

Celebrating

Since 1999



**With your support, we have
been empowered to make
a lasting impact.**

Celebrating 25 years of extending
compassion, holistic care, pain relief,
hope, and justice to individuals and
families in Uganda.



Highlights on PCAU Achievements and Milestones on Palliative Care Development in the last 25 Years in Uganda.

Foundational Development and Expansion



- 1999:** PCAU was established as the first National palliative care association in Africa paving a way for national level advocacy and service development.
- 2003:** Registered fully as a Non-Government Organization (NGO).
- 2006:** Became independent of Hospice Africa Uganda (HAU) which offered a seed capital of UGX 300,000. Operated in shared spaces with the African Palliative Care Association (APCA).
- 2010:** Obtained first new vehicle through granting by USAID
- 2012:** Acquired own office Premises in Kitende on Entebbe Road.
- 2018:** Received 1 Acre of Land Donation in Mbarara
- 2019:** Commenced Life Membership category now with 50 Life Members
- 2019:** Commemorated 20 years of strategic advocacy for palliative care in Uganda
- 2023:** Acquired third new vehicle through local and international fundraising

Advocacy Achievements, Milestones on Guidelines, Structures, Policy and Legislation



- 2004:** The Ministry of Health issued Statutory Instrument No. 24 which permits Nurses and Clinical Officers who have undergone specialized training to prescribe oral liquid morphine legally for pain management.
- 2010:** Advocated for and achieved the inclusion of palliative care in Uganda's National Health Policy.
- 2015:** Was invited and gave a presentation at the United Nations General Assembly Special Session on drugs (UNGASS) in New York.
- 2017:** Advocated for and supported extending oral liquid morphine's shelf life from six months to one year.
- 2017:** The Uganda Human Rights Commission reported on the Right to Palliative Care in their 20th Annual Report following PCAU Advocacy.
- 2023:** Government integrated positions for Palliative Care Providers in Public Health Facility Structures from National Referral to HC III.
- 2023:** Advocated for a balanced legislation on the Narcotic Drugs and Psychotropic Substances (Control) Bill, ensuring access to essential pain relief medications for palliative care patients.
- 2024:** The National Essential Health Care Package for Uganda integrates Palliative Care from National Referral to HC III.

Partnerships and Collaborations



- 2008:** Began a partnership with Center for Hospice Care (CHC), Indiana, USA through Foundation for Hospices in Sub-Saharan Africa (FHSAA), now Global Partners in Care.
- 2010:** Began University internship program hosting international students and have hosted over 50 students from USA and other continents.
- 2017:** Established Memorandum of Understanding with Uganda Cancer Institute (UCI)
- 2021:** Established Memorandum of Understanding with Uganda Christian University (UCU) for collaborative Research and Education.
- 2023:** Joined other seven organisations to establish a new NGO HelpAge Advocacy Network Uganda (HANU) a consortium of Age Care Organisations in Uganda.
- 2023:** Established a partnership with the HAN University of Applied Sciences in the Netherlands for collaborative research.
- 2024:** Established a Memorandum of Understanding with Soroti University

Research, Education and Training

- 2009:** Accomplished the first national palliative care audit for Uganda. Only 34 of 84 districts then had palliative care practitioners & Morphine availability.
- 2010:** Developed a 5-day national palliative care training curriculum for health workers with USAID support.
 - Initiated palliative care units in 13 Regional Referral Hospitals.
 - Launched Palliative Care Education Scholarships and has offered 164 Diploma and BSc in Palliative Care Scholarships by the end of 2023.
- 2012:** Published "The Development of Palliative Care in Uganda", documenting the history of palliative care in the country.
- 2013:** Began hosting biennial national palliative care conferences that have been sustained to date cohosting the largest cancer and palliative care conference in the region.
- 2015:** Piloted the Palliative Care Surveillance Program using mHealth technology that transformed and supported full integration of palliative care data in HMIS.
- 2015:** Commenced implementing the Pain-Free Hospital Initiative with support from the American Cancer Society.
- 2017:** Co Hosted the 1st Uganda Conference on Cancer and Palliative Care and have hosted four conferences to date attracting an average of 400 delegates from Uganda, the region and globally.
- 2018:** Developed and approved the National Advanced Diploma in Palliative Care Nursing curriculum with the Ministry of Education and Sports.
- 2019:** Began sponsorship program for nurses under the Advanced Diploma in Palliative Care Nursing (ADPCN) program at Mulago School of Nursing and Midwifery.
- 2022:** Published the PCAU Research Agenda and began offering PCAU Research Grants, and have offered 6 scholarships for MSc in Palliative Care.
- 2022:** Supported the Ministry of Health to fully integrate Palliative Care Data in HMIS. Over 132 Health Facilities trained and over 66 fully report on Palliative Care in the DHIS2.
- 2022:** Published study on status of Palliative care showing 226 accredited palliative care facilities across Uganda.
- 2023:** Accredited to be a Continuous Professional Development (CPD) Provider for Nurses and Midwives in Uganda
 - Hosted 1st cohort of Nursing students from HAN University of Applied Sciences in the Netherlands on an internship program.
- 2024:** Published a study on Depression, anxiety, psychological distress, and perceived social support among Ugandan palliative care providers during the COVID-19 pandemic



Establishing Hospices and accrediting health facilities for palliative care services

Over the years PCAU has supported the initiation and the establishment of hospices and palliative care units in Uganda. The country has 17 home care programs.

In 2010 PCAU was mandated by the Ministry of Health to accredit health facilities meeting palliative care standards. By the end of 2023, at least 227 health facilities were offering palliative care in Uganda.

Since its founding, PCAU has established 10 regional committees (PCAU Branches). PCAU is composed of 30 member organizations, and over 1550 individuals and has a membership presence in nearly every district of Uganda.



Empowering people and communities to improve access to Palliative Care in Uganda

- 2010:** Commenced programming for palliative care as a Human Right in partnership with Uganda Network on Law, Ethics, and HIV/AIDS (UGANET) and APCA reaching over 45 districts.
- 2012:** Launched the Road to Hope Program to support child caregivers supporting over 130 children by the end of 2023.
- 2020:** Commenced Special Hearts To Nature Every (SHiNE) Child Program to support cancer treatment and care navigation for children suffering cancer.
- 2023:** Commenced Compassionate Community initiatives working with Lweza Community Health Program and Taibah International School.



1999

2003

2006

2010

2018

2020

2023

2024

■ Highlights on gaps and challenges on the provision and access to palliative care in Uganda

- ➔ **Lack of stand-alone national palliative care strategy, guide and standards** to enable guided strategic interventions and standardised quality of care across health facilities and community.
- ➔ **Limited trained human resources** especially at health facilities and those trained may not be retained due working conditions.
- ➔ **Limited awareness leading to misconceptions** about palliative care among health care professionals and the public leading to delay or rejection in seeking the service.
- ➔ **Limited palliative care research and evidence** to inform improvement in the quality of care and informed decision making.
- ➔ **Low funding and resource constraint** for the highly needed community and home-based palliative care services.
- ➔ **Low integration of palliative care into the broad spectrum** of social services to meet the needs of special groups such as vulnerable children, older persons and people in humanitarian settings.
- ➔ **Dire lack of access to essential medical sundries** and other supplies by the indigent patients and their families especially in communities and homes leading to undignified living.

■ PCAU interventions in the medium and long term beyond the silver Jubilee

- ➔ **Strategic advocacy and supporting efforts towards realisation of the national strategy, guidelines and standards for palliative care in Uganda.**
- ➔ **Continued resources mobilisation and support for palliative care education in Uganda.**
- ➔ **Advocacy and support for integration of palliative care data collection and utilisation into the national health information systems.**
- ➔ **Sustained advocacy and support for universal access to essential medicines, patient supportive devices, equipment and technologies.**
- ➔ **Continued focus on research, generating evidence and strengthening the Uganda Conference on Cancer and Palliative Care for research and information dissemination.**
- ➔ **Continuing to strengthen programming on empowering patients, families and communities to understand their right to palliative care and actively engage in compassionate care initiatives.**
- ➔ **Continuing to harness and support PCAU membership resources mobilisation needs including establishing the members SACCO.**
- ➔ **Continued advocacy for full integration of palliative care in Uganda's health and other social services sectors for universal access to the service.**

Our Mission

To accelerate the provision and integration of palliative care in Uganda's healthcare system through capacity building, advocacy, research, governance and resources mobilization.

Our Vision

Palliative Care for All in Uganda

Goal

Universal provision and access to culturally appropriate palliative care in Uganda.

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