



The South African Academy of Family Practice's Rural Health Initiative (RHI) is proud to be able to bring you the following section of the journal, that will concentrate on issues pertaining to rural health in South Africa. We hope to provoke discussion on these issues and would encourage anyone interested in rural health to offer contributions to future issues.



## Thusananga – a rural home based care organisation



Thusananga began in 2002 when I met with a Barkly born woman, Maggie Thethelwa, a veteran of the struggle, who was helping to keep the local hospital clean and tidy along with a dedicated group of friends, all volunteers. My husband's family had been great friends with Maggie during the difficult 1980's.

Having been swept off my feet by a local farmer, I found myself living in Barkly East, far away from England, where I was born and had been working. After one visit to the local hospital, it was clear that we were not handling the HIV/AIDS epidemic in an organized and compassionate way. I had heard on the rural grapevine that Maggie got things done if things needed doing. **Something needed doing.** There had to be a better way of caring for people with terminal end stage AIDS and also those with opportunistic infections that come with HIV infection.

So I met with Maggie and her valiant core of volunteers. We asked Sr Cathy Thomas (a Roman Catholic Nun and Hospice nurse from Middleburg) to train 25 volunteers who had been handpicked by Maggie from the Barkly townships, in basic home based care and counseling skills.

And so we began. For many of the volunteers, it was a real baptism of fire. One of our first patients was a young HIV positive woman with fungating breast cancer affecting both breasts. She was desperately thin and weak, with young children. She also had to contend with secondaries in some of her bones as well as smelly, painful wounds on her breasts. The first day we began dressing her wounds, our volunteer almost fainted and had to run out to be sick. After a few days, the caregiver was dressing the wounds on her own and helping the patient take her morphine medication. That particular caregiver is still with us, runs workshops on safe sex issues, and is now having basic computing lessons funded by Thusananga.

Perhaps one of the hardest things for the volunteers is dealing with terminally ill children. It is hard enough watching a 30-year-old person die, but to become closely involved with a mother and her child and watch them both slowly deteriorate and die was heartbreaking for many of the volunteers. We found that regular formal de-briefing sessions were not always appropriate. Individual volunteers felt more at home going to Maggie for a cup of tea

and a chat to get things off their chests. Since we began, over 200 of our patients have died. That's a lot to take on board.

We have evolved into an organization that not only provides a high standard of primary and palliative care, but also views preventative work as essential. Much of the volunteers' day to day work is still taken up with patient care, e.g. fetching medication, DOTS, organizing benefits, dispensing food parcels and looking after the complex needs of bed bound patients. However, these days volunteers and positive patients run workshops around areas of HIV/AIDS Awareness and related topics including the sensitive subjects of child abuse, rape, domestic violence, safe sex and masturbation. It always brings a smile to my face when I remember how shy everybody was talking about sex at the beginning. Now I take great pride in the fact that many volunteers can stand up and say to patients: Don't be afraid to Do It Yourself, before going into great detail about male and female masturbation! Some volunteers are still shy, but most are prepared to educate others in a way that is clearly understood, without any need for euphemisms!

There are now 9 active volunteers, supervised by Maggie. For many of the original 25 who were trained, the role did not suit their personalities. We have found from experience that woman make the best carers, especially those in their middle age. The role definitely requires a nurturing, non-judgmental and pragmatic approach and many people find this difficult. The best hands-on carers have tended to be quiet and low key; the best educators have tended to be the more outgoing personalities. Maggie and I decide together which caregiver goes with which patient, and this takes in the personalities (and consent) of both.

Overall the volunteers' role covers the following areas:

- Patient Care, including care of the bed bound/housebound patient, spiritual care (including bereavement counseling and funeral attendance), DOTS, advocacy and practical help with attaining benefits, organizing care for potential orphans, counseling in aspects of healthy living (eating, sex, exercise), and dispensing food parcels, blankets, clothing, and coal (winter months only)
- Income Generation, through vegetable

gardens for patients and volunteers, with excess vegetables to sell

- Prevention, including HIV/AIDS workshops in local schools, correctional services, farms, clinics and hospital

Volunteers receive ongoing training in the above areas and others including TB, Holistic Medicine and Alternative practices, Computing and Patient Literacy with regard to antiretroviral drugs. All volunteers receive a monthly stipend (R400); this is a miniscule amount considering the work that is done by many, but better than nothing. All volunteers are asked to sign a "commitment and understanding" with Thusananga, which is not a contract but demonstrates a degree of commitment to Thusananga.

"A woman's work is never done" can also be applied to our volunteers. There is so much scope and room for imagination in their role. They play a vital role in our community and continue to provide love and care in demanding situations.

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Patients and volunteers in the vegetable garden



Positive volunteers of Thusananga