

# SWAZILAND HOSPICE AT HOME

**ANNUAL REPORT 2002/2003**

*"SIKHONELA KUSITA"*

*"HERE TO HELP:"*

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***"HERE TO HELP:"***

**ANNUAL REPORT 2002/2003**

**BANKERS:** Standard Bank (Swaziland), Nedbank Swaziland

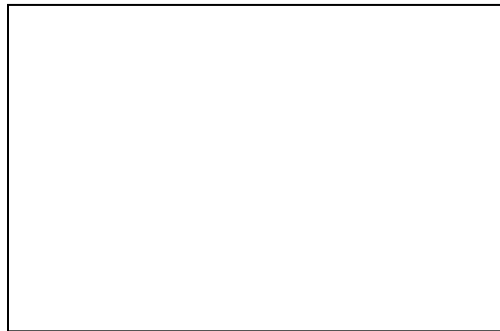
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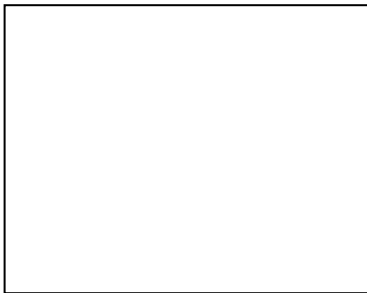
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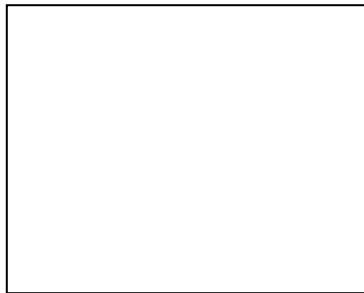
## MEMBERS OF THE EXECUTIVE COMMITTEE



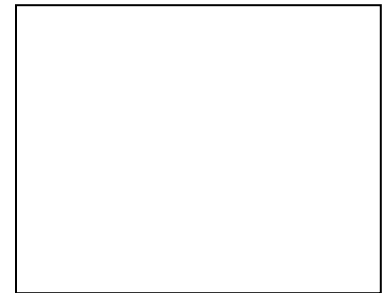
H.R.H. Inkhosikatio Langanaza  
**PATRON**



Ms. Christabel Motsa  
**CHAIRPERSON**



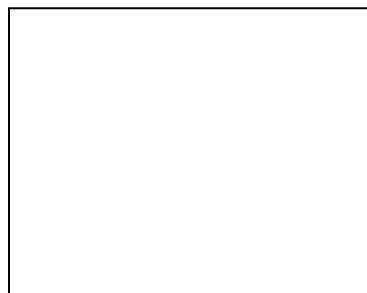
Mr. Stephen Motsa  
**VICE CHAIRPERSON**



Ms. Gugu Phungwayo  
**TREASURER**



Ms. Gcinile Buthelezi

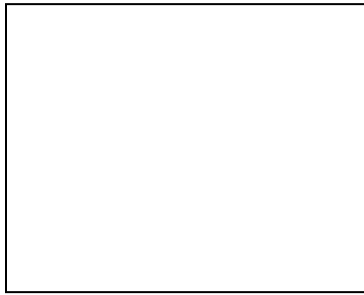


Ms. Thulile Dlamini - Msane  
**Director**

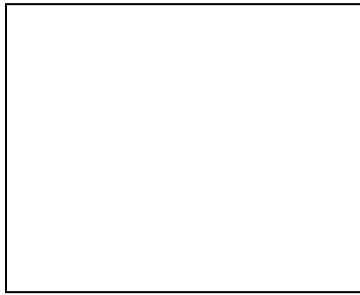


Ms. Busie Ndlela  
**Member**

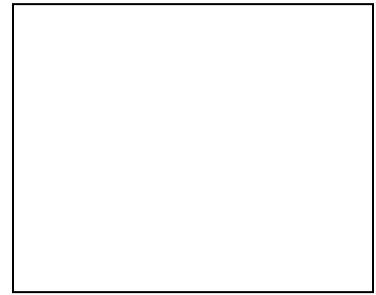
**STAFF:**



Khanyisile Sibiya  
Office Attendant



Thabang Masangane  
Programme Officer – Clinic/ VCT



Philile Ndlangamandla  
Programme Officer  
(Manzini Region)



Johannes Hlatshwayo  
Facilities Supervisor



Olwen Donald  
Skill Share Extension Worker



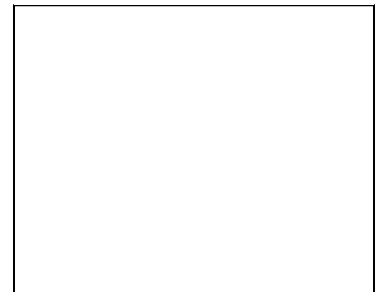
Sam Nxumalo Programme  
Officer (Shiselweni Region)



Dumsane Maseko  
Programme Officer  
(Hhohho Region)



Teluleko Maseko  
Storeman



Themba Gina  
Groundsman



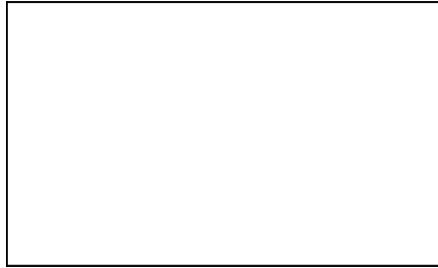
Sibusiso Zwane  
Accountant



Lungile Khumalo  
Personal Assistant



Thoko Nhlabatsi  
Senior Promotions Officer



Gugu Zondo  
Receptionist



Jabulani Gamedze  
Senior Program Officer/Lubombo Region

Swaziland Hospice at Home has maintained its staff throughout the year. However, when the year ended some officers left the organisation for greener pastures and we wish them success in their new engagements. They are:-

Member Dlamini – Fundraiser  
Jabulile Magagula – Programme Officer – Clinic  
Zodwa Gamedze – Educator  
Vuyisile Khumalo – Promotions Officer

The organisation was joined by new officers:-

Sibusiso Zwane – Accountant  
Thoko E.Nhlabatsi – Senior Promotions Officer  
Sam Nxumalo – Programme Officer Shiselweni region  
Gugu Zondo - Receptionist

## Voluntary Counselling and Testing

Swaziland Hospice at Home's main aim is to provide holistic services to its clients. By establishing the Voluntary Counselling and testing (VCT) the organisation intended to access this service to all clients under Hospice Care and to the general public. This will help them to start on treatment early and change their behaviour or lifestyle to minimize their HIV risk exposure. It is envisaged that this service shall be fully operational mid-year (2003).

The VCT service has since been established at a crucial time when the HIV pandemic is at its highest level. Clients shall now, not be referred to other VCT providing institutions for HIV test thus they shall have full confidence to the services they obtain from SHAH and confidentiality maintained.

## HOSPICE OVERVIEW

- |                      |  |
|----------------------|--|
| 1.1 Classification:  | Non Governmental Organisation                                  |
| 1.2 Year Established | 10 <sup>th</sup> July 1990 registered as a locally<br>NGO 2002 |
| 1.3 Location:        | Lusushwana Road, opposite Salt'N<br>Pepper Club Matsapha       |
| 1.4 Leadership       | 1 Patron, 4 Members of Board                                   |

- 1.5 Strategy
- (i) Care and Support of Terminally ill patients at home. Home Based Palliative Care
  - (ii) Palliative Care Clinic
  - (iii) Day Care Centre
  - (iv) Information, Education and Communication
- 1.6 Resources
- (i) personnel: comprises of full-time staff and volunteers
  - (ii) Finances: supported by Government of Swaziland through subvention of 45% of total expenditure, local companies, friends of SHAH and donations from international friends of hospice and organization.
  - (iii) Equipment: office furniture, Computers and six vehicles
  - (iv) Donations in Kind of
    - Food
    - Farm produce from local farmers
    - Used clothing print materials

## ACRONYMS AND ABBREVIATION

- |          |   |  |
|----------|---|--|
| ABC      | - | Abstinence, Be Faithful and Condom use                                 |
| AIDS     | - | Acquired Immune Deficiency Syndrome                                    |
| AMICAALL | - | Alliance of Mayors Initiative for Community on Aids at the local level |
| CBO's    | - | Community Based Organisation   |

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FLAS	-	Family Life Association of Swaziland
TASC	-	The Aids Information and Support Centre
HIV	-	Human Immune Deficiency Virus
IEC	-	Information, Education and Communication
HH	-	Hhohho Region
LU	-	Lubombo Region
MZ	-	Manzini Region
SH	-	Shiselweni Region
SHAH	-	Swaziland Hospice At Home
CA	-	Cancer
ISS	-	Immune Suppressed Syndrome
FOSH	-	Friends of Swaziland Hospice at Home
HBC	-	Home Based Care
NGO	-	Non – Governmental Organization



## **FROM THE PATRON**

H.R.H. Inkhosikati Langangaza

### **Speeches (The Patron)**

The HIV| AIDS pandemic has meant that hospice care has taken on greatly increased significance in the kingdom and in all countries that are badly affected by this terrible disease.

A result of this crisis is that Hospice has to use imagination in our programmes, and to integrate non-Hospice activities as a matter of necessity to meet the many sided challenges of HIV\AIDS.

We know that in Swaziland we are taking great strides in meeting the challenge through such initiatives as Nercha, the various NGO`S and donor agency programmes that are providing a valuable foundation for helping the nation to cope with the disaster and to prevent the slide towards a situation of hopelessness.

One major impact has been on the Kingdom's hospitals, which are inevitably finding it tough to meet the demand for beds and care. Recent surveys show that over 60% of all hospital patients are suffering from AIDS-related illnesses, leading to over-crowding and pressure on the health care state.

The principle behind Hospice at Home provides the logical answer to the problem and ties in with the Home-Based Care strategy that is being promoted by all who are working in the HIV/AIDS arena.

**As pioneers in Home-Based Care, Hospice has recognized the need to adapt to circumstances and to take on such important tasks as Voluntary Testing and Counseling as an integral part of the services we provide to the communities and families. This service will be provided in the communities and at the Hospice terminal clinic where it is most needed. This will enable clients under Hospice care and the general public to start treatment early and change their behaviour\lifestyle to minimize their HIV risk exposure.**

Let me take this opportunity to thank all those who have helped us to make this centre a reality. It is through such combined efforts that this organisation strives to provide holistic services to its clients, which are badly needed. This brings me to another very important issue that of anti-retroviral drugs. SHAH is an integrated health organisation, with health-oriented staff, a doctor and nurses. ARV'S should therefore be prescribed and given to all deserving clients to prolong their lives.

This is indeed a milestone in the History of Hospice at Home as we shoulder our responsibilities in the fight against HIV/AIDS.

I am appealing to all the International Donor Community as well as to the Nation at large to support us to raise funds for our vital activities especially in the area of capacity-building and running costs so that the organisation will be able to provide the essential services that are badly needed by our clients.

**FROM THE CHAIRPERSON**

Ms Christabel Motsa

We have observed as an organisation that immuno-suppression among our clients is increasing every year resulting in the capacity of the decentralized nursing staff to be strained and this also undermines the organisation's efforts of providing quality care services. This increase has also seen the limited resources of the organisation diminishing by the day. Despite all these problems it is encouraging to note that the organisation has a group of committed staff who are determined to improve the care and support programme by alleviating pain and suffering to our clients.

The problem of poverty cannot be over-emphasized as it has a bearing on drug administration. As highlighted earlier on, Hospice services are decentralized and the regions hard hit by poverty are where most of our clients are based. This becomes very difficult to our dedicated staff to administer any drugs on an empty stomach. This has necessitated the organisation to deviate from its original objective and scout for donors for its poverty alleviation programme.

This past year has also seen the introduction of the Voluntary Counseling and Testing Unit. It is envisaged that this will enhance the approach of providing holistic services under one roof. This unit has also been established at a crucial time when the HIV pandemic is at its highest level. Clients are now not referred to

other VCT providing institutions for HIV testing, thus they have full confidence in the services they obtain from SHAH and confidentiality is maintained. It is our hope that in the long run anti-retroviral drugs will be provided by the organisation to its clients then our objective of providing holistic services will be achieved to the fullest. Currently, the organisation refers its clients to other institutions for ARVS that is those who can afford. With this scenario it becomes difficult to follow up such clients. Whereas, if the drugs were administered by the organisation, potential clients would start on treatment immediately. They would also change their behavior and lifestyle to minimize their HIV risk exposure and prolong their life.

I invite all of us to continue the good work for the survival of this organisation in spite of the challenges ahead of us. I hope that one day we shall overcome.

Many Regards,

**CHRISTABEL MOTSA (Mrs.)**  
**CHAIRPERSON**



**FROM THE  
DIRECTOR**

Ms. Thulile Dlamini - Msane

The prospect of the awesome and inescapable finality of death fills most people with apprehension fear or even stark terror. Despite the advances of modern medicine and expertise, some patients die in utter misery, with unrelieved pain and with distressing symptoms inadequately controlled. It is particularly sad that this should happen when there are various therapies and medications. Hospice core business is to alleviate pain and suffering to all terminally ill patients in the country.

The HIV/AIDS pandemic is responsible for the increase in mortality and morbidity in the country. Hospice is not spared from this reality. This is evident by the increasing number of patients with full blown Aids at terminal stage who form 80% of the total clientele.

HIV/AIDS has come with demands hence hospice had to be very innovative to meet the needs for these people. A VCT programme was established and is fully functional with a full time trained VCT nurse. The VCT programme is widely utilized by the affected and the general public. This much needed programme was funded by DFID and we want to record our sincere gratitude to DFID for funding this project.

Poverty is one of the drivers of HIV/AIDS and one of the major causes of neglect of those infected. Hospice had to come up with a strategic approach in delivering hospice care, hence, the birth of food parcels distribution to the needy patients in order for carers to better manage the terminally ill patients. Families that are impoverished are often helpless and sometimes would turn to commercial sex which further exposes them to HIV infection. Furthermore, these families are undernourished and if infected the diseases is exacerbated by the poor health conditions. Local farmers, the business community and churches have assisted hospice in this endeavor to alleviate pain and suffering by providing food parcels. And their help has benefited a lot of poor patients. I want to thank everyone that made this project a big success for hospice, even though we have this programme poverty remains a hinderence to the delivery of quality care. A vast majority of the people we serve have been bereaved more than once such that care givers are not willing or reluctant to continue caring due to the hopelessness of the situation.

The organization has established a firm ground operationally. We have had a few staff members leave the organization. They were replaced by professional staff members making the organization to meet one of it objective which, is to imbue the culture of professionalism stated in our strategic plan. Effective care of a patient during the last few weeks or months of life requires compassion, competence and constant attention to monitor every aspect of the patients' condition. The dying patient is still a living

person and needs to be treated as such hence, the issue of professionalism comes to play.

Hospice cannot do it all alone, hospice services have been made possible by collaboration and networking with other key players whom without them success of hospice would not be possible. I would like to record these players as TASC, Perish Nursing, Churches, NERCHA, US Embassy, British High Commission, His Majesty's Government, SNAP, VCT Centre. We at hospice commend these players for the active role they have played in assisting hospice to meet all its endeavors.

Furthermore, I would like to allude to the support that we have received from our Patron and the Board, FOSH UK, Friends of Hospice Swaziland for working tirelessly to assist hospice achieve its objectives. The media in particular for their positive initiative towards terminally ill patients and Home Based Care.

We all need to join hands and support the terminally ill patients

## **THE MISSION STATEMENT**

### **THE MISSION STATEMENT OF SWAZILAND HOSPICE AT HOME WILL BE AS FOLLOWS;**

“To contribute to the improvement and attainment of the best possible quality of the terminally ill patients and their families, irrespective of their religion, nationality and social status, by providing a holistic approach of caring, comprehensive management and an array of interventions that are intended to ensure that the physical psycho-social, psychological, emotional and spiritual distress are managed and suffering attenuated; through, appropriate counselling and support measures, supportive treatment; as offering advice and training of their families and communities; throughout the four regions of Swaziland, and ultimately assist the dying die with comfort, dignity and love, and help the survivors cope both before and after death.”

## **THE VISION, GOAL, AND OBJECTIVES**

### **THE VISION:**

The Swaziland Hospice At Home (SHAH) aspires to become the centre of excellence in palliative and home based care in the Southern Region and subsequently, in the whole of Africa.

### **GOAL**

“The Swaziland Hospice At Home seeks to provide a unique management technique to the terminally ill patients and their families, through a well orchestrated and dynamic palliative care system, designed to achieve the highest quality of life, and to ensure that terminally ill patients are kept as comfortable as possible and to help prepare them for a death that meets the needs and wishes of the patient and family”.

### **STRATEGIC OBJECTIVES**

1. To establish and develop an institutional framework designed to strengthen SHAH and there by overcome its identified weaknesses.
2. To strengthen and provide an improved operational strategy on the service delivery and management of SHAH
3. To strengthen and provide professional palliative and home based care at SHAH
4. To design and establish an appropriate effective and efficient information, education and communication (I.E.C.) system at SHAH
5. To design and establish aggressive and massing marketing strategies
6. To promulgate and propagate appropriate and sustainable financial strategies
7. To promulgate and propagate appropriate and sustainable strategies.

## **OPERATIONAL OBJECTIVES**

### **INSTITUTIONAL DEVELOPMENT OBJECTIVE**

- To establish an appropriate management and information system (MIS) that enables hospice to manage its activities effectively and efficiently.
- To imbue a culture of professionalism among hospice staff at all levels to adequately meet client needs.
- To improve the image of hospice in societies, amongst clients, the donor community and government.
- To develop an organizational structure that supports the strategic requirement of hospice and enables the institution to be managed effectively and efficiently.
- Instigate a programme of income generating activities, which will include, rent of hospice properties, counseling and expertise rendered on both palliative and home based care

### **KEY OPERATING PRINCIPLES**

Hospice agrees to operate under the principle of:

- Professionalism
- Service quality and excellence
- Fairness, consistency and equity
- Transparency and accountability
- Integrity and honesty
- Diligence
- Accessibility
- Ensure good health – ethics
- Deliver professional programmes, which address client needs
- Undertake continuous staff development

## **CONTROLS**

Hospice agrees to control by:

- Establishing and monitoring key performance
- Developing and implementing a monitoring and evaluation system
- A yearly audit of accounts

## **HOSPICE COLLABORATION**

Due to the HIV/AIDS pandemic, other organisations have introduced home-based care in their programmes. Hospice at Home collaborates with these organisations in various ways which includes advocating for better services for the terminally ill patients, sharing of hospice palliative care information and knowledge and providing in-service education on terminal issues with different health and civic groups. Hospice provides drugs and medical equipment to other organisations involved in providing home based care. Most home based care givers collaborate their efforts so that the terminally ill patients and their families are given quality care and support.

### **Understanding Hospice Palliative Care**

1. Aims to relieve pain, suffering and improve the quality of living and dying
2. Strives to help patients and families address physical, psychological, social, spiritual and practical issues.
3. Treat all active issues and prevent new ones from occurring.
4. Promote opportunities for meaningful and valuable experience which involves personal and spiritual growth.

Hospice palliative care may enhance disease modifying therapy because it is most effectively delivered by a interdisciplinary team of health care providers who are knowledgeable and skilled in all aspects of care, the caring process related to the discipline and practice. Those providers are trained by schools, organizations that are governed by educational standards. Once licensed, providers are accountable to standards of professional practice.

## Values

All Hospice palliative care activities recognize and support the following values:

- The inclusive value of each person as an autonomous and unique individual
- The value of life and natural process of death and the fact that both provide opportunities for personal growth and self-actualization
- Care guided by quality of life as defined by the individual
- Care-givers enter into the therapeutic relationship with patients and families based on dignity and integrity.

## Principles

The following principles guide all aspects of Hospice palliative care

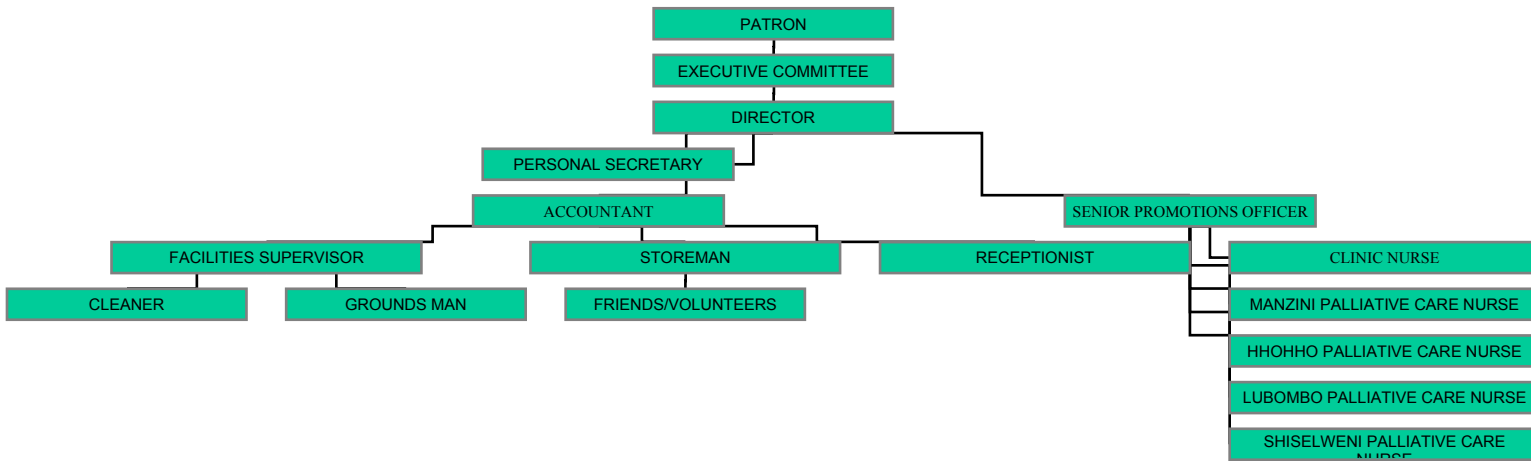
- Patient/family focused, treated as a unit and all aspects are provided in a manner that is sensitive to the patient and family.
- 

## Guiding Principles

- Patient / family focused
- High quality
- Accessible
- Adequate resources
- Collaboration efforts
- Knowledge based
- Advocacy based
- Research based

**Please donate in cash or kind so that Hospice at home continues to provide quality care and support to the terminally ill patients and their families, which is desperately needed.**

# HOSPICE AT HOME ORGANOGRAM



## **Information Education and Communication Project (IEC)**

The main objective of the department still stands as dissemination information, creating awareness about Hospice and improving our communication systems/strategies.

To meet this objective training was done. The categories of the groups trained can be classified as professionals and non professionals, as the following table indicates:

MONTH	TARGET GROUP	TOPICS COVERED	NO. OF PARTICIPANTS
APRIL 2002	World Vision Community Careers	Death and Dying Stigma and Discrimination	38
MAY 2002	Rural Health Motivators	Death and Dying	21
JUNE 2002	Methodist Congregation	Death and Dying, caring in HIV and AIDS	116
JULY 2002	Sithobela Career Guidance	Children's grief and bereavement	20
"	SOS Home Based Carers	Home Based Care	32
"	Nurses	Grief and Bereavement	21
"	Chiefs	Death and Dying	50
"	Chiefs	Death and Dying	43
OCTOBER 2002	Mbulungwane Branch Teachers	Children's grief and bereavement	27
"	Nhlangano Branch Teachers	Children's grief and bereavement	51
"	Mbabane Branch Teachers	Children's grief and bereavement	53
"	Piggs Peak Branch Teachers	Children's grief and bereavement	40
"	Big Bend Branch Teachers	Children's grief and bereavement	49
"	Madlangempisi Branch Teachers	Children's grief and bereavement	17
"	Mankayane Branch	Children's grief and	13

	Teachers	bereavement	
"	Manzini Branch Teachers	Children's grief and bereavement	20
"	Mliba Branch Teachers	Children's grief and bereavement	23
"	Gege Branch Teachers	Children's grief and bereavement	28
"	Hlathikhulu Branch Teachers	Children's grief and bereavement	22
"	Mhlume Branch Teachers	Children's grief and bereavement	27
	Mhlosheni Branch Teachers	Children's grief and bereavement	28
	Siteki Branch Teachers	Children's grief and bereavement	22

November 2002	Usuthu Branch Teachers	Children's grief and bereavement	27
January 2003	Hhohho Nurses	Grief and bereavement Death and Dying	25
February 2003	Hhohho Nurses	Grief and bereavement Death and Dying	21
March 2003	Hhohho Chiefs	Grief and bereavement	32
March 2003	Manzini Nurses	Grief and bereavement Death and Dying	24
March 2003	Manzini Chiefs	Grief and bereavement Death and Dying	25
March 2003	Manzini Nurses	Grief and bereavement Death and Dying	23

The organization noted that children were left out on issues of death and dying. But more especially on grief and bereavement. Teachers were then identified to be the ones to make a difference if made to understand the importance of children's grief and bereavement and how to handle it, because teachers spend more time with the children. The organization through SNAT organized and conducted one day workshops for teachers in their branches.

## SERVICE DELIVERY

An analysis of the countries health statistics reveals an alarming increase in the number of HIV/AIDS patients and no further improvement in the diagnosis, treatment and cure of other disease predicted as potentially terminal.

SHAH's mandate is to alleviate pain and provide high quality care and support. This increasing number of patients is now placing an overwhelming demand on the limited hospice staff.

	96/97	97/98	998/99	99/00	00/01	01/02	02/03
Hhohho	55	73	101	115	140	101	263
Manzini	79	101	106	110	151	316	427
Lubombo	41	63	73	77	116	128	193
Shiselweni	17	36	68	84	115	138	154
Clinic							1483
TOTAL	192	273	348	386	522	683	2520

AIDS still remains a major leading single diagnosis among patients referred to SHAH and the number of referrals continues to increase in an alarming rate. This confirms that the demand of service we provide alluded on earlier is undermining the good efforts of this noble organization.

### **Clinic Attendants:**

Clinic	Cancer	ISS	Other	Total
	457	739	237	1483

## HOME BASED PALLIATIVE CARE

### Terminally Ill Patients by Region

Region	Cancer	ISS	Other	Total
Hhohho	73	201	37	311
Manzini	78	298	23	399
Shiselweni	43	81	17	141
Lubombo	41	249	-	290
Total	235	829	77	1141

### Death by Region

Region	Cancer	ISS	Other	Total
Hhohho	22	41	4	67
Manzini	19	43	23	85
Shiselweni	15	5	2	22
Lubombo	7	14	-	21
Total	63	103	29	195

## DAY CARE

- ◆ Day care/respice care forms part of palliative care because basically it is the care of the carers. This service is under utilized probably because it is not distinct from the clinic. Few people understand it. Hence very few come for the services. There is need to market it using the media and trade fair shows.

## **Poverty Alleviation Project**

The estimated 66% of our population living below the poverty line has caused a major constraint in fostering Hospice mandate, in particular drug administration. Our field staff have come across many cases where a significant number of patients live below the poverty line especially in the Lubombo and Shiselweni regions. The below poverty line refers to those patients who lack the basic needs in life like food which is very important for proper drug administration. As a result, the organisation has had some difficulties in its efforts of providing quality palliative and home based care. The organisation has embarked on poverty alleviation strategies for the infected and affected members of our society by soliciting support and assistance from local business and farming community for the provision of foodstuff. They in turn have responded positively to our plight. However, this has not been adequate enough to cater for all the needy patients and their families. Hospice also hopes to link up with other food distributing programs especially **UNICEF** who has a program in place where food parcels are bought and distributed to the poor and infected members of our society. The demand to administer anti-retroviral drugs to most of our patients has put a lot of strain to the organisation because the drugs are expensive for our poor patients even if the costs were reduced or subsidized they just cannot afford. If funds can be made available, an anti-retroviral programme needs to be put in place with a full-time doctor and support staff.

## **Bereavement and counselling Project:**

Coming to terms with the loss of our loved ones due to death is very difficult. Hospice at Home not only provides home based care to its patients and their families but also continues to offer that needed support and counselling to family members after the demise of the patient until the family has had enough time to grief and come to terms with the loss of their relative. The only obstacle is the shortage of staff whose efforts are over-stretched due to the ever-increasing number of patients referred to Hospice for palliative home based care. The organisation hopes to secure funding from donors or through its fundraising activities to train more nurses in the field of palliative home based care.

## **Friends of Swaziland Hospice at Home:**

- Mbabane Friends
- Manzini Friends
- Mhlambanyatsi Friends
- Light for the Nation Manzini
- Luyengo Friends
- Madlangempisi Friends
- Big-Bend Friends
- United Kingdom Friends

Swaziland Hospice at Home would like to thank all Friends of the organisation both locally and abroad for the valuable support extended to the organisation not only through fund-raising but by also providing voluntary services and awareness campaigns the organisation desperately needs. Friends hosted the following events:

1. Valentine's Day
2. Mother's Day
3. Golf Day

### **To all our friends we say thank you for your tireless support and voluntary work**

Fund-raising is the cornerstone for the existence of Swaziland Hospice at Home because currently the organisation depends on government subventions, friends(both local and overseas)and companies. Donor fatigue continues to cause a major challenge for the organisation. It is in this vein that we would like to thank the following companies and institutions for the generous donations made to our organisation:

- ◆ Gone Rural
- ◆ Bobs Auto Spares
- ◆ Swaziland Sugar Association
- ◆ KPMG
- ◆ Imperial Car Rental
- ◆ Dyson and Lincoln
- ◆ All Stationery
- ◆ Alpha Cement
- ◆ Swaziland Royal Insurance Company
- ◆ Tibiyo TakaNgwane
- ◆ Ebhleni Farm
- ◆ Parmalat
- ◆ Chinese Embassy

◆ Italian Cooperation

**Friends of Hospice:**

- Mhlambanyatsi friends
- Mbabane friends
- Italian friends

**Schools and churches:**

- African Evangelical Church
- Sharpe Memorial church
- Waterford Kamhlaba
- Nazarene Manzini
- Transworld radio

**Individuals:**

- Ethel Matsebula
- Ferreira M F
- Jean Gilbert