

Winter Newsletter 2018

Welcome to our Winter Newsletter. This edition follows a visit we made to Kenya at the end of October. Dr Mike Hughes trustee, and myself, made a self-funded trip to Kenya, along with Fundraiser Catherine Nelson. We spent a week visiting the hospices and palliative care units which we support, to monitor their progress and how they are using the money which you donate.

In Nairobi it was exciting to see the new hospice building nearly finished. It is well placed in the grounds of Kenyatta National Hospital and will have close links with the oncology team. There will be plenty of space to expand the teaching of health staff and develop new services.

We then travelled to Kisumu on the shores of Lake Victoria to visit Dr Julius Onyango and his hospice team. Kisumu Hospice is well established and has taught many groups of community health volunteers. These volunteers are the first health worker contact for many villagers, and when needed they can refer people to the hospice nurses for further investigations. Living in the villages they know all their neighbours, they are enthusiastic volunteers and are very keen to have further training to help them do their job better.



Above right and left: Visiting Elizabeth at her home and outside her house with her family.

Below: The Busia Hospice team outside their small hospice room.







Below: Community health volunteers trained by Siaya Hospice.



Further west, near the border with Uganda, we visited both Siaya and Busia Hospices.

The Siaya team took us on a home visit to meet Elizabeth. Her cancer of the cervix was first picked up by her community health volunteer Jane, who referred her on to the hospice team. Jane has supported her through treatment and recovery. Elizabeth is now well enough to work on her small farm with the help of her great grandson.

At Busia the hospice operates out of one small room in a nursing home. In spite of tiny premises they have a big impact in the county. Once again by training community health volunteers they have built contacts in outlying villages, and have brought basic health care and hope to many families.

This visit has shown us how effective small grants to hospices can be in changing lives. It confirms for us that training community health volunteers is an excellent investment for rural communities. We must also continue to support nurse training and ensure that morphine and other basic drugs are available for all who need them.







The nurses depend on their hospice vehicle for visiting patients at home



Health workers training course at Nairobi Hospice

Hospice nurses provide front-line care for patients and support for their families. Their job is challenging and complex, managing both the clinical care of patients and their medication, and their personal and psychological needs. They travel many miles to visit patients, some using motorbikes, often through difficult terrain and to remote rural locations.

Nairobi Hospice nurse Mercy Kamau explains her typical working day.

8.30am

I start the day at the hospice teaching the principles of palliative care to health workers. Nairobi Hospice runs week-long courses on palliative care for health and social workers. These courses help to increase knowledge on palliative care throughout the health system, helping to integrate palliative care.

11am

I leave the hospice to start today's patient home visits. Unfortunately the traffic and congestion in Nairobi limit our movement and make it challenging to see more than 2 or 3 patients in a day. Nairobi has grown and developed significantly in recent years, and the numbers of people living in poverty and needing our assistance across the city has also grown. I also make sure that home visits are not rushed and I spend as much time as is needed to support each patient and their families.

12pm

I visit a young man who has just lost his mother to breast cancer. He was her primary carer and I was worried about how he would be coping with his loss. He was worried that something he had done during her care had caused her death. I reassured him that he had cared for her well and done everything correctly. I will keep in touch with him to provide counselling.

1.30pm

I visit Richard and his family. He has rectal cancer with an inoperable tumour, but his family is coping very well with his care and his outlook. We discuss his pain management needs and concerns, and I prescribe morphine to help with the pain.

3pm

My last visit of the day is to see Evelyne who has advanced cervical cancer. She has a very supportive husband to care for her and two beautiful children, but their financial situation is challenging and the children need a lot of emotional support. (Read more about Evelyne's story overleaf).

4.30pm

I finish the day at the hospice by meeting with the rest of the clinical staff to discuss our patients and their treatment. This is an opportunity to ask advice on complicated cases and seek a second opinion from colleagues.



Mercy on her way to a home visit



Explaining prescribed medicines to Evelyne's husband



Giving Richard instructions on how to use morphine

Palliative Care News from Kenya

Paving the way for universal access to palliative care in Kenya

In November the Kenya Hospices and Palliative Care Association (KEHPCA) hosted Kenya's 5th National Palliative Care Conference in Nairobi. The conference theme "Investing in Palliative Care for Universal Health Coverage" brought together professionals working with both children and adults, hospices and policy makers from Kenya, Africa and the world. HCK trustees Dr Sally Hull and Dr Mike Hughes presented the long term role that Hospice Care Kenya has played in the development of palliative care in Kenya, and contrasted the UK and Kenyan experience of Hospice work.

This year the Kenyan government has promised to make universal health coverage a top priority over the next five years. Dr Jackson Kioka, Director of Medical Services in Kenya, confirmed that palliative care will be included in any plan for universal health coverage.

This is a very positive step forward. Kenyan county governments are now obliged to establish palliative care units at all county referral hospitals. KEHPCA has already made great progress to ensure this happens, with 31 out of 47 counties now compliant. However, successful implementation will depend on the political will of each county level government administration.

Another important goal is to ensure that palliative care services are covered under the National Health Insurance Programme. This is the voluntary government insurance scheme available to all Kenyans. Those in need would be able to access palliative care for free under their insurance. However, not all services and treatments are covered by the scheme, and many of the poorest families are not covered as they are unaware of the scheme or the cost of the premium is too much of a financial burden. Unfortunately this means that the poorest people can build up large debts for medical care, or simply go without essential treatment.

Hospice Care Kenya continues to support the hard work of KEHPCA at this important moment for palliative care development in Kenya.



The conference opening speech by Rob Yates, Policy Forum Programme Director, Chatham House.



Dr Mike Hughes speaks about palliative care in the UK.



Dr Sally Hull, HCK Chair, and Dr Mike Hughes, HCK Trustee, with Dr Zipporah Ali, Executive Director of KEHPCA.



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Evelyne's Story



Evelyne and her family live in a small flat in Umoja, a deprived and crowded area of Nairobi. Evelyne was diagnosed with cervical cancer in June at the age of just 37. She has had two courses of chemotherapy but the cancer has spread. Swellings on her breast bone caused by cancer spreading to the bones cause her pain in her chest and shoulders. An ultrasound confirmed a blood clot in her leg, causing painful swelling. She is feeling very weak and sleepy.

"I don't feel well. With getting the news that the chemo didn't work, the cancer coming back, I just feel so down", she told us tearfully, unable to speak in more than a whisper.

Mercy, the nurse from Nairobi Hospice, has been visiting Evelyne regularly to help with her medication and to provide support. Evelyne is taking medication to control both her pain and symptoms, and to counteract the side effects of some of the drugs. This complex combination of medicines is closely monitored and balanced by Mercy.

Mercy is concerned that Evelyne's son has become withdrawn and is not coping well. She will ensure that she spends time to counsel him and provide the support he needs. Evelyne has also attended day care sessions at Nairobi Hospice. She told us:

"When I go to the hospice it feels like home. It's good to go and discuss with other cancer patients, it really helps. The nurses provide a good service".

Evelyne now needs a blood transfusion to regain strength. Despite the family being enrolled in the government's National Health Insurance Fund, the cost of a blood transfusion will not be covered. Her husband is her full-time carer, so they rely on family members to pay their living costs and support their two children. The lack of free comprehensive healthcare is an added strain on a family that is already living with the devastating effects of cancer.

Please help us to help more people like Evelyne. A regular gift would make a real difference to people living and dying with a terminal illness in Kenya. Thank you for your support.

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