



29th July 2020

To: Uganda Cancer Trust – UK

Uganda has had 1,128 people who have tested positive for corona virus, many of these have recovered and 2 people have died as a result of covid-19 to date.

We are very grateful to UCT-UK for offering us funding that has enabled our team to continue providing our services amidst the covid-19 lockdown. In the initial stages of the lockdown there was a complete ban on public and private transport except for essential workers and this made it difficult for the team and patients to travel to hospital. The team was able to get around this by getting an official permit to travel from the Ministry of Health using this permit on Dr.Mhoira's car so that this car could pick up all team members to be able to go and see patients. We are grateful that the funding from UCT-UK enabled us to meet the fuel costs and costs of hiring a driver to take staff to work.

The funding also helped the team to have airtime and data on the phones to communicate with patients who were unable to come to hospital and to follow up patients that were discharged as many home based palliative care services could not access many patients. The data was also used to have communication within the team because few staff cover each site per day to keep within the physical distancing guidelines.

The funding also helped support patients' transport costs to come to hospital because transport costs had increased a lot.

The funding also helped us purchase personal protective equipment for staff as they worked with patients.

The lock down measures were eased at the beginning of June and public and private transport are now allowed but because of the need to keep within the physical distancing guidelines, public transport now carries fewer people and therefore transport costs have more than doubled.

Our staff are now using public transport but the costs are very high. We are also still meeting more virtually to keep within the prevention guidelines and also we are increasingly using the phone to follow up patients and therefore the team needs credit on their phones and data

Our current areas of greatest need now are;

- **Transport:**

We need to give staff some extra funds for transport to top up on the usual transport fare they used to pay to come to work because transport costs have more than doubled. (e.g if usual transport fare was 10,000 UGshs it is now 25,000 UGshs so we give them 10,000 -15,000UGshs)

- **Personal Protective Equipment**

The consumption of PPE and hygiene measure items is high and we need more PPE and hand hygiene measure items for protection.

- **Internet connection**

Since the opportunities to meet face to face as a team as less now, we are now making more use of online platforms like WhatsApp and zoom to keep in touch and update each other. The team now has a weekly schedule where a few members and volunteers meet at the various sites, discuss patients' needs and care plans then update the rest of the team on WhatsApp and any comments are made from there.

We have also been able to be a part of the various online meetings and discussions that are going in the Palliative care fraternity both in Uganda and internationally, to keep ourselves updated with what is happening elsewhere as far as Palliative care in this era of Covid 19. So every member of the team gets a monthly internet bundle that helps in the connection.

Below is one of the discussions that we have participated in organized by the Palliative Care Association of Uganda.

PALLIATIVE CARE FRATERNITY ONLINE DISCUSSION
 "The Right to Palliative Care in Uganda during the COVID-19 Pandemic"
 15th May 2020 11:00AM

Moderator
 Mr. Mark Mwesiga - Country Director, PCAU

Presenters
 Dr. Charles Oloo - Director Health Services, Ministry of Health
 Mr. Geoffrey Opiyo - Program Officer, CSIEA

Panelists
 Dr. Andrew Otero - Board Member, PCAU
 Mr. Justus Rugambwa - Executive Director, Knowu Mobile
 Mrs. Florence Nalintanya - Palliative Care Nurse, MPCU

REGISTER: <https://zoom.us/j/8256174444?pwd=ZjZkdjY0dDZlR0p0eUo1aGh1aUJmZjZl>

@PCAUganda | Palliative Care Association of Uganda

- **Patient care and support:**

The transport restrictions did not only affect the team but the patients as well who needed to come to the hospitals for follow up and treatment, so we have enabled patients by providing transportation for them to come to the hospital and food support to those that need it. This is an ongoing need and we need to continue some patients in need.

Giving hope to the vulnerable amidst hopelessness during the Covid 19 era



Toko offers psychosocial support to RN

RN is a 32yr old female who was diagnosed with synovial sarcoma of the left thigh and had surgery for tumor debulking at CoRSU in one of the private hospitals where her leg was disarticulated and later referred to the cancer institute for her chemotherapy treatment. She was referred to the palliative care team for pain and symptom control and it was at this point that we as volunteers, were asked to get involved in her care as part of the multidisciplinary palliative care team that was providing her with holistic care.

We regularly visit her and the sister who is also her main care giver. A good rapport was fostered, which allowed her to feel comfortable voicing her fears and concerns regarding her illness, which included social circumstances like not being able to afford the cost of chemotherapy, some investigations, and

transport to the cancer institute for review, she was so distressed about having one leg and failure to be able to walk normally and work as before. She had just lost her father about 6 months and then her sister who succumbed to cancer of the breast 2 months before we met her. She is married to a security officer who is not at home to take care of her all the time and does not earn enough to support the family. She is a mother of 3 boys 7, 4, and 2 years and is worried of living her children when she dies. Providing companionship, a sense of self-worth, and information, are among the important services we provided as volunteers

We also were able to provide practical, psychosocial, and spiritual support through liaising with the palliative care team members who were able to support her with some funds for investigations, treatment and transport to Hospital during the lockdown period collecting drugs such as morphine from the pharmacies, also help with the navigation in the hospital, offer counselling through listening to her concerns and worries and this is ongoing

She and family, continue to appreciate the time, help, care and love they are shown at their darkest moment by the palliative care team and they had this to say *“Thank you for visiting us and loving us this relationship should not end! May bless you all for the great work that you do! You give as hope.*

She also added *that “even when I know you can’t change my destination; you have done a lot to change our journey!”*

A word of encouragement from the patients that we care for;

*“... When I was told that the palliative care team was coming to see me I knew I just had a few days to live, but when I met you palliative care team I wished I met you earlier you are special you changed my way of looking at life, you have controlled my pain and I am more peaceful and happy. I no longer look at death as an enemy but just focused on the quality of life...” **Patient Joyce***

We thank all those who have continued to support us during this time always!

God bless you

PcERC-MPCU team