

## **Every Child Counts - Year 1 achievements**

After thorough stakeholder research, we developed our Every Child Counts project, together with partners in Kajiado, Meru and Siaya Counties. The project was designed to tackle three key barriers to the development and delivery of child palliative care; 1) Lack of health workers with knowledge and skills in child palliative care; 2) stigma and discrimination and 3) low demand from affected families. In October 2023 the project activities commenced, taking a focus on child palliative care for the first time in these counties. Here we share the highlights from the year.

We trained 204 Community Health Volunteers to provide child palliative care and psycho-social support to families of children with palliative care needs in their homes

"The training has been of great impact as I can now provide support and accurate information to families with a child with cancer and other conditions which require palliative care in my community. I feel confident to refer children and give valuable advice to parents all because of the skills and knowledge I have learnt."

~Sharon Kajuju – trained community health volunteer

Photos right: Top - Community health volunteers training in Mulaha, Siaya; Bottom - Training in Meru national park area







Meetings with Embao community, Kajiado West and Hono community, Siaya.



We met with 217 community and religious leaders to discuss positive messages and information around children with life-limiting illnesses and disability

The training sessions have been instrumental in enhancing community leaders' understanding and proactive involvement in palliative care, fostering a supportive environment for children with life-limiting illnesses.

"As a religious leader, I am happy that I will share the teachings received from Siaya Hospice team with my congregation. I did not know what palliative care is but now I can teach my congregation how to identify children with palliative care needs"

"Church elder Kaluo

"There is a child in my village and I have never understood why he didn't attend school despite taking medicine. I will be sure to follow-up the family. Thank you for coming to enlighten us"

~Ole Tolua - Chair of community elders, Kajiado

We have visited 29 schools, reaching almost 400 teachers and over 10,000 school children, who were engaged through dance and singing, and encouraged to reflect on and play a role in fighting the stigma and discrimination faced by children with palliative care needs.

Teachers now have the skills to actively recognise and support students with palliative care needs, enhancing the overall care and support system within schools. Teachers pledged to champion the care of children with palliative care needs within their schools and committed to identifying and referring children with health challenges to the appropriate hospice team.

"We have been noticing some children with different challenges. Some are always sick and on off at school.

Most of the teachers were not aware of their sickness, but after the palliative care talk we as teachers will be

on the front line to identify such children and call the hospice team"

~Teacher at Siaya Central Primary school

"It is difficult for teachers to do follow-up of sick children due to the culture; parents always keep off the child from school without communication. I will do more to make contact with these families and encourage the child to school"

~Monka – Teacher at Olekemunke school







Events at primary schools in Kajiado, Meru and Siaya (left to right)

## We trained 85 paediatric and oncology doctors in child pain management and appropriate referral systems for children with palliative care needs

During ward rounds, our hospice nurses were alarmed to find that doctors often prescribed adult doses of morphine to children, or in many cases, didn't provide any pain relief at all in the belief that children must not take morphine. This left children to suffer in unnecessary pain.

Through training, we successfully improved health care workers' knowledge, confidence, and engagement in providing comprehensive palliative care to children. It dispelled the belief that child palliative care is only for HIV/Aids and cancer patients, broadening their understanding. Health care workers are now actively tracking children with palliative care needs, conducting follow-ups, and consulting with the hospice team.



Health care worker training at Siaya County Referral Hospital

## **Every Child Counts - Children's Lives Improved**

To date the project has identified and is supporting 96 children with palliative care needs who were previously not receiving appropriate care; a 200% increase on numbers registered before the project. We're delighted to be supporting these children and their families through hospice care, home visits and family support groups.



Family support groups give children and siblings much needed opportunities to play and socialise with children facing similar challenges, helping to improve mental and physical wellbeing, and strengthen bonds and communication within families.





Family support groups taking place in Meru and Siaya



Nurse Stella in Kajiado County has been working with Daniel (photos left) and his family after discovering he had been kept at home away from school due to his disability. Our team referred Daniel to hospital for investigations into his condition and the project is supporting the cost. Stella also visited Daniel's school and his community leaders to help his teachers and elders understand his condition and how they can support him.

Brian was recently diagnosed with Burkitt's lymphoma, causing his family significant emotional and financial strain. Support from Siaya Hospice provides counselling, nutritional aid and regular home visits. This comprehensive care allowed Brian to return to school and engage in everyday activities.

"I am happy my parents and I were introduced to Siaya Hospice where we were received with a lot of care and compassion. So much love was shown to us. The team has been visiting me and my family and the visits bring a lot of peace, comfort and love in my heart"



~Brian Omori (photo right), 10 years old from Randago, Siaya



At just a year old, baby Kefa is the project's youngest patient (photo above left and centre, held by his mother at home). Kefa has a colon tumour and uses colostomy bags. Nurses from Meru Hospice are teaching his family how to care for him hygienically and supporting them through his treatment.

Lisper is 15 years old and is under treatment for leukaemia (photo above right, with nurse Gladys and her grandparents). When she became ill her parents left her with her grandparents. Meru Hospice nurses visit regularly to support Lisper and her grandparents and ensure she has adequate nutrition to cope with her treatment.