



# PCAU Newsletter

Jan-March 2020



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Welcome to the first edition of the PCAU online newsletter and thank you for your membership and subscription. We send you greetings well aware that this may find some at home or at work contributing to the COVID-19 response.

Every part of the world is facing unprecedented circumstances and restrictions in response to the current pandemic.

We thank each one of you that is playing your role to contribute to the response. We express our gratitude to all health workers at the front, facing this pandemic.

At PCAU Secretariat, we continue to engage all those responsible make sure that every patient and their family in need of palliative care receive it. We have made sure that PCAU members continue to interact and share experiences during this

period. This has contributed to continue service delivery albeit some challenges. No hospice or palliative care organization is closed during this lockdown. Our take is that we cannot abandon those in need at this time.

One of the tools that we are using to maintain our coordination role during this period is Social Media including WhatsApp. We have a weekly virtue meeting for all PCAU members for continuous experience sharing and learning. Contact our communications team to join these lively conversations if you are not yet part. We are working with the broadcast media.

PCAU Members are at the front line in the COVID-19 response in Uganda. Nearly, each District Coronavirus Task Force has a PCAU member. We encourage all, PCAU Members and nonmembers at different levels to play their role and to be relevant to this response. For our members, we request you to get in touch and share what you are doing in response to the pandemic. We will add yours to the many stories and share with everyone to learn from you.

To emphasize the need for strengthened integration of Palliative Care into the COVID-19 response in

Uganda, we have submitted a statement to the Chairperson of the Coronavirus National Taskforce. 

At the beginning of the year, we led a team to interface with the Committee on Health in Parliament which was scrutinizing the National Health Insurance Scheme Bill 2019. In our detailed statement is we emphasized that the scheme should cover palliative care which is part of Universal Health Coverage. 

In February, we held our national update meeting and over 90 Members attended. Contact the communications team for the detailed report in case you missed. We had a great Road to Hope Camp 2020 and we continued to offer scholarships for the Advanced Diploma in Palliative Care Nursing.

For those who would like to become PCAU Members, to renew your membership and subscriptions or send a generous contribution to our work you are welcome.

**Please use Momo pay merchant code 315849 (Palliative Care Association of Uganda)**

Continue to adhere to the guidelines of set by the Ministry of Health and Stay Safe.

## PCAU TO ENGAGE ACTORS ON INTEGRATING PALLIATIVE CARE IN UHC PROCESSES

**F**or the next two years, beginning January 2020, PCAU will engage national and international actors that work around Universal Health Coverage (UHC) to integrate Palliative Care.

This will be done under an African Palliative Care Association (APCA) led project dubbed “Fast-tracking strategic advocacy for inclusion of palliative care in Universal Health Coverage in Africa”. This important project will also be implemented in two other African countries, i.e. Kenya and South Africa. It is funded by the Open Society Foundations (OSF) and Open Society Initiative for Eastern Africa (OSIEA).

Ideally, UHC is designed to provide full spectrum of health services which include health promotion, prevention and treatment, rehabilitation, and palliative care irrespective of economic status or gender. The 2014 World Health Assembly Resolution calls on governments to ‘integrate palliative care services in the continuum of care, across all levels, with emphasis on primary care, community- and home-based care, and universal coverage schemes.’ The Uganda government was a key participant during the adoption of this resolution at the world stage, but has not implemented it fully.

One of the key deliverables for the two-year project will be to popularize the African Essential Palliative Care Package for Universal Health Coverage. This package was adopted by African Ministers of Health during their session at the 6th International African Palliative Care Conference in September 2019.

This package has 4 components that touch:

1. essential palliative care medicines,
2. essential equipment, patient supportive devices, technologies and supplies,
3. Human Resources and
4. psychosocial interventions.

During the project, palliative care providers in Uganda will be trained on strategic advocacy.

The project will also entail empowering direct stakeholders (palliative care patients and their families) to take frontline positions in advocating for their own rights.

## ESSENTIAL PALLIATIVE CARE PACKAGE FOR UNIVERSAL HEALTH COVERAGE, SEPTEMBER 2019

**Adults and children with serious chronic illnesses must not be left behind in Universal Health Coverage (UHC)**

# PALLIATIVE CARE FOR THE ELDERLY IN MUKONO DISTRICT

In aging societies, the last phase of people's lives changes greatly, which, in turn, challenges traditional care provided in geriatric medicine. In this case, geriatric palliative care should be conceptualized as an interdisciplinary field of care.

The number of older persons had increased from 686,260 in 1991 to 12,800,000 in 2014. This growth in number is not being matched with growth in support, thereby continuously making older persons to be the most vulnerable group of people in Uganda.



In order to improve their health, ROTOM established health centers for geriatric care to provide health care for older persons and their households. In the process of providing care for the older persons, ROTOM realized that most of the people they come across

As a way of building up more partnerships and further develop palliative care services in Uganda, the Palliative Care Association of Uganda (PCAU) visited Reach One Touch One Ministries (ROTOM) in Mukono District to discuss how they can integrate palliative care services in their facility.

are facing chronic devastating conditions like diabetes, cancer, heart diseases, HIV, dementia, and physical impairments among others. Many of these illnesses occur together among older people, hence having persistent symptoms such as pain.

ROTOM is a non-denominational Christian organization reaching out to older persons and children in their care through promoting their spiritual growth, improving their overall health, increasing their food and income security as well as supporting them to raise children under their care with education and health care.

Based on this, ROTOM realized the need of integrating palliative care in their health centers to enable them care for the old persons better. Among their key needs was training of the team to offer palliative care services including the health care professionals, carers and volunteers in community. The training would enable them to care for people within their places of choice, and manage their pain. ROTOM also requested PCAU and other palliative care specialists to front the need of palliative care among geriatrics and further engage in research in geriatric palliative care. Palliative care services need to be developed to meet the complex needs of older persons.

The United Nations defines older persons as people aged 60 years and above whereas the World Health Organization considers 50 years and above. In Uganda, about 85% of the older persons are engaged in crop farming with no security, thus rendering them economically vulnerable. Their situation is worsened by the burden of looking after orphans and other vulnerable children left under their care.

Medical personnel have a moral responsibility to provide effective pain relief and prevent unnecessary suffering for the aged.

According to ROTOM, the need to support older persons and their dependents in Uganda is great.

## 1 PCAU ANNUAL GENERAL MEETING 2020.

This year, the PCAU Annual General Meeting will take place on 29th May 2020 at Fairway Hotel, Kampala. The meeting will start at 9:00am up to 12:00 noon and we expect the Permanent Secretary Ministry of Health to be the Guest of Honor. The AGM brings together individual and organizational members of PCAU to reflect over the activities of the past year including those from the district branches. We therefore invite all members and partners to join us at the PCAU AGM 2020. **The meeting is subject to change if the current situation does not change.**

## 2 COMMEMORATING THE WORLD HOSPICE AND PALLIATIVE CARE DAY (WHPCD) 2020

World Hospice and Palliative Care Day (WHPCD) takes place on the second Saturday of October every year. It is a unified day of action to celebrate and support hospice and palliative care around the world. The theme for this year's WHPCD is "Nursing and Palliative care" in recognition of the WHO's declaration of 2020 as the year of the nurse and midwife. PCAU, which is the National Coordinating NGO for the Palliative Care Organizations in Uganda, has the mandate to coordinate the commemoration of this day nationally, working together with the Ministry of Health. The 2020 event in Uganda will be held on Saturday 10th October 2020 in Kampala. The main objective of this event is to create awareness and promote collaboration for advancement of palliative care in Uganda.

There will be a Palliative Care Walk which will comprise of members from Palliative Care Organizations in the country, wellwishers and other stake holders as well as the general public. More information will be posted on the PCAU website.

## 3 5th PCAU ANNUAL FUNDRAISING DINNER 2020.

The Palliative Care Association of Uganda (PCAU) holds the PCAU Annual Fundraising Dinner during the Month of December.

The dinner is held in Kampala under a specific theme aimed at supporting the strengthening of cancer and palliative care response in upcountry communities. During the Dinner, different activities are carried out including the PCAU Merit awards given to individuals and institutions that have contributed greatly to the growth of Palliative Care Services in Uganda, patient's voices, and entertainment among others.

The following have been the outcomes and impact of the past events:

- 1st PCAU Annual Fundraising Dinner – Funds were contributed and 2.5 acres of land was purchased for the establishment of New Life Hospice in Arua (NELIHA).
- 2nd PCAU Annual Fundraising Dinner – A Motor Vehicle to support outreach and home visits was donated in addition to funds contributed to purchase of a permanent home for Rays of Hope Hospice Jinja.
- 3rd PCAU Annual Fundraising Dinner – Funds were contributed for the renovation of Mobile Hospice Mbarara. The Dinner was also used as the main commemoration event for 25 years of Hospice Africa Uganda.
- 4th PCAU Annual Fundraising Dinner – Funds were raised to kick start the acquiring of a mobile van for Kitovu Mobile in Masaka. This dinner was also aimed at celebrating 20 years of PCAU and the Vice President of Uganda was the chief guest. This year's dinner will be held on 4th December 2020 and is aimed at raising funds for Hospice Tororo and we request you all to join us as we work towards the sustainability of Palliative Care services in Uganda. More information will be posted on the PCAU website.

# ENGAGEMENT WITH MEMBERS OF PARLIAMENT ON THE NATIONAL HEALTH INSURANCE SCHEME BILL.

On 12th February 2020, the Palliative Care Association of Uganda (PCAU) together with partners were invited and interfaced with the Committee on Health in Parliament which is scrutinizing the National Health Insurance Bill 2019 before it is tabled before the house for debate.



The meeting was attended by members of parliament representing different constituencies on the committee and partners from Hospice Africa Uganda, Mulago Palliative Care Unit, African Palliative Care Association and Dr. Jacinto Amandua the former Commissioner for Clinical Services at Ministry of Health. The meeting was focusing on the need to include palliative care in the bill.

The national health insurance scheme aims to ensure that all people have access to essential health services especially the most vulnerable members of our population, guided by the principles of equity and social justice. The inclusion of palliative care is a clear demonstration that the scheme is conscious of the health needs of those with serious chronic life limiting illnesses, such as HIV/AIDS, cancer and other Non-communicable Diseases (NCDs) and the health needs of the elderly, among others. The financial burden involved in the treatment and care of such conditions is pushing many into poverty in Uganda. Out of pocket payment for health services by patients and families who are experiencing overwhelming pain and suffering due to these disease conditions is an injustice which needs to be addressed by the scheme.

Analysis of the National Health Insurance Scheme Bill was done in the perspective of current research and practices in the field of palliative care in Uganda, the African region and globally. The unmet need for palliative care services is high due to low coverage that stands at only 4.8% across all government public hospitals. Most of these are urban based, leaving the majority of palliative care patients and families who live in rural areas to die in pain and suffering.

During the meeting, some of the asks from the palliative care fraternity to the committee included the following;

1. The National Health Insurance Scheme should include Hospice/Palliative Care organizations in the context of the interpretation of what a "Health Facility" is.
2. The Scheme should cover home based care for palliative patients and their families, which is the most appropriate and effective way of offering care especially at end life, as opposed to institutionalized care.
3. The scheme should also cover the Essential Package for Palliative Care which entails Interventions, Medicines, Equipment, Human Resources, and Inter-sectoral

Supports as highlighted in the attached memorandum.

4. Older person above retirement age should not be required to contribute towards the scheme unless they are in salaried employment or paid managerial positions. There should be government contribution to the scheme which should cover for contribution for the elderly.

The Chair person to the committee Dr. Micheal Bukenya welcomed all views presented and pledged to members that the committee will draft a report informing parliament of all the recommendations put out as we look forward to the next step.

To the palliative care practitioners, fulfilment of the above recommendations will mean inclusion of 400,000 Ugandans in need of palliative care to benefit from the scheme which is in line with objective 4 (a) of the scheme. i.e. to facilitate the provision of efficient, equitable, accessible, affordable and quality health care to all residents.

# The Road to Hope Camp 2020 – I AM EMPOWERED



With the aim of continuing to offer psychosocial support to children under the Road to Hope Program, PCAU held a camp on 23rd - 25th January 2020. This camp is an annual event where beneficiaries come together to bond with one another, share their experiences throughout the year and be supported in their areas of need, as well as discuss their future to impart hope. Children come from their different home areas to a central place in Kampala where the activities for the camp are conducted.

Road to Hope is one of PCAU's programs under advocacy and awareness creation aimed at supporting child care givers with education and psychosocial support. The program currently has 55 children from different regions of Uganda. These children are identified by palliative care practitioners who come across patients who have children as their main carers. The children are forced by their circumstances to give up all the rights entitled to them as children. To date, 5 children have graduated from the program; they are now independent and currently working in their different professions.

As children arrived on the first day, they engaged in several activities e.g.

- Wrote letters to their sponsors,
- Participated in introductions & interactions, and
- Voted for their camp president among other things.

The evening was climaxed with a remembrance ceremonial in memory of Annet Nakaye, where a gallery of her photos was projected and then all children and staff lit candles as a way of praying for her soul. Annet was one of the beneficiaries on the program who passed on in 2019.

On the actual day of the camp, the team was guided to tour the zoo where children were able to see different animal species. They later received a talk from councilors who had come from Wakisa Ministries. The session included topics like sexuality and avoiding early pregnancies, choosing good friends, future prospects as well as living a religious life. On the part of early pregnancies, they came along with a 16 year old girl who shared her experience about early pregnancies and highlighted the challenges of getting pregnant before the right time, lessons learnt and how to avoid early pregnancies. This being a practical example, children learnt a lot from it.

Children then had a one on one counselling session with staff and volunteers aimed at discussing their personal life including their performance at school, relationships at home with family members, challenges and getting a way forward based on their needs. These sessions helped the children psychologically but also informed PCAU on how best each child can be handled.

Children later had time to participate in different activities including swimming, donkey ride, bouncing castles, swings, and dancing among others. This was all crowned by cake cutting and traveling back to the area of residence to prepare for the next day when they would travel back to their home districts.

Our appreciation goes to the palliative care practitioners in the different districts that act as liaison between PCAU, the children and their families, as well as to the schools, the Center for Hospice Care in USA and the individual sponsors of these children that keep the Road to Hope program moving forward and contribute to these children's future.



# THE PALLIATIVE CARE NATIONAL UPDATE MEETING

**The Palliative Care Association of Uganda (PCAU) held her first quarterly national update meeting on 28th February 2020 at her premises in Kitende. The meeting brought together over 90 people including PCAU members, Ministry of Health officials, supporters and other stake holders.**



The Palliative Care Association of Uganda (PCAU) holds quarterly national update meetings which bring together people from different areas of the country including PCAU members, Ministry of Health officials, supporters and other stake holders. The update meetings offer a platform for discussion of different selected topics.

On 28th February 2020, PCAU held the 1st quarter update meeting at their premises in Kitende along Entebbe road which was attended by over 90 people. The theme of the meeting was, "Palliative Care in the current trend of HIV/AIDS care and treatment in Uganda". It was facilitated by presenters from Mildmay Uganda, Rays of Hope Hospice Jinja and The AIDS Support Organization.

The PCAU Country Director Mr. Mark Mwesiga welcomed all members to the meeting and thanked them for all the support in 2019 towards the development of palliative care in Uganda. He shared with members some of the main events set out for the year 2020 including the Annual General meeting on 29th May 2020 at Fair way Hotel, the World Hospice and Palliative Care Day which will take place on 10th October 2020 as well as the Annual dinner to happen on 4th December 2020. He concluded by introducing new staff to the members and officially opened the meeting.

Dr. Nabatte Violet and Dr. Jane Nakweesi from Mildmay Uganda shared with members the status of HIV/AIDS highlighting that globally, Uganda was doing better in HIV/AIDS care and treatment. Of all people living with HIV, 79% knew their status, 62% were accessing treatment and 53% were virally suppressed in 2018. 62% of adults aged 15 years and older living with HIV had access to treatment, compared to 54% of children aged 0–14 years.

Joanita Mbabazi and Josephine Namugambe from Rays of Hope Hospice Jinja noted that on a monthly basis they serve over 500

patients in the Busoga region of which 56.2% are Cancer patients, 22.2% have severe HIV/AIDS, 8.4% are Cancer and HIV patients and 13.1% with other chronic illnesses. They noted that in the different cases of HIV they come across, there is a high need for palliative care among HIV/AIDS patients due to their challenges like, lack of support from family members, poor adherence to drugs, long distances to reach the ART centers, inadequate follow up systems among others.

According to Dr. Priscilla Ajambo from TASO, 1.2 million people are living with HIV in Uganda, 3% have both HIV and cancer and 73% of patients who need palliative care are living with HIV. 60–80% of AIDS patients experience pain which is only treatable by palliative care.

All the presenters highlighted some of the challenges that need to be overcome with the increasing need for palliative care in HIV/AIDS care such as, ART drug non-adherence (stock outs, poor retention), increased incidence of non-communicable disease, limited palliative care research & scant career opportunities, insufficient budgetary allocation, limited advocacy and leadership by MOH to champion palliative care, inadequate capacity building of health workers in palliative care among others.

In 2019, the Ministry of Health created a division for palliative care and at the meeting, members officially welcomed Dr. Miriam Ajambo a senior nursing officer in charge of palliative care at MOH.

Dr. Miriam acknowledged all members present and informed them that she was ready to work with the palliative care fraternity in her new role. She pledged to support the development of palliative care and to present all issues that had been presented at the meeting including budget allocation for palliative care in the national budget, encouraging people to do research in palliative care among others.

Joyce Zalwango the PCAU Capacity Building Officer rounded off the meeting by thanking members and presenters and having members select the topic of next meeting which was agreed on as "research in palliative care"

# PCAU, UCI TO OPERATIONALIZE THE CANCER CENTER IN WEST NILE REGION

With the growing cancer burden in Uganda, partnerships between different stakeholders facilitate in jointly addressing the different issues that require various perspectives for implementing and evaluating the services.

The Palliative Care Association of Uganda (PCAU) in partnership with the Uganda Cancer Institute are working towards operationalizing the cancer center in the West Nile region to offer proper cancer care and palliative care services.

In an attempt to adopt a planned response to the cancer crisis through initiation of a comprehensive National Cancer Control Program as recommended by WHO, the government took steps to set up cancer treatment centers in different regions. These centers aim at decentralizing cancer treatment services as well as decongest the Uganda Cancer Institute.

PCAU has been supporting Arua Regional Referral Hospital (ARRH) Palliative Care unit for over 15 years. The support included scholarships for training, placement of an Administrative volunteer and facilitation for a Palliative Care Nurse who had retired from public service to continue offering services at the Unit. PCAU further supported the unit to improve their reporting by training the team and providing two laptops as well as a mobile phone for mHealth reporting, a system used to collect data using mobile phones.

The Palliative Care Unit at ARRH has always worked in a limited space. However, in 2019 they moved into the space that was provided for the Cancer Center because the palliative care team felt they needed

to secure the space for the center. They also preferred to coexist with the cancer center since the majority of the patients seen at the palliative care unit had cancer.

One of the biggest challenges faced by the unit is the retirement of palliative care nurses (hospital personnel). This led to patients being referred elsewhere, since those who were trained had moved.

In a meeting held between UCI and PCAU, the Executive Director for UCI, Dr. Jackson Orem noted that the team in Arua showed high interest in supporting the scale up of cancer services in the hospital and UCI would offer them all the support needed. He further noted that since the hospital had provided the space, and the medical equipment purchased, PCAU and UCI needed to explore how best synergies can be built to have the cancer and palliative care services scaled up in Arua.

BECOME  
A PCAU  
MEMBER

### Membership Fees

Membership Type	Fee	Frequency
Individual membership	20,000/=	Annual subscription
District Palliative Care initiative & CBO membership	500,000/=	Annual subscription
Individual Life time membership	1,000,000/=	One time subscription
Institutional/Organizational membership	1,000,000/=	Annual subscription

# PCAU TRAINS HEALTH CARE PROFESSIONALS ON PALLIATIVE CARE



PCAU held a training for health care professionals on Palliative care at Mulago School of Nursing and Midwifery from 17th-30th February 2020. The five days palliative care introductory course was aimed at developing participants' understanding of the philosophy, principles and practice of palliative care through giving basic information and

knowledge to health care workers on the concepts of Palliative Care.

The training empowers participants to identify patients with palliative care needs, undertake holistic assessment and manage pains and symptoms of the patients. At the end of the course, participants had gained knowledge on how to integrate palliative care concepts in the daily health care activities and appropriate referrals systems to specialized palliative care centers.

The training attracted a number of providers including doctors, nurses and councilors from 10 facilities including Mengo Hospital, Rubaga Hospital, IHK, Nsambya Hospital, Rays of Hope Jinja, Case Clinic, Kisubi Hospital, Kibuli Hospital, Life Mate Clinic and Medical Teams. The participants shared experiences and dilemmas they face as they deal with patients including communication with the patients & families with life limiting illnesses, assessing and managing patients' symptoms, holistically handling the patients' needs among others.

The participants remarked that Palliative care is critical and the training was timely for the work they do and applauded PCAU for the knowledge imparted.

## Palliative care in the news.



### EXTERNAL LINKS

<https://www.softpower.ug/health-insurance-bill-palliative-care-association-wants-elderly-persons-exempted-from-making-contribution/>

<https://www.independent.co.ug/palliative-care-should-be-included-in-national-health-insurance-scheme-pcau/>

<https://ugandaradionetwork.net/story/palliative-care-should-be-included-in-national-health-insurance-scheme-pcau>

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