



ST HELENA SANDVELD HOSPICE

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NEWS LETTER

I used to think that everyone knows what Hospice is and what we do. Yet, I often come across people who have no idea what it is all about, so promotion of our Hospice is an important aspect of getting the service to those who need it. For myself, learning more about aspects of Hospice other than the purely clinical care of our patients is an ongoing experience. The "holistic" approach to many activities is a buzzword, which is bandied about quite often. Our Hospice actually practices the holistic care of our patients and their families, from the first contact to long after the patient dies.

Of course it starts with the referral form and getting the clinical diagnosis and medical requirements sorted out. But what of the practical aspects of caring for a patient in the home, feeding, making them comfortable, giving a bed bath? Our sisters can advise and our home-based carers can visit as often as required giving the practical relief for the family. When things get too much, patients can be referred to in-patient facilities available in our area. Patients in remission and not totally bed-ridden can visit our day hospice once a week for interaction with other patients, staff and volunteers as well as taking part in therapeutic activities. A break from the daily routine can be a Godsend for patients and families.

On festive occasions we hold a party for those who can attend and make something of an event of Christmas, Hospice week and similar special days. Our indigent patients very often are not aware of the benefits they are entitled to. That is where our social worker

comes in. She is also available for counselling of the family and patient during the illness and bereavement counselling after the death in the household.

We try to live up to the Hospice motto of "no end to caring", and during Hospice week from the 4th to 11th May we will be holding a Remembrance Service for all those families who have suffered a bereavement and have been cared for by our Hospice.



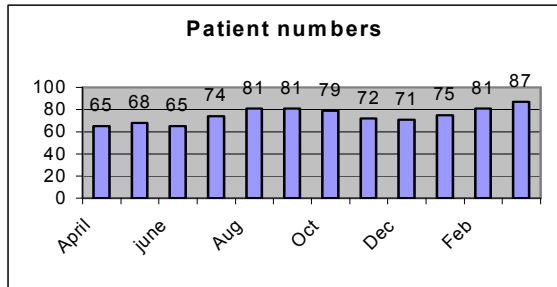
The Day Hospice Volunteers

Patient Services

In the last newsletter we reported on something of a plateau in growth, but over the last few months the upward trend has again started. As usual, there are no doubt many factors, but networking and excellent service provision are perhaps largely responsible. The municipal clinics and the HIV clinic have now realised that we are here and why. We are also getting more enquiries from individuals who have heard of the work we do and need our help.

Disease Profile	%
HIV/AIDS	25
Cancer	38
Chronic conditions	37

Race Profile	%
Black	9
Coloured	60
White	31
Gender Profile	%
Male	34
Female	66



News around the Hospice

The best news was the delivery of our brand new Toyota Avanza obtained through Rotary. We are very grateful to the Rotary clubs of Misbourne Matins, Beaconsfield and Jordans and District. They are all in District 1090 of Rotary International who also made a contribution. For those of us who do not live in the Green and Pleasant land, you will find them on the map in Buckinghamshire half way between London and Oxford. The Rotary Foundation, who contributed a third of the total grant, supplemented these funds. The first car we acquired in 2004 will be traded in for a more up-to-date vehicle with the remainder of the funds that are still available from the grant.

Hospice week will be marked by an awareness programme in local churches, posters in clinics, radio interview on Weskus Radio and newspaper articles.

Finances

The somewhat gloomy picture painted three months ago has improved, although we still live somewhat from hand to mouth. Perhaps this is the lot of all NGO's in South Africa these days. Thanks to all those who continue

to support us with donations for the shop and financially.



Felicity Holmes and Sr Haley pictured with the winner of the ladies competition at a Charity Golf Day.

Staff

We are sad to report something of a turn over of staff. One of our home-based carers is now receiving a disability grant and can no longer perform her duties. Two other carers have resigned to take up more lucrative positions in unrelated fields. Unfortunately the grants we receive for the payment of home-based carers can not compete with salaries offered on the open market, so we need to recruit and train again. We are also very sorry to loose the services of our social worker Zenobia van Brakel. She has been with us from the early days and has made a big contribution to the success of the Hospice to date. Her husband has taken up a position elsewhere, but we hope that Zenobia will not be a loss to the wider organisation and will find a place in another hospice. Karin Hubbard, who is currently our Volunteer Co-ordinator, and being a trained social worker, will take over Zenobia's position.

With an increase in patients and the expected further growth, our sisters are hard pressed to keep up with the workload. Many of our chronic patients, the care of whom is funded by the EU, do not require strict palliative care and

may be looked after by our staff who are not trained in this discipline, but for a part time palliative nurse to look after 25 or more patients is asking a lot. We have decided that it is time to start to look for additional trained staff.

A good news story

In our last news letter we promised to tell you more about the little boy photographed on the lap of Norma Venter, one of our sisters looking after the EU patients.

The story of Xolili

He was referred to us in April 2006 at 4 years of age, requiring Anti-retroviral treatment, which was not available at that stage in our area. We had agreed to transport patients requiring ARV to the ARV clinic in Malmesbury.

On admission, he was being cared for by his grandmother (who is also HIV+ and was also referred us as a patient) as his mother had already died as a result of this disease – Sept 2005.

The first visit was completed by Sr Venter and it was apparent that he was very sick. He had many symptoms, including coughing, shortness of breath, poor appetite, loss of weight, tiredness and sleeplessness. He had just completed a 6-month course of TB treatment and had been diagnosed with PCP pneumonia (which is usually fatal).

He and his grandmother were transported to the ARV clinic for an appointment on the 18th April and commenced on ARV immediately due to his condition. Within a week an improvement in his condition had been noted.

At this time Sr Venter and Sr Pienaar were the two 'other grannies' who cared and nurtured this little boy. Sr Venter making the appointments for the tests and sometimes hounding state departments for the results, supporting his grandmother and

checking that he was getting all of his 14 medications as prescribed. Sr Pienaar transported and held his hand during several of these tests – she will not easily forget her dismay when blood had to be drawn from Xolili's neck and he rightly put up a fight.

In May he suddenly became ill again – with a dreadfully noisy chest infection and at the ARV clinic it was thought that he may have immune reconstitution inflammatory syndrome (IRIS). IRIS occurs when the patient's immune system is so depleted that it does not initially detect that dangerous organisms have invaded the body, but as the immune system strengthens due to ARV treatment, all of a sudden the body is alerted and responds to these organisms.

All the staff were anxious, as this was now the second time that this small, frail 4 year old (his size and weight were comparable with the average 2 year old) was critically ill.

Within a week he had bounced back and was playing outside with friends and from this point he has not looked back.

When day hospice was started in August 2006, Xolili and his grandmother were present and his attendance has brought joy to fellow patients, the volunteers running day hospice and the staff. When new people have arrived and felt a little uncertain, Xolili and his antics have often been common ground for conversation.



Srs Venter and Pienaar were also part of the initial group of volunteers who got the day hospice off the ground, providing food and transport and caring for all those who attended. Sr Pienaar always brought milk from her farm and chocolate nesquik especially for Xolili. His great pleasure in life is to ride in Sr Venter's car where he always sits in the middle of the back seat with a hand on each seat in front of him surveying the road ahead, as well as Sr Venter's every movement as she drives (regardless of how many other patients are in the car). His observation of Sr Venter's driving technique stands him in good stead as his favourite game at day hospice is "driving" – he uses a round container lid as a steering wheel and runs around outside or even when lying on the floor totally absorbed in his own world. When asked the colour of his car the answer is: "Rooi" – no prizes for guessing who drives a red car?

Day hospice is a quieter place as of this year and all the "aunties and grannies" alike, whether patients, staff or volunteers miss him. The reason being that he is a grade 1 learner at St Andrews this year! Needless to say there was some anxiety attached to the event – "He has grown a lot but he is still a bit on the small size for his age – hope he won't be bullied." He was supplied with a school case and some items of school clothing from the donations received for the shop, for which his grandmother was extremely grateful.

More good news

As part of our quality improvement programme, we have recently had some of our volunteers conduct a survey amongst 28 of our palliative patients. We were very pleased with the results and would like to share them with you.

Of concern is that 65% of our patients had not heard of our service prior to becoming patients. It seems our awareness campaign on the West Coast needs to be intensified.

- So how did they get on to our books?
Most referrals came from cancer units at Tygerberg and Groote Schuur or from medical practitioners; others hearing of the service from family members.
- All the patients said that they received sufficient information and care from our staff.
- Asked if they knew that we can also provide spiritual counselling, 65 % were not aware of this, another area that requires attention.
- When asked if the care team made a positive difference to their lives, all but one agreed that they had.
- A few respondents, 14 %, did not feel totally assured that we are available 24 hours a day every day of the year.
- All but one patient felt that the team gave them the opportunity to discuss their problems, but also allowed them to make their own decisions regarding their treatment.

Thank you very much to the four volunteers who conducted the survey. The information from the survey reassures us that we are on the right track, but also highlighted a few areas that require a bit more effort.

For your records

Our PBO number: 93009262

Our bank is: Standard Bank Vredenburg; Acc No 186295073; Branch code 050-511.

If you require or would like a tax receipt in order to claim against your tax, the PBO number allows us to do this, so please let us know and we will supply the necessary receipt in the correct format.