HOSPICE AFRICA UGANDA

Hospice Africa Uganda

Silver Jubilee Commemorative Publication

September 1993 - 2018

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HOSPICE AFRICA UGANDA
CELEBRATING 25 YEARS OF PATIENT CARE

HAU Patron's message in the Commemorative publication

Dear Friends of Hospice Africa Uganda,

When I started my journey as the Patron of Hospice Africa Uganda over four years ago, I did not know the full extent of the need for Palliative Care in Uganda. On learning that there are over a quarter of a million Ugandans, mostly in their own homes in the community, who are suffering the real possibility of an agonizing death I quickly accepted to use my voice to advocate for a holistic approach to their care throughout the course of their illness right up to the very end.

Up to today I feel empathy for that first Hospice patient I visited at home in May 2014, and sigh with relief knowing that her last days were with family supported by the Hospice team who go the extra mile. I now understand that Palliative Care is not just an approach to the care of those with life limiting illnesses, but a vocation for those who are called to service in this way.

On this occasion of Hospice's Silver Jubilee we must therefore celebrate not only the great work started by Dr Anne Merriman- who was nominated for a Nobel Peace Prize for HAU's efforts to bring peace to the suffering in Africa, but also the great friendship and partnerships with several stake-holders who have made Uganda the success story of Africa.

As we start HAU's next 25 years, let us always remember that the hard work ahead of us is finding that patient who is not as lucky enough to have reached Palliative Care. Uganda and the world must need to extend that helping hand- so that many more patients' stories can be changed.

HRH Sylvia Nagginda
Patron of Hospice Africa Uganda and
Nnabagereka of Buganda Kingdom

Message from the Ministry of Health, Uganda

On the occasion of the Silver Jubilee of Hospice Africa Uganda the Ministry of Health wishes to convey our congratulations to the Founder Dr Anne Merriman, the Board, Management and Staff of the Hospice Africa Uganda, for their work in Palliative Care. Palliative Care focuses on improving the quality of life of patients with serious illnesses.

Whereas modern methods of pain control and support care for patients with AIDS and other illnesses has always been part of Uganda's health systems, the Ministry of Health in 1993 allowed the first imports of powdered morphine for the making of an essential opioid medicine, and supported the pioneering work of Hospice Africa Uganda as they introduced a new specialty to Uganda for the first time. Through partnership HAU provides home based care to patients. This is part of the government's commitment to support community level care.

From 2000 Palliative care is within Uganda's Health Sector Strategic and Investment Plans and the Ministry of Health recognized that **"Palliative care is an essential clinical service for all Ugandans".** In 2002 the laws of the country were changed so that nurses and Clinical officers trained in palliative care could prescribe oral liquid morphine. Since 2004, Uganda has provided free oral morphine to all prescribed by a recognised prescriber and is the first country to do so in the world. Starting in 2011 the Ministry of Health/ Government of Uganda has been in a Public-Private Partnership with HAU through which HAU manufactures oral morphine for all Uganda. This has been overseen by the National Drug Authority which inspects every year the manufacturing facility. Through the professionals HAU has trained Palliative Care is now available in over 93 of the 112 districts in Uganda. In May 2014 the World Health Assembly, to which Uganda was signatory, resolved that palliative care be integrated in health care systems at all levels and the Government of Uganda through the Ministry of Health has supported this integration. Uganda is now the country with most integrated palliative care in Africa on a par with UK, USA and Australia, and is seen as the second best place to die in Africa today.

These proven achievements have been through close working with the Government and the Ministry of Health which has provided a conducive environment for Palliative Care to thrive.

As the need for Palliative Care is increasing rather than reducing the Ministry of Health is ready to work and partner with all stakeholders who will contribute to advancing quality health care in Uganda.

For God and my Country!

Dr Jackson Amone,
Commissioner- Clinical Services
Ministry of Health

Message from Board Chair — Joan Kelly

Since I met Dr Anne in 2001 I have been a worker and supporter of HA (Hospice Africa) and of HAU (Hospice Africa Uganda) in particular. I have lived in Uganda for 24 years now and have seen the enormous changes in the country. Over the years I have seen HAU grow and overcome many difficulties, but it has many achievements of which it can be duly proud. When HAU started even the basic concept of PC (palliative care) was almost unknown in Uganda. Dying in pain was common and little could be done to alleviate suffering. This led to a fatalistic attitude. The lack of awareness both amongst the population and the medical professions meant to serve them meant that little if anything was being done to improve the situation. Now, twenty five years on, PC is deeply embedded in the Ugandan Health System. A whole generation of new doctors and nurses are practising PC. Oral morphine is widely available and HAU is the key player in its nationwide provision. HAU was able to help the wider spread of PC both within Uganda, through PCAU (Palliative care Association of Uganda), and throughout Africa generally, with APCA (The African Palliative Care association). IP (International Programmes), a function within HAU, has been particularly active in spreading the message to the wider African audience. Education has always been seen as fundamental to the spread of PC and through IHPCA (The Institute for Palliative care in Africa) it has moved the process on and contributed to raising the skills and qualification level of those engaged in delivering PC

As Chair of the HAU Board I have seen the day-to-day struggles of patients and through my own experience with cancer I have seen the profound importance of maintaining the ethos of PC, putting the patient and the team at the centre of all we do. HAU will continue to embrace this ethos whilst it works to spread the concept of an affordable, culturally appropriate PC throughout Africa. There are many challenges ahead, but HAU will not let financial and organisational matters prevent us from continuing with our mission. We must look forward to the next 25 years, maintaining our achievements and building on them.

Joan Kelly

Message from Founder

I thank God for a long life with many blessings. Having worked with so many cancer patients facing the end of life, this 25th year brought cancer to me. But I am so lucky! It is one with a good prognosis so no worries there once the pain was gone

I did nearly die 2 days post op. I was not afraid to die but sorry that I would not live a little longer to see the next 25 years! A big wish!! But we need to have more written down if the spirit and ethos of Hospice Africa is to continue, not only in palliative care, but also to continue across all medicine so that caring compassionate teams are available when ever needed.

Fazal who started the work with us.

One of the many blessings I had while recovering from the surgery, was the many people who actually came to visit me from all over the world, bringing memories of our past together. But the greatest blessing was that we were able to have Rose Kiwanuka and Martha Rabwoni for the celebrations here in UK and to look after me for 5 days after my discharge from hospital . We shared many memories of the early days when we struggled, with so many problems, including opposition from medical colleagues, misunderstanding of what we were bringing to Uganda (some thought that it was euthanasia) and facing the high learning curve for me personally as Uganda was new to me, although I had much experience of several African countries prior to this. We also struggled for funding but this was never our greatest worry! We trusted in our God and the fact that we were following the work of Christ and other founders of religions, with compassion and care for the suffering and particularly the poorest, many of whom had never seen a health worker.

But today, as we cannot see into the next 25 years, we are so worried about the money we need. Living in UK for the longest time in the 25 years, I see that the values here are so different. Those who know me, know that I love animals and hate to see them suffer. I have taken in so many suffering dogs that people think I have a hospice for animals too! But here I find raising funds for animals (suffering and otherwise) is much easier

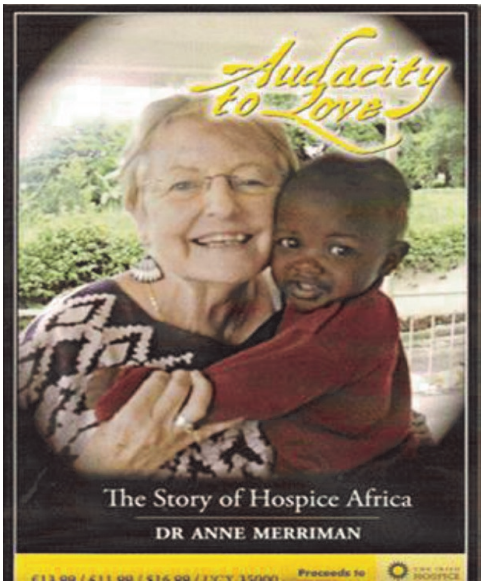
than raising funds for the suffering people of Africa. Are we humanitarian people here in the developed world?

It costs us £1M to care for an average of 2000 patients in their own homes. In UK 5 years ago, it cost the same £1M to care for 10 cancer patients in a Hospice for the year. Where have all the generous millionaires gone?

But we must trust in God, and rejoice in the 25 years and the many successes we have been able to be part of, changing mindset of Ugandan Government and bringing pain relief to so many. This was only possible with the help of the Ugandan people. Our team was once 135 but now down to 80 between 3 sites because of shortage of funds. But every one of our wonderful teams have been Ugandan apart from the generous overseas doctor volunteers who have given up to 1 year of their time to assist us.

I thank God for the many blessings we have received and that now palliative care is in 35 countries when in 1993, it was only in 3 countries. We trust in you, our friends, to pray for our work and support it in many different ways
The poor and the suffering will always be with us but we can be there with compassion and comfort. Please join your own compassion to ours and help us to bring peace at this special time of life to all in need.

Our first temporary home



You can read much more about the history of palliative care in Uganda in this book

Message from the Chief Executive Director- Dr Eddie Mwebesa

I warmly welcome you to this publication commemorating HAU's 25 year journey.

Driven by the passion for the suffering patient and with neither a strategic plan nor a matrix within which to systematically outline how she will execute the work, Dr Anne Merriman founded Hospice Africa Uganda and saw the very first patient in 1993. Tag teaming with just one nurse and a driver the small team juggled the responsibility of clerking patients to extract a detailed history, managing their symptoms, dispensing medications to relieve pain, meticulously documenting what they had done, and teaching the family caregivers the nuts and bolts of attending to their loved ones who were on perilous journeys. Little did this nucleus of devoted professional know that 25 years later there would be a nation-wide celebration of the fruits of their sweat, tears and perhaps even a little blood!

This foundation started 25 years ago formed the basic building blocks for a service which today is recognized as a model for the rest of Africa, offering impeccable clinical care and bringing glimmers of hope and a semblance of peace to cancer patients whose lives had been upset by the chaos of the diagnosis of serious illness. From the informal teaching of the main caregiver in the patients home and the local village elder in the community emerged, initially an education department, and then an Institute of Hospice and Palliative Care in Africa. This Institute today offers short and long courses, now up to postgraduate diplomas and very soon a Master's of Science degree in Palliative Care. The written record of the situation in which Hospice's index patient lived and his family tree has given rise to a huge database- a gold mine of case notes of 34,000 patients.

The first research done at the patients' bedside has inspired further searches for answers to the questions which had eluded clinicians, and yielded findings which have informed governments to change the laws of the land to allow nurses to prescribe morphine and provided the arsenal of words to use for advocacy to reach far-away sub-Saharan African countries. Through Hospice Africa's International Programmes over 33 countries have heard the message of Palliative Care and many have now started services based on the model they learnt in Uganda.

From the first room given free of rent at Nsambya Hospital for the courageous trio Hospice Africa has grown to be in 3 sites, positively impacting the lives of those within our catchment boundary and beyond. Visitors coming for their first time to our headquarters in Kampala would otherwise have left in awe if they were not reminded that Hospice is an approach to care rather than a building- and whilst we have some great properties the real asset is the ethos of hospitality for the patient, caring for one another on the team, and the vibrant strong networks we have built over the years.

Morphine, once produced over a "kitchen sink" in a plastic bucket is now manufactured to the highest standards by a professional pharmacy and quality assurance team- but we retain the formula for making the precious opioid using the simplest of technologies which can be afforded by the humblest of budgets of low and middle-income African countries.

If we did not know better we would have imagined that HAU has a Midas touch, but we are now sure that this has all been possible because Palliative Care is a vocation, and the work of God

Eddie Mwebesa

A word of thanks

Dear friends, colleagues, partners, donors and all stakeholders,

We are very grateful for all your support over the last 25 years of Hospice Africa Uganda's existence which has contributed immensely to the vision, brought so much change in Africa and enabled great successes for Hospice. Thanks from us all for your wonderful spirit of hospitality and generosity. So many people have helped Hospice that the list would fill all of this publication but without mentioning individuals they will know who they are and they will know that the most important thanks comes from the patients, their families and carers.

Space for your thoughts….

We invite you to put here your own thoughts about palliative care and what it might mean to you, your family and friends.

Thinking about palliative care

The three founding principles of *Hospice Africa* which also form the heart of **Hospice Africa Uganda** are**:**

- To provide an appropriate palliative care service to patients with cancer and/or HIV/AIDS and their families
- To promote and provide palliative care training for health care professionals across sub-Saharan Africa
- To facilitate the initiation and expansion of palliative care to all in need as an affordable African model

Palliative Care has two essential components

•Supportive care

•Pain and symptom control

An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness. Palliative care should be a holistic approach not only pain and symptom relief but also with attention to other problems - physical, psychosocial and spiritual

" You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die."

Dame Cicely Saunders,
founder of the modern hospice movement

The need for palliative care in UGANDA in 2018—some facts

- Population 40 Million
- Cancer prevalence 105,000
- HIV/ AIDS 122,500
- 1% need PC, 320,000
- NCDs, cancer& HIV/AIDS increasing;

Population is ageing

- Only 5% of people with cancer reach specialists
- Only 10% being reached with Palliative care
- Some 57% never see a health worker

The World Health Organisation definition of palliative care

Palliative care is an approach that improves the quality of life of patients and their families who are facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Hospice Africa Uganda at Makindye

Brendan House is the clinical centre, with purpose built examination and consulting rooms. It also houses the Administration.

The site at Makindye was the first permanent home for HAU. The site originally had a single building , now called Merriman House, which served as a centre for clinical, educational and all administrative purposes. Over the years additional buildings have been added, funded by some very generous donors. Now there some splendid buildings there.

Katterega House was designed as to supply student accommodation for student svisting Hospice fro practical training but now houses a medical supplies company.

The view from Mobutu road shows Rutwemba House which houses both The ***Institute for Hospice and Palliative Care in Africa*** and the ***Morphine Production Unit*** which supplies morphine to all of Uganda.

A large central grassy space is regularly used for the many events held at Hospice.

Fazal House offers more space for offices and also some places for visitors to stay.

Getting the keys to Merriman House

Merriman House today

The view from Mobutu Road

The view from Mobutu Road

Rutwemba House

Katterega House

Brendan House

Fazal House

LITTLE HOSPICE HOIMA

Little Hospice Hoima is a part of Hospice Africa Uganda founded in the Hoima District in 1998. It was set as a model Hospice in a rural setting.

Up to the 90s, Hoima was a neglected district in Uganda ever since their king opposed the British rule long before independence. The area was deprived of services, it had the worst roads, no electricity and water and it had the highest prevalence of HIV/AIDS in the country. Access to ARVS was not available and any local people who had AIDS suffered terribly. In 1997, a team from Hospice Africa Uganda, Kampala ran a health professionals course and made preliminary visits to the District talking to opinion leaders, local hospitals and other Non-Governmental Organisations that were supporting people living with AIDS.

Among the many local leaders was Dr Stella who is so very significant in the birth of Little Hospice Hoima . She was a general practitioner and Minister of Health in the Bunyoro Kitara Kingdom.

Dr Stella was invited to chair a session on a training course. However, once she saw the program she decided to attend the whole program and other opinion leaders attended. Many discussions went on and there was great thirst for palliative care to be brought to Hoima.

Dr. Stella led this and she offered space in her small retail shop on the main street where palliative services could be run. It had neither water nor electricity running. Dr. Stella was trained in case sheet assessments and she started seeing patients and recorded them for the program.

The number of patients seen increased and the space became too small. A year later, a catholic Bishop offered space to Little Hospice at Bujumbura Health Centre where palliative care services continued. Even though the space was enough, the place was poorly attended as it was far and patients were not able to reach the premises easily. It was at that point that the day care services commenced and the OPD a*nd* Home In 2001, the team received a car from Rotary club in Victoria, Australia. A couple of years later, the place grew and more space was needed, so Betty, who was the Health services Coordinator at that time, and the team went to Hoima town and hunted for more space suitable for renting.

Betty Kasigwa who helped get LHH started

They eventually got a "*Nile Special*" warehouse which was reorganized, painted and generally given a face lift. They partitioned spaces with areas where patients were attended to, an area to teach from and pharmacy space from where to dispense medications. The place was on the main street and was easily accessible for patients.

LITTLE HOSPICE HOIMA

From 2002 to 2005, the team was renting and along came funding to secure land at Kijjungu Hill which up to date is the site and an owned premise to LHH. Still, over those years, the total number of AIDS patients have exceeded the cancer patients at this site

HOIMA NOW

Over the years, the face of a very poor district has changed after the discovery of oil which has led to a development of the infrastructure in form of roads, water and electricity which are now readily available so that business people from urban places like Kampala are doing good business in the area.
Little Hospice has been getting support from different donors both small, and the big one, USAID, that has made this possible and helped support the services carried out to run smoothly.
In the era of the USAID funding, everything related to patients care was almost fully supported and in the 12 years we had this grant, we expanded greatly and forgot to fish as all programs were fully under their care. In 2015, the grant finally ended and a huge gap was left and we had to go back to the drawing board and explore ways on how we were to continue offering services to our patients and family without affecting the quality of care. Different strategies were been set henceforth for both short and long term strategies to see how uninterrupted service would continue.

In 2016, the team went back to the community of Hoima to request for support and since the community had already experienced the impact of the great work Little Hospice had done in the area over the last twenty years and they indeed responded to our cry for help. They raised for us a reasonable amount of money and it is this very support that has seen us through along with other small donors that are offering support to us.

With the vast development in terms of service delivery from our other partner organizations, and the availability of ARVs , the trend of the site having the highest number of HIV/ AIDS patients has changed in the last two years. The team is receiving more cancer patients as compared to HIV/AIDS.
In conclusion, I would like to acknowledge the efforts and devotion of the people of Hoima, the spiritual leaders, the political figures, the ever present arm of donors, our partner organizations, the community volunteers workers, the patients and their families.

Mobile Hospice Mbarara (MHM)

Mobile Hospice Mbarara commenced a palliative care service to patients and families in January 1998 following a Health Professionals Course that had been conducted in 1995 to health professionals, Mbarara Regional Referral Hospital and also a feasibility study conducted in Mbarara district. The major reason why Mbarara was chosen was because Mbarara University of Science and Technology (MUST) was the second medical school in Uganda at the time. It was the vision of the University to work with the communities so it was through teaching palliative care to the medical students that Hospice Africa hoped to reach all those in need especially those in the surrounding poor and remote communities.

Initial funding was from CAFOD (1998) and in January 1999 the project received a major boost of 3 years funding from a 3H grant by Rotary International through Rotary Club Mbarara The donation of a Landover from the then retiring Professor Pat Pathak (RIP) (shown right) was very helpful from the very beginning. Pat Pathak (right) who was an International Rotarian and Professor of Obstetrics and Gynecology at MUST was very instrumental in the application for the 3H Grant

Before moving to our own building, Mobile Hospice Mbarara was loaned two rooms at the current girl's hostel at Mbarara University of Science and Technology. A residential house in the resident's compound was also given to Hospice rent free. This was occupied by Martha who was leading the team at the time. By 1999 the two rooms had been taken away from us. We moved to the garage of the residential house that we still had. We were then offered rooms in the nursing school. We started looking for a property to buy. We found one about 2 km off the university and only a few meters off the junction of Kabale-Fort Portal roads. This was a semi-finished building and we had to renovate and complete it on our own. On 3rd November 1999, we officially entered the current building ("***eka y'obusingye omuri Mbarara***") with the official opening presided over by the first lady, Mrs. Janet Museveni

A team of four people led by a senior palliative care Nurse Martha Rabwoni, Nurse Hellen Iyekat, a Driver, Hassan and Accounts Clerk Jackson pioneered MHM.

The team was later joined by two VSO volunteers – Clare Fitzgibbon and Brian Fitzgibbon a palliative care nurse specialist consultant and administrator respectively. In 1999 a volunteer doctor Karen Frame also joined the team. She was very helpful in supporting the teaching at MUSTand the clinical aspects at MHM. In the same year we received our first Uganda doctor Dr. Andrew Nadamira and Nurse Harriet Kebirungi came at the same time. Now the team had grown and the number of patients had increased . Meanwhile before the arrival of Dr. Karen and Dr. Ndamira. In addition, Dr. Sheila Beingana a lecturer at MUST helped to support us with both teaching and clinical sessions.

The early beginnings of Mobile Hospice Mbarara were overseen by the steering committee from the benefiting community. Mainly from the local service clubs and other friends of Hospice. These include: Mr. Tushabome Charlese Kazooba, Mr.Wilson Tumwiine, Dr. Benard Maniraguha, Dr. Edwin Mugume, MS Gudo Aluwalia (RIP) A number of other friends also supported MHM from the beginning. These include; Poor Clares, The White Fathers, Montfort fathers, Fr, Charlie, Dr. Oliver Murphy and his wife , Margaret, both (RIP)

Mobile Hospice Mbarara (MHM)

As the number of patients increased, mobile and roadside clinics were started. One in Bushenyi 57 km and the other in Ibanda 65 km and later another one was started at Ntara health centre – Kamwengye district. These were meant to reduce the transport burden for the patients by taking the service nearer to them whereby the MHM team would meet the patients neighboring the mobile clinic area at one place. However, as time went on it was deemed necessary to meet people on the way to the mobile clinic. This is because to some patients the mobile clinic was as far as travelling to MHM and yet the vehicle would pass by their trading centre or village while going to a mobile clinic. MHM team would meet patients at volunteers' clinic, home, or shop provided the privacy of the patients was maintained. Sometimes patients would be met under the tree or at an agreed sign post near the road hence the name roadside clinics.

There a plans for a new building, close to town, but on a bigger site. This is known as the **Beehive Project** from the exciting shape of the proposed buildings. Of course, the project can only go ahead when funds have been raised but great efforts are being made both locally and nationally as well as internationally.

The Institute for Hospice and Palliative Care in Africa

The Institute of Hospice and Palliative Care in Africa (IHPCA) is the education wing of Hospice Africa Uganda (HAU), a not for profit organization which has been working in Uganda for 25 years supporting the sick and the dying with holistic palliative care to enable a dignified, peaceful and pain free end of life.

IHPCA is a one specialty Tertiary Institution of Higher Learning specializing in palliative care education. It is recognized and Licensed by the Uganda National Council for Higher Education (NCHE) and IHPCA is described as "Other Degree Awarding Institution".

Vision and Mission:

IHPCA shares the same vision with HAU. Its Mission is to ensure the highest quality tertiary education in palliative care to students and practitioners within Uganda and internationally.

Academic programmes

- **Bachelor of Science in Palliative Care:** A three year programme by Distance Learning.
- **Diploma in Palliative Care**: A one year programme also by distance learning.

These programmes are conducted in affiliation with Makerere University and the qualifications are awarded by Makerere University.

- **Diploma in Clinical Palliative Care:** A one year residential programme taught and awarded by the Institute itself.
- **Postgraduate Diplomas in Clinical Palliative Care, Pediatric Palliative Care and Psychosocial and Spiritual Palliative Care** One year programmes, delivered by distance learning awarded by the Institute. Students who complete these programmes successfully, can join the Masters programme in the second year.
- **The Master's Degree in Palliative Care** A two year programme that will be launched in January 2019 in affiliation with Makerere University.

IHPCA is the only Institute of its kind in sub-Saharan Africa offering academic programmes in palliative care. Its students come from all over Sub Saharan Africa.

It's Research and Ethics Committee (HAUREC) is accredited by the Uganda National Council for Science and Technology.

Non-academic programmes.

The Institute also conducts short courses in palliative care for the following personnel: health and allied health professionals, community volunteer workers, religious and spiritual leaders, traditional practitioners and *ad hoc* trainings at request.

Strategic Objectives (2018/23)

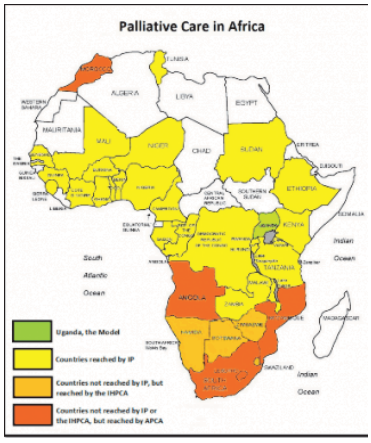
To work towards autonomy from HAU, gain accreditation from NCHE and charter; Expand, diversify, strengthen scope and quality of educational programmes; Increase research productivity and utilization to increase evidence base for palliative care and influence policy; Achieve sufficient financial and other resources to sustain operations and developments of the Institute; Establish and operate Partnerships in research, education and palliative care service delivery; and Support the work of the International Programmes.

The Institute for Hospice and Palliative Care in Africa……

Rutwemba House—Education building

Lighted candles symbolise hope and the passing on of the flame of care to others

The Department of International Programmes (IP) was created in 2000 to carry forward the founding mission of Hospice Africa ***"palliative care for all in need in Africa"*** and also subscribes to the third objective of HAU ***"to facilitate the initiation and expansion of palliative care in Africa by providing an affordable African model"***.



The five week initiators course

IP offers two intensive five-week courses, one in English the other in French, to African healthcare professionals who are willing to be 'initiators' or 'pioneers' of palliative care services in their respective countries. During this there is a two-week course on pain management and psycho-social support, a two week clinical placement and a one-week training of trainers . The most important part of this course is the hands on experiences said the trainees. That is what makes Uganda different from other countries and that why this course is continuing to be conducted in Uganda.

Since 2000, IP has carried out 22 of these Palliative Care Initiators' Courses, 15 for Anglophone countries and 7 for Francophone countries. With experience in Uganda, and 12 years in Anglophone Africa, IP started its first Palliative Care Initiators' Course for Francophone Africa, in 2012 and now has an English-French bilingual team. Since then about 20 African Francophone health professionals from the 18 Francophone countries are trained annually in Uganda. When need be, the team also carries out Initiators' Courses in country and does advocacy with ministries of health and other health care organisations.

The follow-up on action plan which students write before leaving Uganda is a tool to use, however , after reaching work place they face challenges or the small progress they wish to make is not always welcomed by the authority, therefore mentorship, follow-up visits are a key to progress.

Support supervision visits to countries

The team from IP conducts visits to other African countries to provide support, supervision and mentoring of trained health professionals to ensure quality standards are maintained, both in training and service provision. During such visits activities include ongoing support to the trained health professionals; review progress of palliative care integration process; support and training of new health professionals if arranged; provision of clinical support through active patient assessment & management. Since 2000 14 Anglophone 17 Francophone countries have been visited and supported by HAU.

Total number of trained professionals

To date IP has trained 235 health care workers from 14 Anglophone countries and 135 from 19 Francophone countries. On completion of the course participants go back to their countries with an action

plan to be completed in a period of 6 months.

Spreading the word -Initiator's Programmes for Francophone Africa

"Each year, an estimated 912,000 people, including 214,000 children, require palliative care in Francophone Africa" says the report ***"Ending Needless Suffering - Improving Palliative Care in Francophone Africa"*** co-edited by the IAHPC.

"The need for this essential health service is likely to rise significantly in the coming years as the percentage of people over 65, the segment of the population most affected by chronic illnesses, is expected to more than double in Francophone Africa by 2050."

"More than half the countries in the region for which data is available use so little morphine that it is not even sufficient to treat 5 percent of people dying in pain from cancer and AIDS each year" recalls the same report quoting the International Narcotics Control Board, a United Nations agency.

"Most of the Anglophone African countries are much more advanced in palliative care than Francophone countries" says Sylvia Dive, the focal person for Francophone Africa in Hospice Africa Uganda. "It is vital that Uganda which is at the forefront of African palliative care shares its successful story through quality education and advocacy".

20 health

So far 3 Francophone countries (Benin, DRC and Cameroun) have imported morphine powder through HAU's help . When palliative care starts becoming reality in Francophone Africa the pioneers will need support, confided Dr Lionel Kamgain from Cameroun in his last day in Uganda. And Dr Bibiane Kubindana from DRC added: "we will need you to respond to our calls, this is so important." Our plan is for one of the countries to become centre of excellence for clinical, educational for Francophone Countries. The need is big and this is becoming humanitarian emergency. The students we trained has become also trainers. Each year we call upon some of former trainees to come and facilitate on course

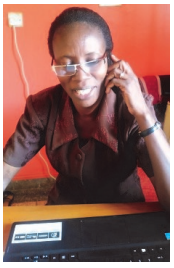
Mali "I fully reached my objectives and I now have the competence to deliver appropriate care to the people suffering from life-threatening illnesses, and to teach and advocate for palliative care" says Dr Zakari Saye, surgeon oncologist from Mali who attended the Francophone Initiators' Course.

Dr Saye added :" My father died of cancer of pancreas in severe pain. I was helpless, yet in Uganda the patient I visited home with similar diagnosis welcomed us during home visit while smiling . After finishing my studies in Dakar I will do the same back home". I

Benin:"I had not had any training in palliative care before taking part in this course. There was practically no palliative care. Now we have a palliative care unit in the hospital. We produce oral morphine solution as well for pain management. We organise home visits.'

Burkinafaso 'There wasn't palliative care, neither provided nor known' I founded an Burkinabe association for palliative care, Hospice Burkina, [which is] recognised by the authorities.

Togo: Palliative care wasn't well-organised in my country and there wasn't the same understanding of what exactly palliative care was.' I have organised a talk on paedriatic palliative care with the 150 healthcare professionals participating. I have organised in-house trainings palliative care for many healthcare professionals. The project for the creation of a palliative unit and a morphine production unit is in progress with the support of APCA. I have integrated strategic plans for the development of palliative care in the National Programme for Health Development of Togo and in the Programme for the Fight Against Non-Transmissible illnesses'



Bernadette Basamera

The Morphine Production Unit

Pain is a very important aspect of our lives because it's the body's way of warning us that something is not going right and that we need help. For some the issue is quickly discovered and resolved so they go away pain free, for others it's a the beginning of a very long life journey of medication, pain and distress due to both physical and psychosocial factors. Diseases like cancer, HIV, etc. are often times associated with severe crippling pain especially in advanced stages and this can greatly impact the general livelihood of the patient and their care givers. In the past, it was really a nightmare to be diagnosed with a chronic illness because pain management was not effective. In the 1990s, the HIV epidemic was wide spread and it doubled the incidence of cancer. For such patients, diagnosis was as good as a death sentence, and this death would be slow and excruciatingly painful. In addition to this, these were issues that were not often discussed in the open and even patients could not freely express themselves to their carers, so at that point they would totally give up and wait for death. Something had to be done! The pain had to be managed, the caregivers needed a support system that would help them to know the best way to look after themselves and their loved ones. Patients needed to live and die with some dignity. There was therefore need to come up with a solution to improve the lives of the people living with chronic illnesses in Uganda.

By 1993, having seen the agony patients went through with pain in Singapore, Nigeria, Kenya, etc. Dr. Anne Merriman founded Hospice Africa Uganda, as a non-profit making organization, whose vision was to provide palliative care to all in need in Africa.

Palliative care is defined by WHO as an approach that improves the quality of life of patients and their families facing life threatening illness through assessment and treatment of pain and other problems physical, psychosocial and spiritual. To provide pain relief to patients, medication is required and opioids are one of the most frequently used analgesics for cancer pain. Hospice needed to be able to provide morphine to patients but the laws then were quite stringent on import of narcotics. In 1995, this challenge was over come as an endorsement to import narcotics was then approved by the minister in charge of health therefore morphine powder could be imported from Europe. The procedure for preparation was a very simple one, morphine powder was mixed in previous boiled and cooled water, packed in mineral water bottles and then it was ready to be given to the patients. This was done for 20 years and the number of patients grew steadily. What started as a small organization with about three clinicians and a handful of patients had now grown into a bigger organization, with more patients, more staff and more donors contributing to this noble cause. However they were still some challenges that

they were facing at that time that limited accessibility to morphine. Apart from people not knowing about its existence, there were few doctors trained in palliative care and the law allowed only doctors to prescribe morphine to minimize abuse. In addition to this, with the increase in number of patients, the efficiency of the "bucket method" was low as it could only meet the needs of few people at a time. Then there was also an issue of opiophobia both in the public and among health professionals associated with fear of addiction. In addition to this, some people thought it was a form of euthanasia.

In 2004, the law was revised to allow nurses and clinical officers trained in palliative care by Hospice to prescribe opioids. This was a huge success as it increased availability of the morphine to as many cancer patients who needed it as possible. In 2010, the Ministry of Health set aside funds to supply morphine to all the health units in the country. With this support, there was an increase in the output of morphine by HAU with 3.24% of patients in the country having access to palliative care. In 2012, treat the pain, an organization under the American cancer society gave HAU a grant to buy automated equipment that would increase the sterility of the process of morphine manufacture and also increase the output of morphine to cater for the increasing number of patients. There has also been continuous advocacy by partners like the Palliative Care Association of Uganda (PCAU) and African Palliative Care Association (APCA) to improve provision of palliative care in the country with continuous sensitization of the general public through workshops, etc to increase awareness on palliative care and be able to deal with opiophobia.

Today Uganda is a model for palliative care on the African continent and we have extended these services to other African countries. In addition to this, HAU has three branches in Uganda that is in Kampala, Hoima and Mbarara to increase access to palliative care in the country. Institute of Hospice and Palliative Care in Africa (IHPCA) was set up at HAU and it provides palliative care education many to students from all around Africa. In addition to this, it collaborates with Mbarara University of Science and Technology and Makerere University to teach palliative care to Ugandan medical students in their fourth year. Through all this, palliative care has been able to be reach 18.75% of the population by 2017 and we are still going strong.

Medical care is a human right and it affects us all. We at HAU have decided to give back to society through provision of palliative care services. We are grateful to all our donors without whom this would have been a lost cause. We have also been working closely with sister organizations like PCAU, APCA to mention but a few to be able to realize our mission and vision and we thank them for their collaboration and cooperation. We are also grateful to the government for its continuous support through the Ministry of Health, National Medical Stores and the National Drug Authority. Last, but not least, we are grateful to our patients who have had confidence in us and allowed us to be a part of their palliative care journey and to the team for their dedication and commitment to this cause. The Lord loves a Cheerful Giver.

Mirembe Anna Mary Resty.
Christopher Ntege.

Dr Jack G. M. Jagwe FRCP (London), FRCP (Edin.)

Long serving Board Member Dr Jagwe ,formerly National Adviser on Drug Policy did much to help develop HAU's drive to legalise morphine and extend prescribing to nurses who had successfully completed the Diploma.

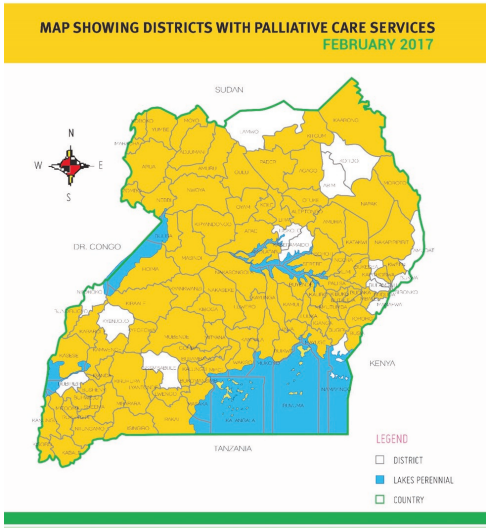
Community Volunteers and Traditional Healers

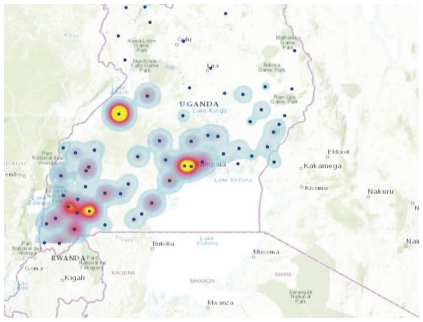
Community Volunteer Workers and Traditional healers

HAU recognizes the wealth and depth of knowledge that traditional healers have of the herbs of immense medicinal value for the control of pain and alleviation of symptoms. We have been privileged to learn from the traditional healers that dried papaya/ pawpaw seeds relieve constipation and that the milky sap of the frangipani tree contains a local anesthetic which reduces pain when patients have vesicles erupting from shingles. Hospice has visited the traditional healers' "pharmacy" in the forest where they have exhibited hundreds of roots, leaves and tree barks which contain medicines yet to be synthesized into their pure forms and made into tablets and capsules for the whole world to access in a readily usable form. We thank the traditional healers for their partnership with us, because they have been open to learning and sharing. Together we are making good contributions towards the care of suffering human beings.

Hospice has also worked with hundreds of Community Volunteer Workers over the course of over two decades. These lay persons are identified as caring persons by their communities and seconded by the local leaders of the villages they reside in to come for a 5 days training by our team. They learn the holistic approach to care of very sick person and return to their communities equipped with knowledge and enthused to seek out patients who would otherwise have had a difficult time reaching Hospice. CVWs are our "eyes and ears in the community", extending care to the remotest and alerting the team when the health condition of patients deteriorates and warrants more urgent interventions by them. CVWs are proud of wearing their T-shirts which always carry a message of the love, hope and difference which

Spreading palliative care in Uganda

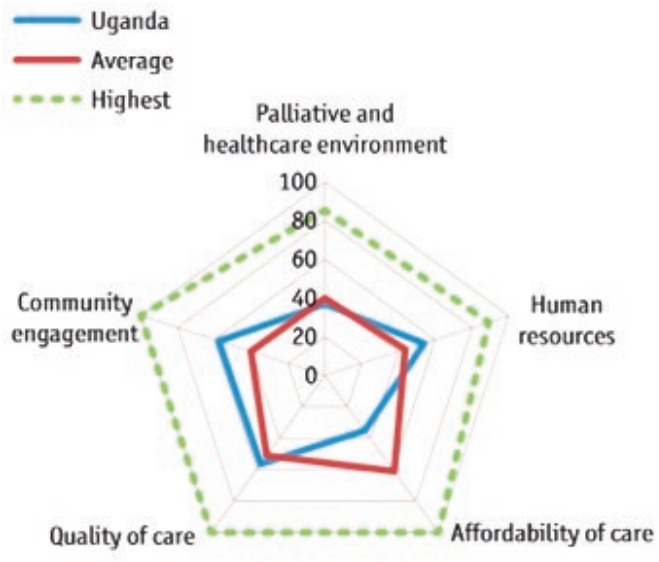




In 1993 Palliative Care was unknown in Uganda, as indeed it was in most parts of Africa. Over the succeeding 25 years much has changed. Now Uganda is 35th overall in the widely reported 2015 Economist international "Quality of Death Index" and third only to Israel and South Africa in Africa. A long, slow and sometimes difficult process has put PC firmly into the Ugandan health care system. The latest development in which PC now has a dedicated Department in the Ministry of Health shows just how much progress has been made. Palliative care has reached 90% of the Districts in Uganda.

This enables ever more patients to be treated in their home communities. However, the need still far outstrips treatment capacity; we have a long way to go! The presence of PC within a District does not mean that it is widely available and the distribution of facilities and trained staff is still very patchy. Nevertheless, the seeds have been sown and the green shoots are showing. What is needed now is constant effort to build on this and to ensure that the progress is not lost.

Scoring for the provision of palliative care



Paediatric Palliative Care

You don't have to be old to need palliative care! Bashir (left) was Dr Anne's very first patient. He had had a radical removal of the arm and shoulder and was in intense pain. Dr Anne was able to control the pain and get him home where he could die at peace in the arms of his family. Paediatric palliative care is still a key strand in HAU's programme of care. Recent developments with an outreach project at Mbarara have brought renewed focus onto the needs of children and offers the possibility of expanding paediatric services in West Nile District

The World Health Organisations's definition of palliative care for children states that palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's 1998 definition of palliative care appropriate for children and their families is given below and the principles apply to other paediatric chronic disorders

Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological, and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres and even in children's homes.

On a lighter note these children with Burkitt's lymphoma are shown holding dolls knitted by a circle of elderly ladies in Southport where Hospice Africa is based in England. It is important to remember that everybody needs affection and that making the children smile is as much a part of our palliative care as supplying medicines!

My 25 Years with Hospice Africa Uganda-Martha Rwabwoni-PC nurse

I joined Hospice Africa Uganda (HAU) in 1994 when it first opened in Kampala. I was coming from a curative hospital; while there I used to wonder what happened to patients when they were told there is nothing more we can do for you.

I joined HAU as a volunteer but by August 1994 I was employed as a full-time nurse. HAU had started a course in palliative care for health workers which initiated me into the work of hospice. At first it was very challenging, as the patients were in such terrible shape and experiencing great pain. I still recall the first patient I cared for, a young girl of 15 years with abdominal malignancy and a fungating tumour on her abdomen. Another early patient was a woman with disseminated Kaposi's Sarcoma who was left in the house alone because she could not move. It had rained and the house full of water; the poor woman was stranded on her bed alone and in total pain. These two patients showed me the importance of listening to stories of worry and despair and doing what I could to provide physical pain relief.

Patients were very grateful even for the little things we did, and especially for our ability to relieve them of the foul smell and pain that colored so much of their lives. It made all the difference to them and to their families. Through caring for all kinds of patients, I learnt to accept people as they are and to help them with what I have to offer.

We soon realized how important it was to teach other health workers about palliative care. Starting in 1994 every morning we would go to Mulago Hospital and teach medical students about palliative care. Teaching was another skill I acquired from HAU because I had never taught except one-to-one to student nurses. I was one of the few nurses who taught Palliative Care for Health Professionals in 1994 at Mulago medical school.

In 1995, I was one of the teachers for a Palliative Care course HAU taught to Health professionals in the Mbarara University Teaching Hospital, now Mbarara Regional Referral Hospital (MRRH). Soon after this, the Vice Chancellor of Mbarara University of Science and Technology (MUST), the site of Uganda's second medical school, invited HAU to come and teach palliative care. MUST partnered with the nearby Mbarara University Teaching Hospital. We were easily able to teach the students at MUST and follow them up in with patients in the hospital.

On 6th Jan 1998 the team set out from Kampala to start teaching at MUST, as well as providing service to the hospital patients and families. The university had students from all over Africa, which helped to spread palliative care to all in need not only in Uganda but the whole of Africa. We soon expanded our reach beyond the hospital. Our team was small: two nurses, a driver and a general assistant. With a Land Rover generously donated by Professor Pat Pathak, who had just left Mbarara Hospital, we began providing palliative care in Mbarara and the surrounding areas.

Mobile Hospice Mbarara officially commenced on 6th January 1998, but we were challenged by the lack of funding. By the grace of God, our earlier benefactor Professor Pat Pathak was a Rotarian who con-

nected us with the local Rotarians. Mbarara Rotary provided us with a 3H (Health, Hunger & Humanity) grant that funded much of our start-up phase. There were many other donors who helped us during that time like the Andrew Mitchell Trust, which donated the money to buy our premises, which included a large home that we renovated into the MHM site with the Rotary's 3H grant funds.
Before the purchase of the premises and relocation to our present site, where we've been since 1998, MUST provided a house in the university quarters for Mobile Hospice Mbarara program. We started our work in one room in the girls' hostel in the university.

It was an uphill battle at first; palliative care was a new specialty and very few people understood it. We had a problem with patients dying and how this was perceived. In many cases, the patients' diseases had already advanced so far by the time they were referred for palliative care that they would die almost immediately. This did not go well with families and the health workers. The good news was that for those whose disease was not too far advanced, the patients and families were very appreciative of the pain and symptom control we provided.

I recall an old man called Kabamwerere who walked to our place of work after he was given morphine the evening before. He told us how grateful he was for the medicine we had given him. He'd had his first good night's sleep and could comfortably walk from the ward to our program office. He said, "I am going to die but please, I am asking that you kindly keep this medicine for all those who will come after me and will need it as well." Indeed he was discharged and soon died from Disseminated Kaposi's Sarcoma and HIV, but his touching, encouraging words remain with me.

I recall my first home visit, back in 1998. I greeted a woman working in her banana plantation, telling her that I had come to see the patient. She said "I am the one." We sat on a mat and I did the clerking, after which I gave her a few medicines and left. She was very grateful because for the first time someone took time to explain to her the nature of her disease and tell her that she would live with a colostomy for the rest of her life.

I could go on and on about my experiences with the patients. Working with hospice has taught me never to take anything for granted. Death is something we all must face; we have to be appreciative for the moments we spend with each other and at the end of every day make peace with people with whom we live and work.

Education has helped other health professionals and the entire community appreciate the importance of palliative care. We are not 100% where we want to be but at least now most people understand what palliative care is about and we are able to control pain and symptoms and ease the end of life for so many.

It has been 25 years but it feels like yesterday when we started. There is still much need to be done to meet the goal of expanding palliative care to all in need in Uganda and Africa in general. Some health professionals still feel they have failed their patients when they die without accepting that it is part of life. I can take pride in having played a role in helping patients, families and health professionals understand and use of palliative care, both through my direct care-giving, supervising and training nurses and caregivers and teaching courses throughout my time with HAU.

Martha Rwabwoni

Message from African Palliative Care Association (APCA):

The African Palliative Care Association (APCA) Congratulates Hospice Africa Uganda and all its partners for making 25 years of dedicated and selfless service to adults and children with serious chronic illnesses in Uganda through palliative care and extending this care to the African continent. APCA is very proud to have been associated with Hospice in this journey in many ways.

The establishment of APCA in 2003 to promote and support access to palliative care by all those who need it in Africa is part of this 25 year journey and leadership of Hospice Africa Uganda. We wish to recognize the many milestones we have achieved together over the years towards our shared vision, mission and objectives. Through our partnership efforts, we have supported advocacy, service development, education and research in palliative care, resulting into the recognition of this important area of public health, human rights and discipline, at the national level, regional and global level. Our joint efforts have brought palliative care developments in more than 30 African countries.

Through the service model established by Hospice Africa Uganda, APCA has been able to support experiential learning visits on palliative care for policy makers, health care providers and officials from national medicines authorities and supply chain systems. This has facilitated the establishment of national and institutional level palliative care services in many African countries as well as improving access to controlled medicines for pain relief. Through our education scholarships programme, health care workers from across the African continent have obtained skills from the Institute of Hospice and Palliative Care in Africa and are providing leadership in service development in their countries. Countries such as Botswana, Kenya, Rwanda, Mozambique, Eswatini, Malawi and Namibia, have benefitted from this support.

We recognize our partnership in your pioneering work of extending palliative care services to people in humanitarian/refugee situations in Uganda and see in this, yet another important best practice and model to be shared with the African continent.

On this occasion of celebrating 25 year anniversary, we stand with you in looking back and celebrating these achievements for Uganda and Africa. We pledge our continued support and partnership in bringing hope and dignity to patients and their families by addressing their pain and suffering.

Congratulations once again Hospice Africa Uganda and partners!

Dr Emmanuel Luyirika

Executive Director

African Palliative Care Association

Message from The Palliative Care Association of Uganda (PCAU)

Palliative Care Association Of Uganda

25 YEARS OF HOSPICE AFRICA UGANDA IN PALLIATIVE CARE SERVICE PROVISION AND EDUCATION.

Rose Kwanuka

The 25 twenty five year journey of palliative care in Uganda, has transformed the attitude of health care workers towards death. Dr Anne Merriman, the God sent angel we thank you for introducing Hospice and palliative care concept in Uganda.

Hospice and palliative service started humbly from St Francis Nsambya hospital. Little was known about this kind of service, it was all new to health care workers, spending time trying to understand the physical, physiological, social and spiritual needs of the patient and family all seemed a waste of time to health care workers.

Hospice and palliative care is now seen as one of the essential service Ministry of health must deliver to the people of Uganda for it complete the circle of care. It is for this reason that Ministry of health requested Ministry of Education and Sports in April 2016 to introduce palliative care course in the nurses training institutions, so as to increase specialised palliative care nurses to handle the increasing number of patients with palliative care needs in Uganda.

Hospice and Palliative care concept which was initially in Kampala district only, has now spread to 97 districts of Uganda and over 200 health facilities are accredited to provide palliative care. Thirteen Hospice/standalone palliative care programs work with hospitals by following up patients discharged from hospitals to communities, thereby enabling continuity of care till death and beyond.

As a country we are proud to celebrate achievements made in 25 years of Hospice and palliative care work. Below are some of the achievements we can quickly and proudly enumerate.

- A strong vibrant national association that coordinate palliative care organisations and health care workers in Uganda.
- Having palliative care in the MOH policy documents like; the Health Policy 2010, Health Sector Strategic Implementation Plan 2018/19- 20/21.
- A 2004 statute that allow nurse to prescribe oral morphine, that task shifting accelerate palliative care delivery in the country.
- Spread of palliative care services to 97 districts of Uganda with over 243 health facilities providing services in the districts.
- Reconstitution of oral morphine locally under the Public Private Partnership arrangement.
- Introduction of palliative care in the health training institutions
- Ministry of Health and Education and Sports accepting to introduce PC as one of the specialization program nurses and midwives can undertake.

Long Live Hospice Africa Uganda, without you we wouldn't have registered these important milestones.

Greetings from Hospice Africa (UK)

"Imagine a world where whatever the pain the strongest pain killer is just paracetamol…….
When Hospice Africa started in Kampala, Uganda, in September 1993 this was the reality……."

We often use this quote to set the scene ….. but that was then and 25 years further on the situation is totally different! Uganda has led the way in sub-Saharan Africa in the development of palliative care. During those 25 years Hospice Africa has been working as a fund-raiser to support the spread of palliative care in sub-Saharan Africa, associated principally with HAU but also with other partners in many African countries. In particular HA has helped support "International Programmes" led by Dr Anne herself. IP has visited many countries and helped initiators in all sorts of ways, but always it has relied on HAU to provide the base and expertise of all sorts , clinical, organisational and ethical.

HAU is the model for our three founding principles which aim to provide an affordable, culturally appropriate model for holistic care of the patient, family and other carers. The ethos defined as *"caring for all patients and staff"* is at the centre of our principles.

Hospice Africa proudly boasts that in the UK it is an all volunteer organisation. Many volunteers are long serving, some have been with us almost from the beginning. Age is no barrier and there are several volunteers in our two charity shops who are over eighty and two over ninety. They take a keen interest in the progress of HAU and send their very best wishes!

L eft to right: Ainsdale shop and staff , Liverpool Shop and staff

We have seen HAU go from the penny-pinching, hand-to-mouth budgets of the early days, through the periods of relatively good funding and back to the struggle for sufficient resources to keep the dream alive. HAU is now planning for the next 25 years (well, starting at least with the next three years) placing a renewed emphasis on reaching the decision makers who can build palliative care into a health systems approach which will gain the support of governments. Already this is taking shape and HAUK will be working to help fund HAU in its work with other committed organisations, such as APCA (The African Palliative Care Association) and PCAU (The Palliative Care Association of Uganda). HAU is constantly working on advocacy and sensitisation. In a major development, where once again Uganda leads, and the Ugandan Government have just recently further embedded palliative care in the new National Health Programme by creating a dedicated department within the Ministry of Health.

We are proud to be associated with HAU and the Trustees of Hospice Africa will work to support HAU and try to provide any assistance they can. Trustees will continue their work of fund-raising and other supportive roles including working with HAU on applying for and managing grants.

David Phipps

Honorary Chair
Hospice Africa
UK Charity Number: 1024903

Greetings from Hospice France (Soins Palliatif)

Hospice Africa France advocates for the Merriman Model of palliative care in many parts of Francophone Africa and teaches that model to their health professionals.

This year we had a cancer doctor, sent by his country, to our training in Uganda. During the theoretical part of the course he remained unconvinced but that changed when during home visits he was soon convinced by seeing a patient dying in peace of the same cancer as his father had died from in agony. He is now an advocate or PC in his country.
HAU is our mother ship, the source of all our teaching and the practical example of the peace brought by the Merriman method.

Jim Bennett

Message from Hospice Africa USA

Hospice Uganda USA was established in 2005. We are so proud to be part of Hospice Uganda and all that it represents: the staff the patients and the communities which support it. Like Hospices all over the world it is a constant battle to find the support and money that is needed to keep the organization going and we will continue to work hard in the next 25 years to make this happen. We strive to provide financial and educational support as Hospice Uganda moves forward.

Judith Hills

Message from Hospice Africa Ireland

Hospice Africa Ireland
...enhancing life at every stage

Hospice Africa Ireland (HAI) is a support organisation Hospice Africa Uganda (HAU). In the last 20 years HAI supported the volunteering by Irish palliative care clinicians (doctors, nurses, pharmacists) in developing the first homecare services at 3 sites in Uganda. Additionally our volunteer pharmacist led the establishment the first oral liquid morphine production unit in Kampala, which now provides morphine for pain control to the whole of the Health Service in Uganda. We helped, in partnership with Irish Aid, fund the construction and refurbishment of 3 buildings at the headquarters of hospice services in Kampala. As medical and non-medical volunteers from Ireland returned from their placements in HAU, many wanted to continue helping in some way, and Friends of Hospice Uganda was established as a registered charity in Ireland in 1999. The charity was formally changed to **Hospice Africa Ireland** in May 2008. Hospice Africa Ireland promotes awareness of the role and activities of Hospice Africa Uganda and also supports fundraising initiatives with our donors and supporters throughout Ireland. Today we focus exclusively on fundraising to fund essential services and development projects. We are delighted to wish Hospice Africa Uganda many congratulations for all their efforts over the last 25 years and to offer our best wishes and support for the future.

Eugene Murray

Five years that changed my life, and gave Malawi a new spirit of Palliative Care Service

On 17th March 1997 at the Irish Society St. Patrick Day's dinner dance Dr Anne Merriman said I could join her immediately as a volunteer nurse at Makindye. The next five years working at Hospice Africa Uganda changed my life completely. Seeing and helping relieve pain and suffering of patients became then, and continues to be my life's work.

Dr Anne Merriman gave me the inspirational *fire-in-the-belly* passion that is still needed so much throughout sub-Saharan Africa: the difference appropriate practice of Palliative Care makes to people lives. I saw its importance and relevance to many fellow Malawians who were, and continue to suffer terribly in many parts of Malawi from chronic pain that is usually due to cancer and other life threatening illnesses.

In 2002 I left Hospice Africa and came Salima district where for the next 3 years I again volunteered my time to Salima AIDS Support Organisation (SASO) and the Salima Catholic Parish home based care service. My purpose being to show how effective a deep sense of Palliative Care service commitment to its delivery is within the community.

That experience gave me time to figure out how a fully meaningful service within Salima district could be established. In 2005 I attended Hospice Africa's 3-month Clinical Practice Palliative Care course.

NdiMoyo's Palliative Care services have cared holistically for over 1700 patients and their families on an entirely free basis since 2006. It currently looks after over 400 patients on a regular basis; and is one of the Ministry of Health's key partners actively improving palliative care service provision in Malawi.

As the founder of Ndi Moyo Palliative Care Centre I built up this service with my husband from scratch, modeled largely on Little Hospice Hoima as it was in 2005. Today the Centre has 5 Palliative Care nurses, 1 Palliative Care clinical officer and 12 support staff. In addition Catherine Nawangi joined us in 2015 to help us establish Hospice Africa Uganda's Initiators course here in Malawi, and support those so trained at their health facilities.

Ndi Moyo has held 4 Palliative Care Initiator courses since 2015 in association with HAU and its present and former staff, most especially Dr Anne Merriman, Dr Ludoviko Zirimenya, and Catherine Nawangi. As a result there are a further 1,500 or more patients gaining an active Palliative Care service from 40 health professionals who were participants of those Initiator courses. These Palliative Care providers are working in 17 districts of Malawi (17 hospitals and 10 health centres).

Lucy Kishindo Finch 28th September 2018

Message from Ndi Moyo

Lucy Finch and her husband Tony, founders of Ndi Moyo

Message from Tyanjane, Palliative Care Support Trust

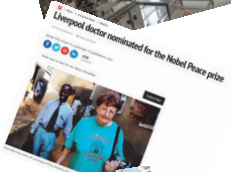
Congratulations to HAU on reaching 25 years – that's a remarkable achievement, and testimony to many hours of hard work and dedication! A big thank you for the generous support and encouragement during the early years of palliative care development in Blantyre, Malawi – without you we could not be where we are today – a centre of excellence in teaching, training, research and most importantly service provision for patients and families with palliative care needs. In recent years your open handed and supportive approach enabled us to maintain the employment and develop the skills of our staff team carrying us through a critical funding gap. Palliative Care Support Trust (Tiyanjane and Umodzi) have continued to contribute significantly to the development of palliative care and training in Malawi because of the continued support of HAU over the years. This has been invaluable. Wishing HAU long life and many more years to come.

Dr Cornelius Huwa
Medical Director

Dr Jane Bates
Board Chair

Palliative Care Support Trust
Blantyre, Malawi

History .. a timeline for Hospice Africa Uganda



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 HAU trained have looked after an estimated **35,000+** more.