SWAZILAND HOSPICE AT HOME
Board Members

**Patron**
Inkhosikati Make LaNgangaza

**Chairperson**
Pastor Kenneth Jefferson

**Vice-Chairperson**
Mr. Stephen T. Motsa

**Treasurer**
Ms Busie Ndlela

**Director**
Senator Thulile Dlamini-Msane

**Secretary**
Dumisani Maseko (Programs Manager)

**Doctor**
Dr Tsibungu Lukoji

**Members**
Senator Ngoma Gamedze
Thandi Maziya
Sibongile Mndzebele

**Bankers**
Nedbank Swaziland

**Internal Auditors**
Affordable Consulting Practitioners (PTY) LTD

**External Auditors**
Kobla Quashie
# TABLE OF CONTENTS

- PATRON’S INTRODUCTORY REMARKS
- CHAIRPERSON’S REMARKS
- DIRECTOR’S REMARKS
- PROGRAMS MANAGER’S REPORT
- MONITORING & EVALUATION REPORT
- CLINIC NURSE REPORT
- EDUCATOR’S REPORT
- HUMAN RESORCE DEPARTMENT
- FUND-RAISING REPORT
- TREASURER’S REPORT
Swaziland Hospice At Home has been operating for the past twenty years, battling with life limiting diseases, by providing Palliative Care to all eligible clients. Notably the organization has been grossly affected by limited resources which are a constraint in service provision.

The AIDS pandemic continues to contribute to the increase in the country’s disease burden. My organization has had a series of interventions in promoting Palliative Care in the country such as advocating for a Palliative Care Policy and Standards/Guidelines, rolling out the Palliative Care concept through trainings in an endeavour to make Palliative Care available to communities.

I want to applaud His Majesty King Mswati III, the Government, and Parliament of Swaziland for the role they played in advocacy and supporting our endeavour, and recognizing this noble organization as an extended arm of Government in the implementation of Palliative Care especially in the rural areas serving the destitute and the poor.

We cannot over emphasize the fact that medicines and medical equipment should be made accessible and easily available at grassroots level. This would help in making the medication and medical supplies to be on time in the PRSP and NDS, which in turn would assist the country meet its objectives on the Millennium Development Goals.

Palliative Care should be viewed as a right to health which is supported by our constitution. Hence, Home Based Palliative Care should be used as a vehicle in providing palliative care at the grassroots level in order to minimize pain and suffering while maximizing the quality of life for patients with life limiting diseases. I would like to state that my organization declares zero tolerance to pain and suffering, by providing equity of care and affording clients and their families’ quality of care.

I would like to congratulate Pastor Ken Jefferson, Director of Claypotts Foundation for the Director’s Award that he received on the Hospice and Palliative Care day and the staff at Swaziland Hospice At Home. I urge you all to dedicate yourselves to SHAH and serving the organization even under the challenging conditions.

In conclusion, I would like to thank the board members, Director, all members of staff and Hospice friends (volunteers) for dedicating themselves to work for the less privileged.

Inkhosikati Make LaNgangaza
PATRON - SHAH

“We need to inculcate a culture of innovation. That is because innovation is the heartbeat of modern economics. That is the reason why the world’s most advanced nations are also the world’s most innovative. Their governments have built economic and social infrastructures that encourage creativity and innovation. Their people are highly educated, highly skilled, and highly competitive. So as hospice is being innovative by developing an inpatient care unit to improve the quality of care”.

Inkhosikati Make LaNgangaza
PATRON - SHAH
Chairperson’s Remarks

The year 2009 was yet another good year for Swaziland Hospice at Home in terms of achieving performance in line with the goals and objectives as highlighted in the strategic plan.

I must state that I am very much impressed about the new developments in the organization, especially the improvements that have taken place in the counselling department. We now boast of two highly qualified counsellors in the organization, one is still undergoing training at the Association of Professional Counsellors in Kenya and will be graduating soon.

Counselling services for the patient and loved ones are an important part of hospice care. After the patient’s death, we make it a point that bereavement support is offered to families. These services can take a variety of forms, including telephone calls, visits, written materials about grieving, and support groups.

I would also like to genuinely thank the friends of hospice (volunteers) for all the sacrifices they make to the organization. Hospice volunteers enhance quality of life and help reduce the burden of care-giving. They are generally available to provide different types of support to patients and their loved ones including running errands, preparing light meals, staying with a patient to give family members a break, lending emotional support and companionship to patients and family members.

In conclusion, I would like to congratulate the dedicated staff of Hospice at Home, especially the nurses, who drive long distances trying to reach out to all our clients in the four regions, some of the roads are very bad. The cars they drive are no longer in good condition; they require service now and then thus draining the little money we have. However, despite of all the hardships they undergo they perform their duties diligently. I also pass my gratitude to all those who have supported the organization during the past year. Your support is very much appreciated we urge you to continue supporting hospice.

Regards

Pastor Kenneth Jefferson
CHAIRPERSON

“At the heart of any successful branding must be consistent quality and integrity not hype or advertisement. You have to be what you say you are and doing what you say you do, and doing it better than anybody else”. 
Director’s Remarks

Palliative Care is an integral part of dealing with life limiting conditions. As a Non-profit making Organization (NGO) that provides Palliative care, we have seen a relative increase in HIV/AIDS related cancer (Cervical cancer and Kaposi’s sarcoma being the most prominent). WHO statistics report (2008) states that in the world cancer kills more people than HIV/AIDS and malaria combined.

The most common cancer among males is Kaposi’s sarcoma followed by prostrate cancer and third is cancer of the liver. Amongst females the most common cancer is cervical cancer followed by Breast cancer.

This is worrying to note that as a country we were not strategically braced for these symptoms. However, the treatment available for Kaposi’s sarcoma is not accessible to the masses that need it and this could be ascertained to several factors: Lack of knowledge about treatment existence, lack of bureaucratic measures in place, lack of access to treatment. This subjects a lot of clients to pain and suffering.

Other diseases that require Palliative care management are reluctantly on an increase with the majority being aggravated by HIV/AIDS. As an organization, we have witnessed uncontrollable diabetes despite patients being on treatment.

The HIV/AIDS epidemic in Swaziland continues to be the deadliest emergency and biggest social and economic crisis facing the country today.

Rates of HIV infection continue to rise sharply, for reasons that are sadly evident. Firstly, denial about the existence of AIDS is widespread. Secondly, there has been little change in people’s sexual behaviours, and finally, there is a high rate of sexual activity among young people.

Political leaders, international agencies and national and international NGOs need to increase awareness of the scale and urgency of the AIDS situation. Exchanging information about successful experiences and projects can spark and guide action especially among the youth. International and governmental development agencies, as well as NGOs, can play an important role in facilitating such cooperation and exchange.
Our government also needs to significantly monitor the impact of HIV/AIDS on children and families, to plan interventions and determine their effectiveness. Accurate information on the numbers of children orphaned, where they are, the circumstances of their lives and the nature of their needs are vital. As an advocacy tool, such information can also help raise awareness about the social impact of AIDS and promote realization of children’s rights.

It is essential to address the emotional needs of children devastated by their parents’ deaths from AIDS. Commonly, children orphaned by AIDS not only watch their parents die but often nurse them through a long period of wasting disease, which may include incontinence, depression and dementia. Parents with HIV or AIDS must also be helped to come to terms with their approaching death and to plan for their children’s welfare. Assistance to families prior to parents’ death should also encompass practical help for the household in such areas as nursing care, food production and preparation, and upkeep of the home.

Before I conclude, credit should go to my staff (Hospice staff) for their skill and service, which means so much for so many people out there. To the Board members, I thank you for your hard work and support, not just to me, but for what you bring to enrich Swaziland Hospice At Home. I also pass my sincere gratitude to all those who have supported the organization during the past year, including his Majesty’s Government, NERCHA, Claypotts, and all partners in the palliative care movement. God bless you all.
“I firmly believe that innovation should not be confined to scientists and the industrial giants. Innovation is something that we all can and should, think about to improve our daily lives. Innovation in health facilities is key in the caring strategies for all patients”.

Home Based Palliative Care Report

Hospice care has to be more than the morphine, the joys, and rewards. It has to be the pursuit of truth about the human condition through acts of wondrous imagination, skill and compassion.

In acknowledging the scale of the HIV/AIDS problem, many local organizations and individuals are also facing the realisation that they urgently need guidance in dealing with the epidemic. This is where Swaziland Hospice at Home can help. As our ‘vision’ asserts that we aspire to become the centre of excellence in palliative and home based care in the Kingdom of Swaziland. Our experienced consultants can offer first-hand knowledge and expertise in AIDS care, training and education, plus proven teaching and management skills.

When a person has been diagnosed with a life-threatening illness, the news can be very traumatic and worrying, especially if there are dependants to think of. It is in these situations that the expertise and care offered by Swaziland Hospice At Home can really make a difference.

The number of patients and families we are working with continue to expand, as do the services we are offering to all those who need our help. Our Home Based Palliative Care is functioning to capacity to meet the growing demands on Hospice. Occasionally, I shudder to think how these services would be provided had it not been for the foresight and drive of our founders nearly 20 years ago. Since then, we have developed and built on our vision with remarkable success, despite the pressure on resources, often consumed by the needs of the day.

The Hospice team is on hand to provide individual support and advice on all aspects of living with a life limiting illness such as symptom control, support for families and physical and psychological therapies. The team, which includes therapists, a doctor, nurses, family support workers, to name a few, work closely with the patient.

Ultimately, the year under review has been a challenging period for Swaziland Hospice At Home, we encountered constrains which hindered us from caring out our mandate efficiently; as a result the organization’s performance was strained due to inadequate funding especially for maintenance of cars and fuel. These two areas made it very difficult for the organization to satisfactorily provide services as mandated by our constitution. This was a set back on home visiting and it decreased hospice visibility on the ground.

However, despite all the problems Hospice has always tried to put first the needs of her clients, and will continue to do so even this year with the help of the Swazi Government and the nation at large.
During the past year (April 2009 to March 2010), the organization carried out its program area activities ranging from Home Based Palliative care (HBPC), Clinical Palliative Care, HIV Testing and Counselling (HTC), and CD4 Count.

**Home Based Palliative Care:**
In the Home Based palliative care program a total of 11379 clients were reached in the four regions of the country. Figure 1 below shows the number of clients who were attended through SHAH’s Home Based Palliative Care services during the year beginning April 2009 to March 2010.

There were 2754 clients that received care and treatment in the second quarter of 2009 (April – June). A total of 3181 clients received care and treatment during the third quarter of 2009 (July – September). 2935 clients received care and treatment during the fourth quarter of 2009 (October – December) whilst 2509 clients were attended during the first quarter of 2010 (January – March).
Clinical Palliative Care:
In the clinical care, 14079 clients were provided care and treatment during the past year. Figure 2 below shows that there were 3640 clients that were attended in the second quarter (April-June 2009). 3872 clients were attended during the third quarter (July-September 2009). During the fourth quarter (October-December 2009), there were 3716 clients that were attended at the SHAH clinic/daycare centre whilst 2851 clients were attended during the first quarter of 2010 (January-March).

Among the 14079 clients that were attended at the SHAH clinic, there were 4556 first attendances and 9523 re-attendances. There were 944 first attendances in the 2nd quarter (April-June 2009), 1244 first attendances during the 3rd quarter (July-September 2009), 1390 first attendances during the 4th quarter (October-December 2009), and lastly 978 first attendances during the 1st quarter of 2010 (January-March) as depicted in Figure 3 below.
It is evident from the statistics that clients attended in the clinic are a lot higher than those attended in the regions combined, 14079 clients seen at the clinic as compared to 11379 clients seen in the regions. From this it can be seen that less clients are reached through HBPC. This may be due to that amongst others:

- Nurses take long to make re-visits to clients and the clients opt to go to the SHAH clinic.
- Medication at SHAH is a challenge since some Government clinics depend on Palliative care medication from SHAH.
- Home care in Government clinics rely on SHAH transport in order to make their visits, thus delaying client’s access to home care.
HTC:
There were 1206 people who took an HIV test in the HTC service facility at the SHAH clinic in the past year. A total of 329 people got tested at the SHAH clinic HTC facility during the 2nd quarter of 2009 (April-June). In the 3rd quarter (July-September 2009), 214 people were tested. There were 281 and 382 people who got tested during the 4th quarter (October-December 2009) and 1st quarter (January-March 2010), respectively, as shown in figure 4 below.
Figure 5 below depicts that a total of 181 people tested positive for HIV with 61 males and 120 females in the 2nd quarter of 2009, whilst 148 testing negative for HIV with 37 males and 111 females. During the 3rd quarter of 2009, there were 124 people who tested positive for HIV with 39 males and 85 females, whilst 90 people tested negative for HIV with 31 males and 59 females. In the 4th quarter of 2009 there were 169 people who tested positive for HIV with 49 males and 120 females, whereas 112 people tested negative for HIV with 30 males and 82 females. During the 1st quarter of 2010 there were 225 people who tested positive for HIV with 67 males and 158 females, whilst there were 157 people who tested negative for HIV with 46 males and 111 females.

More females than males utilize the HTC service facility at the SHAH clinic; this can be seen by the fact that there were 846 females who visited the SHAH clinic for HIV testing as compared to the 360 males who came in for the same services.
CD4 Count:
There were 1404 clients who took the CD4 Count test at the SHAH clinic during the past year. Figure 6 below depicts that there were 353 people took the CD4 count test in the second quarter of 2009 (April to June), 356 took it in the third quarter (July to September), and 392 people took it in the fourth quarter of 2009 (October to December). The remaining 303 people took the CD4 Count in the first quarter of 2010 (January to March).

The CD4 Count is one of the most important blood test done to patients, especially those that are suffering from HIV/AIDS related illnesses. The CD4 Count test determines the number of the white blood cells in the bloodstream. These white blood cells help fight infections in the body. This test (CD4 count test) determines when an HIV positive person can start the Anti-retroviral therapy.

In order to know where we are heading in terms of the work we do, we need to have an overview of M&E responsibilities from the all the levels in our program activities. There is a need to create a sense of ownership of M&E and the information it produces among all staff at SHAH and have lessons to learn from the information produced by M&E.
The credibility of the program activities we do depends on a large extent in the manner in which our M&E is conducted, which in turn depends (the M&E) on proper design of our programs. If programs are poorly designed or are based on faulty assumptions, even the best M&E system in the whole world is unlikely to ensure its success. Furthermore, M&E depends on team-work and without team-work M&E is doomed to be error-prone.

Also for M&E to succeed, it needs to be driven by management’s need for information, their use of the information and their desire to create a learning experience. M&E cannot be used as a compliance tool since M&E is not and cannot be a substitute for good management (that is, M&E does not solve problems, it helps identify problems – only management (managers) can/have to solve the problems identified.

THABO MOTSA
M&E Officer
Clinic and Day Care Centre Report

Another year has flown past, and that indicates how busy we have been in the Day Care Centre. Since taking over as Head of the Day Care Centre from my colleague Timothy Vilakati, I have noted that working with the terminally ill on a daily basis is very taxing and needs one to be dedicated to his work and clients. The number of patients and families we are working with continue to expand, as do the services we are offering to all those who need our help. Our constant scrutiny of how effective our patients and their families tell us we are, or are not, at helping them enable us to double our efforts in performing our duties.

With the escalating statistic of HIV/AIDS and eruption of cancer we (hospice nurses) need to put extra effort to meet the needs of both the patient and the family e.g.

- Physiological needs
- Psychological needs
- Emotional needs
- Spiritual needs

We are delighted at the news that the organization will soon be signing a Memorandum of Understanding with the Swazi Government (Ministry of Health and Social Welfare) to set up an Inpatient Unit structure which we desperately need for our clients so that they can have sufficient space to relax and access quality care. The clinic is becoming too little to accommodate all our clients.

As much as I enjoyed my first year at the clinic, however, I noted that we still have a lot to do in making sure that our clients access quality care and treatment. Outlined below are some of the challenges and achievements I noted as the year progressed:

Achievements:

- Mortality rate was very low this time around
- Standard of care has greatly improved, this was apparent when the Director appointed a full time Counselling Coordinator to monitor the counselling sessions of clients
- Record keeping and reporting has seriously improved, probably due to availability of working equipment e.g. daily register and report forms.
- Cleanliness of staff members and the building has always been a priority
Challenges:

❖ Shortage of working equipments e.g. oxygen and section machine

❖ Emergency car for gasping patients who need to be transferred urgently especially when all the other cars (used for visits) are out.

❖ Shortage of drugs – Medical stores doesn’t deliver in time

❖ Lack of workshops to equip us to meet national guidelines

❖ We urgently need a full time specialized physician who will always be available for our clients.

❖ Lack of proper tools to monitor and evaluate the staff e.g. nurses

❖ Lack of proper tools to monitor the use and abuse of drugs by both clients and staff

Regards

Themba Simelane
Clinic Nurse

“I have seen changes occur in people who are dying once they have grasped and accepted the fact that they are in the final stages of growth. I have seen how dying has released those factors that inform us that life is for living and dying such factors as compassion, courage, acceptance, patience, faith, hope and love. They encourage us to look within and build upon the stillness of peace within our inner selves. It is from within this stillness that we reach out to one another”. Kirkpatrick 1997: 17
Information, Education And Communication (I.E.C) Report

The Information, Education and Communication (I.E.C) department’s main focus is on capacity building and rolling out Palliative Care services to all eligible clients.

Hospice at Home is involved in outreach training programs working closely with Swaziland National Aids Program (SNAP) through Home Based Care. The main purpose of the I.E.C department is to provide training to health care professionals across the nation on how to take care of those with a life threatening illness.

As records disclose that Swaziland has one of the highest percentages of HIV/AIDS in the world. This is an unprecedented tragedy. Yet so much of the suffering could be relieved if communities had appropriate training, care and support strategies. We realize this is no easy task. Nevertheless at Hospice we now have 20 years experience of helping people to put these systems at place.

We advise health professionals on how to develop existing services even where the HIV/AIDS burden is intensified by acute poverty and deprivation. We show how to improve patients’ quality of life through a holistic model of care. We educate and train senior health care personnel and build up the pool of trainers to spread information to new audiences.

I am happy that we have been receiving accolades from our friends locally and abroad that we are doing a wonderful job, however we also encounter challenges as we execute our activities. Outlined below are some of the achievements and challenges we encountered in the previous year.

Achievements:

- Hospice has been recognised as the leader in Palliative Care issues
- We have seen an increased number of clients receiving our care and support services
- We have skilled and experienced professionals in Palliative Care services
- We have Formulated a training manual for the country
- Increasing the quota for opioids as a country, however hospice has to advocate for that
- Implementation of the palliative care policy
The previous year our department managed to train the following professionals:

<table>
<thead>
<tr>
<th>Name of Organizations</th>
<th>Number of students</th>
</tr>
</thead>
<tbody>
<tr>
<td>Swaziland Red Cross</td>
<td>18</td>
</tr>
<tr>
<td>PSHACC</td>
<td>25</td>
</tr>
<tr>
<td>Task</td>
<td>10</td>
</tr>
<tr>
<td>Good Shepherd</td>
<td>24</td>
</tr>
<tr>
<td>New Hope Centre (Bethany)</td>
<td>20</td>
</tr>
<tr>
<td>Nazarene College</td>
<td>36</td>
</tr>
<tr>
<td>Flas</td>
<td>18</td>
</tr>
<tr>
<td>Government nurses</td>
<td>100</td>
</tr>
<tr>
<td>Parliamentarians</td>
<td>35</td>
</tr>
</tbody>
</table>
Counselling Coordinator’s Report

AIDS is a worldwide epidemic. Its escalation has prompted an urgent need for relevant facilities and trained professionals to provide care and help combat its spread.

It has always been the Director’s (Senator Thulile Msane) wish to strengthen the operations of the Counselling Department in the organization. Hence, she ordered that I undergo vigorous training in counselling at the Association of Professional Counsellors in Kenya, where I would be graduating soon. The organization also has two counsellors who possess Diploma certificates.

As stated in the organization’s strategic plan that Hospice at Home’s main aim is to imbue the culture of professionalism amongst its staff members so that they can effectively and efficiently perform their duties diligently. This is a huge challenge to us as we have to provide excellent palliative care services which would see our patients accessing specialized and individualized care.

As an organization we will always set out to ensure that when executing our duties we hold on to the holistic nature of hospice care and in particular the qualities of caring; concern, compassion and support which single out hospice care.

Counselling services for patients and loved ones are an important part of hospice care, and as an organization we are doing our utmost best to remain the most reliable and trustworthy organization in the country.

With this approach I am confident that we will achieve our vision of making sure that Hospice at Home becomes a centre of excellence in palliative and home based care in the Kingdom of Swaziland.

May I also congratulate my colleagues (counsellors) on their continuing commitment and for the very professional way in which they carry out this emotionally taxing work.

Gugu Zondo
Counselling Coordinator

“At Swaziland Hospice at Home, we have noted the importance of “being with”, of connecting with the dying in a caring and intimate relationship. Sharing spiritual pain can put care professionals in a very exposed situation, especially when the patient is despairing. Not being able to give clear answers to deep questions, especially when care staff are not able to relieve pain, may lead to feelings of guilt. Intimate care remains necessary”.
Fundraising Report

The year under review has seen Hospice at Home fundraising team hosting a number of events with the aim of raising funds for the organization. All the events were a success and we managed to achieve our goal.

We hosted a:
- Seven-A-Side soccer tournament
- Family fun Day
- Hospice and Palliative Care Day

On behalf of the fundraising team I would like to thank all those who lend a hand in making sure all these events were a success, especially the commemoration of the Hospice and Palliative Care Day. The event was a success as we celebrated with a population of approximately five hundred people, which included representatives from government and the business community. The main objective of the day is to raise public awareness and funding for hospice and palliative care services around the world.

Other intentions of this special day are:
- To create an advocacy opportunity for local, regional and international hospice and palliative care organizations
- To draw attention to the services they provide to relieve the pain and suffering of patients with terminal illness, and their need for accessible opioid analgesics
- To provide an opportunity to make the case to government officials and policy-makers for the integration of palliative care into basic health care policies and clinical education programmes
- To stimulate national governments and public funders to be more realistic in their financial support for hospice and palliative care.
I would also like to express thanks to all the media houses (electronic and print media) for the good coverage on Hospice activities, and also be grateful to the Director of the organization Senator Thulile Msane for believing in us and always being there to offer advice.

Concluding, may I inform everyone associated with the organization that she/he is part of our sustainable development agenda.

Mhlonishwa Hlophe
Communications Officer
COVERAGE OF THE PALLIATIVE AND HOSPICE CARE WEEK CELEBRATION:

Honourable Minister of Agriculture Clement Dlamini representing SHAH Patron Her Royal Highness Make LaNgangaza

SHAH Director receives a cheque of E132 043.90 from Inyatsi Construction’s representative Merrisa

Board member Pastor Ken Jefferson receives an award from SHAH Director Senator Thulile Msane

FRIENDS OF SWAZILAND HOSPICE AT HOME

Private and Public sector donors:
The above listed companies and individuals have contributed immensely to the operations of Swaziland Hospice at Home financially and otherwise. We acknowledge your role in assisting Hospice at Home for the benefit of the Swazi people. Without your support we wouldn’t be here today celebrating twenty (20) years of existence. Hospice will continue to value and rely upon your support as it implements its work programs in the year ahead.

HOW CAN YOU SUPPORT HOSPICE AT HOSPICE?
Please, continue supporting Swaziland Hospice at Home, without the support of all caring citizens such as yourself, Hospice would not exist and the hundreds of unsupported people would die in pain.

Pic. sourced from internet

THERE ARE TWO WAYS IN WHICH YOU CAN HELP:

- By sending us a donation which we can use to buy pain relieving drugs.

- By becoming a Friend of Hospice, which will enable you to participate in Hospice activities such as fundraising events.

Treasurer’s Report
The organization’s Strategic Plan highlights the expansion in services being provided by Hospice at Home, and the enhancement in facilities planned for the inpatient unit. These initiatives give the organization challenging financial targets.

However, I can gladly state that the organization’s financial records were excellently performed and well maintained. The books were properly prepared. All the reporting to the multiple donors was done exceptionally well.

As a treasurer, I approve of the financial recording and status of Hospice and congratulate the management for the good work.

Regards

Ms Busi Ndlela
Treasurer