

# Summer Newsletter 2024

We are delighted to share with you our Summer Newsletter for 2024. In this issue we look at current morphine shortages in Kenya and how we have responded to the problem. We will share the stories of a handful of HCK friends and how they have contributed to HCK over the years, and we'll also update you on our latest projects and work in new areas of Kenya.

Thank you for helping to make all this possible.

## HCK emergency fund for critical morphine shortage



We have received reports from our hospice partners of serious delays in morphine procurement and delivery by the Kenyan Ministry of Health. Initially, our partner hospices told us they were having to ration their morphine supplies; now, many have completely run out. Consequently, patients are suffering unrelieved pain, resulting in physical and emotional distress, not only for the patient but also their families who witness their loved one in continuous agony.

Morphine is a cornerstone of palliative care. It provides essential pain relief for patients with severe, life-limiting illnesses like cancer and advanced Aids, thereby dramatically improving quality of life. In 2016, the Kenyan government committed to purchasing and distributing morphine for palliative care, marking a significant step towards improving access to essential pain relief for palliative care patients. However, purchasing and distributing morphine and other essential drugs to hospices has not been straightforward, leading to frequent delays and shortages.

To address the urgent shortage, the HCK board made the decision to offer emergency funds to enable our most severely affected independent hospice partners to self-purchase a supply of morphine to plug the gap caused by the delay. We also need to encourage the Kenyan Ministry of Health to deliver an effective service, so we have written to the Kenyan Hospice and Palliative Care Association, requesting that they prioritise advocacy with the MoH to increase commitment to palliative care and quickly resolve the delays.



We need more emergency funds to address this urgent morphine shortage. It costs just £10 to provide a month's supply of morphine for a person living with cancer. Please help us bring relief from pain and suffering by donating to our morphine appeal today.

#### Celebrating the heroes behind Hospice Care Kenya

Everything that has been achieved in Kenya by HCK over the past 30+ years, in the early days until now, is down to the hard work and generosity of many individuals; founders, trustees, staff and volunteers, our hard-working Kenyan partners, and of course you, our supporters who have made it all possible. Here we meet just a few of the individuals who have helped Hospice Care Kenya make change happen in Kenya.

Gordon and Anne Davies have been supporters of Hospice Care Kenya for over 25 years and explain their motivation to support palliative care in Kenya:

"I first went to Kenya in 1959 as a young graduate student and spent two years teaching at the Mombasa Institute of Muslim Education. Subsequently, I got a job working for Magadi Soda Company at Magadi Lake in the remote south of Kenya, near the border with Tanzania. I loved the wildness of the place, but after 4 years I moved to Nairobi, where I met and married my wife, Anne. Towards the end of my ICI career I returned to Magadi as Operations Director of a mining operation in a township in the heart of Masai tribal territory. We operated a 50 bed hospital, a reliable water supply and did a lot to support the tribe. I always found Kenyans such lovely people and so friendly towards us. These experiences left me with many happy memories and I developed friendships in Kajiado District."



Anne and Gordon Davies, at Hunter's Lodge in Kenya celebrating their 50th wedding anniversary

~Gordon Davies

"A friend persuaded me to join the African Women's League (EAWL). This was around the time the new Nairobi Hospice was being set up. Several of the EAWL members helped with the new hospice so I got to hear a lot about it. I'd never come across hospices before, it was new to me but it sounded a rather nice idea. So, from then on I became involved with convincing others who might be interested in helping. In 1994 we moved back to Devon. I continued as an EAWL member on the committee, hosting annual fundraising lunches in our house and garden. It was such fun and we enjoyed hosting it so much that we decided to hold a coffee morning as well. This became quite a big event and we raised a good amount of money for charity. We wanted our events to support a charity working in Kenya and liked the sound of a small charity, so Hospice Care Kenya was chosen. We have always felt that paying back is important and have been happy to support HCK ever since."

~Anne Davies

"We love Kenya, it has given us so much and we wanted to give something back by leaving legacies in our wills. We felt that a small charity like HCK will use our gift in an efficient manner to help Kenyan patients at the end of their lives."

#### Hospice Care Kenya and Nairobi Hospice co-founder, Ruth Woodridge, shares her story:

"In 1987 I cared for Nancy, a school teacher in Kibagari slum where I was volunteering as a nurse. She had two little boys and lived in a very humble one roomed dwelling with her mother. For Nancy, her cervical cancer was diagnosed too late for any treatment to be helpful. Caring for her at home with no morphine was very difficult. Eventually she died in hospital in great pain and very alone. I then spent a year visiting all the major hospitals in Nairobi, meeting oncologists and medical staff and enquiring how they might care for patients with advanced illness, cancer in particular. Mostly the consensus was that patients wished to go to their traditional home area to die and therefore it was not a great problem. Or that they could do nothing for them.

At the same time Jane Moore, also a nurse, had been caring for Sir Michael Wood who pioneered AMREF, the flying doctor service in Kenya. She too struggled to find appropriate pain relief as his illness advanced. And importantly, Professor Kasilli, a wonderful haematologist and paediatrician, was introduced to us. He had spent time in Glasgow and understood what palliative care could bring to people with advanced illnesses and pain. After one of our early morning meetings at Professor Kasili's office, before his busy day began, the vision we were working towards came to me in words: "Put life into their days, not just days into their lives". This has become the motto for Nairobi Hospice and much quoted elsewhere too.

We worked hard to introduce the hospice concept to the Ministry of Health, and at the same time we stalked the grounds of Kenyatta Hospital looking for a site large enough to open a centre for palliative care. Eventually, a site was identified and approved by the MoH, and our little centre opened in 1990 with a £25,000 donation from a UK trust."





Left: Nairobi Hospice in 1992, Kenya's first hospice. Right: Dr Mike Hughes with a patient at Nairobi Hospice in the early 1990s

In 1991, the Nairobi Hospice Charitable Trust (now HCK) began in the UK as a charity to support hospice care in Kenya. Our UK trustees came from medical and non medical backgrounds, and raised funds for supporting and extending the service in Nairobi. We raised funds large and small from participating in the Hospice UK Global singing of the Messiah at Dulwich College, to dog shows and fetes, to Archbishop Tutu, a Patron of HCK at the time, delivering a Radio Four Appeal which raised over £65,000 in 1996. We were not prepared for such a huge response as you can see from the photo counting out the cheques on our kitchen table! This enabled the purchase of a vehicle for the home care team, medicines and paid staff salaries.

In 1992 HCK supported Dr Mike Hughes to join the team in Nairobi to assist with hands-on training and patient care. Mike, now a trustee, really took palliative care forward in Nairobi and inspired other centres to start outside the capital too."

#### Celebrating the heroes behind Hospice Care Kenya

"The development of the hospice movement in Kenya has been inspirational and a model for other African countries. Much of this has been underpinned by the funding and generosity that supporters of HCK have given over many years. Funding for nurses to have further training, vehicles for home visits, medical supplies, for running day-care and support groups, and training community volunteers to serve in rural villages where often health care is very limited.

Much of what has been achieved could not have been done without support from HCK. Your donations have made miracles happen and helped to reduce so much suffering for thousands of patients and their families."



Ruth Wooldridge (right) together with Lady Jean Johnson (centre) and Bronwen Biles (left) count the piles of cheques received in response to HCK's BBC Radio 4 Appeal in 1996.



Sharon (left) with Chair of Trustees, Sally Hull (centre) and HCK Director Pauline Everitt (right)

#### Sharon Maweu has been a Hospice Care Kenya trustee since 2021:

"As one of HCK's newer trustees, I feel privileged to be part of a team that provides compassionate care and support to those in need. My journey with HCK began while I was finalising my master's dissertation at the University of Westminster, three years ago! My desire was simple - to make a positive impact in the lives of people facing tough times back in my country, especially cancer patients receiving palliative care. My background, working in South Sudan managing nutrition projects and in one of Kenya's major hospitals as a dietician, made me deeply value the importance of comprehensive care for individuals with life-limiting illnesses.

I took part in HCK's recent monitoring visit to Kenya where I saw the challenges patients and carers face; lack of access to essential pain management drugs and affordability of wound dressing kits, in addition to long distances travelled to health centres for check-ups. The amazing work HCK does through our partners, the

commitment of the hospice staff, the strength of the patients, and the incredible community support left a lasting mark on me. It reinforced my belief in the impact of our work, and I returned more motivated to continue supporting HCK's vital mission. As we think about the influence of HCK and the enduring legacy of its supporters, I urge everyone to think about leaving a gift to ensure that this crucial work can continue for years to come.

A special call out to fellow Kenyans based here in the UK, we can create a lasting difference in the lives of those who need it most. Asante!"

Hospice Care Kenya would not have achieved what it has without the committed support that so many of you have given us. Leaving a gift in your will is one of the most valuable ways you can help our vital work continue making a difference into the future. If you would like more information on leaving a gift in your will please get in touch or visit www.hospicecarekenya.com/legacygiving.

## **HCK** project news in brief

Community and home-based care are essential for maintaining patients' comfort, dignity and quality of life in familiar surroundings. It also reduces costs for the poorest of patients. Over the past year we have helped develop community palliative care services across Vihiga County in western Kenya for the first time by working with the county palliative care unit, the only one in the area. We have already helped 170 adults and children living with cancer and other life-limiting illnesses, to benefit from compassionate care in their homes for the first time.







Garissa County, one of the poorest in Kenya, is a rural area where limited healthcare infrastructure compounds the struggles of those facing chronic illnesses. Our partner, the newly established Garissa County Palliative Care Unit, is desperately needed; in 2021-2022, Garissa County reported over 7,000 new cancer cases. Yet despite the huge need, the new services are underused as potential patients are unaware of them. Even healthcare workers lack knowledge on palliative care and patients miss out on referrals for services. Over the past year we have worked with Garissa Palliative Care Unit to take the first steps in developing the new services and raising awareness of them.







So far, we have equipped 70 individuals with palliative care knowledge. This includes healthcare providers who now have the knowledge to correctly refer patients into the services they desperately need, and community health volunteers who are now empowered to bridge the gap in community health care provision through community based palliative care and who will share the information widely within their communities. The inclusion of hospital managers will motivate their support and commitment to palliative care services.

Palliative care nurse, Catherine Katuku, reflected on the achievements:

"The project has been overwhelmingly successful. Feedback from the participants highlighted the effectiveness of the meetings as they reported increased knowledge and confidence in providing palliative care services."

## Building palliative care skills in Dadaab refugee camp

In March, HCK supported a team of palliative care specialists to travel to Dadaab refugee camp in the north of Kenya, in the first steps towards developing palliative care services in the camp. Around 300,000 people live in Dadaab and Hagadera refugee camps near the Kenyan border with Somalia, with thousands facing chronic or life-threatening illness. There are no options within the camp for cancer treatment. Any person diagnosed with cancer must gain special permission to travel within Kenya, then make the journey to Garissa to receive treatment. Very few manage to access treatment in this way, the vast majority go without any curative treatment at all. This creates an urgent need for palliative care within the camps, but lack of resources and very limited provision means that patients are forced to live and die in severe distress.

The trip was the result of complex coordination involving United Nations High Commissioner for Refugees and NGOs working in the camp. The stringent controls over access to the camps, as well as challenging geography, created huge challenges for our team when planning and entering the camps to deliver the project.

The team provided palliative care training to a group of 7 health care professionals working in the camp and 13 nursing support volunteers, in a first step to improving access to care for the many people in need. The trainees will now work at facility and community levels to provide palliative care services, referrals and home-based care.

"I came in with a mind-set that palliative care is for the dying, now I know it's about improvement of quality of life. I may be limited due to less or unavailable resources here in the camp, but my attitude should communicate care, compassion and support. Truly, palliative care is about living" ~ a nurse trainee from the camp





Photos from top left clockwise: Dadaab refugee camp; Training led by Dr Zipporah Ali; Group work and role plays between training participants; Group photo of the newly trained Dadaab palliative care providers.





#### **Empowering Kericho County with Palliative Care**

In Kericho County, western Kenya, there is no public provision of palliative care. With a population of over 900,000 people, many individuals in this rural setting who are battling non-communicable diseases like cancer, are facing physical and emotional challenges without proper care and support. With your support, we began work last year with a new partner, Oasis of Hope, a dedicated local community organization, led by experienced palliative care nurse Leonard Kiprono.

In response to this pressing need, Hospice Care Kenya and Oasis of Hope have launched the Palliative Care Empowerment Program. This initiative aims to provide comprehensive training and support to volunteer caregivers, religious leaders, and healthcare workers in the community.

Since the project started in January 2023, remarkable progress has been made with participants showing a significant improvement in their understanding of palliative care. Over the course of a year, we trained 70 individuals, including health care workers, volunteer caregivers and religious leaders, in palliative care awareness, knowledge, and skills, using a curriculum tailored to the cultural context of Kericho County. These trained individuals now serve as ambassadors for palliative care in their communities, advocating for better access to services and providing essential support to those in need. Volunteer caregivers are better equipped to provide physical and emotional care to their patients, while religious leaders play a crucial role in offering spiritual support and guidance. Families caring for loved ones with terminal illnesses now receive enhanced support. Patients benefit from improved symptom management and holistic care, leading to a better quality of life during their journey.



"The training has given me a lot of knowledge on palliative care and how to take care of a cancer patient. I now have a lot of courage to give hope, medication and train the patient's family members to understand palliative care and how to take care of the patient at home. My own husband has cancer and the caregivers training has helped me learn a lot on how to take care and talk to him so we no longer need to spend so much money and time looking for someone to help us."

~Mama Esther Rono - in photo standing, together with her husband Samwell (seated centre) and nurse Leonard (left)







#### A Two-year-old's story of hope through palliative care

Anwyll is a resilient two-year-old boy from Garissa County in east Kenya. He brought joy to his parents after the loss of their first child. Anwyll was a healthy, happy boy until he developed worrying symptoms with abdominal swelling, reduced appetite and vomiting. Concerned, his parents sought medical help, eventually leading to a diagnosis that left them shocked and devastated – nephroblastoma, a type of kidney cancer. Anwyll's parents felt helpless.

The palliative care team, supported by Hospice Care Kenya, stepped in, providing crucial psychosocial support to help the family to cope, advice on treatment options, and supporting Anwyll through some distressing symptoms – pain and breathing difficulties caused by the growing mass. Thanks to this care, hope was restored for Anwyll's parents.

"We couldn't make it through this journey alone without the help of the palliative care team" ~ Anwyll's mother

Palliative care supported by Hospice Care Kenya transformed Anwyll's life and made a profound impact on the whole family. Please donate today to ensure that more children like Anwyll, and whole families, can receive life-changing palliative care and support.

## **Please click here to Donate**