

Kitovu Mobile Palliative Care Report 2010

Introduction

This is our tenth Annual Report from Palliative Care. Each year we are seeing an increased number of patients and an increasing number of diagnoses. We ask ourselves, is Cancer increasing in the population or are we seeing more because more people are aware of the service we offer? Whatever the answer, we are delighted that we are still here to offer pain and symptom management to these patients.

We started off 2010 with 102 patients receiving care and during the year we received 278 new patients. That is 60 more new patients than we saw in the previous year. We start each year with a planning week and in January we set our goal at 20 new patients a month. We saw 38 over the goal we had set. As always, we receive referrals from a variety of sources but this year we have actually had referrals from patients or families that we have cared for in the past. This is a sign to us that we have been doing a good job and that patients and families are happy with our care.

Activities

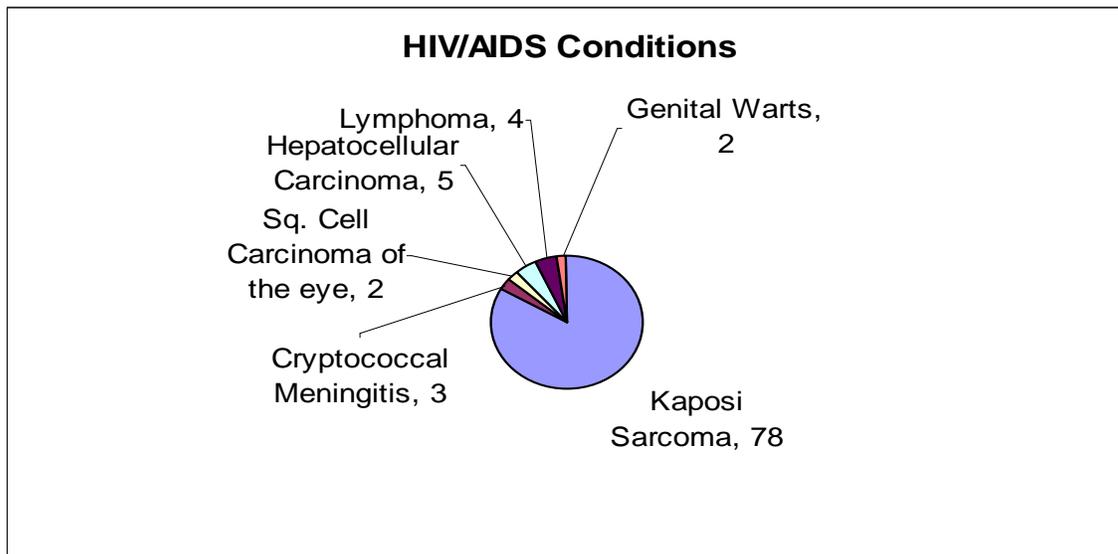
As in the past the palliative Care Team does Home Visits three times a week. We have tried to make an effort this year to devote one day a week to patients and families that need extra time. On these days, the Nurses go out alone to see the patients and only a few are selected. This gives the nurses the opportunity to spend more time counseling the patients and families. Even though most patients are aware of their diagnosis, many fail to understand what is happening to their bodies. They have many questions. Many patients have been attending herbalists or traditional healers and they too need extra time to convince them that this treatment is not affective.

This year a total of 380 patients were cared for by the Palliative Care team. This compares to 270 in 2009. 629 Home visits were made to patients as well as 38 bereavement visits to patients' families. 491 patients were seen at the Home Care Centres as well as 113 patients started on step two analgesics and 464 patients were seen in our office. Office visits usually include new patients who have been referred from the field and patients coming for Chemotherapy who report to the office first so they can be assessed before going for chemotherapy. 181 patients died and 51 completed treatment. The latter were patients with KS who initially came to us for chemotherapy and pain management. Upon completion of their chemo they were usually pain free and returned to the care of the sending agency.

HIV & AIDS related palliative care

Our new patients referred this year included 116 with HIV&AIDS. This is compared to 70 last year, which is a big increase. Once again, the majority of patients came with Kaposi Sarcoma. We have been giving Chemotherapy to patients with KS for over ten years and we continued to give it this year as well, despite the fact that the cost of the drug itself has raised considerably as well as the cost of administration in Kitovu Hospital. One of our challenges for the coming year is to see how we can carry this cost. We will have to be much more strict in our assessment of patients who will benefit from chemotherapy and we may have to ask patients referred from other HIV&AIDS Organizations to contribute to the cost. With all of this in mind however, we cannot fail to appreciate the difference this chemotherapy has made on patients lives.

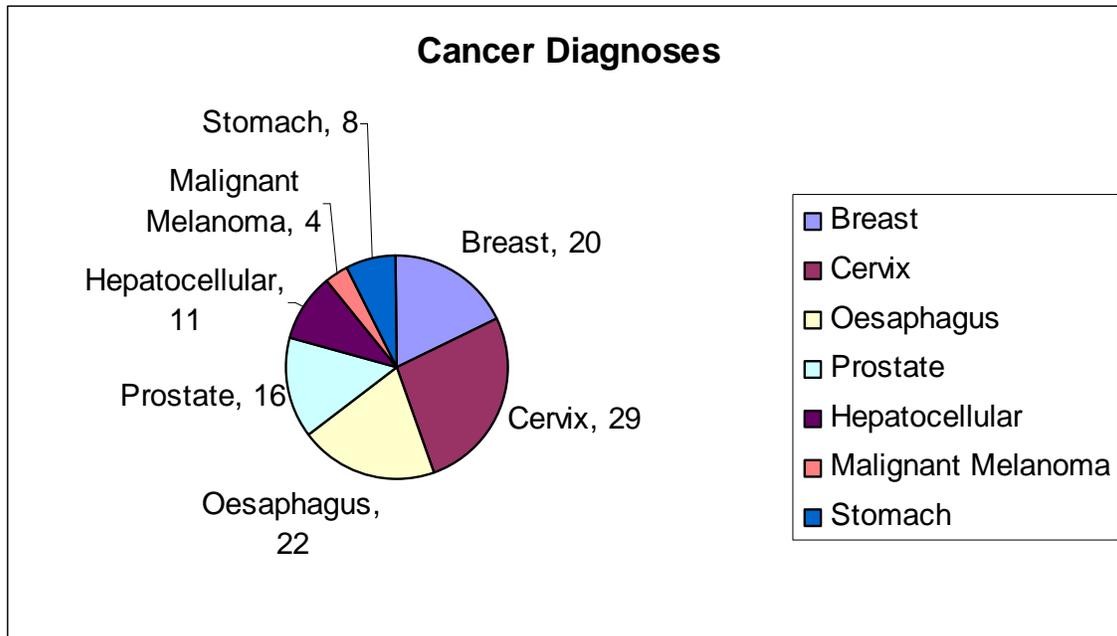
An example of this is the case of Joseph. Joseph is 9 years old and is HIV +ve. He was started on Anti-retroviral drugs by one of our sister organizations in June of this year and in August they sent him to us because he had Kaposi Sarcoma. His KS was in his mouth, a large lesion on his tongue which was becoming progressively larger. When he came to us, he was a very sad little boy, suffering not only from pain but also from hunger as it was very difficult to eat with this mass in his mouth. He was a perfect candidate for chemotherapy, as we have found that KS of the mucous membranes responds very well to therapy. Joseph's mother was reluctant to bring him for chemo because of the cost of the transport but we convinced her it was necessary. After 3 doses, the KS was almost gone and both Joseph and his mother were both very happy as can be seen in this picture when Joseph came for his 5th and final dose. On his first visit he was unable to eat a sucker!



30 of our HIV&AIDS patients also had Cancer, frequently Liver or Cervix, Burkitt's Lymphoma, Squamous Cell Carcinoma of the Conjunctiva, tongue and Oesophagus. These patients are always challenging as many of them are on Anti-retroviral drugs and are under the impression that the ART will act to stop their cancer as well as their HIV. It can take many hours of counseling to help these patients understand that ART has no effect on Cancer. This is, of course, with the exception of Kaposi Sarcoma which responds to chemo much better in combination with ART. If patients come to us with a primary diagnosis of Cancer and later learn that they are HIV+ve, we try to help them to understand that ART may in fact prolong their lives, but they may also prolong their suffering. Then it is up to the patient to decide whether to take ARV's.

CANCER

58% of our new cases this year suffered from Cancer. This is down from 65% last year. The Chart below shows those Cancers that predominated, yet we saw forty different cancer diagnoses.



Cervix tops the list as always, but this year we have seen more Cancer of the Oesophagus than Cancer of the Breast. At a recent PCAU workshop, a cardiothoracic surgeon gave a presentation on Ca. Oesophagus and mentioned the dramatic increase being seen all over the country. The cause is not known, but it is thought to be due to the distilled spirits that people drink. He reported that 80% of the patients seen in the Cancer Institute Kampala come when it is too late for any intervention hence, the need for Palliative Care. We usually offer the patients a chance to have a gastrostomy tube inserted which means that they can go on feeding for some time. But many do not want any operation and we manage pain and symptoms with liquid morphine.



Appolonia was referred to us in March 2010. She was 70 years old and lived with her husband of the same age who was a paraplegic after a fall from a tree. Appo had Cancer of the Oesophagus and was referred to us by Kitovu Hospital after having had a gastrostomy tube inserted. On discharge from the hospital, she weighed 26 Kg. She had no pain, just hunger! We visited regularly with maize meal and soya. A neighbor who

happened to be one of our Mobile drivers supplied her with milk everyday from his cow. Every time we visited Appo she thanked God for the gift of life and for us! In October, Appo started experiencing pain and hyper-salivation which we treated with liquid morphine and atropine drops. Late in November she died, after eight months with her g-tube. Since we don't



carry a scale with us we never knew if she had gained any weight but until the end she was lively and energetic. She was a joy to visit and a real Palliative care success story.

The third most common cancer is Ca. Breast. We continue to see many women in very late stages but the most moving is a young woman of 24 who had a mastectomy for cancer in 2009 and presented to us in June with massive liver metastases. She is a mother of two and has left us to move back to Kampala to be with her husband and children. Each time we visit her parents, they say she is fine but we can't help but think that she is attending either an herbalist or a "prayer palace" and that we will eventually see her again.

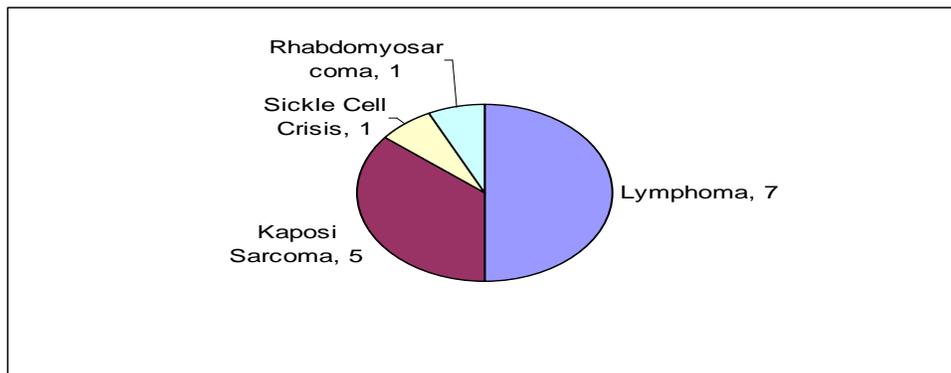


One success story we can report is James, a 70 yr. old man referred to us by one of our staff. James had a large black growth on his foot which made it impossible for him to walk. He was reluctant to have surgery but we convinced him that the surgeon would make every effort to save some of his toes. And, in fact, he woke up to find all five toes still there. Doctor had been able to shell out the tumour (which was, as we expected, malignant melanoma) and James is now back at home. His friend tells us that every Sunday he insists on walking to the Cathedral for Mass rather than attending at the

local sub-parish. We have no idea if James tumour had metastasized but for the present he is a happy man and if he needs us in the future, he knows where to find us.

Children

This year we cared for 14 children. The youngest is four, the eldest 17.



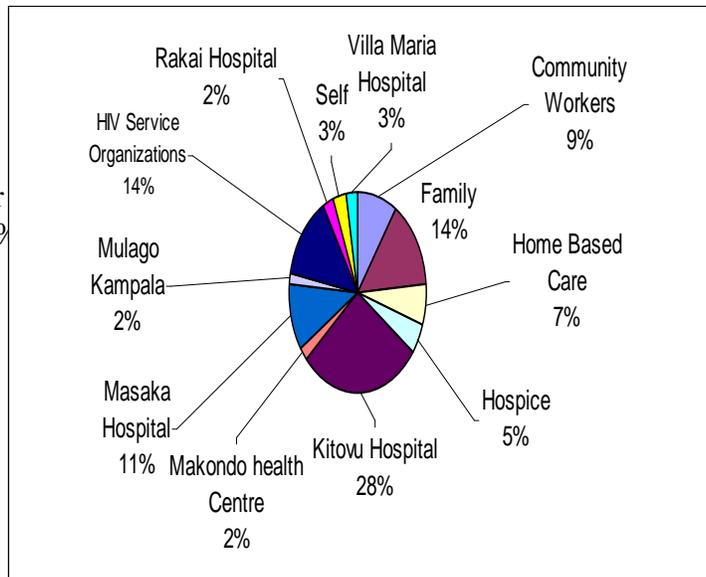
As can be seen from the graph, the largest number of children suffered from Lymphoma, either Hodgkin's or Burkitt's. Unfortunately in both cases the children come very late for treatment and we can only offer pain and symptom management. If there is any hope that chemo will be effective we refer them to the International Hospital Kampala (IHK) which has a special service for patients who cannot pay for treatment. At present we have one little boy of 12 on chemo for Hodgkin's Lymphoma. What often happens is that a child is diagnosed in the Government Hospital in Kampala and sent home to look for money to pay for the chemo. By the time they come to our attention, it is too late. We also have a four year old girl Maria, who came to us with advanced Rhabdomyosarcoma of her eye. We were able to send her for surgery which we supported and she is now at IHK for chemo and at last report her prognosis is good.



5 of our children came to us with Kaposi Sarcoma. And as has been described in the section on HIV&AIDS, their outcomes are usually very good.

Patient Referrals

As can be seen our referrals come from many different sources. The majority are hospital referrals, but family, self and our Community Workers make up almost 30%. Family members hear about us when the Nurses sensitize different groups and when they see us visiting a neighbor or friend. This year we had the opportunity to do an hour radio programme about Palliative Care and this brought a good response from people in the community.



Hospital Referrals

We, in turn, make referrals throughout the year. As already has been said, we sent 70 patients with Kaposi Sarcoma to Kitovu for Chemotherapy. 24 patients were sent to Kitovu Hospital for various procedures, gastrostomy tube insertion, supra-pubic catheter placement, biopsy and x-rays. 2 children were sent to CORSU, the Children's Hospital in Kampala for surgery. 3 patients were sent to IHK for chemo, 3 to Mulago Kampala for Radiotherapy and 2 patients to the Eye clinics in Mbarara and Kampala.

Social Care

We have always been aware that medication alone is not enough for total care. Most of the patients we care for are very poor and when we visit them we always take a supply of food and other basic necessities. Food is particularly necessary for those patients receiving chemotherapy since they cannot have the chemo if their haemoglobin is too low. These patients are usually given, soya meal, milk powder and sometimes money for eggs. A good example of this is a patient named Silas, a man of 41 who was referred to us by another AIDS Organization. The first day he came, he was carried to our office by his two wives. He had Severe KS in his mouth; he had been unable to eat for weeks and was cachectic. Furthermore, his Hgb. was only 8.5 (we like to see it over 11). We sent him home with liquid morphine for his pain, Iron, Vit C and Folic Acid to strengthen his blood and milk powder, soya and maize meal, sugar and money for eggs. Three days later one of the wives came in to say she was worried because he wasn't eating and he was cold. We gave her a blanket for him and told her how to make drinks with the soya, milk and sugar and to try and get him to take these. It was a Friday and we promised to come and see him on Monday. I was sure that he was going to die over the week-end so on Monday morning we phoned and his wife said he was a bit better! When we went out, we were surprised to find him much better. He started his chemo two weeks later accompanied by both wives. By the time he was coming for his third dose he was unrecognizable. His mouth had cleared about 60% and he came on his own for his chemo. Had it not been for the food supplements, I am sure we would have lost Silas but in January he will receive his last dose of chemo and we will happily say good-by.

Over the year we have supplied: 54 Blankets, 996 pieces of soap, 514 kg. Maize flour, 276 kg sugar, 274 kg rice, 48 kg. Milk powder and 50 kg soya flour. In addition to nourishing food we also carry suckers for the children. This started several years ago when a group of children in Ireland actually sent us suckers for children. We saw how happy it made the children as well as their families. It makes the Doctors visit pleasurable despite the reason for the visit. The primary Teacher who first sent the suckers continues to tell her classes about the children in Africa and every year we get a big bag of coins that the children have given.

As well as food, blankets and soap, we have also constructed a house for a patient whose house was collapsing and put a new roof on another. We supply crutches for those KS patients who need them and we have a wheel chair that has been used by three of our patients with paraplegia secondary to Cancer of the Prostate this year. All these added extras go towards improving the quality of our patients' lives.

And our care extends beyond the death of the patient. Monica was a widow with three children whom we had arranged to pay school fees for some years previously but now, only one boy remained in school. The two girls had dropped out to care for their mother. When Monica died, it was a challenge to know what to do about the children. The boy was doing P7 and was in a boarding school so that wasn't a problem. But the two girls were now left alone in the house with an older brother who worked as a mechanic and could not be responsible for them. The elder girl, Josephine, is 16 and had left school for several years so there wasn't really a possibility for her to return. The younger, Agnes was 9 and had left P2 the year before. What to do?..... Very generously, our Palliative Care Nurse, Resty offered to take Agnes into her home where she could continue school and Aloysius, our driver said that Josephine could come to live with his family as his wife teaches hairdressing and this would be excellent training for her. Apart from the

education aspect, placing these children in stable loving homes will go long way to healing all they have suffered over the last few years caring for their mother.

Our social welfare budget line also includes money given to patients for transport to the hospital if necessary, hospital bills and occasionally money for extra food that we don't have.

Organizational Development

Community Workers (CWs) training

In the past few years we have been doing sensitization workshops in parishes throughout the Diocese. This year we decided to go back to refreshing our CWs and Expert Clients. Some of this was done at the monthly meetings of the CWs and three full day workshops were arranged for CWs in those Districts where we felt that patients were not being referred. At these workshops, health care professionals from Health centres in the area were also invited. In all 491 people attended.

Counseling Courses

Counseling Department invited us to speak at 4 workshops they were giving for Teachers. 144 teachers attended and enthusiastically received the information. One teacher referred her own mother, a woman of 62 who had been having vaginal bleeding for two years. She had attended several doctors but received no diagnosis or treatment. When we went to see the woman, it turned out that she actually had had a biopsy done two years previously but the Doctor never gave her the results. We encouraged her daughter to demand the pathology report and it was endometrial carcinoma. We immediately referred her to the Gynecologist in Kitovu who did a hysterectomy. Thankfully the cancer had not spread and the woman and her daughters are so grateful that they were exposed to Palliative Care even though they don't need it now!

Continuing Medical Education (CME)

6 CME sessions were carried out in 4 Hospitals, 1 in Rakai Health Services and 2 in Bikiira Health Centre. We contributed to Health Care professional workshops given by the Palliative Care Association of Uganda (PCAU) given to Senior Staff from 5 Hospitals in the Central Region, 1 session with TASO Masaka, and 1 given for Masaka Regional Referral Hospital. Participating in these workshops is mutually beneficial as they come to know what services Kitovu Mobile offers and we are put in contact with patients needing those services. It is hoped by PCAU that eventually all large hospitals will have active Palliative Care Teams and these workshops and seminars are directed to that end.

Meetings and Courses attended

- The Palliative Care Team attended 6 PCAU quarterly Up-dates, four in Kampala and two in Masaka. At one of the Masaka meetings we presented our experience with chemotherapy in Palliative care.
- Dr. Simmons is a member of the Palliative Care Country Team which meets quarterly. She also took part in an AIDSTAR follow-up workshop and contributed case studies for the Training Guide
- Three Kitovu Mobile Staff, two nurses and one Counselor attended the Pediatric Palliative Care Course offered at Mildmay Uganda.
- One Nurse attended the Hospice Health Care Professionals Course.
- One PC Nurse attended a week's course on Data Management sponsored by Trocaire in Nairobi.

A highlight of the year was the opportunity for all the four Palliative Care Team staff to attend the 3rd APCA Conference in Namibia. It was a truly enriching experience. Dr. Simmons presented a paper on The Spectrum of Palliative Care in HIV&AIDS. This paper was well received, as many of the participants were from countries where not only Palliative Care, but HIV&AIDS work is just getting started. Our ten year experience gave valuable information for those starting out in this all important work. We are particularly grateful to the Diana Memorial Fund for sponsoring our staff to attend this Conference. It was a reward for their very dedicated work in a stressful field.

Visitors

Hospice Uganda sent two groups of students from their Clinical Palliative Care Course. Five students were in each group and they spent two weeks with us. Kitovu Mobile is an excellent exposure for these students as they have the opportunity to see the full spectrum of HIV&AIDS care, including ART as well as how Palliative Care has been grafted on to the programme. The students this year came from far afield, Districts in Northern Uganda as well as one student from the democratic republic of Congo.

We had three groups of visitors come to film our work. The palliative Care Association of Uganda sent a group from their partner organization in Indian, US. They came out with us on home visits and saw Palliative Care at the grass roots. Their plan was to create a film to be shown for fund raising purposes in the U.S.

Hospice Africa-Uganda sent a group from the National Hospice Association of Ireland. This group was documenting the work of Hospice and since we are their partner and an excellent illustration of how Palliative Care can be grafted onto an HIV&AIDS programme, Hospice felt that it was important to include our work in their filming. They hope to produce a documentary to be televised nationally in Ireland.

A third group came from the University of British Colombia in Canada. These were students making a documentary about Palliative Care in resource poor settings. They chose Uganda, India and Afghanistan. Once again, our programme was chosen because of its unique combination of Palliative Care for both HIV&AIDS patients and Cancer patients in a Home Care service in a rural setting.

Challenges

Morphine

The greatest challenge of the past year has been the scarcity of liquid morphine. For the past years, morphine has been supplied free from the Ministry of Health. In March of this year morphine powder became scarce until June when it was not available at all. We were forced to improvise by using MST, sustained release morphine tablets. Since these had to be purchased at quite a high price (45,000 Ug shs; approx. 12 Pounds for a month supply for one patient) it put a strain on our budget. However, there was no way that we could tell patients already on morphine that it was no longer available. With new referrals, we initiated their treatment with codeine tablets. Codeine does give pain relief, though not as good as morphine, and it too is costly (19,000 Ug shs approx. = 5 Pounds to 38,000 Ug shs approx. 10 Pounds a month). Furthermore, it is much more constipating and thus our bill for laxatives also went up. In August we made an agreement with Hospice Africa to purchase liquid morphine from them as they still had a supply. This eased our problem slightly, especially for patients who had to have liquid morphine like

those with Cancer of the Oesophagus. The morphine crisis continued until the end of the year when a solution was finally agreed upon by the National Drug Authority to resume supplying liquid morphine free of charge for the next two years. It is hoped that by the end of January we will be able to supply all those in need of liquid morphine, including those patients that have been on codeine for some months.

Advanced Disease

Patients continue coming to us with very advanced disease. The answer to this problem is education; first of all to tell people what to look for and to encourage them to see a medical doctor immediately. Many of our patients have spent useless time and money attending herbalists and traditional healers. We recently had a patient with Cancer of the tongue who had spent months and 5,000,000 Ug shs (1,400 Pounds) on herbal treatment. When she finally went for radiotherapy it was too late and she came home to us for pain management. Our patients coming to us with KS never fail to amaze us. They have very advanced disease and yet they have only recently had an HIV test. Again, they have been attending traditional healers or witch doctors as there is still a common belief that this condition is caused by witchcraft.

Increased cost of drugs

The cost of living has risen dramatically in the last year and this is reflected in the cost of drugs. Chemo for KS has increased from 37,000 Ug shs to 55,000 Ug shs + 25,000 Ug shs for hospital charges. That means that each dose of chemo costs 80,000 Ug shs (23 Pounds) and each patient gets 5 doses. We have had to become very particular in assessing patients for chemo. We are also trying a new drug, Bleomycin, that is less costly and as effective a Doxorubicin.

Need for extended counseling

As has been previously mentioned, many patients need extended counseling to come to terms with their illness. Since the team doctor does not have the local language, we have arranged special home visit days for the nurses alone as they are excellent counselors.

Need for sensitization in Districts and Hospitals esp. Lyantonde & Ssembabule

From our data we can see that fewer patients are being referred from these Districts. We have already started to do extra sensitization of CWs and Health Care Professionals in these areas and will continue to do so in the coming year.

Conclusion

2010 has been a busy and difficult year for us. However, despite the challenges and problems we have given an outstanding service to the people of Masaka Region. We have had great satisfaction in caring for our patients; seeing them comfortable and relieved from pain. Our trip to Namibia was a special delight for us as a team. Words cannot express our gratitude to the Diana, Princess of Wales, Memorial Fund for making possible all that we do. Our happiness lies in knowing that all at the Fund find real value in the work that they have supported.

Dr. Carla Simmons

Date