

# Essential Palliative Care Package for Universal Health Coverage in Uganda



Do not leave Children and Adults with life limiting illnesses behind in UHC



**Universal Health Coverage (UHC)** means that all people have access to needed health services (including prevention, promotion, treatment, rehabilitation and palliation) of sufficient quality to be effective while also ensuring that the use of these services does not expose the user to financial hardship (WHO)



## SUSTAINABLE DEVELOPMENT GOALS (SDGS)

3.8 is to achieve (UHC), including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all.

WHO estimates that about **40 Million people** are in need of PC



**78%** of them live in low- and middle-income countries such as Uganda.

Only **11%** of those in need of pain control and palliative care access in Uganda.



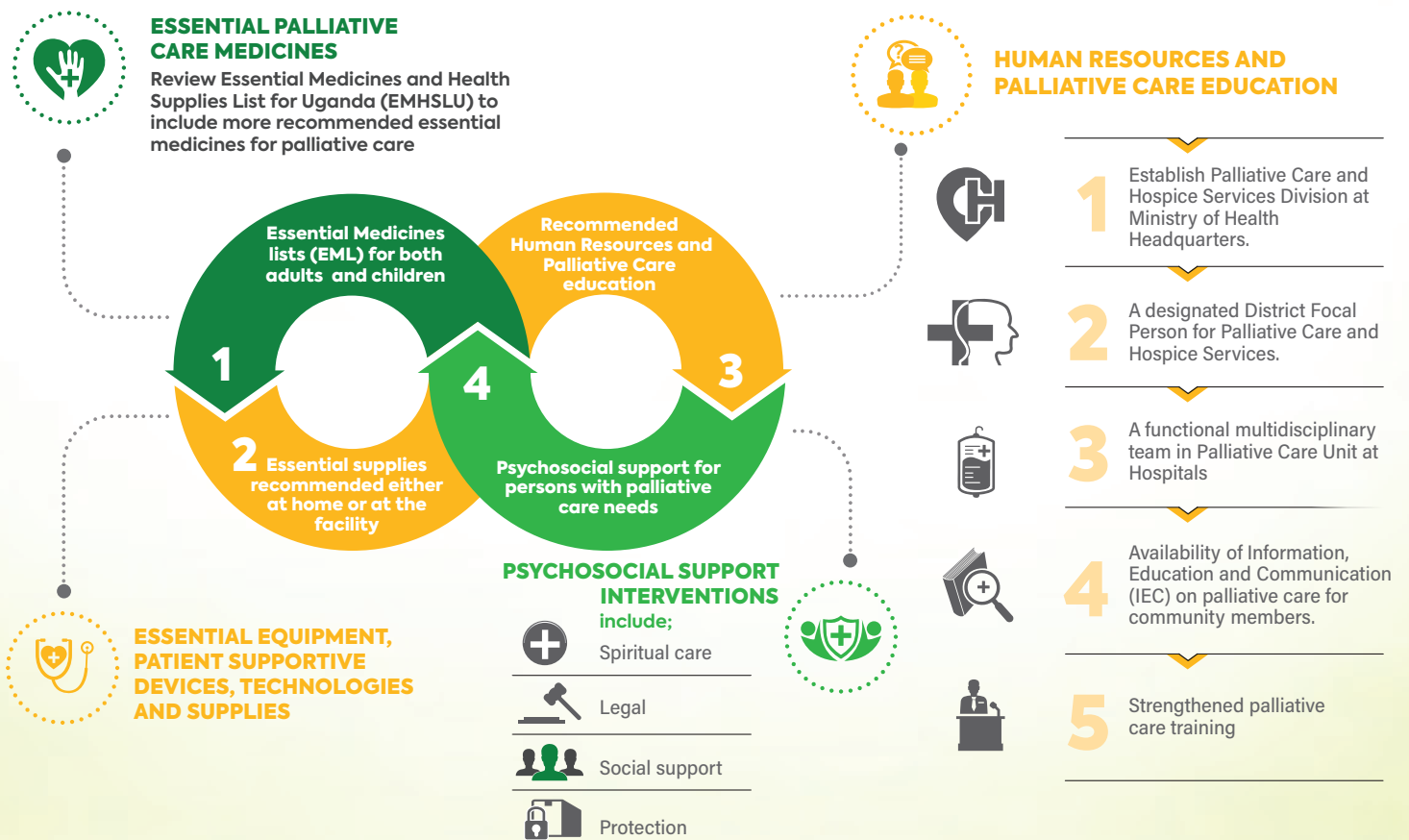
Palliative Care is required for a range of diseases, for adults;

- Alzheimer's and other dementias
- Cancer
- Cardiovascular diseases (excluding sudden deaths)
- Cirrhosis of the liver
- Chronic obstructive pulmonary diseases
- Diabetes
- HIV/AIDS
- Kidney failure
- Multiple sclerosis

In addition, for children, other diseases that require palliative care include:

- Congenital anomalies (excluding heart abnormalities)
- Blood and immune disorders
- Meningitis
- Neurological disorders and neonatal conditions.

## The Recommended Essential Palliative Care Package for UHC



# 1. Introduction

The Sustainable Development Goals (SDGs) target 3.8 is to achieve Universal Health Coverage (UHC), including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all<sup>1</sup>. The World Health Organization (WHO) defines UHC as ensuring that all people have access to needed health services (including prevention, promotion, treatment, rehabilitation and palliation) of sufficient quality to be effective while also ensuring that the use of these services does not expose the user to financial hardship. Universal Health Coverage covers two key elements: that everyone should be able to access a full range of health services and that people are protected from financial risk when they are seeking care<sup>2</sup>.

It is therefore critical that UHC processes evolving at global and national levels ensure that no one is left behind. That includes the millions of people who are living and dying around the world without access to hospice and palliative care, including pain treatment<sup>3</sup>.

**Palliative Care (PC)** is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. PC is the prevention and relief of suffering of any kind – physical, psychological, social, or spiritual – experienced by adults and children living with life-threatening health problems<sup>4</sup>.

Each year WHO estimates that about 40 Million people are in need of PC; 78% of them live in low- and middle-income countries such as Uganda. Palliative Care is required for a range of diseases, for adults and they include the following:<sup>5</sup>

- |   |                        |
|---|------------------------|
| • Alzheimer's and other dementias                   | • HIV/AIDS             |
| • Cancer  | • Kidney failure       |
| • Cardiovascular diseases (excluding sudden deaths) | • Multiple sclerosis   |
| • Cirrhosis of the liver                            | • Parkinson's disease  |
| • Chronic obstructive pulmonary diseases            | • Rheumatoid arthritis |
| • Diabetes  | • Drug-resistant TB.   |

In addition, for children, other diseases that require palliative care include:

- Congenital anomalies (excluding heart abnormalities)
- Blood and immune disorders
- Meningitis
- Neurological disorders and neonatal conditions.

Reports from hospices and palliative care organizations in Uganda note an increase in number of patients with sickle cell disease requiring palliative care service.

1 The United Nations Sustainable Development Goals (SDGs) <https://sustainabledevelopment.un.org/topics/sustainabledevelopmentgoals>  
 2 Universal Health Coverage and Palliative Care, Do not leave those suffering behind [http://www.thewhpc.org/images/resources/publications-reports/Universal\\_health\\_coverage\\_report\\_final\\_2014.pdf](http://www.thewhpc.org/images/resources/publications-reports/Universal_health_coverage_report_final_2014.pdf)  
 3 Knaul, Bhadelia, Atun, et al. Palliative care: an essential facet of universal health coverage [https://www.thelancet.com/journals/langlo/article/PIIS2214-109X\(19\)30323-7/fulltext](https://www.thelancet.com/journals/langlo/article/PIIS2214-109X(19)30323-7/fulltext)  
 4 Palliative Care <https://www.who.int/news-room/fact-sheets/detail/palliative-care>  
 5 World Health Organization and Worldwide Hospice Palliative Care Alliance, 2014. Global Atlas of Palliative Care at the End of Life. [pdf] Available at: <[http://www.who.int/nmh/Global\\_Atlas\\_of\\_Palliative\\_Care.pdf](http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf)>

## 2. Brief Status about Palliative Care and UHC in Uganda

According to the 2018 Africa scorecard on domestic financing for health, countries aspiring for UHC (as of 2015) needed to have a government expenditure on health of more than \$86.3 per capita and 5% of their GDP<sup>6</sup>. Only 11 African countries met the target of 5% of their GDP. Two countries met the 2001 Abuja Declaration target of spending more than 15% of annual government budget on health.

In Uganda, the Health Sector accounts for 5.1% of the national budget in FY 2020/21 down from 7.9% in FY 2019/2020. Total nominal allocation is projected to decrease by 40% from UGX 2,589 Billion in FY 2019/20 to UGX 1,550 Billion in FY2020/21<sup>7</sup>. Over 89% of the African countries including Uganda; out of pocket health payments were more than 20%. According to WHO, this means there is a financial catastrophe or impoverishment caused by health payments<sup>8</sup>.

In 2017, civil society organizations in Uganda submitted a joint statement to the UN Human Rights High Commissioner during the Universal Periodic Review Process 2nd, 26<sup>th</sup> Session of the Human Rights Council in 2017<sup>9</sup>. The statement gives a highlight on the status of palliative care in Uganda and recommendations by the civil society actors.

Uganda Vision 2040 that aims to transform Uganda into a competitive upper middle-income country sets 14 health targets<sup>10</sup>. Uganda's National Development Plan sets out seven health sector development priorities one of them being palliative care services. In addition, one of the objectives of the National Health Policy (NHP) II is to increase financial risk protection of households against impoverishment due to ill health. Furthermore, the Health Sector Development Plan 2016-2020<sup>11</sup>, clearly outlines implementation framework to achieve objectives of the NHP II. This included palliative care.

Two Acts of parliament recognize the need of palliative care at both governance and service levels of tertiary level health care facilities: The Uganda Cancer Institute Act, 2016<sup>12</sup> The Uganda Heart Institute Act, 2016.<sup>13</sup> Unfortunately, Uganda does not have a stand-alone National Palliative Care Policy. The process of developing the Policy has taken over 10 years. UHC provision is emphasized in key national strategy documents.

To date, the availability of risk pooling mechanisms such as National Health Insurance is not available in Uganda. According to the Uganda Health Sector Development plan 2015, households still account for about 37% health care financing. As this is majorly from out-of-pocket payment, households are pushed into impoverishment.

In 2017, the Uganda Human Rights Commission reported for the first time on the Right to Palliative Care in their 20<sup>th</sup> Annual Report<sup>14</sup>. This was done within the broader framework of the right to health and its attendant components such as availability and accessibility. The UHRC established that 70% of the services were provided at health facilities, 25% at the district health office, while only 5% are home-based care.

6 African Union and the Global Fund, 2018. Africa Scorecard on Domestic Financing for Health, 2018. [online] <http://aidswatchafrica.net/index.php/africa-scorecard-on-domestic-financing-for-health/document/75-2018-africa-scorecard-on-domestic-financing-for-health-english/12>

7 Economic Policy Research Center, Investing In Health <https://www.unicef.org/esa/media/5961/file/UNICEF-Uganda-2020-2021-Health-Budget-Brief.pdf>

8 World Health Organization (WHO) African Region Expenditure Atlas November 2014 [https://www.afro.who.int/sites/default/files/2017-06/who-african-region-expenditure-atlas\\_november-2014.pdf](https://www.afro.who.int/sites/default/files/2017-06/who-african-region-expenditure-atlas_november-2014.pdf)

9 Joint Civil Society Report on Palliative Care in Uganda Submission to the United Nations Universal Periodic Review (UPR) Of Uganda Second Cycle, Twenty Sixth Session Of The UPR Human Rights Council. Accessed file:///C:/Users/Mark%20PCAU/Downloads/JS31\_UPR26\_UGA\_E\_Main%20(1).pdf

10 Uganda Vision 2040, <https://www.greengrowthknowledge.org/sites/default/files/downloads/policy-database/UGANDA%29%20Vision%202040.pdf>

11 Ministry of Health <https://www.health.go.ug/cause/health-sector-development-plan-2015-16-2019-20/>

12 The Uganda Cancer Institute Act, 2016 file:///C:/Users/Mark%20PCAU/Downloads/Uganda%20Cancer%20Institute%20Act%202016%20(1).pdf

13 The Uganda Heart Institute Act, 2016 <http://ugandanlawyer.com/wp-content/uploads/2019/03/Uganda-Heart-Institute-Act-of-2016.pdf>

14 The 20th Annual Report of the Uganda Human Rights commission (UHRC) accessed here <https://www.uhrc.ug/download/uhrc-20th-annual-report-2017/?wpdm-dl=426&refresh=608d0bb39d1d21619856307>

Findings also revealed that majority of the palliative care patients travel a distance of more than 5km from their homes to access palliative care services. The number of public health facilities offering a form of palliative care and stocking oral liquid morphine stand at 226 as of December 2020 and these are located in 107 out of 146 districts. The number of standalone Hospices stands at 13 while health facilities with home care programs stand at 17 by December 2020<sup>15</sup>.

The new structure of the Ministry of Health established a Division of Hospices and Palliative Care at the Ministry's headquarters<sup>16</sup>. The new staffing structure of the national specialized hospitals also has integrated positions of palliative care consultants. The staffing structures at Regional Referral Hospitals, District hospitals, lower health facilities and community health workers have not yet integrated palliative care.

Uganda reconstitutes its own Oral Liquid Morphine at Hospice Africa Uganda (HAU) and this is paid for by the government of Uganda. Patients in need access the pain medicine free of charge. Progressively, the Essential Medicines and Health Supplies List for Uganda (EMHSL) 2016 by the Ministry of Health has been improved to include essential medicines for palliative care including laxatives.

### 3. Brief on the challenges for Scale up of Palliative Care service in Uganda

Investment by the Ugandan government in palliative care work remains low. The coverage of the service is still low. A total of 39 districts do not have any form of palliative care being offered. The 2019 statement<sup>17</sup> by Ugandan civil society actors led by PCAU pointed out the key challenges impacting palliative care services in Uganda. Hardly any public health facility offers home care even when this is recognized as the most suitable mode of palliative care provision in Uganda. Whereas Uganda has approved various palliative care training programs and specialist course, the qualified health workers are yet to be recruited, retained and remunerated by the government civil service as a palliative care cadre. The financial position of standalone hospices and the national association for palliative care which currently fill the gap in palliative care service provision has been threatened by the COVID-19 pandemic. Standalone hospices in Uganda largely depend on external donors and generous contributions. The COVID-19 report<sup>18</sup> by PCAU showed that the hospices had reduced their operations to more than 50% mark during the country's lockdown.

### 4. Importance of the Essential Palliative Care Package for Universal Health Coverage

The UHC processes and steps in Uganda have so far not had palliative care as one of the central pillars. By recommending an essential palliative care package for UHC, the Palliative Care Association of Uganda is providing a tool on basic parameters for UHC actors in Uganda. This Essential Palliative Care Package for Universal Health Coverage (EPCP) for UHC is also advocacy tool for health care advocates seeking to ensure the integration of palliative care in all UHC process and interventions. Government Ministries and agencies seeking to serve the vulnerable and championing the SDG slogan of '*Leave no one behind*' will also find this document an informative and useful tool on assessing their interventions concerning access to services by persons living with life limiting illnesses.

15 Palliative Care for Chronic Cancer Patients in the Community: Current State of Palliative Care in Uganda, Namukwaya E, Mwaka D, Namisango E, Mwesiga M, Downing J 2021 [https://link.springer.com/chapter/10.1007%2F978-3-030-54526-0\\_24](https://link.springer.com/chapter/10.1007%2F978-3-030-54526-0_24)

16 Ministry of Health Hospice and Palliative Care Division <https://www.health.go.ug/programs/ministry-departments/office-of-the-director-of-curative-services/department-of-clinical-services/palliative-care-and-hospice-services-division/>

17 Statement by Civil Society Organizations in Uganda on Budget Allocation for Palliative Care Services <https://pcauganda.org/wp-content/uploads/2020/12/Civil-Society-Statement-on-National-Budget-Allocation-of-Palliative-Care-April-2019-1.pdf>

18 Palliative Care Association of Uganda (PCAU) Report on Interventions in response to COVID-19 Pandemic [https://mcusercontent.com/7aaaf507baf2bf061e70e603c/files/d8130ca3-04dd-4098-8c5d-3ebd2a6b88c9/COVID\\_19\\_Interventions\\_report.pdf](https://mcusercontent.com/7aaaf507baf2bf061e70e603c/files/d8130ca3-04dd-4098-8c5d-3ebd2a6b88c9/COVID_19_Interventions_report.pdf)

## 5. The Recommended Essential Palliative Care Package for Universal Health Coverage

The Uganda National Minimum Health Care Package (UNMHCP) as stated in the National Health Policy II includes Palliative Care.

An affordable, Essential Package of Palliative Care (EPPC) and pain relief interventions can ameliorate a large part of the preventable burden of suffering if made universally accessible to all in need in Uganda.

This EPPC for UHC in Uganda is based on the Lancet Commission Report on Palliative Care and Pain [5], consultation with palliative care specialists, input from persons with lived palliative care experiences (patients and caregivers) and has been adapted from the EPPC developed by the African Palliative Care Association (APCA) for Africa.

The EPPC includes the recommended essential palliative care medicines, equipment, patient supportive devices, technologies and supplies, human resource and education, as well as psychosocial support interventions.

The recommended package is presented below:

### 5.1 Essential palliative care medicines

The Essential Medicines lists (EML) for Palliative Care by the International Association for Hospice and Palliative Care (IAHPC) and one recommended by WHO in 2017 have the following for both adults<sup>19</sup> and children<sup>20</sup>.

• Amitriptyline	• Ibuprofen	• Omeprazole
• Bisacodyl	• Lactulose	• Ondansetron
• Carbamazepine	• Levomepromazine	• Oral rehydration salts Diarrhea
• Citalopram	• Loperamide	• Oxycodone
• Codeine	• Lorazepam	• Paracetamol (Acetaminophen)
• Dexamethasone	• Megestrol Acetate	• Prednisolone (as an alternative to Dexamethasone)
• Diazepam	• Methadone	• Petroleum jelly
• Diclofenac	• Metoclopramide	• Senna
• Diphenhydramine	• Metronidazole	• Tramadol
• Fentanyl	• Midazolam	• Trazodone
• Fluconazole	• Mineral oil enema	• Zolpidem
• Fluoxetine	• Mirtazapine	
• Furosemide	• Morphine (Immediate & Sustained release)	
• Gabapentin	• Naloxone parenteral	
• Haloperidol	• Octreotide	
• Hyoscine butylbromide		

19 WHO Model List of Essential Medicines for Children. <https://apps.who.int/iris/bitstream/handle/10665/273825/EMLC-6-eng.pdf?ua=1>

20 African Palliative Care Association (2011). APCA Standards for Providing Quality Palliative Care Across Africa. Online: [https://www.africanpalliativecare.org/images/stories/pdf/APCA\\_Standards.pdf](https://www.africanpalliativecare.org/images/stories/pdf/APCA_Standards.pdf)

The Essential Medicines and Health Supplies List for Uganda (EMHSL), 2016 should be aligned with the above list by including the following medicines:

- Citalopram
- Diphenhydramine
- Gabapentin
- Methadone
- Megestrol Acetate
- Mirtazapine
- Octreotide
- Petroleum jelly
- Senna
- Trazodone
- Zolpidem

## 5.2 Essential Equipment, patient supportive devices, technologies and supplies

In Uganda, the following essential supplies are recommended to enable Palliative Care services either at home or at the facility;

- Bag for carrying or keeping all the required supplies
- Thermometer
- Blood pressure machine
- Gloves
- Pressure-reducing mattress
- Nasogastric drainage or feeding tube
- Urinary catheters
- Double locked cupboard / Opioid lock box
- Torch with rechargeable battery (if no access to electricity)
- Adult diapers (or cotton and plastic, if in extreme poverty)
- Colostomy bags
- Protheses as may be appropriate
- Radiotherapy for palliative modality for cancer patients *where it is available* in the national system
- Mobile phone-based platforms for medicine and patient tracking as well as for patient-health-worker interaction
- Oxygen

### 5.3 Human Resources and Education

Palliative care is a multi-disciplinary team approach. The skilled human resources work together to ensure the best quality of life for the patient and their family. These are defined by the WHO and APCA Palliative Care Standards<sup>21</sup> cognizant of the role of multi-disciplinary teams – general doctors, specialist doctors, clinical officers, nurses, pharmacists, psychosocial support workers, spiritual support workers, other allied health workers and volunteers. The volunteers need to be supported and supervised.

The following is the recommended Human Resources and Palliative Care education:

- 5.3.1 An Established and functional Palliative Care and Hospice Services Division at Ministry of Health Headquarters.
- 5.3.2 A designated District Focal Person for Palliative Care and Hospice Services for each District in Uganda.
- 5.3.3 A fully functional multidisciplinary team working in a well-established Palliative Care Unit at National, Regional and District Health Facilities at least up to Health Center IV level.
- 5.3.4 Availability of Information, Education and Communication (IEC) on palliative care for community members.
- 5.3.5 Strengthened palliative care training in training policy for health professionals, training of existing health professionals on palliative care, embedded palliative care curricula of all new health professional courses and palliative care curricular for training community volunteers and communities.

### 5.4 Psychosocial Support interventions

Palliative care offers a range of psychosocial interventions including spiritual care, legal and social support and protection for the most vulnerable including the older persons.

This package recommends strengthening active collaboration at national and policy level for government ministries and agencies concerned with social security, protection and development for harmonized strategies on palliative care. Health facilities offering palliative care including the public should have psychosocial support interventions. Health facilities including the public ones should have in place collaboration and partnership arrangements intended for psychosocial support for persons with palliative care needs

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*This package has been adapted from the African Palliative Care Association Essential Palliative Care Package for Universal Health Coverage, September 2019. And with consultation and input from Hospices and Palliative care organizations together with persons with lived palliative care experiences.*

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<sup>21</sup> The prevalence of life-limiting illnesses at a Ugandan National Referral Hospital BMJ support PC, 2015 Jacinto A.



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