



# **PALLIATIVE CARE FACT SHEETS FOR MEDIA HOUSES IN UGANDA**



## ISSUE #1

### **What is palliative care?**

Palliative care is the service that is provided to improve the quality of life of patients and their families facing the problems associated with life-threatening illness.

It is provided through the prevention and relief of suffering by means of early identification, thorough assessment and treatment of pain and other complications including; physical, economic, psychosocial and spiritual.

Palliative care is applicable early in the course of an illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy, radiation therapy or Antiretroviral Treatment (ART). It includes investigations needed to better understand and manage distressing clinical complications, starting from the time of diagnosis of a life-limiting illness such as cancer, HIV and others, throughout treatment, and extending into endoflife care and bereavement support for the family.

It also focuses on informed decision-making, and coordinated services across the continuum of care; that is, communication, information sharing, patient preferences, advanced-care planning, bereavement care, ethical principles related to hastening death and peace and dignity for the patient, the family and other care providers.

***Please refer to this site for further elaboration on palliative care and its principles: <http://www.who.int/cancer/palliative/definition/en/>***

## ISSUE #2

### Who needs palliative care?

According to the World Health Organization (WHO) and the Worldwide Hospice Palliative Care Alliance (WHPCA), both adults and children with the following disease conditions in any setting may require palliative care:

- **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, Parkinson's disease, rheumatoid arthritis, drug-resistant tuberculosis (TB).
- **Children:** cancer, cardiovascular diseases, cirrhosis of the liver, congenital anomalies (excluding heart abnormalities), blood and immune disorders, HIV/AIDS, meningitis, kidney diseases, neurological disorders and neonatal conditions.

Being holistic in nature, the palliative care approach can

however be used to provide holistic health services for other disease conditions, outside those listed above.

**Remember!** A key factor influencing the type of service people with life-limiting illnesses require depends on the intensity of their needs.

***For more information, please refer to the WHPCA and WHO Global Atlas of Palliative Care at the End of Life, accessible at: <http://www.who.int/cancer/publications/palliative-care-atlas/en/>***

## ISSUE #3

### **Where can one access palliative care services?**

As of April 2015, there are 203 health facilities that provide some form of palliative care in Uganda. These include: Mulago National Referral Hospital, 13 regional referral hospitals, 70 general hospitals, 65 health centre IVs, and four health centre IIIs. Fifty private health facilities also provide palliative care services and these include 11 standalone hospice centres, and other organizations that are providing palliative care, with programmes extending into the communities they serve. The Uganda Ministry of Health, in collaboration with the Palliative Care Association of Uganda (PCAU), has accredited these facilities to provide palliative care services.

For further information on the actual facilities providing palliative care and contacts for interviews, email or phone PCAU at [pcau.admin@pcau.org.ug](mailto:pcau.admin@pcau.org.ug), tel: (039) 2080713.

***Recommended further reading:***

*Worldwide Hospice Palliative Care Alliance (2011). Mapping Levels of Palliative Care Development: A Global Update 2011, accessible at: <http://www.thewhpc.org/resources/item/mapping-levels-of-palliative-care-development-a-global-update-2011>*

## ISSUE #4

### Essential medicines for palliative care patients

The following list is based on the WHO's list of Essential Medicines in Palliative Care (2013). They include but are not limited to:

	<b>MEDICINE</b>	<b>RECOMMENDED USE IN PALLIATIVE CARE</b>
1.	Amitriptyline	Anorexia/Fatigue
2.	Dexamethasone	Anxiety
3.	Diazepam	Depression
4.	Docusate sodium	Depression
5.	Haloperidol	Delirium
6.	Hyoscine Butyl bromide	Respiratory tract secretions



	<b>MEDICINE</b>	<b>RECOMMENDED USE IN PALLIATIVE CARE</b>
7.	Ibuprofen	Pain
8.	Loperamide	Diarrhoea
9.	Lorazepam	Anxiety
10.	Metoclopramide	Nausea and vomiting
11.	Morphine	Pain and Dyspnea
12.	Senna	Constipation
13.	Sodium Picosulfate	Constipation

***Additional information is available at: [http://www.who.int/selection\\_medicines/committees/expert/19/applications/PalliativeCare\\_8\\_A\\_R.pdf](http://www.who.int/selection_medicines/committees/expert/19/applications/PalliativeCare_8_A_R.pdf)***

## ISSUE #5

### **Cost of providing palliative care services.**

Various studies from different countries have found that the healthcare costs of people who are dying are extremely high, particularly in the last year of life. A growing body of evidence suggests that inpatient and in-home hospice and palliative care services can reduce these costs. Palliative care services in Uganda are offered as part of a package of health services at government health facilities, and these are free to the patients that need them. However, it has been estimated that the cost of providing comprehensive palliative care to one patient per week is currently approximately 86,000 Ugandan shillings. This estimate is based on Hospice Africa Uganda's (HAU) assessment, which largely uses a home-based care model and could cost less for facility-based care. HAU's home-based care model includes medicines, home visits, cost of professional care providers' logistics and support services.

Other examples of studies which highlight cost savings as a

result of hospice and palliative care include:

- a. A study by Shnoor and others found that in Israel, the overall per-patient cost of care for patients with terminal metastatic cancer was \$4,761 for those receiving home hospice care (a figure that includes program operating costs) and \$12,434 for those receiving conventional health care services.
- b. A study by Hongoro and others in South Africa of the potential benefits of hospital outreach services found concluded that such services have the potential to avert hospital admissions in generally overcrowded services in low-resource settings and may improve the quality of life of patients in their home environments. Palliative care is a cost effective approach and saves governments' money by reducing the amount of time and resources spent on a patient who is admitted in hospital due to chronic illnesses. Models of palliative care, including community and home-based service delivery, can be inexpensive. Because it can be delivered at home, it further creates space for patients

who require acute care in the health facilities.

**Further reading:**

- Shnoor Y, Szlaifer M, Aoberman a, et al. *The cost of home hospice care for terminal patients in Israel. American Journal of hospice and Palliative Care.* 2007;24:284-90.
- Hongoro C, Dinat N. *A cost analysis of a hospital-based palliative care outreach program: implications for expanding public sector palliative care in South Africa. Journal of Pain and Symptom Management* 2011 41(6):1015-24. Epub 2011 Feb 17
- Hongoro C, Dinat N. *A cost analysis of a hospital-based palliative care outreach program: implications for expanding public sector palliative care in South Africa. Journal of Pain and Symptom Management* 2011 41(6):1015-24. Epub 2011 Feb 17

## ISSUE #6

### **How big is the need for palliative care in Uganda?**

The World Health Organization estimates that 1% of each country's population needs palliative care. Therefore, there is currently an estimated 3,490,000 people in Uganda requiring palliative care services. In 2010, 80% of the 16,526 patients who died of cancer in Uganda had moderate to severe pain and 50% of the 112,065 people who died due to HIV related causes had moderate to severe pain. Meanwhile, only 2.6 % of patients who needed pain relief in Uganda received it, leaving the total estimated untreated deaths in pain at 67,000(Treat the Pain, 2010).

Despite all efforts that have resulted in the extension of palliative care services to 112 districts in the country, just over 10% of individuals in need of palliative care can access it. This figure does not include the needs of families where lack of palliative care support leads to the exacerbation of poverty, social stigma, and family breakdown.

## ISSUE #7

### **What is the government and development partners doing about palliative care in Uganda?**

Palliative care is one of the basic essential clinical services the Government of Uganda provides to its people and is highlighted in the Health Sector Strategic Plan of 2010/11 -2014/15. The Ministry of Health provides free pain management medication in the form of oral liquid morphine, among other forms. They support their healthcare workers to provide palliative care in all accredited health facilities by allowing time for capacity building and allocating space for palliative care units within the facilities. The Ministry is currently in the process of finalising a national palliative care policy that will enhance the provision of palliative care services in Uganda.

Uganda has legal instruments that date back to 2004 to allow appropriately trained nurses and clinical officers to prescribe

oral morphine for pain and symptom control for patients with lifelimiting illnesses. This is in addition to medical doctors who by law have historically been the only health workers allowed to prescribe narcotic medications. Uganda was the first country in Africa where this category of health officers – nurses and clinical officers - are allowed to prescribe morphine. Uganda's medical and nursing teaching institutions have also integrated palliative care into its curriculum.

The development partners that are working very closely with the Ugandan government to ensure the integration of palliative care services into the health systems include: the African Palliative Care Association, Palliative Care Association of Uganda, Mildmay Uganda, Hospice Africa Uganda, Makerere Palliative Care Unit, Kawempe Home Care, and many others. Each of these partners provides unique palliative care services in various ways including: capacity building, policy development support, palliative care education, research, service delivery, and medications, among others.

## ISSUE #8

### **Benefits of palliative care to patients and their families**

The right to health and the right to dignity are both important human rights. All people have a right to these basic needs and principles. Ensuring that people with lifelimiting illness have access to palliative care helps to make sure that their human rights are realised throughout life. The benefits of the palliative care approach include:

- Reduction of pain and improvement to the quality of life of patients with illnesses that cannot be cured.
- Effective palliative care can significantly improve the physical, emotional and spiritual wellbeing of such patients - and that of their families.
- Palliative care helps to prepare patients and their families for the death of a loved one – and allows death to occur with dignity and minimal suffering.
- It also helps caregivers and family members to cope



with the distress associated with seeing a loved one in pain and improves the care-giving experience, therefore enhancing patient and family communication and relationships.

- It improves the health of a patient, and helps a terminally ill patient to maintain dignity in the final stages of life and in death if it is appropriately provided by care takers and health care providers.
- Palliative care helps patients, their families and the health care providers in making important decisions on issues pertaining to the patients' holistic life in a timely manner.

## ISSUE #9

### **Challenges in access and provision of palliative care.**

- *Lack of a policy to support the provision of palliative care services:* while there is currently a policy under development that shall enhance palliative care service provision once it is in place, the lack of a national palliative care policy has resulted in limited investment in its provision by the Government of Uganda.
- *Inadequate financing of palliative care activities:* also arising from the lack of a national policy is a barrier to its access by all adults and children who need it in the country.
- *Inadequate knowledge and awareness of palliative care among policy makers, health and social care professionals, communities and individuals:* There is a general lack of understanding of what palliative care is

and how it enhances life. It is often erroneously seen as synonymous with death.

- *Limited integration of palliative care into health systems in Uganda:* Although efforts have been made toward the integration of palliative care into health systems in Uganda, only 203 health facilities currently provide palliative care services and less than 10% of the people that need palliative care services actually receive it.
- *Delayed diagnosis and treatment:* Most Ugandans have no access to effective screening, early diagnosis, treatment or palliative care. Consequently, those facing a diagnosis of cancer can experience a painful and distressing death.
- *Inadequate health and social care infrastructure:* Even where a confirmatory cancer or HIV diagnosis is made sufficiently early, Uganda still lacks the health and social care infrastructure to provide the necessary care to those infected by the disease.

- *Inadequate number of trained palliative care professionals:* not only is there a shortage of general medical staff in Uganda, but there is a significant skills training deficit in palliative care in particular. Few opportunities exist in general nurse and medical officer training to gain experience in palliative care, with even fewer opportunities in specialist palliative care post-qualification settings.
- *Lack of evidence for palliative care:* there is a general lack of evidence to support and document the dire need for palliative care due to insufficient resources allocated to undertake robust research in palliative care in Uganda. Evidence is required to inform the delivery of effective and appropriate care.
- Inadequate supply of medications, including palliative care medications, for patients in need.

## ISSUE #10

### Myths and misconceptions about palliative care

*Myth #1:* Palliative care is a service that is given to people who are in their final days.

**Correction:** Palliative care is not only for people who are in their final days before death but for people with a terminal illness, including noncommunicable disease. It is important for doctors to explain to terminally-ill patients why and what will happen to them when making patient referrals to the palliative care ward or referring the patient back to their home. Patients can be distressed by the lack of information.

*Myth #2:* Palliative care caters for only the old and dying patients with end-stage diseases without further treatment.

**Correction:** The specialty of palliative care is provided to patients with a progressive incurable illness to allow them

to have the most out of their remaining time to spend with families and friends. It is not limited by age or illness and they can still receive treatment where necessary.

*Myth #3:* Patients will be sedated until their end of life.

**Correction:** Each patient is different in every way. Every pain management and treatment option must be tailored to meet the individual needs.

*Myth #4:* Patients will not be able to be discharged once admitted for palliative care.

**Correction:** Palliative care is not just limited to the hospital setting. Many patients prefer to remain at home surrounded by loved ones as they are approaching the end of their life. Even admitted patients will be discharged once their symptoms are well under control.

*Myth #5:* Palliative care is not only about the process of dying for the patient.

**Correction:** Palliative care is not limited to the patients receiving it, but also extends to their families. Taking care of a dying loved one can be very tiring and detrimental to one's health, in terms of physical and emotional. With that being said, bereavement counselling, pastoral care and support groups are offered to families to help them through this difficult time. They are an invaluable part of the palliative care team that specializes in dealing with difficult issues with the aim of aiding families to come to terms with the condition of the patient.

***Recommended further reading:***

<http://www.webdicine.com/palliative-care-the-myths-and-misconceptions.html>

## ISSUE #11

### **Legal and regulatory frameworks guiding palliative care.**

- The World Health Organization clearly recognises palliative care as an essential health service. <http://www.who.int/cancer/palliative/definition/en/>
- The United Nations (UN) Political Declaration on Non-Communicable Diseases (NCDs) in 2011 recognised palliative care as playing a vital role in this global response. [http://www.un.org/en/ga/ncdmeeting2011/pdf/NCD\\_draft\\_political\\_declaration.pdf](http://www.un.org/en/ga/ncdmeeting2011/pdf/NCD_draft_political_declaration.pdf)
- Palliative care was considered a critical component in the response to NCDs and Neglected Tropical Diseases (NTDs) at the African Union (AU) Ministers of Health conference held in April 2013 in Addis Ababa, Ethiopia. <http://www.carmma.org/event/sixth-session-african-union-conference-ministers-health>



- The sixty-seventh World Health Assembly in its agenda item 15.5 urges member states to strengthen palliative care as a component of comprehensive care throughout the life course.<http://ncdalliance.org/67th-world-health-assembly-may-2014>

## In Uganda

- The Uganda Narcotic Drugs statute was reviewed to enable nurses and clinical officers to prescribe morphine in 2004. Therefore, Uganda has legal instruments dating back to 2004, which allows appropriately trained nurses and clinical officers to prescribe oral morphine for pain and symptom control for patients with lifelimiting illnesses. Uganda was the first country to allow such a category of health officers to prescribe morphine.
- Morphine is listed on Uganda's Essential Medicines List and its use is controlled as per international regulations for narcotic use.<http://www.medicines Transparency.org/fileadmin/uploads/News/Essential%20Medicines%20%26%20Health%20Supplies%20List%202012.pdf>

***Further Reading;***

*National Drug Authority (Supply of certain Narcotic Analgesic drugs) Regulations, 2002*

## ANNEX #1

### References and recommended further reading

- WHO: 2013. 'Background note: Towards Universal Health Coverage: concepts, lessons and public policy challenges WHO/World Bank Ministerial Level Meeting 2013.[http://www.who.int/mediacentre/events/meetings/2013/uhc\\_who\\_worldbank\\_feb2013\\_background\\_document.pdf](http://www.who.int/mediacentre/events/meetings/2013/uhc_who_worldbank_feb2013_background_document.pdf)
- Political declaration of the High-level Meeting of the UN General Assembly on the Prevention and Control of Non-communicable Diseases.<http://www.growyourwellness.com/tools/advocacy-resources/political-declaration-high-level-meeting-un-general-assembly-prevention-and>

- Global Atlas of Palliative Care at the End of Life. [http://www.who.int/nmh/Global\\_Atlas\\_of\\_Palliative\\_Care.pdf](http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf)
- WHO Essential Medicines in Palliative Care. [http://www.who.int/selection\\_medicines/committees/expert/19/applications/PalliativeCare\\_8\\_A\\_R.pdf](http://www.who.int/selection_medicines/committees/expert/19/applications/PalliativeCare_8_A_R.pdf)
- African Common Position on Controlled Substances & Access to Pain Management Drugs. 5<sup>th</sup> Session of the AU Conference of Ministers of Drug Control (CAMDC5) Addis Ababa, Ethiopia, October 2012
- Sixty-Seventh World Health Assembly WHA67.19. Agenda item 15.5 24 May 2014
- Strengthening of palliative care as a component of comprehensive care throughout the life course. [http://apps.who.int/gb/ebwha/pdf\\_files/WHA67/A67\\_R19-en.pdf](http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf)

## **ANNEX #2**

### **Major annual palliative care events**

- Palliative care week in May
- World hospice and palliative care day celebrated Every 2<sup>nd</sup> Saturday of October.
- African Palliative Care Association triennial conferences (Next in 2016)
- Quarterly national update meetings hosted by PCAU every last Friday of February, May, August and November
- National Palliative Care conference held every 2 years, with the next one in August 2016.

## Key Contacts

### African Palliative Care Association

Plot 95, Dr Gibbons Road

Box 72518 - Kampala, Uganda

Tel: +256 312 264978/312 265978

Email: [info@africanpalliativecare.org](mailto:info@africanpalliativecare.org)

Website [www.africanpalliativecare.org](http://www.africanpalliativecare.org)

### Palliative Care Association of Uganda

Block 383, Plot 8804 Kitende, Entebbe Road

Box 72518 - Kampala

Tel: +256-(0)392 080 713

Email: [pcau@pcau.org.ug](mailto:pcau@pcau.org.ug)

Website [www.pcauganda.org](http://www.pcauganda.org)