



HAU IHPCA

ETHOS & SPIRIT OF CONSTITUTION OF HOSPICES IN AFRICA

(from Hospice Africa (Uganda))

“How can I understand a figure or a statistic unless I have held the hand that it represents? The people we are talking about are the same as us. By the way we treat them, we know just how much like Jesus we have become.”



Dr. J P Muliyl, Epidemiologist with CHAD, ECC, Velore, India
in “Women in the Time of AIDS”, Gillian Patterson, 1996

Introduction

About Hospice Africa Uganda

Hospice Africa was registered as a charity in UK in August 1993. Hospice Africa (Uganda) is the model Hospice for Hospice Africa and commenced their service for patients and families on 23 September 1993. Hospice Uganda was registered as an NGO in Uganda, October 1994.

Hospice Africa was conceived to support palliative care initiation throughout Africa. This would be done through an African Hospice which would be a model, not only for the country in which it was based, but for all African countries so that Hospice philosophy and care could be adapted to the cultural and economic requirements of each country.

Following a feasibility study of those African countries requesting Hospice services in 1993, Uganda was chosen for the “Model” Hospice.

The **objectives of Hospice Africa** and Hospice Uganda in 1993 are:

- 1. To provide an appropriate Palliative Care service to patients with Cancer and/or HIV/AIDS and their families within defined operational areas*
- 2. To enable the provision of Palliative Care services in Uganda, through Advocacy, Education and Training*
- 3. To facilitate the initiation and expansion of Palliative care in Africa by providing an affordable African model.*

Our Ethos:

At Hospice Africa, we were practicing the ethos long before it was written down. We had the spirit of Dame Cicely, the African spirit of Ubuntu and the compassionate approach of others who developed differing religions and good works. We also recognised that all our services must be developed from the heart as part of a compassionate care.

There are three major elements to our Ethos which can guide us forward:

1. The patient and family must be at the centre of all we do, whether we are involved directly in patient care or supporting those who are.

2. Caring for each other means that we are ready to support each other and ready to be supported by our team members. This ensures the heart of Hospice is within our working area and that we bring a peaceful hearts to patients and families.

3. We cannot work alone. Africa needs all the help it can get to bring peace to those who are suffering from severe illness or at the end of life. We must share, use and support each other.



If we conceptualise the ethos in a diagram similar to that for the public health approach for bringing a new specialty into a country we see that the over riding spirit for the ethos is that of “hospitality”. This is the meaning of the word “Hospice” and this is not a building but a concept of care based on compassion and the ensuing hospitality.



This is woven into the context we find within each country.

The Spirit of Hospice/Palliative care:

“It is in giving, that we receive...”

The inspiration for Hospice in Africa comes from the suffering patient and family. The centre of care is the love for patient and family and our concern to relieve suffering, support with love and to be there with them as long as we are needed.

The care arises from our own acknowledgement that we too are in need of care. That caring is an essential part of God's plan for the world and that caring and being cared for are two sides of the human condition that can make us fully human.

Hospice/palliative care, believes that the time before death is a special time for the patient and family, when hurts can be healed, secrets can be shared and true love based on the recognition of the uniqueness of each person is acknowledged. This includes the patients' beliefs. Hospice respects religious beliefs and is prepared to support relationships and spirituality with patients and families of all religions.

The Team (including teams for Hospice services and National Organisations):

The Hospice team is made up of health and non health professional members and volunteers. The spirit of Hospice is found in the Latin word "hospitium", or hospitality. This means that we are a family, showing love for each other and for those who visit us, whether patients or visitors interested in our work helping our patients and families.

Every member of the team is precious and can be expected to support and to be supported in times of trouble. This caring within the team overflows to those we care for.

The leaders at Hospice are the servants of all: this is their privilege. It is the privilege of our teams to respect and support our leaders.

The word bureaucracy is anathema in Hospice/palliative care.

Management makes decisions after consultation with all concerned. Communication is essential for an efficient service. News of visitors and major decisions are disseminated daily (at HAU this is immediately following the morning inclusive prayer) so that the whole Hospice family is involved and prepared. The Board of Directors is kept informed and confirms major policy decisions.

Volunteers:

Volunteers include our Board of Directors and those who come to give practical help or donate. If possible, Volunteers are requested to attend a course at a Hospice suitable to their professional training. This allows them to see in greater depth several aspects of Hospice and the new specialty of palliative medicine. Volunteers are also encouraged to go out with the team on home visits. This allows them to see the difference Hospice can make to a patient and family.

It is most important that the spirit of volunteerism is understood. *Selfless giving of self, without expectation of monetary reward, defines the Hospice volunteer.* Having said this, the rewards received from the patient and family and the experience of sharing this special time with them, bring rewards that are not measurable in this world.

The Patient and family:

The patient and family are our guests and have choices in their relationships with us including their treatments and which secrets they share. They are reassured that we will not abandon them whatever their choices.



The relationship with the patient and each other is not authoritarian. Confidentiality and ethical issues are a priority.

Attention to Detail:

Because our patients are in a vulnerable position, attention to detail and immediate response to needs is essential. There cannot be a laid back attitude from the team. Each member must be prepared to take immediate action when the comfort of the patient and/or family is at stake, *no matter how long it takes.* Our consultations, by reason of our Mission, cannot be curtailed, confined to time lines or demands for increased numbers requested by donors.

This attention to detail is echoed in the administration and support for the medical team. This means that families are welcomed and attended to immediately. People waiting for attention are offered a drink to make them feel at home. Payment of invoices, releasing of funds to those in need, attending to personal details, are all acted on immediately. This prevents hardship and pain to those in need as well as ensuring that support services are not delayed.

Building on Initiatives:

New ideas, or initiatives are often brought forward by the humbler members of the team. These should be listened to and changes made if the initiative will improve our patient care. Squashing of initiatives by a management can impede the growth of Hospice and our adaptation to changes in society and culture.

The Management Team (or the Association Board):

Those managing a service or responsible as Board members of a Hospice or National Association must be able to demonstrate their loyalty to the needs of the patient and family. Each member must be of the highest integrity. They are entrusted with the sustainability and continuance of the organisation. Their dedication will be rooted in their individual spirituality and selflessness in giving without reserve.

Hospice recognises the unique contribution of each member of the team to this special work. The individual development of team members is encouraged in order to enhance their usefulness to the team work.

Each member of Management will be aware that they must be an example to all and that decisions must be made without selfishness for themselves or immediate family, but with the good of all in need of our services, at heart.

Individual organisational rivalry must be forgotten with the objective of meeting all the needs of the patient and family by networking where a group cannot provide all care individually.

Working in Partnership:

"No man is an Island" John Donne

Each part of the body is required to make a whole functioning being. So if we are busy following our own thing without referring to the rest of the organisations working in palliative care, we will not move on and are bereft in many areas.

Networking for the good of the patient and family is a trade mark of palliative care, especially in resource poor settings where we need to share to give holistic care to our patient. We need to share, respect each other and never put each other down.

WE pray that each country will grow in this spirit so that peace and growth can happen when our time comes as well as for those we are caring. We must always remember.....



There is an appointed time for everything and a time for every season under Heaven...

A time to be born and a time to die.

Ecclesiastes 3.vs1 and 2

Anne Merriman, re-edited from 2000 edition on 15 April 2005 and again 11 July 2009 and 1 October 2014



Our Mission

To bring peace to the suffering in Africa, through providing and facilitating affordable and accessible palliative care in Uganda and other African Countries.

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Donations, sites for wedding gifts and other celebrations
may be given through the website below:

www.justgiving.com/hospiceafrica