Hospice Africa

25 years of palliative care in sub-Saharan Africa

1993-2018

Hospice Africa is committed to providing,

or supporting the provision of,

palliative care in Sub-Saharan Africa

for cancer and HIV/AIDS patients suffering with pain.

Working with HAU a timeline

History .. a timeline of achievements for Hospice Africa









1993: **Hospice Africa (HA)** formed in the UK. Uganda chosen from 4 countries as the country for the model for all Africa. Work started in a loaned small house in Nsambya Hospital. A clinical service in Mulago Hospital (Kampala), mission hospitals and outreach to the community commenced immediately. Education is recognised as a priority. Oral morphine introduced, made by a "kitchen sink method" . Undergraduate teaching in palliative medicine commenced at Makerere Medical School.

1994: **Hospice Africa Uganda** (HAU) registered as an NGO. After several moves HAU finds a new home at **Makindye,** close to the centre of Kampala.

1998: **Mobile Hospice Mbarara (MHM)** and **Little Hospice Hoima** (LHH) start. Palliative care introduced to the undergraduate medical curriculum at Mbarara Univeristy Medical School (MUST)

1999: **The Palliative Care Association of Uganda** (PCAU) founded and initially run from HAU.

2000: **Rutamweba House- a** Clinical Services and Education building opened. In 2010 it became totally Education, housing IHPCA. International Programmes (IP) starts and begins to trains Initiators.

2001-2002: **Dr Anne Merriman**, Founder of HAU, awarded **MBE.**

2002-2004: HAU heads steering committee for the **African Palliative Care Association** (APCA) and provides major professional and financial supports .

2003: After lobbying by HAU, a change in Ugandan statute law makes it the first country in Africa to allow **nurses specially trained in palliative care by HAU to prescribe morphine** . Previously, this was restricted to doctors only. First Diploma in Clinical Palliative Care (DCPC) commences to train PC Nurses in PC and prescribing oral morphine. Uganda becomes the first country to do this.

2004: **Free oral morphine** to all prescribed by a recognised prescriber. Uganda was the first country in Africa to do this. This has led to the integrated services in Uganda.

2005: Hoima gets new building. **International Programmes** (IP) starts. And trains Initiators. APCA is first registered in Uganda.

2009: **The Institute for Hospice and Palliative care (IHPCA)** formed from the Education Department of HAU. It offers diplomas and later on the only degree course in palliative care in sub-Saharan Africa

2010: **Brendan House** complete as centre of excellence for IP and clinical.

2011: The **Diploma in Clinical Palliative Care** (DCPC) conferred on an additional 95 nurses in Uganda, as prescribers of morphine. A new degree programme (B.Sc. Palliative Care) validated by Makerere University. HAU becomes sole supplier for **morphine** for all Uganda. HAUhas a re-organisation as funding changes, but aims to retain the ethos
Lesley Phipps, Founding Trustee, awarded **MBE**

2014: Dr Anne nominated for **Nobel Peace Prize.** Uganda now has the most integrated palliative care in Africa on a par with UK, US and Australia. **(WHO and WHPCA Atlas of Palliative Care 2014).** The Economist Intelligence Unit rates Uganda highly in the **"Quality of Death Index"**

2015: HAU becomes national provider of morphine for all Uganda. HAU, with the support of DFID, brings further **paediatric palliative care** to Western Uganda

2017: IHPCA introduces **Post-graduate Diplomas** and plans for **M.Sc.** in 2018.

2018: Today, the work begun by HAU has brought palliative care to 93 **of the 112 Districts in Uganda**. HAU has cared for over **35,000 patients,** mainly in their own homes, where they wish to be at this special time of life, with their families and close to their ancestors. In addition, those tHAU trained have looked after an estimated **35,000+** more.

Hospice Africa: February 2019

SUMMARY:

1. Hospice Africa (HA) formally registered as a UK charity in 1993 is now 25 years old.

2. HA works largely through partnership with Hospice Africa Uganda (HAU) which it founded in 1993.

3. HAU is an NGO registered in Uganda.

4. HA has representation on the Board of HAU.

5. In the UK, HA is a principally a fund raising organization.

6. HA also acts as a link for HAU when it applies for funds which require a UK registered charity as a beneficiary.

7. HA is part of an international consortium (The Anne Merriman Foundation) where membership includes Hospice Africa Ireland, Hospice Africa France, Hospice Africa Australia, and Hospice Africa USA.

8. HA is an all-volunteer organization and none of the Trustees, shop volunteers or other supporters are paid or claim expenses.

9. Though work with HAU, HA has been a key player in the introduction of palliative care to sub-Saharan Africa.

10. HA can claim that by its support for HAU to have helped achieved systemic changes in Uganda. These include:

- *Inclusion of PC in medical curriculum.*

- *Introduction of oral morphine as the key component in pain relief. This has revolutionized PC pain control*

- *A change in Uganda law to allow qualified nurses and clinical officers to prescribe morphine.*

- *Advances in paediatric palliative care in West Nile District*

- *Education in PC to diploma and degree level.*

- *Help during 1999-2007 in the formation of a national body PCAU (The Palliative Care Association of Uganda) to spread PC in Uganda PCAU is now fully independent.*

- *Help from 2003 to 2005 in the formation of an international body APCA (The Africa Palliative Care Association)) to spread PC to other African countries.*

- *Support in 2006 for the commencement of a palliative care Unit in the Department of Medicine in Makerere University Medical School.*

- *The provision of Anglophone course for initiators of PC from other African countries and in country support for initiators and others in these countries.*

- *In addition HA has provided some support for PC organisations elsewhere in Africa.*

- *HA acts as a clearing house for UK nationals wishing to volunteer in Uganda.*

11. HA helped introduced PC into the Diploma in Tropical Medicine and Health at Liverpool School of Tropical Medicine, which was subsequently followed by a similar inclusion in London.

HA fully recognizes the importance of other organisations working to spread PC in both Uganda and sub-Saharan Africa generally and notes that their work will be subject to their own reporting.

Introduction:

Hospice Africa (HA), is a UK charity[1], founded in 1992 by Professor Anne Merriman MBE. HA, registered as a charity in 1993, is based on Merseyside where acts principally as a fund-raiser.

The vision for Hospice Africa is **"Palliative care for all in need in Africa".** This is to be done through a model in one country which would be culturally and economically acceptable and accessible. From the model country, training would carry African palliative care to the other African countries. Uganda was chosen for the model, with the support of the Ministry of Health. Morphine powder was imported for the first time, and the service commenced in September 1993

Hospice Africa and Hospice Africa Uganda

HA helped found and still works very closely with Hospice Africa Uganda (HAU) which, amongst other roles, provides a PC service as a demonstration of how PC can operate in a variety of resource poor settings with an ethical, affordable and culturally acceptable model that can be adapted to the needs of other African countries or to areas within each country. To ensure close cooperation a member of the HA Board Mrs Lesley Phipps MBE) is also a member of the HAU Board.

Hospice Africa funding for palliative care in sub-Saharan Africa

Since 1995 HA has sent over five million pounds (at 2018 value) to Africa, mostly to HAU. In addition HA has sent an estimated **five hundred thousand pounds** of goods, mainly medical supplies. HA also provides advice and support to assist the development of PC wherever possible in sub-Saharan Africa.[2] In particular HA has acted as a point of contact for **the many hundreds of UK citizens wishing to volunteer at HAU**.

Over a period of years HA has received donations a wide range of individual donors, other religious or charitable organisations, corporate donors and the UK government for which it is extremely grateful.

HA helps fund a model of PC which is low cost or free at the point of care. HA advocates the home-care and day-care service, as demonstrated by HAU, since in-patient care, on the UK model, is both impractical with very restricted medical expertise available and far too expensive.

Holistic care

HA supports the view that PC is not only pain and symptom relief but must also be a **holistic** approach to the needs of the patient, the patient family and carers. For example HA helps "Give a Chance" a small charity which provides school fees for the children of HAU's patients, thereby removing a source of worry for the parents.

[1] Hospice Africa :- Registered Charity 1024903 : Company registered by guarantee 2835469.

[2] HA has previously worked with initiators in both anglophone and francophone countries in West Africa but now the development of PC in francophone Africa is being led by Hospice Africa France (Soins Palliatif).

Oral Morphine

The key to pain control is our formula for **affordable oral morphine**[3], based on a formula created initially by the Founder in Singapore, brought to Kenya in 1990 and then introduced to Uganda in 1993. A key element in a successful introduction was engaging cooperation and support of the Government of Uganda which from the start allowed the importation of morphine powder. Until this was introduced patients not reaching treatment for their cancer, were dying in agony and support care was impossible when patient and family were in great distress from total pain.

Affordable and simple to use, oral morphine has revolutionised pain control in PC for Africa.

Despite some concerns expressed by people not familiar with oral morphine, properly used it is safe and non-addictive.

For 17 years, supported in part by HA, HAU prepared oral morphine for use by its own patients using a simple "kitchen sink" method. Today oral morphine is manufactured for the whole of Uganda in a modern dispensary at HAU funded by a public-private partnership with the Ugandan Government.

See for example: How Ugandan hospice makes cheap liquid morphine", BBC News, June 2nd 2014. Available at https://www.bbc.co.uk/news/av/health-27664121/how-ugandan-hospice-makes-cheap-liquid-morphine

See also https://www.cbsnews.com/news/a-world-of-pain/ for information about the adverse publicity to morphine use.

Initially, the availability of oral morphine at point of care was greatly restricted by the law confining the prescribing of morphine to just doctors, vets and dentists. Since the great majority people were not able to access these health care professionals and therefore unable to obtain oral morphine, even where available, there was great need for the categories of authorized prescribers to be expanded. Led by HAU, with the help of other interested parties, the statute that allows midwives to use pethidine for women in labour, was expanded to include nurses specially trained with a Diploma from HAU, to become prescribers. From 2004 the Ugandan government permitted qualified nurses and clinical officers who have completed a 9 month course at Hospice Africa Uganda and registered with the Ministry of Health, to prescribe morphine. Now there are nurse prescribers in 85% of Districts in Uganda.

Uganda was the first country in the world to have legalised Nurse and Clinical Officer Prescribers.

Oral morphine itself costs[4] about **£2 for 10 days treatment** with breakthrough doses for the average patient. This is 500mls with 1mg per 1ml (identified by colour code as green solution) made of 4 ingredients only.

[3] A simple solution of morphine + preservatives in water, colour coded to show strength

Beneficiaries of palliative care

Since 1993 more than **thirty three thousand patients, together with families and carers**, have received the holistic care, comfort and support provided by HAU and a significant part of this has been funded by HA.

Education and training

HA fully recognizes the need for education and training. Since 1993, HA, through HAU, has contributed to the training over **11,000 health professionals** and carers in Africa. From the start HAU commenced teaching medical undergraduates, recognisng that they would be the doctors of tomorrow. This has helped to change the face of PC, as all who have qualified since 1995 from Makerere University and Mbarara University of Science and technology (MUST) have been taught PC and particularly the use of oral morphine. In 2008, a PC degree, taught by HAU, but validated by the Department of Medicine at Makerere University Medical School, was commenced. This attracts students from a wide range of African countries. **HA has provided scholarships in support of this work**.

Spreading palliative care

HA recognizes that the introduction of PC requires first the sensitization and then the recruitment of decision makers. PC has been demonstrated and taught to initiators and leaders, from 30 African countries through **International Programmes** (a part of HAU) which is **funded directly by HA**. Palliative care now has a foothold in these countries though this may be affected by in country security and other problems..

Recognising the huge need for PC, HAU, with the support of HA, helped found two new organisations.

First, The Palliative Care Association of Uganda (PCAU) https://pcauganda.org/ which aims to implement and cover the services for management of patients in Uganda. PCAU began work at HAU 1999 and became independent in 2007.

In 2003, The African Palliative Care Association (APCA) https://www.africanpalliativecare.org/ also started at HAU and was registered as an independent organization in 2005. These two organisations are now internationally recognized as leaders in the field.

By 2015 Uganda was recognised as 35th in the Economist Intelligence Unit "Quality of Death Index" being second only to South Africa in sub-Sharan Africa and well above many western countries.
https://eiuperspectives.economist.com/sites/default/files/2015%20EIU%20Quality%20of%20Death%20Index%20Oct%2029%20FINAL.pdf

[4] This is for the medication only and does not include costs for patient such as nurse led visits or day care clinics.

World Palliative Care, 2014 “Global Atlas of Palliative Care at the End of Life”- Available at http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf

In addition HA has been able to help other fledgling organizations get off the ground by providing advice and sed-corn money. For example, HA was present at the start of Ndi Moyo in Malawi, http://ndimoyo.org/wp/ which is now recognised as a leader. HA also helped support work in Cameroon and Nigeria. More recently HA has provided seed-corn money for Hospice Ethiopia which now has its own support group https://en-gb.facebook.com/hospiceethiopiauk/.

Uganda now has a Department in The Ministry of Health dedicated to PC

In 1993 there were only 3 countries with PC: Zimbabwe 1979, S Africa 1980 (richer countries able to import western products) and Kenya 1990. There are now 35 of the 54 African countries who declare they have PC but only 22 have affordable oral morphine available in their country for use in the home. This is where most patients and carers wish to be at the end of life.

Countries claiming to have some form of PC

HAU, supported by HA has carried out a large number of innovative projects such as the DFID/HA funded work on paediatric palliative care described below:

Recent developments in PC – PPC (paediatric palliative care)

HAU conducted a Baseline survey of Palliative Care for paediatric patients Living with HIV/AIDS and or Cancer in Western Uganda with the financial support from the Department For

International Development (DFID) through the Global Poverty Action Fund (GPAF) for the project to Expand Access and Scope of Paediatric Palliative Care services in Western Uganda which was implemented by Mobile Hospice Mbarara (MHM). See Appendix 1 for details.

Recognition of HA

The work of HA has been acknowledged both locally and internationally. Amongst very many other marks of recognition The Founder was nominated for the Nobel Peace Prize in 2014 for the approach to bringing patients to peace with God and their families, at the end of life, through compassionate management and recognition of the social, psychological, economic and spiritual needs within the culture and religion which has brought them to their God. One Trustee, Mrs Lesley Phipps, was also recognized in the UK with the award of an MBE in the Diplomatic and Overseas section of the 2011 New Year's Honours list for "her work on palliative cancer care with charity Hospice Africa".

Overall HA has played a significant part in the development of PC in Uganda particularly, and other parts of sub-Sharan Africa generally. Of course this could not have been done without a wide range of supporters and the help and active intervention of many other players. HA thanks all those who have given freely and volunteered to support it.

HA recognises it is only one part of a disparate group of organisations which have a broadly common aim and looks forward to further cooperation with them.

APPENDIX 1

Paediatric palliative care in Western Uganda

By the end of 2012 Western Uganda had a total population of 6,298,075 of this those below 18 years are estimated at 3,533,220. In this region there are few health facilities offering very limited Paediatric Palliative Care, and MHM is the only facility offering comprehensive paediatric palliative care. Over the period April 2013 – 31st March 2014 MHM cared for 98 children, which is less than 2% of the total number of children in need of Palliative Care service in the region. On average children are reviewed once monthly and total of 340 contacts were made for the 98 children at home, outreaches, day care, OPD and telephone.
Currently the curriculum for training 4th year medical students at MUST does not cater for Paediatric Palliative Care (PPC). Interviews with the dean of students at MUST indicated that they were in support of having PPC in the curriculum and pledged to give full support. It should be noted that by the time of the survey efforts were underway to revise the curriculum so as to include PPC so that it doesn't interrupt with the smooth running of the project, training commenced in August 2014. The Community Volunteer Workers (CVW) curriculum also lacked sessions on Paediatrics. The team at MHM indicated that plans were underway to design a tailor made curriculum with sessions on Paediatric Palliative to deliver sessions to CVWs.

MHM CVWs to smaller extent have some basic skills in provision of basic PPC to the fact that they have been dealing with them; however they all still believed that they required training tailored to caring for children.

All the six partner organisations interviewed indicated that PPC is integrated in other services but done on a very minimal scale due to factors like funding challenges-no budget for PC activities and having no capacity to offer PPC services among others.

Anticipated challenges for the project included, but were not limited to, very poor patients who could not afford basic needs and transport to access transport, health workers have limited knowledge about PPC, shortage of pain control drugs and limited budget for PPC activities.

The training needed to also target practicing health workers on ground, rather than only medical students who are likely to move out of the region on completion of training.

HAU also conducted an Action Research in MHM with support from DFID UK and matched funding from HA

Between September 2015 and March 2016 HAU also undertook an Action Research titled *"Increasing the number of household members trained in basic paediatric palliative care in South Western Uganda".* The research was spearheaded by the project medical officer supported by the senior PC trainer, a social worker and clinicians at Mobile Hospice Mbarara. Key findings were:

- The training needs of caregivers of children were mainly around prognosis, symptoms, socio-economic and psychosocial issues.

- Main challenges faced by family caregivers included financial constraints, inadequate social support, difficulty managing symptoms, anxiety, poor hygiene and the control of infections affecting the children.
- Training household members is more effective when conducted in patient homes than at when done at the hospice or while admitted hospital.
- Training had positive effects on the confidence of family caregivers and improved the quality of care the patients received.
- Appropriately trained family members were an important resource for the HAU clinical team to work more effectively with for the better care of patients.

Project title Expanding Access and Scope of Paediatric Palliative Care
Project start date 1st June 2014
Project end date 31st May 2017

Year 1: £70,826 Year 2: £ 95,752 Year 3: £ 104,853 Year 4: £ 31,020
(£ 52,499- Matched funding from HA)
This project aimed to introduce the first specialised PC services for children living with cancer, HIV/ AIDS and other serious illnesses in the South Western region of Uganda, providing education and training for medical students at MUST, Uganda's second medical school, and a center of impeccable clinical practice and bedside teaching for medical students, and through a Community Volunteer Workers (CVW) programme empower community-based lay persons in efforts to have and extend Palliative Care to families in the communities many of which are hard to reach.

Children living with cancer, HIV/AIDS and other serious illnesses can easily access palliative care.

- The project introduced the first specialised PC services for children living with cancer, HIV/ AIDS and other serious illnesses in the South Western region of Uganda
- Increased number of children can now access PC covering modern pain control, relief of symptoms and a holistic service which incorporates psychosocial and spiritual care
- Patients were cared for at the location of their choice- mostly in their own homes in the community but also on outreach clinics
- Through our collaborations patients attending the oncology clinic at Mbarara Hospital received quality care expeditiously. The project allowed more thorough investigation, specific diagnosing, and support for treatments for patients.
- The quality of life of paediatric patients was improved and some have been able to return to school.

Creating a training base for palliative care students/health workers and community volunteer workers

- Medical students have been trained in children's palliative care- Since the medical school recruit students from all regions of the country, we strongly believe that once they qualify they will practice palliative care in the health units they will be working in, hence expanding the scope of palliative care.

- Through the training of the medical students we have managed to interest a significant number in pursuing a career in palliative care. One intern doctor trained during the project has already expressed interest to serve at MHM.
- Through negotiation and timely applications MHM trained more palliative care nurses in specialised paediatric PC on courses offered at Mildmay, https://mildmay.or.ug/
  These professionals will be useful beyond project's lifespan.
- There is a team of community volunteers trained in PPC who are continuing to support care for children and are a perpetual resource for their communities.
- Family members were trained in children's basic health care needs. This will continue to help the community to address health issues especially palliative care needs of children with serious illnesses.

Family and Community-level impact of project:

- The community has been sensitised about the availability of palliative care services and the families.
- Through our advocacy it has been made clear that despite diagnosis of serious illness quality of life can be improved through PC.
- Parents of children whose life has improve have gone back to their daily work as opposed to fulltime caring for the children hence are able to earn some income.
- Parents have learnt that children with cancer also need care; good feeding and some cancers once caught early can be cured.
- Economically the project indirectly translated into cost saving for families through support for investigations and transport, but also for return to usual economic activities like farming and cattle keeping.