



## Building Blocks - a report by Gwen (Bar) Cottrell, Trustee



I am recently back from holiday in Kenya during which it was so good to see the steady building blocks of our valuable hospice centres and, despite the difficult conditions, the steadfastness of all involved over there. Back in 1989 with a modest grant of £30,000, local multicultural support and land allocated by the Ministry of

Health, we laid the first building block for the hospice movement in Kenya. That was the Nairobi team, in a modest yet distinctive building. Since then there have been six more building blocks towards countrywide care of the dying. First Nyeri, then Eldoret, Kisumu, Coast, Meru and most recently the fledgling teams at Nyahururu.

Now Nairobi is planning new sustainable premises with income generating facilities; Nyeri has moved to a larger building in pleasant grounds with room to grow; and Nyahururu has been allocated land at the Provincial Hospital for building. We were made so welcome at Nairobi, Nyeri and Nyahururu, yet the gratitude was all ours as we met and talked with staff and patients. The stark fact is that cancer is irrefutably on the increase in Kenya and that the diagnosis for so many "wananchi" is still far too late. This combined with the AIDS crisis, means that the country desperately needs more hospice resources and more palliative care skills amongst medical and community sectors. So whilst I thank you from the bottom of my heart for your gifts thus far, I urge that we redouble our efforts in order to help provide comfort, pain relief, dignity and understanding to double or treble the number of ordinary Kenyans who face terminal illness.

Joyce, one of the Nairobi nurses, told us "We try to get alongside the family and help them with practical matters as well as palliative care for the patient".

Asha is one of a proud Nubian family living in Nairobi's biggest and infamous slum, Kibera. Since February she has been a patient of the hospice. Until recently she attended day care, however her breast cancer has taken a turn for the worse and she is now confined to her one



Joyce escorted on home visit

room home which she shares with a large quantity of roof tiles! I accompanied nurse Joyce when she visited Asha. We found her rasping for breath, semi-conscious, not recognising anyone and I feared the worst.



Home visit to Asha

She was now bed-ridden (a couch) with nasty sores on her feet and swelling to her arms and the breast cancer weeping unpleasantly. Joyce patiently helped her take some oral morphine, tended to her sores and quietly talked to her and her sisters about how to improve her comfort, whether she should be taken to hospital or stay at home and how to brief the community health worker. As we said our goodbyes Asha's smile was verging on radiant with a quiet serenity in her bright eyes. This was the culmination of an amazing transformation within 45 minutes of the arrival of Joyce with her kindly voice, patient manner and gentle efficiency. Fellow Supporters, this is what we are backing.

### Next Building Blocks

I met Jennifer Chebet in the shop at Outspan Hotel and we got talking about Hospices. She asked "Why isn't there a hospice in Nakuru?" I explained how the Kenyan hospice services were growing yet recognised a long way to go. In return she told me about her relative, Mama Ann, from Baringo who had died of a brain tumour just 3 months earlier. Nakuru 150 kms away was the nearest Provincial hospital where the doctors diagnosed her tumour yet failed to counsel the family. They discharged Mama Ann saying "she's a bit fair, take her home, she's not bad". After one day back at home she was in such pain that the family took her to the district hospital at Marigat and she died in agony two days later.

By individual giving of regular monthly and annual gifts, and donations through our wills, HCK will support the solid building blocks that will get Hospice Care up and running in Nakuru and other provincial centres. We estimate we need a minimum fund of £100,000 to back a strategic development plan for hospice care in Kenya. Can you help us?

Gwen (Bar) Cottrell Trustee

## Kenya Hospices & Palliative Care Association

Between 1990 and the present day, seven hospices have been registered and opened in Kenya. They offer Palliative Care for those suffering from terminal disease, originally just cancer, but more recently, HIV/AIDS too. Prior to this, once a patient was diagnosed as beyond cure, he was sent home to die. There was little knowledge and even less opportunity for help and support, and most died in agony, with the family unable to do anything except look on helplessly.

The hospices – with five Mission hospitals too, have changed all that, at least in the areas in which they operate. But with about 14% of the population being infected with the AIDS virus, and about 70% of cancer sufferers being already terminal by the time they are diagnosed – not to mention the underlying HIV in many cancer patients, there is an immense, urgent need to scale up Palliative Care services, with a greater emphasis on awareness, capacity building, training – as well as advocacy to influence policy makers.

The formation and registration of the Kenya Hospices and Palliative Care Association in November 2005 is a big step forward to achieving this. KEHPCA will provide a forum for all Palliative Care providers to share their expertise, learn from each other, upgrade and standardise procedure and practise, and, most importantly, plan strategically, which has been missing up until now.

With Dr Bactrin Killingo (Meru Hospice) elected Chair of the Association, and Dr Zipporah Ali (Nairobi Hospice) its Coordinator, and with board members from the other providers, there is already a project in place to assess need and scale up Palliative Care provision across Kenya. Once some funding is secured to “drive” the project and it is well underway, a national workshop will be called to discuss findings and plan the next stage.

Kenya struggles with massive problems compared to those of us who live in the UK. Poverty, (which of us has to choose between food for the family or medicines?), poor roads, very little public transport, high unemployment, and no welfare state with its benefit system, make existence difficult, and when illness strikes – impossible!

The KEHPCA will have its work cut out, and faces many challenges, but nevertheless, this central, strategic approach is the way ahead, if life threatening disease is to be recognised earlier, and if high quality care and support for the dying and their families is to be maximised and offered across the whole of Kenya.

*Liz Salmon, Chair*

## Case Study From Meru Hospice: Lucy's Story

**Marriage:** Lucy was married for 10 years but bore no children. Her husband, anxious for sons, “replaced” her and she was obliged to leave the marital home. After a while, she met another man, but when she had lived with him for a few months, she noticed a lump in her breast, which seemed to grow rapidly. Her partner told her to go home to her own village, and to her parents. She did so – and they took her to Meru Hospital and left her there.

**Hospital:** Lucy was due to have surgery on her breast, realised she was pregnant, and so the operation was cancelled. She lay in bed for the next few months, but with no money to pay for drugs and no relatives to prepare food, life was not good. Her Cancer was declared beyond cure.

**Hospice:** Meru Hospice staff heard of her plight, visited, prescribed drugs to keep her pain free and comfortable – and generally cared for her. In the fullness of time, her baby was born and was named Moses. By this time, Lucy was very weak, her tumour was gross, but she suckled Moses from her healthy breast.



**And Moses:** The Hospice team stepped in again. Moses at 2-3 months, had no life, lying on his mother's bed all day, and she was too weak to care for him. The team, with Lucy's consent, arranged foster care then official adoption. They bought Moses some clothes and saw to



all the details. A couple with two little girls took Moses into their home, and he settled well and happily with his new family.

They took him to see his mother fortnightly, until she died. The team then arranged Lucy's funeral. Moses will have the joy of knowing that his mother found a new and loving “family” to care for her in her final days, and that her death was peaceful.

Thank you, Meru Hospice.



## World Hospice and Palliative Care Day Saturday October 7, 2006

The World Hospice and Palliative Care Day is a unified day of action to celebrate and support hospice and palliative care around the world. This year's theme was "Access to Care for All", highlighting the fact that everyone has a right to high quality end of life care but that more needs to be done to enable everyone to access it. This important day was marked in a number of ways in Kenya, one of which was a visit by a journalist from the *East African Standard* to Nairobi Hospice to talk to a terminally ill patient. There she met Fred Ikutwa who knows he will soon die.

Ikutwa is 30 years old and lives in Kibera with his wife and three children. When he first noticed a pimple on his leg in 2001 he was working as a marketer for a real estate firm. He recalls "first it got swollen then after applying some ointment, it disappeared,". But it later re-emerged much bigger than before and it began to eat his right leg from inside while infecting the left leg at the same time. The damage to his legs was extensive and without proper medical attention Ikutwa was confined to using crutches as the disease continued to take hold of him. He had to stop working in 2002. The situation is worsened by poverty, and his wife is now the sole breadwinner. She feeds the family by washing the neighbours' clothes. Ikutwa spent endless hours lying in his bed covered in his own waste, praying for death to come.

As his health deteriorated, his neighbours said he was bewitched and advised him to seek help from a traditional healer. Gossipy and nosy neighbours are a nuisance but to Ikutwa they were a blessing. They informed missionary doctors passing by his home in the sprawling slums of Kibera about his ordeal. They alerted Nairobi Hospice. Dr Zipporah Ali who attended to Ikutwa describes her first encounter with him as depressing and heart breaking. "His body was literally rotting and the patient was shivering from excruciating pain and had a high fever", Dr Ali says: "Honestly, I thought he would not make it through the week and advised his relatives to prepare for the worst." She whisked Ikutwa to hospice and gave him the strongest painkiller in Kenya, morphine. Pain having subsided Ikutwa was put on medication and was given morphine syrup, antibiotics and a cleaning solution to prevent his body from getting infected. Gradually his wounds began to heal and so did his will to live after receiving counselling. From 2002 to date, he survives on drugs and his health has drastically improved.

"I knew I was dying but no one told me what was killing me. I stopped eating because of vomiting and

waited impatiently to die," Ikutwa recalls. He felt he was a burden to his family because his children had stopped going to school due to lack of fees and one day, Ikutwa overheard his family members organising to take him to his home in Kisumu to die there. "I understood them though because we were poor and it would be expensive to take a dead body back home but I got more depressed and tormented."

Dr Ali says many people do not understand the plight of people living with life threatening disease. And that ignorance runs all the way to the government. The suffering of the terminally ill has failed to win any sympathy from the Government. Dr Ali discloses that painkillers are not included even in the government's essential drugs kit. "Pain seems not be recognised as an important condition to treat," Dr Ali said.

Kenya has no budget for palliative care, which should be part of the funding made to the Health Ministry. According to the World Health Organisation (WHO) there are 35,000 new cases of cancer in Kenya every year. Palliative care is an approach that improves the quality of life of patients and their families facing problems associated with life threatening illness through the prevention and relief of suffering. While 4,000 people are able to secure treatment the rest cannot afford it. They die alone, in misery. Annually, the hospice spends about Sh16 million taking care of people with life threatening diseases.

Although Ikutwa still has the disease, the pain is gone and he is a happier man now. "I even counsel my friends and instill hope in them because I believe stress and pain is what kills people faster," Ikutwa says.

Every Thursday, there is day care at the hospice where patients like Ikutwa meet, play games and indulge in income generating activities so that they can continue to feel wanted in society. "We try to put life into their days, not just days into their life," Ali explains.

This article was taken from *The East African Standard*.



*The Salvation Army Band at Eldoret Hospice  
on World Hospice and Palliative Care Day*

## Accolades for Nairobi and its CEO

Hearty congratulations to Nairobi Hospice and its CEO, Mrs Brigid Sirengo.

Nairobi Hospice has received the AFYA Award for Excellence and Creative Service in Cancer Care, 1st prize in that category. The AFYA awards are presented annually by the Kenya Ministry of Health to recognize the top hospitals in the East Africa region.

Brigid Sirengo has been awarded an Honorary Doctorate by Oxford Brookes University in recognition of "outstanding achievements within the field of palliative care".

These awards recognise the amount of hard work that Brigid and her team have put in to getting palliative care on the map, and the initiatives introduced within the education field. It will also be a boost to the other hospices, and to all who are striving to make palliative care available to all in Kenya. So please accept our congratulations and very best wishes for the future.

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### Much needed dressings make their way to Kenya

Earlier in the year the Maylor household was invaded by boxes of new dressings, bandages, colostomy bags and medical stockings. These had been collected together and donated to the Hospices through one of Kim's family. Kim and youngest son, Joseph, counted, scheduled, packed and labelled everything ready for shipping to Kenya, phew! TNT kindly assisted with the freight costs and ensured the goods safely arrived, to the delight of Hospice staff. Good teamwork! Thanks to all



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### 10th Annual Kenyan Coffee Morning

Once again we are indebted to Anne & Gordon Davies, of Tiverton for all their hard work raising funds for HCK.

## Another Special Birthday Gift for HCK

Earlier in the summer Ruth Wooldridge enjoyed a special birthday celebration to mark her 60th with friends and family, and HCK enjoyed a share of the presents!

Ruth's association with the Kenya Hospices goes back to the very beginning. Ruth, a palliative care nurse, and her family were based in Nairobi during Mike's time as BBC East Africa correspondent. Through voluntary work in the slums, Ruth met Nancy, a young mother in the last stage of terminal cervical cancer, frightened and unsupported by the health services. Following her death, Ruth campaigned with Nancy's story which touched the authorities, professionals and donors. Two years later in 1989, Nairobi Hospice opened its doors as the first dedicated palliative care centre in Kenya. Ruth is a past Chair of HCK and more recently has established CanSupport, a home based palliative care service in Delhi with which the generous birthday presents have been shared.

Ruth says, "It's twenty years since I cared for Nancy and its wonderful to see what has grown out of that experience. There are now eight hospice at home services in Kenya as well as palliative care being introduced and integrated into the care and teaching in many hospitals. In this country if we are diagnosed with cancer we are fortunate to be able to access care and treatment, but in Africa 80% of people do not get treated. Palliative care for pain and symptom control and emotional support sadly still remains the only option. Thank you dear friends for the gifts you gave to continue to develop palliative care where it is so needed".

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Thank you to all of our friends and supporters for your gifts and continuing support. And thank you to everyone who helped with the Gift Aid audit that we had to complete this year - a very good result!

Please continue to give as generously as you can to help us to help the hospices.

*Kate Jones, Editor*



*Nyahururu Hospice*

**The trustees and I wish you all a very Happy Christmas and peaceful New Year**