



HOSPICE AFRICA UGANDA (HAU) is the model Hospice for HOSPICE AFRICA. Hospice Africa was founded in 1992 and registered in UK in 1993. The founding mission is to promote the relief of suffering in Africa through the support of palliative care. Founded for cancer where less than 5% reach chemo or radiotherapy, PC was extended to HIV/AIDS in 1994. The Mission was to be achieved through an affordable and culturally acceptable model. Uganda was chosen as the model for Africa, and thus became the fourth country to commence palliative care in Sub-Saharan Africa However it was the first to commence with a vision for the whole of Africa. At that time, palliative care was being practiced in Zimbabwe (1979), S Africa (1980) and Nairobi Hospice, (1990). Hospice Africa Uganda was registered in Uganda as NGO no. 1064 and since 1998, incorporates Mobile Hospice Mbarara and Little Hospice Hoima.

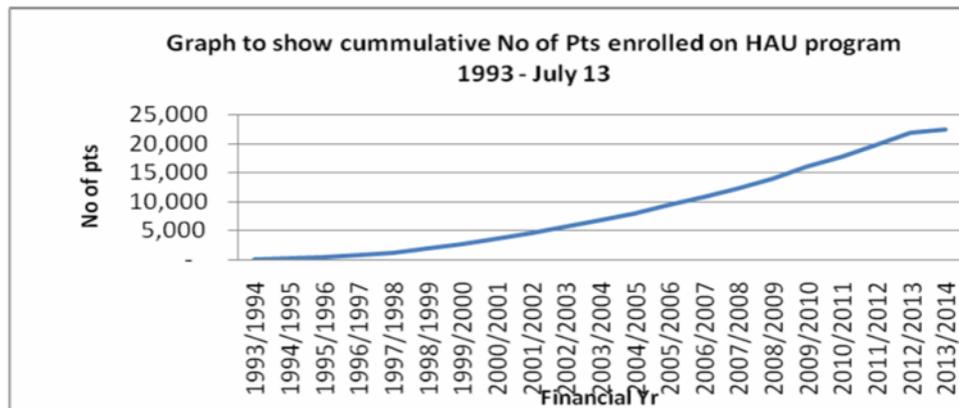
Our service provides palliative care to cancer patients from diagnosis and to HIV/AIDS patients during critical illness and end of life, in the home. We are not a support care organization. Our care is specialized and is time consuming if we are to give impeccable care. Thus our numbers may appear low when compared to Support Organisations. However the coverage to the whole of Uganda is extended through those we train and education is 50% of our work from training of families in the home to University under and postgraduate levels.

I THE SERVICE:

HAU started a service to patients and families on 23 September 1993. HAU looks after cancer and/or HIV/AIDS patients by bringing the modern methods of pain and symptom control, counselling and spiritual support to the patient and family, mainly in their own homes and hospitals. We estimate that up to 50% of our cancer patients also have AIDS.

- 1. Referrals: Most patients in Africa and beyond, prefer to be at home when very ill, we encourage discharge to their homes as soon as possible. Now community volunteers have been referring

patients who are in need from the villages, many of whom have never seen a health worker. Majority of patients were referred from hospitals up to 2003 but more are now from the communities.



From 1993 we have managed the majority of our patients in their own homes, using the modern methods of pain and symptom control. 57% of people in Uganda do not access a health worker but now they too can access palliative care through their community volunteers

- 2. Cost and contributions: Patients are asked to pay 5,000/- per week, towards the total cost of 76,000/-<sup>1</sup> cost for care per week, independent of the no. of visits and medications. About one third of our patients can manage to pay this small contribution. We assist those who cannot afford (60%). We visit our patients and families at home, supporting them with pain and symptom control and counselling. This cost includes transport and specially trained staff.

<sup>1</sup> 2012 cost equivalent to US\$ 30, Euros 25 or £20 per patient per week.

### 3. Three Hospices:

We have three Hospices in Uganda. Each was commenced for a different reason. The three Hospices come under the umbrella organisation based at Makindye in Kampala. In January 1998, Mobile Hospice Mbarara (MHM) was commenced to provide a model service for the communities in Mbarara and a training facility for the second medical school, Mbarara University of Science and Technology (MUST)

In June 1998, Little Hospice Hoima (LHH) was commenced in a shop front in a very poor area of Uganda to demonstrate how Hospice can be commenced with few resources,

By 31 <sup>st</sup> July 2013	Patients on Programme	Patients cared for to date
HKLA	751	<b>11,630</b>
MHM	620	<b>7,692</b>
LHH	438	<b>3,144</b>
<b>Total</b>	<b>1,809</b>	<b>22,466</b>

**Patient care:** Palliative care is time intensive as time is required to make relationships. We estimate that a further 20,000 may be looked after by those we have trained and are working in health facilities and other Hospices in Uganda, However palliative care is still not even reaching 10% of those in need in Uganda.

4. **Spreading the care:** Those professionals we have trained at HAU, are working now in 66 Districts. They are followed up and given

further training in conjunction with Palliative Care Association of Uganda (PCAU). Working with our own teams in Hoima, Kampala, Mbarara and District teams are community volunteers who help care for patients as well as identifying those who need our care when critically ill or at the end of life. We aim to have trained volunteers' country wide. They work closely with those we have trained who are working in the Districts. Presently all three Hospice are working with MoH.

## II TEACHING PROGRAMMES WITH IHPCA:

The Education Department was recognized by the National Council for Higher learning as a Tertiary Institute in 2010, now called "Institute of Hospice and Palliative Care in Africa" (IHPCA). We have a wide spectrum of training programmes ranging from community volunteers to professional health workers with a degree in palliative care for Africa. The degree is conferred by Makerere University. To bring this form of care to all in need in Uganda, it is essential that palliative care is introduced to all health professionals as well as to the community.

Teaching commenced with the clinical service in 1993. The main targets were the undergraduate medical and nursing students and health professionals already in practice. Core short courses were commenced and added to over the years. These include Courses ranging from 3 days to 7 for: Health professionals, allied professionals, carers, community volunteers, spiritual leaders, traditional healers, introduction to counseling at the end of life and Training of Trainers (TOT). 2012 brought the "Rapid Prescribers" course as we train Clinical Officers in palliative care and prescribing morphine. Today these programmes are led and shared across the education departments of each of the three Hospices.

Long courses were commenced in 2003. These are the 9 month residential Diploma in Clinical Palliative Care (DCPC), conferred by IHPCA, which equips nurses and clinical officers to deliver specialized palliative care and to prescribe morphine. 97 who have successfully completed this course since 2004, were conferred with the new Diploma, in August 2011. Uganda is the first country to increase prescribers for those in need in this way. Uganda and other African countries are very short of doctors who are the only prescribers in other countries.

The Degree in Palliative Care (distance learning) is developed and delivered by IHPCA, at HAU and conferred by Makerere University. The first year can be completed as a Diploma, and those with either

this diploma in Palliative Care or have successfully completed the DCPC, can enter the degree at year 2. The Bachelor's degree programme commenced in July 2010. The first BSc in palliative care for Africa was conferred in January 2013. This equips our colleagues in Africa with specialist knowledge, experience and status.



*IHPCA team members celebrating with our first graduates in BSc Palliative Care,*

Since 2006, we have been holding a 9 week programme for Tutors in Health Schools throughout Uganda so that training within undergraduate programmes can be extended to all the health professionals of the future.

**Training in Palliative Care to date:**

1993 up to	Health Prof & Managers	CVWs	Others	Distance Learning Programmes					DCPC	Rapid Prescribers	Med Students	Health Tutors	PC Initiators	TOTAL
				Graduates		Bsc PC (2012/13)								
				DPC	BSC PC	Yr1	Yr2	Yr3						
31 <sup>st</sup> - July 2013	3,266	808	1,911	142	12	25	20	18	97	80	2,653	92	154	8,889

Hospice Uganda has teaching sessions for undergraduate and postgraduate doctors at Makerere University since 1993 and Mbarara Medical School (MUST) since 1998. Palliative medicine is now part of the curricula and examinable. In October 2008, the first palliative medicine unit was developed under Internal Medicine at Makerere University. The remit is education, clinical service and research.

*In Districts:* Training of health professionals, as well as advocacy to the District leaders and communities, regarding the use of morphine in palliative care has been carried out in 66 Districts and followed up by the umbrella organisation, Palliative Care Association of Uganda (PCAU).

**III INTERNATIONAL PROGRAMMES IN AFRICA:**

Since 2000, we have worked with other African countries as the initial vision. The Model is now in place. Thus the founding vision and “third objective” of HAU are projected through our International Programmes. Commencing with training for Tanzania in 2000, we have been visiting other countries, introducing affordable oral morphine and training new initiatives on the ground. Through advocacy to 10 countries, and later by visiting the services, commencing in these countries, Hospice Africa in UK has supported financially, eleven of these initiatives in eight countries. The Initiators programme is run from



International Programmes and to date 96 from Anglophone countries and 14 from Francophone countries have attended this 5 week training. Teams from Uganda have visited, and worked alongside new teams while we learn the cultural and economic needs for palliative care and assist in setting standards and training on site. The countries we are presently working with include Nigeria, Cameroon, Sierra Leone, Congo Kinshasa, Cote d'Ivoire, Senegal (through Hospice Africa France), Malawi, Sudan, Rwanda and Ethiopia. Training programmes have been initiated in some countries and others come to initiators training in Uganda to see how palliative care can work in African countries, within the cultural and economic conditions of today.

Other countries send their palliative care leaders for the degree programme and are followed up in country by International Programmes, the Institute of Hospice and Palliative Care in Africa (IHPCA) at HAU and APCA (African Palliative Care Association).

### **Accommodation in HAU (Makindye)**

We have 15 residential rooms for those in training from other African countries. Other health professionals from Uganda and overseas students on electives with hospice also use this facility. However because of limited space, many of our course participants have to be accommodated in local affordable hotels.

### **IV FINANCIAL SUPPORT:**

Commencing in 1993 with enough funding for 3 team members for 3 months, the budget was £24,000 pounds. The budget is now for the three Hospices with 120 in the teams, risen to £1.1M (1.3M Euros or 2M US\$) per year. Meanwhile the patients on the programme have increased from 30 to 1,809.

Hospice Uganda is entirely dependent on the goodwill of donors. In UK, support comes from two charity shops (Liverpool and Ainsdale) and in France from a Charity Shop in Brittany, run by volunteers. Major donors, including USAID have supported us for the last 8 years. Hospice Africa is registered in UK, Ireland, US, the Netherlands and France. Australia has registration in process. Due to the recession and recent high inflation, we are now in greater need and are grateful for any support to expand this service to the many still suffering in Africa.

### **SUPPORT IN UGANDA:**

Hospice is an NGO registered in Uganda. The Ministry of Health has supported Hospice in encouraging this form of care to extend to the poorest of peoples since we first came in 1993. We have a dedicated Board of Directors who meet every 3 months and whenever necessary. Many volunteers support the work selflessly, particularly improving quality of life for our patients. The Churches, Nsambya Hospital and several companies and organisations in Uganda have assisted us.

If Hospice Uganda is to belong to Uganda, we need to have regular donors and Well-wishers in Uganda. We aim to raise at least 10% of running costs in Uganda. *We need corporate bodies to take on our needs to provide for our patients and families as part of their corporate responsibility.*

If you live in Uganda, please support our fund raising functions, monthly sales and annual Charity Walk and Fund Raising dinner. Items for sale at the Charity Shop (on site), including your wardrobe contents are gratefully received. Donations of items suitable for sale are gratefully received.

If you live elsewhere, donations can be made at <https://mydonate.bt.com/charities/hospiceafrica>.

### **V CONTACTING HOSPICE:**

To continue this essential work we need your prayers, further financial support and volunteers. Those interested please come and visit us at the Hospice "Nyumba Yemirembe Mu Uganda" situated on Plot 130 Makindye Rd, Kampala or Mobile Hospice Mbarara, on Fort Portal Road, first turn right (see sign), first on right, or Little Hospice Hoima on Kijungu Hill Road in Hoima Town.