

**Anne Merriman** recounts her journey from Ireland to pioneering palliative care in rural Africa



# AN AFRICAN JOURNEY

## key points

- The distinctive approach of palliative care is how we bring our own vulnerability to the care of our patients. This was one of the first lessons that the founder of palliative care, Dame Cicely Saunders, learnt from her patients.
- The author recounts how she was called and equipped to take the ethos of palliative care that she learnt from Cicely Saunders to the poorest in Africa.
- It was her relationship with Christ that gave her the spiritual strength to provide open-hearted care to the dying – and this is the challenge to us all.

*'If you want to go fast, go alone; if you want to go far, go together'.* African proverb

### Maria: a recent case story

**M**aria is seven and the second youngest of eight children born to two schoolteachers, a middle-class Ugandan family.

She was a vivacious child and very popular with her siblings and classmates alike until she was struck down with progressive neurological defects which turned out to be a brain tumour. After an initial debulking operation she returned to school, but within a year the symptoms returned indicating that the tumour was extending in her brain. The surgeons recommended another operation. After many struggles, the family raised the money for this only to be told that nothing more could be done.

Now Maria is blind and spastic in all four limbs, aphasic and has difficulty swallowing.

Her siblings (aged from five to 18 years old) have not been told her prognosis. They are all acting as if Maria is going to get better, but they are all

supporting her with total care.

Their neighbours, however, are accusing the family of offering Maria as a sacrifice in exchange for money, as she is their best child. This is an added strain for the family as they are no longer receiving support from the community. Financially, Maria's illness has brought them to their knees.

The family was originally Catholic and more recently attached to a 'born again' church. They have a strong belief in God and gain spiritual support in the knowledge that he is with Maria and the family in these difficult days.

How do we manage Maria in a lower-income African country, even though she is one of the lucky five per cent that receives treatment?

We certainly need to understand both economic and cultural attitudes wherever we are delivering palliative care. But we also need to offer something more, something of ourselves.

### Your vulnerable, wounded heart

We are all vulnerable and therefore wounded healers. Wounded by life in so many different areas, but each of them a gift to increase our under-

standing of others. Are we ready to disclose, in a comforting and appropriate way to our wounded patients, our inner selves; what is in our hearts?

When the young almoner, Cicely Saunders met him in 1948, 40-year-old David Tasma was dying of cancer. A Polish Jew from the Warsaw Ghetto, he was now facing the end of his life in a strange land. Cicely watched as the professors and doctors on rounds passed by his bed, she knew she wanted to do more for him.

When Cicely offered to pray the twenty-third Psalm with him, he replied: *'I only want what is in your mind and in your heart'*.<sup>1</sup>

Mary Baines, the first doctor to work with Dame Cicely in 1968, says *'This short sentence... came for Cicely to embody the two essentials of what was to become palliative care; the application and wisdom of the mind plus the vulnerable friendship of the heart.'*<sup>2</sup>

### My story

Unlike Cicely, Christ has been central to my life since childhood. Cicely found God as an adult and became wholly dedicated to the example of Christ in her concern for the poor and suffering. I was born into a traditional Irish Catholic family. I had declared aged four when seeing pictures of dying children in a missionary magazine, that I would go and help them when I was older. It is only looking back that I can see God's plan for me and those I've met in so many specialities across Africa and Europe.

I went to Nigeria as a newly registered doctor in 1964. It was with the Medical Missionaries of Mary that I learnt to relate to Christ in others, and this has helped me in some of the significant decisions in my life. I found that our relationship to God and his Son is the key. This relationship with the Son of God has been my stabiliser in difficult times. And there have been many such times in the path he chose for me. This relationship has given me the strength to carry on using my vulnerability to help others, knowing this is God's work.

In 1973, I returned from Nigeria to Liverpool to care for my ailing mother. After working in two universities and as a consultant in geriatric medicine, I was now equipped to see needs in different cultures and to seek solutions that were affordable and culturally acceptable, even to the government. It was a real leap of faith to travel from the UK through Malaysia and Singapore, to Nairobi. Together with pharmacists in the National University Hospital of Singapore, we had made up a simple formula of pure morphine for use in the home as well as health facilities. With volunteer nurses, I was commencing a home care programme, later to become the Hospice Care Association (HCA). It was in Nairobi that the vision came to fruition through Cicely asking me to write an article about our work there, for an edition of the Christian journal *Contact*. This article brought letters from seven African countries, asking me to help bring such a home care service to them. These invitations

resulted in a feasibility study in 1993, seeking an African country in which to demonstrate this model of care.

We chose Uganda, a nation just out of war, poverty-stricken and with a vast HIV epidemic that had doubled the cases of cancer. The Minister of Health, Dr James Makumbi told me, *'My people are suffering, please come'*. He had no problem importing the morphine powder for oral liquid morphine, without which I could not commence a service. Also, Uganda was then near the bottom of the corruption list and their president-soldier, Museveni, was the darling of donors, and we felt we could get the financial support.

Soon after, we commenced the model for Africa in Uganda and started moving into other countries; Cicely was very supportive.<sup>3</sup> Her work had come to Africa, and her example of managing total pain, her spirituality and ability not to be afraid to come close to suffering, has helped us in our journey since.

### What are you asking of my African team and me?

But we each need to recognise in our hearts and our minds, that this is a special calling. As Christians, we look to Christ as our example in the way that he showed compassion to the poor and the suffering.

Here in Uganda, we are caring for some of the 95 per cent of cancer patients who do not receive curative therapy. Our community volunteers in the village identify those in need and bring us to see them at home. Many are in a terrible state; isolated by their malodorous, open, fungating wounds, crying in severe pain that is exacerbated by loneliness and rejection, as well as poverty and spiritual longing. Without the means to reach health care, they turn to traditional healers. If the breadwinner is the carer, children stop going to school and there may be no food on the table. Cancer brings a huge spiral down into greater poverty.

My patient needs love and understanding as well as expert treatment of her condition. She needs something of me in the care that I give. Am I prepared to provide this? Am I able to look beyond the disease to the person she is, with the family she loves? Do I seek to understand her needs with empathy while thanking God for the suffering experienced in my own life that has allowed me to understand this pain and do something about it?

### Where next?

Can palliative care bring this approach to decision makers, carers and families? How can it influence professional and international bodies?

Let us make an *Alumn-ethos*, a guiding ethos to help us to work together within our vocation and professions to heal, even without a cure, bringing to peace those who are suffering.

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### Developing Health Course 12-24 July

CMF Global's two-week training course at London School of Theology, Northwood  
[cmf.org.uk/dhc](http://cmf.org.uk/dhc)

### references

1. Du Boulay S, Rankin M. *Cicely Saunders*. London: SPCK, 2007:37
2. Baines Mary: The Essence of Palliative Care: presentation at National Academy of Medicine. Buenos Aires, 8 November 2018
3. Oral communications from Mary Baines 2001 and 2020.