

## A Day in the Life of **Rays of Hope Hospice Jinja.**

### HOME VISITS ON THE NYENGA ROUTE - 14 February 2017

Tuesday 14 February, 2017 was a day like most other days at Rays of Hope Hospice Jinja. After morning prayers, conference and a quick cup of tea, two teams of palliative care clinicians and a driver went off on home visits. Our team had the Nyenga route – and 18 clients were scheduled for visits. Each of the clients visited has his or her own story, problems, joys and worries – below we have chosen to introduce you to only a handful of those we visited. We hope it will give you, if nothing else, a keyhole view into the world of Rays of Hope Hospice Jinja palliative care in Busoga Region.

Let us first start with a beautiful and successful story.....

Rehema is a 40 year old woman with HIV/AIDS

When we first saw her, she was unable to sit or stand. She had HIV/AIDS and TB of the spine. She was in severe pain and was put on morphine. She always kept hopeful and the family was supportive. She would make her beautiful mats when lying down, flat on her back.

She is now able to stand and walk short distances with support, and she is only on basic pain medication (paracetamol and Ibuprofen).

Throughout she has been given adherence support to take her medicines for pain and for HIV/AIDS and TB correctly. She has also been given a little monthly support to help with food. She still makes beautiful mats and we would like to help her market them.





**Wawesa** is a 74 year old man. He has been a client with Rays of Hope Hospice Jinja since September 2015. He is HIV/AIDS positive with neuropathy. He is totally bed bound and dependent on help for everything. His main concern is now serious bed sores.

His wife is still alive and is caring for him together with the son. They are very poor and hard working. Hospice Jinja has helped with regular 2 weekly visits for treatment support. The family is also given monthly comfort fund (UGX10,000 per month), food (3 kg rice, 2 kg beans, 1 kg sugar per month (this ration was doubled in 2017 due to drought) and soap, a mattress and mackintosh. As he fears soiling the mattress Wawesa spends most of his day on a bamboo matt with a small table propped under his head as they have no pillow.

He has a loving son, who cares well for his father. This young man has a lot on his shoulders as the whole family is dependent on his work as a fisherman.





**Nakinta is 28 years.** She is HIV positive and has Kaposi's Sarcoma.

She became a client of Rays of Hope in November 2016, when she had already started treatment of her cancer from Mulago. The cancer treatment is not going well, and she needs to go back for change of chemotherapy. The family is very poor, they have until now managed to get her treatment from Mulago, but is running out of funds. Nakinta is receiving regularly 2-weekly visits from Hospice. She is on morphine.

Rays of Hope Hospice Jinja has 21 clients with Kaposi's Sarcoma – and this cancer can be treated with chemotherapy. If available the treatment is for free, but transport, tests and upkeep at Mulago Hospital in Kampala is a problem for many. Eva's family is running out of funds, but Rays of Hope Hospice Jinja will help her get the treatment she needs.

**Ondoga** is a 47 year old man. He became a client of Rays of Hope Hospice Jinja in August 2016. Since 2008 he has a tropical ulcer and all attempts of treatment have failed. We are providing basic pain management , antibiotics, and special soap for cleaning the wound .In addition he is given **comfort fund** (UGX10,000 per month) and **food support**. His social situation is difficult – the house is too small to lie down in and there is no bedding at all.



Ondoga needs **bedding**, and his house needs to be **re-built** so he can lie down in comfort.

We hope to help him through our newly piloted housing programme. Below a family where the mother suffered from advanced rectal cancer. The mother's biggest wish was to get a bed – but there was no space for bed in the old house, as a matter of fact, there was no space at all for the family and it was falling down. This family was given a new little house. Unfortunately, the mother died before the house was done, but at least her family now can lie down in relative comfort. These children are not in school due to lack of fees, but without **education** the path out of poverty will remain closed for them – let us try to help them.





**David is 57 years old.** He became a client of Hospice in January 2015, but he moved to Mbale and we lost contact with him. Thankfully, he has moved back and contact is now re-established.

He has for the past 11 years had a growing tumor on left side of face. The tumor was diagnosed 3 years ago as a basal cell carcinoma. He was seen at Mulago Cancer Institute and he paid for some tests, but could not afford them all and not the treatment.

Rays of Hope Hospice Jinja has offered to help him get the **tests and treatment** he needs.

He has a good chance for getting cured or at least his cancer to be delayed spreading further.

We have another albino woman with skin cancer, whom we first saw in the early stages of the tumor. She has already benefitted from our new Rays of Hope Hospice Jinja treatment support programme:



April 2016



Sept. 2016



Operated Decemberr  
2016



Back from Mulago ready to  
live on

These Photos show the rapid progress of disease up to operation. The wound has now healed and she is doing well. All tested lymphnodes showed that no spread of the disease.

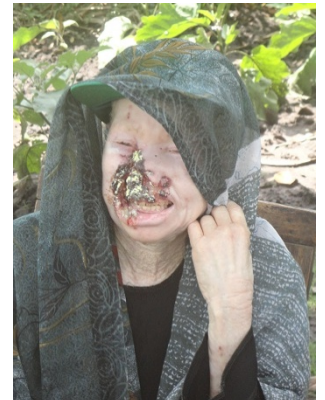
We have presently two other albinos with skin cancer for treatment at Mulago. A 20 year old man, who was deserted by his parents and never went to school. His sister died of a similar condition a few years ago.



Another client, an incredible strong woman, Alisha, came so late to Hospice Jinja that treatment was not possible. We visit her every 2 weeks and her pain is controlled and so is the smell – but her situation is more than difficult. It is getting increasingly hard to eat and talk. This photo of her is taken in November 2015, now half of her face is gone – but we didn't have the heart to take her photo.

Visiting Alisha is in many ways a very humbling experience as she always is positive and graceful.

However, it is also an experience which inspires you to ensure that no-one ever should suffer as she does .....and unfortunately among our clients she is far from alone. There is a lot of work to be done.



On this Tuesday 14 February, we saw 18 clients on the Nyenga Route – these clients above are only a few of them. It was a long day , as many of our days are. However, we are grateful for having the opportunity to help our clients. The need is huge and at times it can seem overwhelming, but let us do it together as best as we possibly can.

Submitted by Rays of Hope Hospice Jinja

February 2017