders was eminently suited for caring for the terminally ill. Her Polish refugee patient had left her a legacy of five hundred pounds which gave a kick-start to her hospice in Kent. A very large transparent glass jar was placed in the entrance hall of St Christopher’s and donations began to pour in. The original Christian principle of ‘no charge’ to the patients was maintained and the hospice also retained the idea that this was not a permanent home – only a temporary abode, to recharge your body, mind and soul, on your cancer journey.

This humanitarian work was very similar to what Mother Teresa had already been doing for many years in Calcutta. In her words ‘the greatest gift one can give the dying is the gift of love’. In her early days in Calcutta she was accused of taking poor vulnerable dying people into shelter and converting them. Her simple answer was, “I am giving them love and helping them to die peacefully”.

Palliative care has moved on by leaps and bounds since Mother Teresa and Dame Cicely Saunders began their lifelong mission of total care of the dying. The story of Mother Teresa, her order of Missionaries of Charity and her recent beatification by the Pope is well known to the world.

The story of St Christopher’s is not so familiar. It was soon to become a model of total care for not only incurable cancer patients but for all persons with chronic incurable diseases such as motor neurone disease. Its work inspired a global movement of hospice and palliative care and, by the end of the 20th century, there were 154 inpatient hospice units and more numerous community teams and hospital support teams in the United Kingdom. Is it all about “holding hands and mopping brows” and filling patients with morphine? Not at all! Doctors, nurses and other health professionals began to pour into hospices for training. By the turn of the century, St Christopher’s alone had taken part in training of some fifty thousand clinical and other healthcare staff from the UK and 90 other countries. In 2001, the Conrad N Hilton Foundation awarded the highest Humanitarian Award to St Christopher’s Hospice. In receiving the award of one million dollars, Dame Cicely highlighted the need for hospice care and for the wider availability of morphine and the training in its use in the developing world.

In the 1980s, the art of palliative care attracted the attention of the academic world. The first trainee senior registrar, naturally from Oxford, joined St Christopher’s and palliative medicine became an academic discipline recognized by the Royal College of Physicians in 1987. A formal four-year structured training programme is now available after the completion of general professional training at the senior house officer level and completion of a postgraduate diploma in medicine, radiotherapy, medical oncology or equivalent qualification. This four year training leading to a Consultant Appointment includes rotations through hospices, the community, general practice and oncology. Similar training of shorter duration leading to diploma and degree is also available for nurses.

The philosophy of hospice and palliative care acknowledges death, dying and bereavement as a reality of life. It recognizes the uniqueness and autonomy of each person and responds to the changing needs of the individual and their family and provides uninterrupted total care, aimed at previously agreed goals.

Based on this philosophy, palliative medicine is the science of the study and management of patients with active, progressive, advanced disease for whom the prognosis is limited and the focus of care is the Quality of Life (Oxford Textbook of Palliative Medicine, 1993). This definition is changing as the science and the art of caring are continuously advancing and now includes management of many chronic incurable conditions such as HIV and AIDS, end-stage renal, respiratory and cardiac failure and chronic progressive and non-progressive neurological conditions.

Palliative care is the art that the multidisciplinary health team practises and is defined by the World Health Organization (WHO) as:

‘The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems, is paramount. The goal of Palliative Care is achievement of best quality of life for patients and their families.

Many aspects of this care are also applicable earlier in the course of the illness in conjunction with anti-cancer treatment’ (WHO, 1990).

The World Health Organization elucidates further, describing palliative care as that which affirms life and regards dying as a normal process and that which neither hastens nor postpones death and provides relief of pain and other distressing symptoms. In addition, WHO states that palliative care integrates the psychological, social and spiritual aspects of care. It offers support systems to help a patient live as actively as possible until death and, finally, supports the family during the patient’s illness and their own bereavement.
What does all this mean? It all sounds a bit altruistic, a soft science or a holistic mumbo-jumbo! Surgeons and anaesthetists are practical people, not dreamers. This is not for us. But it is. Your scientific skills are very much needed to relieve the pain and suffering of the incurable patients.

Palliative interventions are non-curative treatments given by specialists in disciplines other than specialist palliative care, aimed at controlling distressing symptoms to improve patients quality of life, for example, through the use of palliative radiotherapy, chemotherapy, surgical procedure or anaesthetic technique for relief of pain or shortness of breath. The limited prognosis of the patient’s condition should not deter specialists from carrying out these procedures.

Palliative care is not just for specialists either. The model of care offered by this speciality can be followed by any one caring for human beings. This is then the palliative care approach which aims to promote both physical and psychological well-being and is a vital and integral part of all clinical practice, whatever the illness or its stage. The key principles of this approach comprise:

§ Whole person approach
§ Care of both the patient and those who matter to them
§ Open and sensitive communication including adequate (not excessive) information about diagnosis and treatment options
§ Respect for patient autonomy and choice
§ Focus on quality of life and good symptom control.

My own interest in palliative care was triggered by a 13-year-old girl whom we diagnosed as suffering from appendicitis and at operation, to my horror, she had wide spread ovarian cancer. The compassion that this little girl aroused during her terminal care by the team remained with me throughout my surgical career. Eventually my move from the surgical glory of curing to even more stressful career of caring (Palliative) was not entirely by chance.

This interest in the care of the terminally ill took me to India to meet Mother Teresa in Calcutta. When I arrived at the Mother Home, I was told that she was abroad and would not return until after the weekend. Having no other agenda I decided to walk around the inner city area and saw Mother’s nuns in action carrying the dying poor and taking them into the Home for the Destitute. My life was enhanced by this experience of expression of love and care, and I returned home to Jamaica, determined to go back the next year.

The following year, I arrived early for the morning mass only to be told that Mother was in Jamaica setting up a Home for the Destitute. In great disappointment I left the mass early, and as I walked out of the simple chapel I saw a small woman in saree with a very wrinkled face and crooked toes. She greeted me with a smile and asked where I was from. When I said Jamaica, she smiled again and said, “I have just been to your country to set up a home; we need volunteer”. My pilgrimage was successful.

On my return, I started going to Tower Street where my friend Dr Mickey Lowe introduced me to the Missionaries of Charity. We would go to the back streets of East Kingston with the nuns and pick up proud old men and women living alone with no money or food and suffering from several medical problems. They were all cared for by six nuns and a handful of volunteers. We did everything from doctoring to cleaning the drains and again the experience was very uplifting, bringing life’s expectations down to earth and into the right perspective.

The beginnings of Jamaican interest in caring for cancer patients dates back to the 1950s when the Jamaica Cancer Society was founded at a tea-party, for ‘fighting cancer in all its form’. The first patient brought to the door was terminally ill and needed last rites. After several years of similar experience, the society rightly focussed on advanced cancer and built the Hope Institute for care of the cancer patients.

The Jamaican Hospice Movement really began in 1975 when a group of doctors, nurses and a nun held discussions and offered to help terminally ill in the UHWI. In 1984, the role of a hospice in terminal care was highlighted in a CME symposium on ‘the elderly’. The proceedings of this symposium were dedicated to Professor Sir Harry Annanamthodo, teacher, scholar and colleague, soon after his death in 1986.

In 1985, a private hospice named after Consie Walter, a cancer patient, had opened in Caledonia Avenue and later moved to St Joseph’s Hospital grounds. The Consie Walter Cancer Care Centre had one of its eight beds allocated to non-paying patients.

In 1987, through a generous grant from the United Way of Jamaica a purpose-built voluntary day care hospice was opened on the land given by Urban Development Corporation at 7 Laws Street in the poorest area of East Kingston. This was made possible through the pioneering efforts of Sir John Golding who was involved in all the previous brain storming sessions at the UHWI. I joined John soon after my return from Malaysia and we linked up with the Missionaries of Charity who would take in the terminally ill, homeless, persons and care for them until after death. Another charity that helped us was Food for the Poor who have kept our nurse on wheels, until now by donating cars through Mr Poker Chandiram, also a volunteer at the Missionaries of Charity. This close networking amongst various community groups towards the same humanitarian goals was an excellent example of partnership in caring.

The focus of the Hospice Pain Centre at Laws Street was changed to home visiting after five years as it was realized that poor patients were unable to attend for day care as their disease progressed. The hospice movement did a complete circle when the venue of this hospice, now called Hospice Home Care, had to be moved to the Hope Institute, now owned but allegedly not fully paid for, by the Government, in 1992.
Regrettably, more than a decade later, there has been no further progress. Sadly, Sir John died in 1996 after caring for the terminally ill right up to his dying day and for the second time I was left holding the baby, first time being in Malaysia when Sir Harry passed away on his way back from Jamaica. The hospice runs a home visiting service through a dedicated nurse and the terminally ill, who need round the clock nursing, are admitted to the Hope Institute if they cannot be looked after at home. I visit twice a year to supervise overall running of the hospice.

Attempts to get any doctor to donate time to take charge of this hospice have, unfortunately, been unsuccessful. With the recent arrival of Dr Dingle Spence on the island there is suddenly Hope on the horizon. A Jamaican UWI graduate with cancer caring genes from her father and formal training in radiotherapy and palliative care from England, Dr Spence, already working at the Hope Institute, is God sent for the future of palliative care in Jamaica. But unless the University of the West Indies recognizes the importance of this new discipline of palliative medicine and the medical fraternity of Jamaica give her their full support, all her efforts are likely to end in frustration. There is also an urgent need to establish a palliative care support team at the UHWI and all other major hospitals in Jamaica, and I am fully aware that there is no shortage of interested professionals among my medical and healthcare colleagues throughout the island. If Sir Harry were alive today, I have no doubt that palliative medicine would have been a discipline reflected in the Faculty.

Teaching and Research in the Palliative Care Environment

In 1997, I approached our hospice multidisciplinary team in the UK with the idea of having medical students in the hospice for gaining experience in the care of the terminally ill. The first reaction was ‘absolutely not’ from the nurses. The same response was evoked to the question of research in the hospice. Eventually agreement was reached that we would have a trial of one student at a time continuously chaperoned by a consultant. Similarly, the research had to be strictly monitored by the whole MDT and by the Ethics Committee with well informed consent of the patients and the family. Open and sensitive communication was the key.

I approached the Deanery at Birmingham University and they jumped on the idea as it conformed to the GMC recommendations in the new curriculum. Students started attending one whole day a week, one at a time and then on recommendation from the hospice team, in pairs. They had five sessions fully supervised, except the last one where they were introduced to consenting patients and families for informal dialogue.

The assessment of this teaching experiment was: there were no complaints from the nursing staff or any other member of the hospice team; no patient ever refused to speak to a student, including the terminally ill; students felt one day was not enough, they wanted more; according to students’ assessment, the best session for them was the last one where they were left alone to chat with the patients and the least helpful session was the didactic session.

Today, teaching in hospices is common practice and research on symptom-control and pharmacological, psychosocial and spiritual aspects of care, is widely prevalent, and there is a national network for sharing research and good practice.

The importance of a hospice as a place for learning can best be summed up by looking at an American student’s journal. She spent six weeks with us and this is what she said of her experience:

“This is a place where patients with terminal illnesses come for two weeks or so to get their symptoms (usually pain or nausea) controlled or to give their family a rest or to spend their final days. I really enjoyed myself here and it erks me when I am late for work (if that should ever happen). How heartless am I for liking it, right? Actually patients are really amazing, I learn so much from them. There are 24 beds and all the patients have cancer. Obviously the place is not always jolly and fun all the time but as it turns out that it is more often than not. I’m constantly amazed by the high level of care that these patients receive: washed daily, men are shaved, haircuts, delicious food and desserts, tea and biscuits for snack, etc all done by staff who take their job extremely seriously and do their job with great sensitivity to the patient. For an ill patient it absolutely makes a difference. Nurses and doctors spend plenty of time with each patient. Counting the volunteers (a huge team of reliable dedicated workers) and medical staff, the ratio of patient to care-givers is astonishingly small. Point being, great quality of care…”

Conclusions

The concept of hospice was difficult for me to grasp prior to my work here. My understanding was that patients came to this place resigned to the fact that they were about to die and in a way it was robbing them of hope and the will to live. I didn’t understand the direction of care from that point on. How does one help a patient to ‘heal’ from a terminal illness, or enhance the life of a dying person? The time at Myton has made me understand the meaning and the purpose behind palliative medicine…I have taken more out of this experience than I ever expected…”

Amen

To illustrate what Amen, which is her given name, means I would like to share three case histories:
We learnt a lot from Autonomy. Nurses who cared for her were outstanding and in the end, were able to make her physically comfortable but spiritual issues remained unsolved.

What does it feel like to wake up one morning in active working life to be told you are terminally ill? The following case will help to understand some of the issues:

Case three:  

The Bad Penny

The summer of 2001 was glorious in England. The Aussies were thrashing the Pommies in the Ashes cricket series and, once again, I was about to retire. I was on call for the hospice that weekend in July and had been niggled the whole week with this bite on my arm, which now began to swell. By Sunday evening I was shivering with fever and I had excruciating pain in my fingers. My wife took me to the Accident and Emergency department at the local hospital (where I was a consultant) and I went through the screening process of triage. The nurse looked up after doing the vital checks and told me that I was category 5 in her assessment, meaning the lowest priority, and went on to explain that I was the fittest looking man she had seen that day.

After the required waiting of two and a half hours, we decided to go home and see my personal doctor who put me on antibiotics. With no response in two days, he decided to ‘pull strings’ and referred me directly to the orthopaedic consultant. The first bad news was that I had to be admitted for intravenous antibiotics. The real bad news came the next day when they told me that my haemoglobin was 6g, and that I needed transfusion. I asked for it to be repeated in case there was an error; the second estimation turned out to be 5.6.

My wife had just left the hospital and I was alone in my room when I saw the haematologist on the ward. As I knew him well I called him to tell him what was happening to me. He listened for a while and suddenly interrupted me and said, “I have bad news for you, you have leukaemia.” For a moment I felt as if I was shot at close range. As I recovered I saw him shaking and ashen in face. I squeezed his cold hand and told him not to worry. He had just used the ‘hit and run’ technique of how not to break the bad news.

There was no time to react. I had a short deadline and an unknown destination. I remembered a young man, who walked into our hospice of his own will and asked to be looked after on being told exactly the same thing by the same consultant. I had then phoned my colleague to ask if anything could be done and the answer was ‘No.’ The young man died in four days. This time I didn’t ask.

I phoned my wife to return to the hospital and broke the news more gently. What did help us was the presence of my friend and colleague, a cancer care nurse. We had a quick cry and hugs and made a decision to meet the enemy head-on. My first concern was financial security for my family, so we called a lawyer and revised our wills and I passed on the enduring Power of Attorney to my wife and daughter. I was...
now ready to submit my body to the weapons of mass destruction, in this case a lethal chemical attack.

I chose to stay in our local district hospital, rather than become a number in a specialist cancer centre. I met the chemotherapy team who would look after me and the only thing I asked them was to make sure that I didn’t acquire a hospital infection, which was not to be. I was facing death and looking for hope. What kept me going was a book my daughter gave me to read during the first chemo, ‘Learn to fly, in 21 days.’

I was also terribly concerned about our hospice team who were equally devasted and so I wrote a short weekly note to them to keep them informed. In these letters I tried to be upbeat, and positive.

I had excellent treatment but, unfortunately, no Palliative Care. I also had all the side effects and complications but by the Grace of God, I survived.

Returning to Sir Harry, I had the privilege of working with him in the University of Kebangsaan, Malaysia, in his later days. He was highly respected in the department and in the young faculty. They called him ‘Datuk’, which is a title of Honour as well as a way of addressing a senior. Harry enjoyed the multi-ethnic culture of Kuala Lumpur but he missed the Caribbean, where he longed to return.

In the end, Harry had a premonition. On the day he was leaving for Jamaica on his final journey, he called me to his office for a formal handover. To my surprise I found him sitting behind a clean desk with only a big sealed envelope on it, addressed to me. For the next hour, he instructed me how to run the department and pointing to the desk he said, ‘it’s all in there’. In the end I said, ‘I hope you are coming back’. He laughed and with a deep sigh said, ‘I hope to’. Sadly he didn’t return!

I know that Harry was well cared for in his last illness. All his family were near him. From Malaysia, I kept in touch with daily phone calls and his innumerable former students rallied around from Canada, United States of America and the Caribbean. He was far away from his homeland and his two adopted countries, but he was not in physical or spiritual pain. He was mentally alert right to the end. Above all, he had just been to Jamaica where he gave so much. He died peacefully in the knowledge that his life had been fulfilled, an end we always hope to achieve for every person in Palliative Care.

Harry always admired a brass lamp from India, which I had, and in our family we called it Harry’s lamp. With these memorial lectures, Harry’s lamp will continue to glow and guide us with his wisdom, along our chosen paths of curing most times and caring always.

I would like to sincerely thank the Association of Surgeons of Jamaica for this privilege of addressing you and making my wife and I feel more proud of our 25 years in Jamaica. I would also like to thank Bill Aiken, who was always a teacher’s pet, and Lovenia for keeping me in touch and, finally, Fiona, my daughter for technical and linguistic assistance.