Hospice Care Kenya

Winter Newsletter 2023

Welcome to our Winter Newsletter for 2023. This issue features our new look! We wanted a new logo and colour palette to better represent our work as a UK-based charity supporting hospice and palliative care across Kenya. Best of all, we designed this in house so it didn't cost a penny! We would love to know what you think. Also in this issue, we reflect back on achievements to date in Kenya before introducing our new strategy and focus areas going forward. We also share some news on an exciting new project. We hope you find it interesting and please do get in touch if you'd like to know more about any aspect of our work. We wish all of our friends and supporters a Merry Christmas and Happy New Year 2024!

News from Kenya

Congratulations to Dr Julius Onyango (photo right, centre) who was honoured with a lifetime achievement award at the KEHPCA conference in November for his contribution to palliative care, after giving an incredible 50 years of service to the development and delivery of palliative care and oncology services in Kenya. Dr Onyango founded Kisumu Hospice in the 1990s and, at the age of 92, has only recently retired. As the driving force behind the hospice, the facility sadly closed in 2023 as a successor to take on his role could not be recruited, however work is underway to integrate palliative care services at the local hospital.





Machakos Palliative Care Unit has just completed the construction of a new, purpose built palliative care facility with partial support from Hospice Care Kenya. Replacing a small, dilapidated building used for many years, the new building provides a comfortable, welcoming space with two consultation rooms and a large meeting room with sanitation facilities. As the only palliative care facility in the county, much needed day-care service can now take place here, vital for providing psycho-social support for patients and their families, as well as offering essential respite for carers.

Support our work this Christmas with **DontSendMeACard.com**



This Christmas why not send e-cards or a virtual gift to friends and family using **DontSendMeACard.com** and donate the cost of cards and stamps to us! Just visit **DontSendMeACard.com/charities** and search the charity register for Hospice Care Kenya. Simply choose a Christmas card design or our virtual gift, make your donation, then you will receive a set of e-cards to either send in bulk or individually personalise.

Every Child Counts

We're excited to announce our new project, Every Child Counts, which aims to reach the many children and families that live with the challenges of life-limiting illness without the palliative care and psychosocial support they desperately need.

Child palliative care has the potential to transform the lives of children and their families living with a wide range of conditions, from cancer and HIV to cerebral palsy and other congenital conditions. Yet still only 5% of children living with a life-limiting or life-threatening illness can access the palliative care that could drastically improve their quality of life. Without palliative care these children experience distress from unmanaged pain and symptoms, and poor mental and physical wellbeing, preventing them from attending school and participating in play. Families suffer catastrophic financial expenditures associated with their child's care.

To understand the root of the issue and the challenges, we have spoken to paediatricians, oncologists, nurses and families. These discussions have revealed some of the barriers that are preventing development and uptake of child focussed services. We have found that child palliative care is often mis-understood as end-of-life care only. Even health workers do not understand that palliative care can provide long-term support for children with life-threatening conditions. Uptake of child focussed services, where they do exist, is often extremely low. Health workers can be reluctant to refer children for palliative care, and parents are unwilling to accept services, because accepting a child might die is taboo. Often parents simply don't know about the services that are available to them, or due to stigma related to life-limiting illness and disability, children with palliative care needs are often not talked about and hidden away in their homes.

Our new project will develop child-focussed services by training doctors, health workers and volunteers in the specific needs of children, including reaching family members and siblings. We'll reach out to families in need through home visits and family workshops to make sure they understand how palliative care can help them. We'll also reach teachers, school children and community leaders with positive messages around children with life-limiting illness and disability, creating a more supportive and inclusive environment in which these children can thrive.

Initially taking place in three counties, Siaya, Meru and Kajiado, we hope that any successes can be replicated in other counties in the near future. The project started in October and has already made an impact.



Photo left: Gladys Mucee, palliative care nurse from Meru Hospice, whilst carrying out ward rounds in hospital paediatric units, was alarmed to find many children being prescribed adult doses of morphine, and many others in severe pain and receiving no morphine at all. Pain relief is a crucial element of palliative care and vital for quality of life, so we decided to help our hospice partners to run training sessions for doctors and nurses focussing on pain management in children.



Hospice nurses have already visited many schools and met with hundreds of children and their teachers. Children have been taught positive messages around children living with life-limiting illness, and teacher palliative care 'champions' have been identified and trained to provide every-day support for children with palliative care needs and their families. This is also an important exercise for hospice nurses to find children in the community who could benefit from palliative care but are not aware of the services available to them.



Elizabeth from Siaya Hospice told us, "It's been so lovely to work in these schools with children and their teachers. The children are so open, asking so many questions and ready to learn from us."

We look forward to sharing future news from this project and sharing the stories of children and families supported by the project.

Thanking a long-serving trustee



We would like to express our gratitude to David Worthington who has recently stepped down from his role as a Hospice Care Kenya trustee. David is a retired lawyer who joined our board of trustees in 2006. We appreciate his valuable contribution to the governance of our charity over so many years, and his legal advice has been indispensable. David guided us through the process of becoming an incorporated charity in 2011 and provided his legal expertise to help to secure the release of a legacy gift. Thank you David, we wish you all the best for the future!

Hospice and Palliative Care in Kenya - a timeline

1990

Nairobi Hospice was founded. This was the first hospice in the whole of East Africa and represented the first step in making palliative care accessible to Kenyans. At that time HIV rates were very high and access to palliative care gave some hope to those in the advanced stages of the disease.



2006

By 2006, a further six hospices had been established in the country; Nyahururu, Meru, Kisumu, Nyeri (pictured) and Eldoret in central Kenya, and Coast Hospice in Mombasa.

2011

We changed our name from Nairobi Hospice Trust to Hospice Care Kenya to reflect our wider support for palliative care throughout Kenya.



Nairobi Hospice in 1992, the first hospice in Kenya

1991

Hospice Care Kenya was founded in 1991 as The Nairobi Hospice Trust to support the newly opened Nairobi Hospice with funds raised in the UK.

2007

The Kenya Hospice and Palliative Care Association (KEHPCA) was established as a forum for palliative care providers to share their expertise and soon afterwards they began work to integrate palliative care into the Kenyan health system. HCK has supported this work ever since.

Thanks to this incredible progress there is now a wide distribution of small hospices and palliative care units, pioneered by very dedicated individuals. But this is just scratching the surface of need. There remains chronic underfunding, lack of trained staff and large gaps in provision, particularly for the most vulnerable and geographically marginalised people. Our strategy from 2023 has three core pillars:

Partnership- With our trusted partners we will continue to support the treatment, care and counselling of people with life-limiting illness. We will develop new partnerships to address the most critical needs and gaps, including children's palliative care.

Empowerment - Education and training of skilled palliative care providers, general health workers and volunteers remains a priority. We will work together with our trusted hospice partners to strengthen them and build their management capacity, assisting them to become self-sustaining organisations.

Advancement - We will develop new projects to reach the large areas of Kenya where there is no palliative care provision at all.



More than 2,000 community health volunteers from across Kenya trained by Hospice Care Kenya

2012 to 2013

25 hours of basic palliative care training was introduced into the general nursing curriculum and the curriculum for trainee doctors. A small first step in improving health workforce skills in palliative care.

2020

Hospice Care Kenya reaches the milestone of having trained 2,000 community health volunteers in palliative care, creating a large network of community based palliative care providers.

2023

We launch our new strategy, focussing on three core pillars; Partnership, Empowerment and Advancement, cementing our future plans to continue to meet the most urgent needs in palliative care in Kenya.

2013

The Kenya Medical Training college introduced Kenya's first higher diploma course in palliative care nursing, an initiative supported by us since it's inception. Photo below shows the Diploma class of 2018, supported by Hospice Care Kenya with partial sponsorship.



2021

KEHPCA and Kenya's Ministry of Health launched the country's first Palliative Care Policy; a framework for palliative care as part of Universal Health Coverage and a guide for health service managers.

Everything we have achieved over the past 30 years, and our future plans to ensure equitable access to palliative care across Kenya, are only made possible by donations from supporters like you.

Leaving a gift in your will is one of the most valuable ways you can support this vital work. A gift in your will, large or small, could make a big difference and continue your support for families coping with life-limiting illness in Kenya long 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 visit to Kenya

A small group of our trustees, along with HCK Director Pauline Everitt, has just returned from a week visiting our hospice partners in Kenya. The trip was the first in several years so was an important opportunity to meet with partners, discuss important issues around governance and finances, and monitor the use and impact of the funds you donate.

We undertook a long drive to the Mount Kenya area where we visited some of our long term hospice partners in Meru, Nyeri and Laikipia. We were lucky enough to meet several patients, both at the hospices and visiting their homes, who told us first hand how much they value the compassionate support they receive from the hospice teams.



At Laikipia Hospice we met a family struggling with the impact of both mother and daughter living with cervical cancer (photo right). The father had become very depressed and was not coping, but through regular visits to the hospice for counselling and support groups he has found some hope and gained confidence in caring for the women.





We also spent time at the Kenya Hospices and Palliative Care Association conference. This was an important opportunity for us to meet with many of our partners, share experiences, learn from other initiatives, and work with others to identify gaps to better target our funds raised in the UK.

The trip provided valuable insight to help us target our support to palliative care work in the future. Patients spoke of how valuable counselling and psycho-social support has been in helping them cope with their circumstances; our funding of day-care and support group initiatives is money well spent. Times are tough in Kenya and resources are stretched. Yet the hospices continue to provide the best possible care for their patients; achieving significant change with the financial support we provide.

Pauline Everitt reflects on her first visit to Kenya as HCK Director:

I was very excited to be visiting Kenya for the first time and didn't really know what to expect. It was everything I hoped for and more! The country is vast and the roads were not always the best. The scenery is lovely, from the lush gardens of the hotel in Nairobi, to the plains of the Masa Mara. I was struck by how friendly and kind the people are. The staff and volunteers in the hospices we visited are so dedicated and compassionate to those they care for that it was humbling. We met families in some very sad situations that were heartbreaking, yet they were meeting their conditions with resilience and often a smile. The hospice staff were so committed to supporting these people who often would not be able to access any other medical care. Kenya is an amazing country and I feel privileged to work for a charity that is making such a difference to peoples' lives.

News from HCK in the UK

We are delighted to have received the kind donation of a beautiful painting of the original Nairobi Hospice, donated by friend of Hospice Care Kenya, Gwyn Sloan. Hospice Care Kenya was originally founded in 1991 to support the newly opened Nairobi Hospice. This gift will be a treasured memento of our heritage and a reminder of how far palliative care has developed in Kenya in the years since. As a hospice nurse, Gwyn made her first visit to Nairobi Hospice in 1996, together with her husband Iain. During this visit she transported to the hospice a large quantity of syringe driver lines and medication, generously donated by pharmaceutical companies. At the end of her trip, this painting was presented to her by Lydia, a nurse working at the hospice. Over the following years, Gwyn made several visits to Nairobi and other hospices in Kenya to volunteer her expertise in training nurses and supporting home visits. Gwyn later served as an HCK trustee and, together with Iain, has raised an incredible £80,000 for HCK through organising events on our behalf. Gwyn has treasured this artwork for over 25 years and decided now is the time to pass it on to HCK. A huge thank you to Gwyn for her generous gift.



Gift idea supporting HCK!



To support our work in Kenya we are offering for sale a beautiful print of an original painting by Gwyn Sloan, titled 'Tembo at Kili'. High quality prints of the original artwork are available as an A4 mounted print or as a pack of 5 A6 blank notelets, in return for a donation.

To find out more and order please visit <u>www.hospicecarekenya.com/gifts.</u>



Mercy's story

We met six year old Mercy, and her mother, during our visit to Laikipia Hospice. Mercy had recently been diagnosed with retinoblastoma, a rare type of eye cancer that can affect young children, and had undergone surgery to remove her eye.

Mercy's diagnosis and surgery had a devastating impact on her and her family. The stress and worry, as well as the financial cost of lost income whilst caring for Mercy, took their toll. But since finding the hospice, life has started to improve. The family receive regular support from Laikipia Hospice nurses, with counselling for the family and care for Mercy whilst she adjusts to her disability. Through sharing their story and listening to others during support group meetings, they no longer feel alone and have the strength to see some hope for the future.

Photo top: Mercy and her mother. Photo bottom: Mercy's mother shares the experiences of their family during a support group meeting at Laikipia Hospice.

Please help us to support Mercy and other children like her, who desperately need care and support to help them cope with life-limiting illness. Just £50 covers the cost for a whole family to attend family support workshops to receive care, counselling and vital information that can change their lives.

Please Donate Here

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