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Kenya Hospices and Palliative Care Association

PAMOJA

ANNUAL HOSPICE AND

PALLIATIVE CARE UNIT

NEWSLETTER

2011



Welcome note



By December 2011, Kenyan Hospices and Palliative Care Units will have provided care and support for around 30,000 patients, including 1,200 children over the year. Their work changes lives through providing effective pain relief, clinical care, subsidized or free medication, counselling and spiritual care.

Pamoja, the 2011 annual KEHPCA Hospice and Palliative Care Unit newsletter brings together news from Kenya's hospices, painting a picture of the crucial work that has taken place across the country over the past year, and the difference it has made to patients lives.

We are pleased that this year 16 hospices and palliative care units have shared their news and achievements. These range from stories of patients for whom palliative care has made a profound impact to their lives, to updates on impressive amounts of work undertaken by hospices across the year, to accounts of impactful World Hospice and Palliative Care Day 2011 events.

KEHPCA extend its grateful thanks to all organisations for sharing their stories, and particularly to Kimbilio Hospice and Laikipia Palliative Care Centre for submitting their first annual updates, after opening to the public in 2011.

Dr Zipporah Ali
National Co-ordinator, KEHPCA

TABLE OF CONTENTS

Welcome note.....	2
An update from Catherine Mc Auley Hospice.....	3
A short patient story from Chogoria Palliative Care Unit.....	4
2011 at Embu-Mbeere Hospice.....	5
Kijabe Hospital Palliative Care Unit - 2011 palliative care awareness walk.....	6
Kimbilio Hospice in 2011 - I am not forgotten.....	7
Nairobi Hospice annual charity walk 2011.....	8
Nakuru Hospice 2011 update.....	9
A new stoma support group at Nyeri Hospice.....	10
2011 at Meru Hospice.....	11
2011 update from Thika Hospice.....	12
Laikipia Palliative Care Centre.....	13
A successful year at Maua Methodist Hospital Palliative Care Unit.....	14
AIC Litein Hospital Palliative Care programme 2011.....	15
Shepherds of Life Hospice - the success story of Fridah.....	16
Tenwek Mission Hospital - Story of Moses.....	17
2011 at Viagenco, Homabay.....	18

An update from Catherine Mc Auley Hospice



Catherine Mc Auley hospice is within the confine of a new mission hospital, St.Vincent de Pauls, in Muhoroni. This fine building is surrounded by beautiful Kenyan gardens, encouraging an atmosphere that is calm and tranquil. The hospice includes; Male, Female, and Paediatric wards, a chapel of ease, sitting and dining room, and a spacious balcony.

Administrated by Sisters of Mercy, an institute in the United Kingdom, holistic care is provided throughout this all purpose built hospital, by a team of professional and devoted staff. Catherine Mc Auley grants, in patient care, terminal care with pastoral assistance, and support for the whole family. The foundress of the Sisters of Mercy, Catherine Mc Auley, had great love and compassion for people who were suffering. She believed this with her heart, giving comfort to the people, saying that “the poor needs help today and not tomorrow”.

The hospice aspires to build an environment, which is friendly and practical, so that the very sick people and their families are taken care of. By diligent work, and a firm work ethos set by Catherine’s legacy, patients can achieve the best quality of life. Additionally this is accomplished by relieving unpleasant symptoms that might cause distress, such as pain, anxiety, or nausea.

Patients who receive care at the hospice, will not only have improved quality of life, but will also live longer than patients who receive standard care. However, if and when the time comes for the patient to pass on, this is done with dignity, with friends and with family at their side. Catherine Mc Auley’s love continues on, through counselling and support for as many months as the family of the deceased wishes.

I have carved you in the palm of my hands, you are precious, you are mine.

A short patient story from Chogoria Palliative Care Unit



Miss A (not her real name) is a single lady in her forties. She lives alone in a rented room, and was first enrolled into palliative care over 12 years ago for support for HIV, as at that time she could not afford Anti Retroviral medication. She was struggling to undertake her daily living activities, so her family contacted the Chogoria palliative care unit.

A nurse was sent to assess the patient at home and found her to be struggling greatly, with hard food that was unsuitable for her, no bed, and in much pain. The nurse gave medical and nutritional support and promised the team would help her live a dignified life.

Initially the team did 1-2 weekly visits, controlled the pain, provided a bed, wheelchair, medical equipment, and prayed with her. Eventually through the support of PEPFAR funds ARV medication became available to her and today the palliative care unit continues to support her, with visits once a month. The patient is able to enjoy a much better quality of life and is happier, is able to lift herself into a wheelchair and says soon she will walk and leave the wheelchair for someone else!

She is so grateful to the Chogoria palliative care team and also to those who support Chogoria palliative care unit, including the Diana, Princess of Wales Memorial Fund.

Although over 50% of our clients are members of NHIF, they are still discriminated whenever they seek for treatment, as the NHIF programme only covers inpatient treatment. Without the hospice, Miss A would not have been able to afford treatment.

Miss A's story shows that comfort to palliative care patients, relieves pain and provides physical, psychological, and spiritual support.

2011 at Embu-Mbeere Hospice

Embu Mbeere Hospice is a registered charitable organization which aims at achieving total quality care for patients suffering from life limiting diseases. The hospice opened in September 2010, and has been built on land donated by a local well wisher and is currently run with funds donated by the local community, and the good will of local professionals and corporate bodies.

The Hospice covers the entire Embu District and its environs inclusive of Mbeere, lower Ukambani, Kirinyaga and Meru South Districts. The total catchment population is over one million people, and since opening its doors the centre has registered over 162 patients.

2011 has been a busy year for the hospice and has marked some significant achievements, including:

- Increased Cancer awareness in the community, with many people coming out for screening.
- Supply of breast prosthesis to breast cancer survivors - 12 patients benefited.
- Initiation of Memory Book concept, hence reduction of stigma.
- Improved disclosure among persons living with life limiting illnesses.
- Improved health of bed-ridden patients.
- Improved psychosocial support for children affected by HIV/Cancer.
- A donation of four dialysis machine units from Michigan U.S.A.
- Ongoing construction of new Dialysis Unit.
- Improved Networking and collaboration with other partners (local/international).

The hospice still meets challenges along the way, including a high demand for palliative care services versus the available resources, and unreliable means of transport for home visits, as the hospice does not have a vehicle, but we are dedicated to continuing to provide terminally ill patients' with care, dignity and hope to their significant others.



Kijabe Hospital Palliative Care Unit – 2011 Palliative Care awareness walk



On 1 October 2011, the Palliative Care Unit of AIC Kijabe Hospital hosted and conducted a 5km walk to promote community awareness of palliative care services. Participants numbered around 320 people and represented the hospital staff and senior management, the Kijabe School of Nursing, Moffat College of Bible, Naivasha and Ngarariga Girls Secondary Schools, and 12 other additional secondary schools. The route of the walk was from Uplands to the Manguo Grounds at the Limuru junction. Along the way, over 750 fliers and brochures bearing palliative care information were issued to occupants of passing cars and matatus.

Prior to the walk, health advice sessions on cancer had been conducted in all the 14 schools that participated in the walk. Also the schools were invited to assist in fundraising for the provision of palliative services at Kijabe Hospital, with a good response. As an incentive, students who met their fundraising goals were awarded T-shirts with the Palliative Care Unit logo and motto.

Upon reaching the Manguo Grounds, participants were entertained with drama and vocal performers and heard supportive and informational speeches from several speakers including local authorities, hospital Management, Unit leaders, and two patients who have become advocates for palliative care due to the benefits they have personally received from the services.

In addition to raising community awareness about cancer including its prevention, early diagnosis and treatment, the fundraising and sale of Palliative Care T-shirts netted over KSh 96,000 to support the care of palliative patients at Kijabe Hospital. The Palliative Care Unit considers the day a great success and plans to make this an annual event.

Kimbilio Hospice in 2011 - I am not forgotten

On May 6 2011 we officially moved into Kimbilio Hospice. It was a day of great joy. Though we are extremely grateful for the beautiful building that God provided for us; even more so, we are grateful for the many “guests” who have walked through our doors and who have given us a chance to love. There is a song that continually rings in my heart as I have the privilege of serving at Living Room:

“I am not forgotten. God knows my name. Light over darkness. Strength over weakness. Joy over sadness. He knows my name. Father to the fatherless. Friend to the friendless. Hope for the hopeless. He knows my name.”

At Kimbilio Hospice, race, tribe, religion, educational level or the ability to pay does not determine a person’s value nor does it interfere with the care provided by the Living Room team. Through the love and care given to each guest, our prayer is that they come to the understanding and realization that they are not forgotten.

We would like to give you a glimpse into the wonders that have occurred at Kimbilio Hospice this year and some of the names of our beloved guests who have not been, nor never will be forgotten:

- Chepchumba, eight years old, arrived at Kimbilio weighing only six kgs. Special feedings, medical treatment and constant loving care were implemented; and by God’s grace, she came back to life. A beautiful and unique joy radiates through her weakness; and though she has yet to speak a word, her gentle laughter has been healing to us all.
- Simeon, a man who came to the Hospice weak and alone, was told that he is well enough to go home no longer alone as he has found friends at Kimbilio.
- Eddah, a guest who continues to gain strength with each day, helps to feed and care for another patient who is unable to feed herself. It is moving to watch her compassion.
- Annah, a grandmother who came to Kimbilio with excruciating pain from advanced breast cancer, went home to be with her family, pain free.
- Agui, an elderly man who came to find a place of peace and prayer at Kimbilio, went home to be with Jesus.
- Betty, our hero, told us on a Friday morning in June: *“It is time for me to go and be with God.”* A significant part of the Living Room team and without whom Living Room would not exist, Betty’s faith and courage to speak openly about her HIV status empowered thousands to go for testing and to live in freedom. For each one, we are grateful.



Nairobi Hospice Annual Charity Walk 2011



On 18 September 2011 all roads led to Hillcrest secondary school, where one of our biggest fundraising events, the Nairobi Hospice Annual Charity Walk was held. This glorious day, put together by an interdisciplinary team of doctors, nurses, administration, support staff and our volunteers, was sponsored by Safaricom Ltd. Participants who included corporate sponsors, primary and secondary school students and the general public all went through a 10km trail through the Ngong forest where safety is always ensured by the presence of the Ngong Forest Sanctuary, Securex Ltd and Hardy Police Station.

They came in all ages and there was a prize for the youngest walker and the most senior walker. After the walk, kids from the Kibera Hamlets entertained everyone with a smashing performance. There were lots of delicacies courtesy of our well-wishers from all over the country. The day also offered an opportunity for participants to be more sensitized and informed on the management of Cancer and other life-limiting illnesses.

The turnout was incredible and we are delighted to report that the event was very successful. Our heartfelt appreciation goes to all the schools and corporate who signed in for the Nairobi Hospice Charity Walk. Thank you all for your kindness, dedication and effort that you put into making the event such a huge success. With support from friends like you, our vision to help patients with life-limiting illness live as comfortably and pain-free as possible becomes a reality. A Chinese philosopher once said "A journey of a thousand miles begins with a single step. We are already preparing for next year's Annual Charity Walk and we shall be looking forward to you joining us in another successful fundraising event. Let us echo the words of Mahatma Gandhi that "You may never know what results come of your action, but if you do nothing there will be no result".

Nakuru Hospice 2011 Update

2011 has been a successful year for Nakuru Hospice, as we occupied our newly renovated building in April 2011. This building was allocated to the Hospice in 2008 and the renovations financed by Safaricom Foundation amounting to Ksh 5million were completed in December 2010.

The New Hospice facility has various advantages including bigger space, with various examination rooms that have contributed to increased patients' privacy and confidence. The big parking space allows patients to be brought and waited for without paying parking charges. The Hospice compound with beautiful flowers and green grass gives freshness and clean air, and contributes a conducive quiet environment for patients. This has attracted many including the public and medical school students who visit the Hospice frequently. As a result the number of patients has increased by 207% - from 200 to 540 in November 2011.

The Nakuru Hospice was furnished (desks, chairs, visitor's chairs and waiting room chairs) by Lions Club of Nakuru. The Club also bought a fridge and a TV, and supported the purchase of drugs for patients. This has enabled us provide integrated palliative care within Nakuru County and the region.

We have been able to increase awareness creation activities and dissemination of information about availability and access to quality Palliative Care through print media including the Daily Nation, holding a talk show at Milele FM Radio Nakuru, and hosting a dinner which was attended by 220 guests, at Merica Hotel Nakuru, financed by Superior Medical Foundation Canada. This has also contributed too many people knowing the existence of the Nakuru Hospice.

The Superior Medical Foundation from Canada supported a workshop for caregivers, at Milele Resort Nakuru sensitizing them on the risk of forgetting one's self while caring for a loved one. 51 Caregivers attended this workshop. This is an activity as a Hospice we noted was very important and we shall continue holding such workshops in future.

Home based care program was almost a standstill last year 2010 and early this year. This was because we could not travel far from Nakuru Town due to distance and transport problem. However this was eased by a donation from Nakuru Town Constituency Development Fund where a new Nissan Urvan was officially handed over to us on 1st of July 2011 by Hon Lee Kinyanjui, who also gave his personal contribution towards the Hospice. Other individuals who gave personal contributions include the Chairman, Nakuru Hospice Dr. Timothy Olweny, Treasurer J.S. Shah, Mr John Macai, Dr. Kalya. The donations have enabled us reach patients as far as Molo, Njoro, Naivasha, Subukia, Mogotio, Ravine, Baringo and other places.



A new Stoma support group at Nyeri Hospice



In May 2011, Nyeri Hospice started a stoma support group after the team realized the need to have one after patient numbers with colorectal cancers were seen to be increasing steadily. The aim of the group is to provide psychosocial support, provide patients with colostomy bags, and educate them on stoma care.

The support group has 24 patients at the moment and they meet every third Wednesday of the month during the usual day care but later regroup separately to share experiences and to welcome new members in the group. Their families are also encouraged to accompany them so as to appreciate the need to give them support. The patients are delighted since their quality of life has tremendously improved as some of them were using nylon papers before they came to hospice. We sincerely want to thank the stoma support group at the Aga Khan University Hospital for the donation of colostomy bags.

2011 at Meru Hospice

2011 has been as busy year for Meru Hospice. In January 29 cancer patients were enrolled, and by the end of November 2011, the hospice had enrolled 170 Cancer and 60 HIV/AIDS patients who require Palliative care. A number of patients were suffering from both cancer and HIV. This growth of patients is most likely due to increased awareness both locally through Kenyan media, outreaches, and Meru Hospice 10th Anniversary celebrations on 8 October 2011.

Often, patients are referred to the hospice only when they are in the advanced stages of disease, and when they have exploited their financial resources, and are not able to contribute in a cost sharing towards their treatment. This has put pressure on the hospice's resources both in terms of purchase of drugs and man power, however, the staff show much team spirit as they work together towards the wellbeing of the patients.

This year Meru Hospice held the official opening of the hospice's new Hope Posho Mill on 8 October 2011. The posho mill is located at Gakoromone market in Meru town, and will function as a small enterprise development to raise money for the hospice, to assist in buying drugs and food for patients.

Meru Hospice provides trainings to various groups in palliative care and on HIV/AIDS. In March 2011, 25 people were trained on Prevention with Positives for 5 days. The participants involved leaders and members from HIV support groups across the region. In July 2011, the Hospice trained healthcare professionals on an introduction to palliative care for 5 days.

Awareness campaigns also make up an important part of Meru Hospice's work. In 2011 the hospice carried out 6 outreaches at two high schools, two colleges and two churches within Meru county. Topics covered included HIV/AIDS, Cancer, causes, prevention and behaviour change. During the outreaches we advocated for and created awareness to sensitize the community on how best they can take care for the terminally ill patients in their society. Meru hospice also participated in Agriculture Society of Kenya Show – Meru county in June 2011.



Hospice founder (Dr. Killingo B.M) together with our friends from Wisconsin during the official opening of our IGA project (Hope posho Mill) on our 10th anniversary

A 2011 update from Thika Hospice



Thika Hospice is a charity based organization registered in November, 2009. It is located in Thika town within Kiambu County. Its sole objective is to offer palliative care to persons suffering from life threatening illnesses like cancer, and provide a comprehensive therapy from the point of diagnosis to the period of bereavement. Presently, Thika Hospice is located within the Thika Level 5 Hospital (formerly Thika District Hospital). The operations of the hospice are done in a room donated by the hospital and a tent that was recently donated by well wishers.

It serves patients from Murang'a and Kiambu Counties. This was necessitated by the previous challenge that patients had hitherto its inception in Thika. The challenges were the distance the patients had to travel in order to access palliative care and the expense incurred. For instance, a patient in Thika had the option of either going to Nyeri hospice or Nairobi hospice. This was tedious since one had to opt for a journey of between 70KMs or 120 KMs to Nyeri or Nairobi hospice respectively. That in addition to the expense to be incurred was an inhibiting factor to the access of palliative care. The result was persons languishing in pain or stigma associated with the illness among several others.

As at the first day of November, 2011, Thika Hospice cared for 186 patients, mainly with cancer. With a sharp increase in the number of patients it cares for there is need for partners.

Recently we had a walk in Thika on the 8 October, 2011 to coincide with the World Hospices and Palliative Care Day. This was a very successful event, and much awareness was created. A free medical camp was also organized by Thika Level 5 Hospital. In addition, we also had a fundraiser at the Mt. Kenya University on 29 October, 2011 and medical camp organized by the Nairobi Womens' Hospital at the same venue.

Laikipia Palliative Care Centre

Since its inception in 2009, Laikipia Palliative Care Centre has offered palliative care to 150 patients, in addition to training community health workers and conducting advocacy and outreach programmes. The centre is meeting challenges in the continually growing number of patients we are requested to treat, and we are working to gain more support to enable us to build on our work.

The year 2011 has been a busy one for LPCC, with two major issues to deal with;

Search for a bigger space - The facility we are currently using for our services is getting small due to the increasing number of our patients. Laikipia Palliative Care Centre have identified and rented an old bigger building that needs to be renovated to make it suitable for the hospices services.

Food for the hungry campaign - The Laikipia region supports a mixture of well-watered areas in the south to the more semi-arid areas of the north. The majority of patients from the northern area of Laikipia are facing serious food shortages that have been made worse by the prolonged drought we experienced this year. The campaign goal is to improve the quality of life of our patients in Laikipia through provision of good nutrition. To ensure that this specific project goal is met, the hospice is embarking on campaigning for the donation of food stuffs by well wishers, to support the feeding programme of our patients. Dry grains and cereals are most suitable since they are non perishable.



A successful year at Maua Methodist Hospital Palliative Care unit



2011 has been a very busy year for Maua Methodist Hospital palliative care team. We are seeing an average of 90 patients daily who come through our palliative care programme. This makes it roughly 18,000 reviews over the last ten months. Currently 2,376 patients are receiving care and 1,804 patients actively receiving ART treatment. Cancer patients numbers is rising with referrals made from other surrounding facilities offering palliative care.

We held a very successful World Hospice and Palliative Care day activity this year. This event took place on 24 Oct, the annual Methodist Church in Kenya health care Sunday whose theme was; *Early Cervical Cancer Screening Saves Life*. The service, held at the Maua Methodist Church, was coordinated by the staff of Maua hospital where the hospital gynecologist, the palliative care consultant, the palliative care manager and other hospital staff made presentations. A support group of people living with HIV led the church service and had a very powerful message to make to the church.

This year saw the programme start the cervical cancer screening for female patients attending our clinic. So far, a total of 52 women have undergone the screening, and, 6 HIV patients had positive VIA VILLI results and have been managed well. Two have had cryotherapy done to treat early cancer. The PSA test for men is available and slowly men are coming for this test as information spreads out about this service. For the first time, we had very successful Teens with HIV psychological training. The hospital is undertaking PCR tests for babies delivered by HIV positive mothers.

The Maua palliative care team have participated in professional development training throughout the year to strengthen service delivery, in particular one nurse who completed higher diploma training in palliative care, and one nurse who trained in psychosocial training to help the HIV positive teenagers cope with the challenges of lifelong ART treatment. We conducted training for 14 community health volunteers who are helping us roll out community home care and tracing patients back to care. We had opportunity to attend a number of national meetings and made presentations on our programme activities.

The hospital has employed 6 people living positively with HIV in an effort of breaking down stigma and discrimination surrounding HIV, reaching more community members with HIV testing, encouraging positive living and reaching out to infected and affected families. Lucy our field health educator courageously living with HIV stands out as an encouragement who is ready and willing to share her story whenever called upon anywhere to popularize screening as well as treatment adherence.

AIC Litein Hospital Palliative Care Programme

AIC Litein Hospital was founded in 1924 by the Rev. and Mrs. Andrew Anderson, pioneer missionaries of the Africa Inland Mission. It became a cottage hospital in late 1960s before attaining a fully-fledged hospital status in 1990. It is located just outside Litein town in the South Rift, enjoying a serene atmosphere that is conducive for recuperation. It is a rural-based facility with a bed capacity of 160 and bed occupancy of 80%.

The hospital's Palliative care programme takes care of patients with life limiting conditions. It is a hospital- based service providing care to patients in our out- and in-patient units. The Palliative care department has grown rapidly since its inception in 2006 under the able supervision of Canadian volunteers Catherine Garratt and her husband Reginald Garratt.

The hospital has three staff holding a Diploma in Palliative Care from Uganda's Makerere University and Dr. Elijah Kerich has undertaken an MSc in Palliative care.



Shepherds of Life Hospice – the Success Story of Fridah



In the course of its operation in Tharaka, Shepherds of Life - Kenya, has contributed and impacted positively to the lives of many people living with HIV&AIDS. Among them are children who have been orphaned as a result and are also living with HIV& AIDS. Through the intervention of Shepherds of Life however, the lives of these young pupils have been transformed and also given hope in life. A case example is that of Fridah Gakii, who we met in 2011.

Through the help of a community volunteer, Shepherds of Life came to the attention of Fridah's situation and has noted tremendous progress in her life from the time we intervened. She has been having hearing problems since her childhood and her guardian could not afford to take her for medical attention. She was thus not able to attend the clinics for both the anti retrovirals and E.N.T. She was not also able to continue with her education due to lack of school fees and also lack of school uniform.

However, by the intervention of Shepherds of Life through individual sponsors to the program, the organization was able to start paying of the medical bills where needed, offering monthly transport support to attend the clinics, and payment of school fees and buying school uniforms. Fridah can now happily enjoy her life once more just like the other children. Fridah's hearing ability has improved and she is now attending the clinics; both for the ARVs and the E.N.T without failure. She is also doing well in her school work.

Tenwek Mission Hospital – the Story of Moses



When Moses was registered into the Tenwek Hospice and Palliative Care program his wife had no idea how much she would need the hospice services herself. Because our initial focus is on the patient with his life-limiting illness we too often think that the focal point is only on him. But while we do concentrate a lot of our attention on the treatment of his pain and distressing symptoms we should not forget that we are also there to serve the family as well.

Moses' story is a good illustration of this. It starts with understanding an unusual challenge in the year 2011. A healing ministry in Loliondo, Tanzania became very popular this past year. A prophet was promising healing for all comers and many of Tenwek's hospice patients made the long journey to drink the magic potion.

Moses, who had cancer of the tongue, and his wife got into a full 14 passenger matatu in hopes of going to Loliondo for a cure. After paying the large fee for the transport, the matatu headed down the rough, dusty road on its long trek. They finally arrived at their destination and proceeded to wait in an extremely long queue. Eventually everyone in the vehicle received a small quantity of the tasteless brew and they headed for home.

That was when his wife noticed that Moses was no longer breathing. Now a decision needed to be made. Take him to a nearby morgue and pay a small fortune to get his body back home or continue driving. Everyone knew of his condition and all in the matatu had to be in agreement if they were to proceed. They decided to press on and his wife was forced to prop him up and support his body for the entire journey home.

Moses' wife was traumatized beyond belief. When they returned home she didn't know where to turn so she contacted Tenwek Hospice and a home visit was made the next day. She was supported with counseling and prayer over several more visits. Over time she came to terms with this terrible event and was able to see the incredible value of home visits that are made by a few caring people.

Tenwek Hospice and Palliative Care is a donor supported, home based program that charges nothing for its services. We realize that many of the villagers we serve do not understand the value of hospice care until the end and would probably choose to go without it and miss out on its blessings if they were asked to pay. We thank KEHPCA and our donors their support and for caring about the people of Bomet County.

2011 at Viagenco, Homabay

Viagenco - Comprehensive Care & Support Program started in 2002 and is based in Lwanda Nyamasare Trading Centre in Mbita District of Homabay County. The program is primarily supported by visiting Nurse & Hospice Care of Santa-Barbara, and technical assistance from KEPHCA.

Viagenco's 2011 World Hospice & Palliative care day was celebrated very well in October at Lwanda stadium. We organized services of events including, football, netball, volley ball, bicycle cycling, tug of war and a canoe regatta. The event was well attended by government officials, development partners and private practitioners. Some five patients out of 150 palliative care patients had the opportunity to give public testimonies.

This year, one of our Nurses (Jenipher A. Ouko) attended training on legal aspects of palliative care twice organized by KEPHCA. The knowledge & skills gained has impacted positively in our interventions. We're also lucky to have been joined by psychosocial counsellor and social worker who are boosting the community based palliative care. In addition, most of our medical team have been trained on prevention with positives, which is an instrumental intervention in handling HIV/AIDS patients. As a whole the year 2011, has been a wonderful year of great achievements for Viagenco.

