



Statement by Hospice and Palliative Care Organizations in Uganda on COVID-19 and Palliative Care Services for Patients and their Families in Need.

Submitted to:

The Chairperson
Coronavirus National Taskforce
Rt. Hon Dr. Ruhakana Rugunda
Prime Minister of the Republic of Uganda

April 6, 2020

On March 11, 2020, the World Health Organization (WHO) declared COVID-19 a pandemic. By this declaration, WHO called for governments to take urgent and aggressive action to stop the spread of the virus.

Organizations engaged in the promotion and provision of Palliative Care services in Uganda express gratitude to Government for the commitment towards managing this pandemic. His Excellence the President, The Chairperson of the Coronavirus National Taskforce, and committees have done a commendable job and this explains the high level of preparedness and action that Uganda experiences. We thank Hon. Dr. Jane Ruth Aceng, the Minister of Health and her team for the good leadership on this matter. We also commend all health workers at the fore front of this fight.

We would like to state that we will continue to offer support to the COVID-19 response in Uganda and are ready to offer more technical contribution as you may require and request. The integration of Palliative Care into the comprehensive response to COVID-19 is important. Palliative Care providers have skills in psychosocial and spiritual support, symptom control, and communication, including support for goals of care discussions and end of life care. We can therefore offer skills as part of the national, regional, district and community response.

Please note that even during the lockdown, our teams remain committed to offering Palliative Care services to patients and their families with the goal that, despite the severity of their diagnoses, we improve the quality of their lives, albeit with some circumstantial challenges.

In addition to efforts by government in ensuring that essential health services and social support assistance are attained by the vulnerable who include people with Palliative Care needs and their families, we wish to recommend the following to you:

1. Protection for all health workers, including Palliative Care providers, in both public and private health settings who continue to offer services during this period. Government should ensure training and resources for all health workers, including ensuring availability of appropriate Personal Protective Equipment (PPE) and leave no one behind.
2. Inclusion of the Palliative Care specialty in the response to COVID-19, a life threatening illness causing death in a brief period of illness especially among those with other underlying health conditions. This situation calls for a holistic approach to the patient care, a tenet of Palliative Care. It is paramount that Palliative Care teams are included to ensure that COVID-19 patients receive holistic care including end of life support and bereavement care if it ever becomes necessary in Uganda.
3. Supporting patients with Palliative Care needs in health facilities and in homes including those at end of life should be everyone's obligation during this time. Government and local leaders at community level should ensure that Palliative Care patients who need to access health care and social assistance get it.
4. The provision of Palliative Care services in this country includes home care, which is the appropriate model as the preferred site of care for most patients with life-limiting illnesses. Special guidelines for home care services should be developed by the Ministry of Health to ensure that patients are not abandoned entirely, especially at end of life.
5. While government has put in place transport guidelines for essential services, we appeal for further clarifications and effort in the following ways:
 - a) Patients from upcountry to Kampala especially those with cancer and receiving treatment at Uganda Cancer Institute (UCI) should

be given special considerations to help them access hospital at any time they need to travel. The fuel allocated for the pool of vehicles in districts should include that to cover these journeys. Patients and families who can afford to use private vehicles should be allowed.

- b) Staff in hospice and Palliative Care organizations up country be considered for waiver on use of private vehicle because they continue to work.
6. There is need for improved and increased messaging and communication by government to address the following concerns:
- a) Messaging and communication for COVID-19 has been concentrated on urban populations. Content in the local languages is still limited. There is need for more local language content to ensure that myths, misconceptions and half truths about coronavirus are addressed and accurate preventive information widely disseminated. There is need to counter the increased communication by traditional healers and other non-conventional healers which impacts our patient populations negatively. This should also cater for messages by some faith based leaders who are alleging conspiracy theories over this.
 - b) Government should also intensify messaging to counter the downplay of COVID-19 among the youth. The view that COVID-19 'only' affects older persons and those with underlying health conditions is incorrect and unsubstantiated. Evidence shows that young people and those without any underlying health condition are also susceptible to infection, severe disease and death.
 - c) Messaging that offers information for psychosocial wellbeing of populations such as our patients should be developed and disseminated.

Lastly, in the wake of the spread of COVID-19 virus which is not only causing infection, but also panic and fear, we are reminded that as Palliative Care providers, we work in these scenarios nearly every day, when we join patients and families to confront similarly frightening news and uncertain outcomes. We therefore know that our knowledge, skills and attitude which we use daily are important in navigating this situation. We are ready and willing to offer more support as you require us to.

We thank you:



Statement endorsed by:

- i) Palliative Care Association of Uganda (PCAU)
- ii) Africa Palliative Care Association (APCA)
- iii) Hospice Africa Uganda (HAU)
- iv) Rays of Hope Hospice Jinja (RHHJ)
- v) Makerere Palliative Care Unit (MPCU)
- vi) Hospice Tororo
- vii) Joy Hospice Mbale
- viii) Kawempe Home Care (KHC)
- ix) New Life Hospice Arua (NELIHA)
- x) Peace Hospice Adjumani
- xi) Hospice Ngora
- xii) Kitovu Mobile

About The Palliative Care Association of Uganda

PCAU is the National Association for Palliative Care providers in Uganda, registered as a Non-Governmental Organization (NGO) in 2003 and envisions access to Palliative Care for all patients and families in need in Uganda.

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