



HOSPICE Bulletin



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Quarterly newsletter of the National Cancer Society of Malaysia, Penang Branch.

HOSPICE AT HOME PROGRAMME IN THE TIME OF COVID 19

By Dato' Seri Dr T Devaraj

What a year for humanity! By the latest count all the states of the world have been affected since the outbreak was first reported in December 2019 in Wuhan, China. As the novel coronavirus spread to more and more countries we witnessed and are witnessing its devastating effects on life and livelihood. Some countries have suffered much more than others health wise and often it is not apparent why this is happening. All countries are facing drastic economic consequences and sadly only the rich countries have reserves they can fall back on. In many ways Malaysians have been more fortunate. This unexpected challenge has been met by good public health approaches and a kudos to the people for what I would characterise as a mature response. As the virus still lurks all over the world we have to continue to be vigilant and god willing not go into shut downs again. A vaccine is expected by early next year. As has been the practice in Malaysia for vaccines it will be only permitted for use when it is confirmed to be safe and effective.



Looking back, the first patient diagnosed in Malaysia was eleven years old. That was on 25th January and the next day a two year and a sixty year old were diagnosed and all were imported infections. Public health measures were instituted and there was only a trickle of new patients till early March when a serious spike began. Hence the Movement Control Order on 18th March and subsequent orders, less stringent, have been the Conditional Movement Order on 29th April and the current order called Recovery Movement Order which is being extended to the end of the year. Further a few localities in some parts of the country have been specifically targeted to deal with small outbreaks. That the novel coronavirus is around still is the take away message for the public and the regulatory authorities.



What about our hospice home programme? As a health service providing professional care in the homes of patients, the visits by our palliative care nurses and doctors continued on a strict need basis and support was provided by phone and WhatsApp as well.



Our patients and families were co-operative in this new approach to care at home. Safety from Covid was an issue for them too. Over 3000 home visits have been made since the MCO and we thank our nurses and doctors for continuing to help. A noteworthy feature was that none of our patients or family members had Covid.

At the same time liaison continued with the Palliative Care Units at Hospital Pulau Pinang, Hospital Bukit Mertajam and other hospitals in Penang to help support care at home.

Our funding has become a serious problem since March. But we are happy to report that there has been no staff layoffs as financial support of this service has continued though limited. So our thanks to our donors, the State Government, the City Council and the Federal Government for support via the wage subsidy programme. These are difficult times for all of us. We are here to help the suffering. Do continue to help us help them.

Stay safe. God bless.

Contents:



HAPPENINGS:

• CARERS' MEETINGS_Penang Island

Venue : Rumah Hospis Pulau Pinang
Day : Every Thursday
Time : 0900 - 1100

• CARERS' MEETINGS_Seberang Perai

Day : Every Friday via zoom
Time : 0900 - 1100

• CARERS' MEETINGS with Dr Jaishree

Once a month via zoom
Time : 1400 - 1600

About Hospice Bulletin

HOSPICE BULLETIN is the quarterly newsletter of the National Cancer Society of Malaysia, Penang Branch with input from Penang Hospice Society. Please submit at least six weeks before issue date which are the first day of January, April, July and October.

All items submitted for inclusion in the Hospice Bulletin must be signed but author's requests to remain anonymous will be respected. Contributions can be sent to: The Editorial Team, National Cancer Society of Malaysia, Penang Branch/ Penang Hospice Society, 250A Jalan Air Itam, 10460 Penang.

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www.ncsmpenang.org

A survivor's story

By GOH CHIN KIM

My experience of being a cancer patient

I worked in a factory for more than 29 years and often had part time jobs throughout my career. My life style was busy but simple and I did not think much about HEALTH. I was active, energetic and felt strong at all times. When people talked about healthy food, I did not bother. I love to eat non vegetarian food. My hobby is 'makan'. I don't quite like vegetables, fruits and all healthy food as to me all healthy food doesn't taste nice. Due to my busy schedule I hardly spent time to exercise and often slept very late.



At the age of 52, on 1st Nov 2017, I quit my job taking early retirement. I was happy that from then on, every day was '**SUNDAY**'. There was no need to worry about work, no deadlines and no meetings. But after 5th Nov 2017 when Penang was hit by the worst floods in recent times, I began to spend more time helping those who needed my help and participated in some charity and social activities. I realized I had become busier than during my working days.

Time flies, in Nov 2018, I started to plan a big birthday function for our school ex-principal who was staying in a nursing home. It is a blessing for her to live until 90 years of age. With a group of my ex-teachers and ex-pupils, we managed to organize A Big 90th Birthday bash for her at Cititel with 320 people for our SMPP ex-principal, Miss Tan Siew Tuan. Miss Tan was a wonderful lady. She was so caring and well respected. Her birthday was celebrated in a very grand way with reporters from Star, Guang Ming and Sin Chew. This was my greatest achievement that I did undertake after my retirement.

After that birthday-do, I started having chest pains. Before that I did have gastric problems for a few months and had been seeing many doctors and was on gastric medicine.

In April '19, I went for 9 days on a trip to China during which period, I started losing my appetite and lost 5kgs in a month. On return, I immediately went to see physicians at the Gleneagles Hospital for endoscopy, ultra sound, CT scan. On 17th April the results came out. I was scared that I had developed ulcer or stones in my kidney and would need to go for an operation. The doctor said my stomach was fine but would refer me to an Oncologist. I know oncology is related to cancer. When he left, I felt hopeless and began to cry because my elder brother at the age of 34 had died of cancer. I was very sad and I could not accept that I had CANCER as all the while I was very active and seldom fell sick. I felt like it was the end of the world. I'm still so young, I just started my new chapter after retirement and started to plan what I wanted to do with my life. I had a dream and planned to open a day-care centre with volunteers for my school ex-teachers to get together. Several of them were already in nursing homes. I wanted to spend more time with them as many of them treated me like their daughter.

The doctor confirmed it was pancreatic cancer at stage 4. It had already spread to my liver. It was swollen with many patches of cancer cells. I immediately started chemotherapy at Mt Miriam hospital under the very compassionate and experienced doctor, Dr. Ho Kean Fatt. The hospital has a social welfare department that helped to lessen my financial burden. General Hospital advised me to continue at Mt Miriam if I can afford as the treatment suited me. After the first chemo I was able to sleep on my sides. Earlier I had to sleep on my back to avoid pain. It took 4 months to complete my 12 chemos.

My biggest challenge was to drink more water, take more vegetables and fruits which I don't like. I started to change my eating habits. Sometimes change may not be what we want but what we need. Doctors said I could eat anything I liked as I needed energy to fight the chemo. I was so blessed with so many caring friends cooking, lighting candles and praying for me. I even had 5 transport managers to fetch me to hospital and back during chemo and check-up. I was blessed as they accompanied me throughout the chemo sessions and with their support and care, I was recovering quite fast. I would like to thank all my friends here and express my appreciation for their kind thoughts, concern and care.

But in July, there was a relapse of my cancer and chemotherapy was given again. However I suffered some side effects, my tear duct clogged; my skin became dry; my hair started dropping, dandruff, dark skin and both my hands were numb every morning when I woke up.

After I had completed my chemotherapy I felt normal enough to enjoy life again, though my energy level was not the same as previously. I have no taboos about eating any food and I do enjoy food but all doctors tell me to practice moderation in what I eat. I am also being pampered by my friends and former teachers who bring all kinds of food that I enjoy: western foods, Indian foods, chinese foods, desserts, sandwiches, cakes, special coconut oil nasi lemak. Some friends keep providing me with good food, organic stuff and expensive supplements to boost my immune system. It is a blessing to note that when we fall sick we get to know so many people who care about us. I am also blessed with good appetite to eat.

I see my good doctor every 2-3 weeks. But after 14 months, I was asked to go through another round of chemo as there was a relapse again of the cancer. The doctor told me it had nothing to do with diet. It was a matter of time it would happen again. The chemo medicine I took is like a sleeping pill for the cancer cells. It needs to be changed when it is not effective. This round, I was more prepared and not scared of the chemo anymore. A chemoport has been fixed and this helps to ease my pain during chemo and is more convenient.

I was thinking cancer is not a death sentence. But soon we will have to go too. I want to live happily with whatever time I have. And I feel that I'm so lucky and will be able to do it as I have so many supporters, loving and caring friends around me. They make me feel loved and happy all the time. Their love, their care, their support and prayers, money cannot buy. As a cancer patient, I feel good if we have friends who are able to give moral support to us. It is really important and as it can change our thoughts to live happily for the rest of the time that we have left. I have realized, **"Doing good for others is not a duty but is a Joy."**

I asked my doctor based on his experience, what is the life span for of a person who has got pancreatic cancer like my case? I was told at stage 4 life expectancy is about 1-2years or less. I have started to cross that threshold.

Life has 4 stages in Chinese saying "Birth, Old Age, Sickness and Death." The word "Sickness" is already there, so why must I be afraid of being sick which is part of life. I was told to live for the moment and be happy.

Now I am starting to plan what to do with my life while I'm still physically strong. I also plan to spend more time with my family and help them. I also want to spend more time with my ex- teachers as they are aging, friends and loved ones that I would love to be with. Time has passed so fast and is so precious to me and I appreciate every moment I have. I wish all cancer patients never to give up. Practice meditation and prayers and have a positive outlook in life. It would help a lot. Until today, I am still learning to take care of my health until God calls me home.

"May God Bless Me and all the cancer survivors".

Thank you,
Chin Kim Now

DR MARY BAINES – A REFLECTION *By Dato' Seri Dr T. Devaraj*

In this issue of the Bulletin there is a reprint of a lecture given by Dr Mary Baines at the 12th Congress of the European Association for Palliative Care in Lisbon in 2011 entitled "From pioneer days to implementation: lessons to be learnt". It is a worthwhile read as we reflect on the pioneer days of hospice in Penang. I have met Dr Baines three times. Two of them were at St Christopher's in London in 1991 and 1995 and the other was in Penang. Visiting doctors were taken on a ward tour at St Christopher's. The patients we saw were terminally ill from cancer or other neurological illness with good symptom control (for pain they were on regular oral morphine). We noted that the wards were clean with no smell of antiseptics, no drips in sight and only an ambu bag if needed.



The service in London was set up as a hospital of thirty-six beds in 1968. Dr Baines was invited to leave her work as a general practitioner by Dame C Saunders, her friend, as both had started medical training at St Thomas in 1954 to take on the role of a consultant physician there in 1969. Many patients improved sufficiently with good care to want to go home. So Dr Baines was tasked to start a home care programme. She was able to leverage on community care already in place in London – general practitioners and district nurses who wanted to continue being involved in patient care at home. So seamless care became possible with specialist care in the hospital and care at home coordinated by the general practitioner and district nurses. This then became the model for the UK. In 2010 there were 1,800 new patients visited at home and 48% died at home.

When we started in Penang in 1992 we had the choice of an inpatient care or home care. We decided on care at home as there was no such service by health professionals then and sadly, even now, as part of the health care system. The late Dato John Cardosa, then the Hon Secretary of the National Cancer Society of Malaysia, Penang Branch was a prime mover. What we started in Penang has become the model for hospice home care in Malaysia. In contrast to London up to 80% of our patients die at home.

With respect to a strong opioid such as oral morphine we were indeed fortunate in that the DG of Health, Tan Sri Dr Abu Bakar Suleiman directed the public hospitals to supply oral morphine. This must be seen in the context of many developing countries which still make it very difficult for the prescription of oral morphine. A question that arises is why do local studies show that about half the patients who have chronic pain from an advanced illness are still not getting adequate pain relief. Clinicians need to reflect on this issue of such importance to those who have pain.

In her presentation Dr Baines mentions how home care was adapted in Romania from about 1991 and only in 2007 was a law passed for doctors to prescribe morphine with no maximum dose. I found it interesting that Dr Anne Merriman's work in Uganda was mentioned. Dr Merriman was for a short while working at the USM medical school in Penang, then she went to Singapore before going to Uganda in 1993. I had an opportunity to accompany her to visit hospice patients in their homes in Singapore on a visit in 1992. She was doing that during her lunch break! She pioneered hospice care in Uganda and getting doctors to use it. Not only that as she was able to persuade the government in 2003 (after years of pushing) to allow trained nurses to prescribe oral morphine in rural areas where there are no doctors.

In 1993 the NCSMPB organised the first Palliative Care Congress in Penang. We had over three hundred nurses, doctors and supporters from all over Malaysia. Tan Sri Dr Abu Bakar Suleiman opened the congress and Dr Cynthia Goh came from Singapore to deliver the key note address. We had invited Dr Mary Baines to deliver some lectures. She was amazed at the enthusiasm for hospice and that almost all stayed on for three days with three sessions daily: morning, afternoon and evening. She kindly agreed to close the congress. Addressing in particular the doctors and nurses her message was simple YOU CAN START TOMORROW. Her belief was that all health professionals looking after ill patients should take on this responsibility as it was just good medical care. To want to help, to give compassionate care is after all the foundation of medicine.

Dame Cicely Saunders was moved to do something for those who were suffering as they were terminally ill and doctors were losing interest as hopes of cure faded little realising that it was at this time in a patient's journey that good nursing, good doctoring was essential and had to be holistic. Now that it is very slowly being put into practice we need to move away from just focussing on the terminal ill, the dying. With any major illness there is suffering both of the patient and the family. At any one time many more people are having a major illness and do not die. So it follows that if the main goal is to reduce suffering then holistic caring should begin with the diagnosis of a major illness. Then a patient or family will not have to ask "must I be dying to get palliative care". What a change this will be as caring becomes both competent and compassionate. Is this not all of us would want when we are ill?



Perspective

From pioneer days to implementation: lessons to be learnt

Mary Baines reflects on the pioneering days of palliative care, when she worked with Cicely Saunders at St Christopher's Hospice, in an article reproducing the talk she gave in Lisbon last May at the 12th Congress of the European Association for Palliative Care

"I want to start by showing you this photograph of Cicely Saunders, and I am grateful to Avril Jackson, previously of the Hospice Information Service,* for it. I like it because of her smile and because it shows her still at work – in fact giving prizes to hospice staff – though it was taken in 2001 when she was 83, just four years before her death.



*Cecily Saunders in 2001,
four years before her death*

Cicely Saunders was, of course, the founder of St Christopher's Hospice in London and she is generally recognised as the founder of the palliative care movement.

She trained as a nurse, then as a social worker, and it was then that she met David Tasma, a young Polish Jew, who was dying of cancer. It was through her friendship with him that God called her to devote her life to improving the care of the dying – a most neglected group. She then trained in medicine and that was where I met her – we were contemporaries at medical school.

I wish, for your sake, that she could have given this talk on pioneering days. But this talk will be full of what she taught me and countless others. It is dedicated to her, Dame Cicely Saunders – an honour given by Her Majesty the Queen – the founder of our specialty and my dear friend.

The beginning

When Cicely Saunders opened St Christopher's in 1967 she brought together, for the first time in the world, a large number of patients with terminal illness and staff who were committed to discover and then teach the best ways of caring for them. Previously these patients would have been scattered – in various hospital wards or at home. There were a few hospices, mostly opened around 1900. The patients in them received excellent nursing and spiritual care but there was minimal medical input, for it was generally believed that the doctor's role was to cure. These patients were, of course, incurable.

I was a medical student at St Thomas's Hospital in London in the same year as Cicely Saunders. She was much older than the rest of us, having been a nurse and a social worker. When St Christopher's opened, I was working as a part-time general practitioner. Cicely asked me to join her on the staff and, very fearfully, I did. Medical friends said it was professional suicide.

I found myself entering a branch of medicine with no books or conferences. Symptom control was contained in a single sheet entitled *Drugs most commonly used at St Christopher's Hospice*, which was given to all staff. Yet, I suggest, this sheet contains the single most important advance in end-of-life care that has ever been made. It comes, of course, from Cicely herself. To understand its importance, we have to go back to medical practice in the 1950s and 1960s, when it was generally believed that strong opioids were only effective when given by injection and that tolerance and addiction would inevitably occur if they were given regularly. So, in practice, patients were given injections of morphine but only when their pain became unbearable.

So the practice of giving a strong opioid by mouth, regularly and in adequate doses became accepted at the hospice

The revolution in symptom control

Cicely Saunders had seen the value of regular oral morphine in a small London home for the dying that she often visited. After qualifying, she obtained a research scholarship to study pain control in terminal illness and she went to St Joseph's Hospice, where she was allowed to put her ideas into practice. She was permitted only four patients to start with because of the fear that regular giving caused addiction! But, to the surprise and delight of the staff, these patients became painfree and remained alert. So the practice of giving a strong opioid by mouth, regularly and in adequate doses became accepted at the hospice. When Cicely Saunders left St Joseph's, she had carefully documented records of over 1,000 patients dying of cancer – quite a series. The first research project in what was to become palliative care.¹

The strong opioid used at St Christopher's at the beginning and listed in the hospice's symptom control leaflet is diamorphine or heroin, because it was widely believed to be superior to morphine, giving better pain control with fewer side-effects. Cicely Saunders herself said 'Diamorphine does the greatest good to the greatest number'. But she also knew that this was only her impression and had never been researched. And so she invited Robert Twycross to join St Christopher's as a research fellow to conduct studies into many aspects of pain control, including a comparison between morphine and diamorphine given orally.

Because of the strongly held belief that diamorphine was the better drug, the only ethical way to proceed was to do a pilot study first. Half the patients were given morphine and half diamorphine, and people like me were asked to guess which drug they were on. Not surprisingly, everyone who had good pain control with minimal side-effects we guessed to be on diamorphine. Those who were sick and drowsy we judged to be on morphine. In fact, we were right 50% of the time! The trial was then started with 700 patients entering over two years. On completion, when the data were analysed, they showed that there was no significant difference between them.² Cicely Saunders' impression was wrong. Of course, we too have impressions but, like her, we should be keen to have them tested out – even if we too are proved wrong.



If you had joined our ward round in the early years, you would have found that the most common word used was 'why'. 'Why is this patient having this particular pain?'; 'Why has his breathlessness suddenly become much worse?'; and, relating to my own special interest, 'Why has this patient with proven intestinal obstruction stopped vomiting?'. This last question was fascinating. We admitted many patients who had had an 'open and close' operation for intestinal obstruction and nothing could be done. We treated them simply, with a combination of analgesics, anti-emetics and antispasmodics with no nasogastric tube, and the vomiting either stopped or was reduced to once a day with no nausea. In addition, sometimes, after weeks, the bowels opened. Why was this? What was happening? It had never been described before.

Mary Baines worked for many years alongside Cecily Saunders at St Christopher's Hospice: she was one of the founders of the first UK palliative home care service

Fortunately, when St Christopher's was designed, Cicely Saunders included a post mortem room and we had a senior pathologist, Richard Carter, from the Royal Marsden Hospital, who came to perform limited symptom-directed post-mortems. Some of you here today attended them. I wonder if you, like me, remember that they mostly seemed to happen on a Saturday morning! The first 63 autopsies were written up in the first edition of the journal *Palliative Medicine*.³ Eighteen autopsies were in connection with our study of patients with malignant intestinal obstruction and, in each case, the obstruction was confirmed, with 14 patients showing it at multiple sites. This study, with 40 patients, was published in *The Lancet* in 1985.⁴ [It included the 18 autopsied patients and 22 on which it was not possible or not appropriate to conduct post-mortems.]

I hope that, if I joined your ward round next week, I would often hear the question 'why?'. The hospice's symptom control leaflet has grown into the *Oxford Textbook of Palliative Medicine* and countless other publications, but there is so much more to be learnt, not only on symptom control but on all the other aspects of palliative care.

Total pain

I said that the regular giving of drugs to control pain was the most important advance in end-of-life care, but close to it – or even first – is, surely, the inspired concept of 'total pain' having physical, emotional, social and spiritual components. This came, of course, from Cecily herself and she first wrote about it in 1964, having learnt it at the bedside of the dying patients she care for.⁵ This was revolutionary at that time, when the severity of pain was generally measured by the somatic injury that caused it. But this concept of total pain (or total suffering) gives us a wider approach and a framework to our understanding and care for patients at the end of life. The physical component usually needs treatment with appropriate drugs, given regularly. Helping the emotional and social components of pain involves recognising and treating anxiety and depression when they are present, and spending time with patients and families, encouraging them to talk and ask questions, and giving kind but truthful answers. Spiritual pain may be due to guilt about the past or a fear of what happens after death. It was explored with all patients on admission by asking about the importance (or not) of faith, so that spiritual anxieties could be addressed.

Time will not allow me to mention all the dimensions of total pain that were studied in the pioneer days but I will highlight just two.

One important early study conducted by Professor John Hinton compared the experience of care of patients in the radiotherapy ward of a teaching hospital with those who were receiving hospice care either as an inpatient or at home, looking especially at levels of anxiety and depression.⁶

Perhaps the best known of early studies are the work and writings of Colin Murray Parkes on bereavement. He had met Cicely Saunders before St Christopher's opened and she invited him to start a bereavement service from the beginning. Colin developed an assessment card to be filled in after death by the staff member who knew the family best. This gave details of the 'key person' – the one thought to be most affected by the death. Those who scored high were visited at home there is so much more to be learnt, not only by a specially trained bereavement visitor.

The effectiveness of this service, which was the first in palliative care, was written up in 1981 and it is considered by Colin to be his most important piece of work.⁷ It showed that bereavement support reduced the risk in the 'high-risk' group to about that of the 'low-risk' group – a major reduction in symptoms of anxiety and the consumption of alcohol and drugs. Two early evaluations of palliative care looked at anxiety, depression and bereavement. How do you, in 2011, evaluate the care you give?

But for all the advances and research in this field, it is so important that we do not become people who just go around patients with questionnaires and boxes to tick. We need to remember daily the words of Cicely Saunders. 'I have tried to sum up the demands of this work we are planning in the words "Watch with me". Our most important foundation for St Christopher's is the hope that in watching we should learn not only how to free patients from pain and distress, how to understand them and never let them down, but also how to be silent, how to listen and how just to be there'.⁸

Adapting home care

Until 1969 St Christopher's was purely an inpatient unit as were the other older hospices. Patients were admitted and, with very few exceptions, remained there until they died. For the few who went home there was no follow up. Then an incident occurred that led to the founding of the first domiciliary service.

There were no other palliative care services at home to guide us and we felt it was very important to get it right

A woman in her 50s with severe pain from bone metastases due to breast cancer surprised us all by wanting to go home once the pain was controlled. We tried to make careful plans, I phoned the general practitioner, and the drugs, including a moderate dose of diamorphine, were given to her. But ten days later she was readmitted in agony because the doctor had reduced and then stopped the opioid, feeling that it would otherwise turn his patient into an addict. Of course, the pain had returned. Sadly, this story does not have a happy ending. Her pain was easy to control but she had lost her nerve and did not want to go home again. She remained an inpatient until she died.

However, it was this incident that prompted Cicely Saunders to say 'We must start hospice care at home now'. She looked around the hospice to find staff who had worked in the community – a field in which she had no experience. She chose Barbara McNulty, a nurse, and me, and she told us to start a domiciliary service.

The way forward was far from clear. There were no other palliative care services at home to guide us and we felt it was very important to get it right. We needed our service to fit in with the UK pattern of care in the community. So we decided to spend some months going round those already working there and asking them if they wanted a hospice home care team and, if so, what form they wanted it to take. The answers came back, the majority welcomed the hospice going out into the community, but the general practitioners wanted to remain in charge of patients at home and the district nurses wanted to continue the practical nursing that was needed. They wanted a 24-hour service with doctors and nurses in the team.⁹

And so the first home care service was born in October 1969, a model for the UK. This format has remained virtually unchanged at St Christopher's and, in 2010, no less than 1,800 new patients were visited and 48% of deaths occurred at home. This model was right for us but may well not be right for you. You need to design your service to fit in with the needs and resources in your country.

Let me give you two examples that I know well, focusing on how they coped with a common problem.

The Communist years in Romania left an appalling legacy, with many sick children in derelict orphanages and virtually no treatment for older people unable to return to productive work. But, in 1991, just over a year after the fall of Ceaucescu, an appeal to start hospice home care in Brasov was launched by Graham Perolls and others. A senior oncologist came to the UK for training and, on his return, an English nurse joined him and immediately began to train Romanian nurses. There were no community nurses, so the team had to do the care themselves or teach the family. In spite of this, they offered a 24-hour service. At the start there was no oral morphine and the prescribing of morphine injections was so restricted and complicated that few received them. But the hospice team, with outside experts, worked tirelessly to change things and, in 2007, the government approved a law to allow all doctors to prescribe morphine, with no maximum dose.¹⁰

In Uganda, hospice care at home was started in 1993 by Anne Merriman. Before agreeing to launch it, she insisted that oral morphine must be available and local doctors were amazed at the difference that this made. But hospice could only cover a fraction of those who needed help, so an approach to the government was made to permit specially trained nurses to prescribe and deliver morphine, essential in rural areas where there are no doctors. In 2003, the law allowing this was passed and, at present, over two thirds of the 108 districts in Uganda have morphine prescribing nurses working in them.¹¹

Two examples of how palliative care at home has tackled a specific local need. How can your service or the one you are planning serve your community better? This is a challenge to us all.

Palliative care reaching out

There is no doubt that Cicely Saunders did not found St Christopher's purely to care for patients in south-east London. Her aim was to change the world's view of dying and this aim was shared by those of us who worked with her. There were many ways in which this could be achieved.

Even before St Christopher's opened, Cicely Saunders was lecturing in the United States. An eight-week tour in 1963 followed by annual visits inspired many people and was one of the factors leading to the formation of the American hospice movement. She and others went on to lecture widely in the UK and abroad and, from the start, we welcomed visitors. They came to see what we did and went home, not to copy it but to apply it to their own circumstances. These visits are always costly to staff but there are ways to minimise this, such as the monthly 'Friday visit' at St Christopher's, when individuals are combined in a group for talks and a tour.

But we also have visitors who come for a longer time. In 1973, Balfour Mount, a urological surgeon from Canada, visited. He went back and founded a unit in his hospital, the Royal Victoria Hospital in Montreal, and he gave the name 'Palliative Care' to our specialty. Then, Gustavo de Simone from Argentina came to a hospice conference and was persuaded to stay on for a further two weeks of clinical work. He had come across our first textbook of palliative care in a remote part of Patagonia and had decided to come and see the work for himself. He went back and founded Pallium and became one of the leaders of palliative care in South America.

But 'reaching out' is not just a matter of geography. One of the things that pleases me most about the modern hospice movement in the UK is its increasing involvement with different patient groups; for example, those in care homes and those with dementia.

Perhaps the hardest groups to reach, especially at the beginning, were our own professional colleagues. Even speaking about pain control in the early days was fraught with difficulties. I well remember being asked to talk on the use of opioids at a conference on the management of cancer pain. In the question time at the end, I was attacked by both anaesthetists and neurosurgeons! Looking back, I wondered if this was because they could see that, if drugs were successful, there would be less demand for nerve blocks and percutaneous cordotomies. An outstanding exception to this was the late Vittorio Ventafridda from Milan. I remember him telling me that the use of nerve blocks for cancer pain in his clinic had fallen from 83% to 14%. But he was pleased because his concern was for the wellbeing of his patients, not the take-up of his specialty. A remarkable leader.

How are you going to 'reach out'? Perhaps by offering palliative care to a new group of patients, those with intractable cardiac failure or advanced multiple sclerosis. Perhaps by making a link with those trying to establish a palliative care service in one of the 119 countries without one or in one of the countries where the work is very difficult. Perhaps by seeking an invitation to speak to nursing or medical students at your local hospital, or writing an article in one of your professional journals. And there are hundreds more ways that I hope and pray you will explore during this conference. For the need for 'reaching out' is as relevant today as when we started 44 years ago. It makes me want to turn the clock back all those years and join you and start all over again!"

***Avril Jackson was until recently International Information Manager at the Hospice Information Service run by Help the Hospices and St Christopher's Hospice.**

Declaration of interest

The author declares that there is no conflict of interest.

References

1. Du Boulay S, Rankin M. *Cicely Saunders, the Founder of the Modern Hospice Movement*, updated edition. London: SPCk, 2007: 49.
2. Twycross RG. Choice of strong analgesic in terminal cancer: diamorphine or morphine? *Pain* 1977; 3: 93–104.
3. Carter RL. The role of limited, symptom-directed autopsies interterminal malignant disease. *Palliat Med* 1987; 1: 31–36.
4. Baines M, Oliver DJ, Carter RL. Medical management of intestinal obstruction in patients with advanced malignant disease. A clinical and pathological study. *Lancet* 1985; 2: 990–993.
5. Saunders C. The symptomatic treatment of incurable malignant disease. *Prescr J* 1964; 4: 68–73.
6. Hinton J. The Adult Patient: Reactions to Hospice Care. In: Saunders C, Summers DH, Teller N (eds). *Hospice: the Living Idea*. London: Edward Arnold, 1981: 31–43.
7. Parkes CM. Evaluation of a bereavement service. *J Prev Psychiatry* 1981; 1: 179–188.
8. Saunders C. 'Watch with me'. *Nurs Times* 1965; 61: 1615–1617.
9. Baines M. The origins and development of palliative care at home. *Progress in Palliative Care*. 2010; 18: 4–8.
10. Mosoiu D, Ryan KM, Joranson DE, Garthwaite JP. Reform of drug control policy for palliative care in Romania. *Lancet* 2006; 367: 2110–2117.
11. Merriman A. Going the extra mile with the bare essentials: homecare in Uganda. *Progress in Palliative Care* 2010; 18: 18–22.

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THE HOSPICE AT HOME PROGRAMME

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