

OMH Justice in Action Ministry
Witness: Hospice Africa Uganda
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My name is Mary White; the Justice in Action committee invited me to speak with you today as they have chosen this year to generously support a non-profit that is dear to my heart: Hospice Africa Uganda. In these few minutes I'd like to tell you:

1. How I learned about this remarkable service,
2. What this service involves, and
3. How the support of the old Meeting House will make a difference.

1. How I learned of this non-profit organization:

For most of my working life I taught medical ethics and global health at a medical school in Dayton, Ohio. I had no business teaching global health but decades ago some students asked me for help starting a global health elective program. I did this and it grew very quickly, from five to a majority of students each year, with curricula over four years. So when I had a sabbatical in 2005, I chose to gain some first-hand experience. I found a three-month teaching position at a medical school in Mbarara, Uganda (the country's second largest city and university in Uganda). This was a perfect place for me to learn about low resource medicine, the global aid industry, international research, HIV, a collectivist culture, Ugandan gender norms, and much more. I had access to medical students and colleagues, HIV was everywhere, and English was the common language. (Mbarara was also stunningly beautiful, at about 6000 feet, with rolling hills and long-horned cows everywhere - I could almost pretend I was in Vermont.) I quickly discovered Mobile Hospice Mbarara, one of three regional services comprising the non-profit, Hospice Africa Uganda. Once a week, I went out with nurses and medical officers on home visits in the city and surrounding rural regions. I was deeply moved by what I saw, impressed with the quality of the care provided and what it meant to patients and their families. I have supported them ever since, including serving on the US board for many years. Last May, I went back to Uganda; among other activities reconnecting with Hospice and many of the people I first met twenty years ago. It was an extraordinary visit which some of you heard about, and led to your generous gift.

2. What is Hospice Africa Uganda, and what services does it provide?

Before I tell you about Hospice Africa Uganda, I'd like to say a few words about Hospice as the clinical service we know here today. Hospice was founded by Dame Cicely Saunders in the 1960s in England. In her work as a social worker and physician after WWII, she became aware

of the need for comprehensive (bio-psycho-social-spiritual) care for people who are terminally ill or actively dying. A deeply spiritual person, she claimed she found her inspiration for Hospice care in the Book of Matthew, where Jesus is alone in the Garden of Gethsemane, afraid of what he knew was coming, and begged his disciples to “Watch with me.” The fear, anxiety, and desire to avoid death that Jesus expresses, above all the wish for company as he awaits his fate, are familiar to many who have been seriously ill. Hospice care in Europe and the West typically includes commitment to meeting the patient’s (and sometimes family’s) needs for symptom control, pain management, counseling, company, and spiritual care at the end of life. (Here, as you likely know, Hospice care is structured and paid for as a Medicare benefit for those believed to be within six months of dying.)

So what does this mean in Uganda?

Uganda (2025), is a low-income, multi-ethnic country in Central Africa, bounded by Kenya and Lake Victoria to the East, Sudan to the north, Congo to the west, and Rwanda and Tanzania to the south. The equator runs right through it. An extremely beautiful country, it has many large lakes, fertile lands, ample rainfall, and mountains over 14,000 feet. It was never fully colonized but the British considered it a “protectorate” and were there for about 60 years growing cotton, sugarcane, tea and coffee, while Ugandans provided administrative assistance. Independence came officially in 1962, followed by about two decades of violent civil wars until Yoweri Museveni seized control in 1986. He has been a stabilizing force in the region – establishing representative government as an autocratic “Presidential Republic” with both a President and Prime Minister. His achievements include strengthening education and public health (Uganda was in the vanguard of AIDS education and prevention), including women in government positions, and building relationships with foreign donors. More recently, despite civil wars in Rwanda, Congo, and Sudan, he has maintained neutrality and provided a safe haven for thousands of refugees.

Today Uganda’s population is about 50 million, about 70% of which is rural, 30% urban; 70% are under 30. Common communicable diseases include: malaria, HIV/AIDS, TB, respiratory disease, diarrhea, and epidemics (Ebola, mpox). These account for over 50% of illness and death.

A growing burden of non-communicable diseases (NCDs) include: cancers, mental health disorders, diabetes, hypertension, and cardiac disease. Maternal and perinatal conditions contribute to the high mortality. Importantly, there are wide disparities in health status across the country, closely linked to underlying socio-economic, gender and geographic disparities, limited availability of health care, insufficient medical professionals, and ongoing brain drain.

The health care system consists of public and private hospitals and clinics unevenly distributed throughout the country. Specialty care is limited due to lack of adequate training, drugs,

equipment, and treatment alternatives. Where treatment is expensive and getting to medical care is time-consuming and costly, many poor people die with untreated terminal illness, in severe pain, sometimes with open wounds, untreated infections, and hunger. It is in this context that Hospice, by controlling pain and symptoms for the chronically and terminally ill, is so important. (Note: Hospice serves patients with chronic pain and comorbidity; patients need not be terminally ill, as is required for Hospice care in the USA.)

HAU:

This NGO was founded 1993 by Dr. Anne Merriman. She is English, born Catholic; after high school she joined the Medical Missionaries of Mary, determined to bring relief of pain and suffering to Africa. The MMMs eventually put her through medical school, she then spent nine years in war-torn Nigeria, then Singapore, where she discovered the need for palliative and Hospice care for older persons and developed a simple and inexpensive recipe for liquid morphine. Along the way she decided to leave the MMM order, but they have supported her work ever since anyway.

Kenya was her next stop after Singapore – she was invited there to start a Hospice service, but she found the burden of red tape intolerable and didn't stay long. By then she had a vision of providing palliative care services across the African continent. And so, in her late fifties, looking for a place where she could bring this dream to life, she chose Uganda. At that time (1993) the government was trusted internationally, which she knew was critical if she was to raise funds successfully.

Once in Uganda, Dr. Anne set up the first hospice (in her own apartment), trained some nurses, developed relations with the Ministry of Health, and built the beginnings of a program. She then went back to England and Ireland to promote what she was doing. Slowly and steadily she built an organization that now occupies campuses in Kampala (central Uganda), Mbarara (southern), and Hoima (western Uganda). Unmet needs remain in the northern and eastern regions of the country.

HAU TODAY

1. Clinical Services: Today, as in the 1990s, most terminally ill patients suffer from cancer, HIV/AIDS, and cardiac disease. Most patients are seen in their homes. Hospice services are now provided by a few other organizations but HAU is the most prominent, with the closest ties to the Ministry of Health, and the nation's best hospital and medical school in Kampala.
2. HAU manufactures liquid morphine (two strengths, in water bottles, color coded) in quantity, which is sold to the Ministry of Health and distributed across the country.
3. Teaching Institute: The Institute offers multiple training opportunities for trainees (mostly nurses) with different backgrounds and needs. It is said to provide the most

comprehensive palliative care training in all of Africa, and students come from many countries to learn these skills.

4. Research – Nurses, teaching faculty and students conduct research, typically on interventions and outcomes for particular conditions or patient populations.

HOME VISITS:

We start the day at the local headquarters with a short service: tea, announcements, a song or two, a prayer or two, a blessing for the day and off we go. We drive 30 min or 3 hours, dirt roads become tracks, we may walk quite a way when further driving is not possible: up hills, through banana groves or coffee forests, to a concrete house with a metal roof or a dirt and thatch house.

Patients are often dressed in their best, on a mattress or woven mat on the floor, with family members at their side. For new patients, a lengthy medical-psycho-social-spiritual history is taken. Illnesses are usually severe, often undiagnosed, often advanced beyond anything we would see here. Open wounds, infections, major pain - one wonders how people can survive these conditions. But the nurses have a lot to work with in their bags: liquid morphine and other generic meds for pain, bandages, antibiotics, and basic medical supplies. They may also provide food and clothing for those who need them. The goal is to control pain and symptoms enough to make a dignified life bearable, enabling patients to continue some domestic roles and engage in family life as long as possible. The nurses are indefatigable, deeply compassionate and respectful (the “ethos” and core values of Hospice) and take the time to get to know each patient and his/her family. Some families may give the nurses gifts, perhaps a bunch of bananas or some eggs, in gratitude. Fees are encouraged but care is provided regardless of ability to pay.

TODAY: Dr. Anne is still going strong – she lives in a compound overlooking Lake Victoria Kampala with a few Ugandan families who help her with household chores. Dr Anne has streams of visitors, she never forgets a contact, and at 90 is often still up until 3:00am writing grants and dealing with email. When I saw her in May she had just started a new service for cancer survivors with disabilities. Her life has been a courageous, extraordinary story that began as a young girl who didn’t believe she had the intellect for medical school and led her to build an organization that has changed medical care across a continent. If you would like to know more about her, she has recently written a wonderful autobiography, available on Amazon.

But it is the Hospice staff - the nurses and drivers, administrative leadership, and Community Health Workers - who are my heroes. These people work 12-14 hour days, six days a week. Their commitment to their patients, to relieving suffering and providing solidarity with the

families is unlike anything I have seen elsewhere. This work is pursued with passion and dedication despite the low salaries, endless need, and what is now a ruthless political context. In recent weeks our own country has taken frightening turns I never thought possible, including backpedaling on one of our founding principles: that all people are of equal value, equally deserving of life and liberty. The dismantling of USAID will inevitably lead to an increase in the prevalence of HIV and other infectious diseases, increased pressures for immigration, and may belatedly cause us to lose the Cold War. But I'll never forget the call I received from a dear Ugandan friend (I'd first met as a Hospice patient), bewildered that a President of a great nation would deny tens of millions of people access to drugs they had been getting for decades, without which they will slowly die.

Uganda is far from a homogeneous country – it contains over 56 distinct ethnic groups, each with its own language, religion, culture, and economic stratification. But Hospice staff are committed to providing care regardless of their patients' identity (they even found creative and courageous ways to get patients' care during the lockdown when police were arresting people who were out and about.) That they can maintain their humanity – their capacity for compassion and care - despite their dangerous and cruel political environment, gives me hope for our own country in these frightening times. I am very proud of the Old Meeting House community for its long commitment to Justice in Action – to supporting people around the world who are less fortunate than we are.

OMH GIFT:

Unless I hear you would like it restricted in some way, your gift will support Hospice's general operating fund, where it will most likely be used to support ongoing clinical services: salaries, medical supplies, vehicle maintenance, etc.

I am deeply grateful to you all for your support of this invaluable service. I just wish you could see this work yourselves – it is truly humbling to see the enormity of the need and the determination of the Hospice staff to make sure every one of their patients receives care, compassion, and utmost respect.

If anyone has questions, I'd be happy to try to answer them at any time. Thank you again for your support!