

Perspectives on KwaZulu-Natal

Volume One - Number Two - April 2001

Hospice in KwaZulu-Natal: Providing home-based care for Aids patients and their families

Hospice assists patients who have an advanced incurable disease and provides support for their families and carers. Education and training in home based care is an important part of their work, particularly with the increased impact of HIV/Aids in KwaZulu-Natal, writes **Susanna Coleman**.

"My brother came home from Johannesburg to die," says Sibongile, before describing how her family had struggled to receive with open arms the family member who had hurt their mother the most. She looks into the distance. The Dlamini family (names have been changed) had struggled to stand up to the cocaine addict who sold their possessions one by one and became so violent that they had to move to a flat. But the man who returned was a thin, sad stranger whose slow death dominated their family life for nearly six months.

"At first it was terrible. For a mother to see that her son is dying, no matter how cruel he had been. We began to struggle more towards the end when his condition kept him bedridden, we could not wash him. A nephew of mine had to come and live with us solely to lift, wash, feed and toilet him." After turning to a family friend, Sibongile was referred to Hospice where, she says, the family found a support system that helped them through the darkest time of their lives.

"On the first day that I went there they gave us gloves, waterproof bedding and a commode. A home care sister came over and explained to us how to care for my brother, suggested foods and ways to minimise his discomfort. All the problems that had seemed insurmountable now had a practical solution. Just having someone to tell us what to do freed us to face his death from the emotional and spiritual angles," says Sibongile.

The arms of Hospice embrace a large portion of the population of KwaZulu Natal. Highway Hospice fundraiser Heather Walker says that an important emphasis of the organisation's work is visiting patients at home. Domiciliary sisters currently visit about 300 home-based patients every week. Walker says that most people who are dying prefer to stay at home and with facilities to cater only for 16 in-patients, Hospice can assist more people by providing support to patients and their caregivers. A day care centre at the Highway Hospice provides support for another 30 terminally ill patients. A bereavement support group offers individual counselling and group social meetings, a

Perspectives on KwaZulu-Natal was published by Profile KwaZulu-Natal cc in 2001 and 2002. All rights reserved. No editorial material published in Perspectives on KwaZulu-Natal may be reproduced in any form without prior written permission from, and acknowledgement to, Cheryl Goodenough.

Perspectives on KwaZulu-Natal was proofread by Donna Hornby from Absolute Proof.

Copyright Profile KwaZulu-Natal cc, 2001, 2002

regional training centre assists professional nurses and doctors can attend an accredited evening course in palliative medicine.

The premises of Highway Hospice, which sprawls across four properties in Durban's Sherwood suburb, is far from being a sad, quiet place full of dying people. The atmosphere is informal and homely. The first bustle is in the lounge where volunteers run a coffee bar. Beyond one door I hear voices in song. People have met in the quiet room to start their day care visit, which is held every Tuesday and Thursday.

Leaning against the wall in the children's room is the set-up for a Punch and Judy show. As well as providing children with a place to play, the social workers use the hand-puppet show to work through some of the harder aspects of a relative's death. Hospice staff say that children feel much freer to talk and listen to a puppet.

The only hospital furniture to be seen is the traditional hospital bed. Each ward has its own private balcony and there are flowers everywhere. Hospice staff say that most of the contents of the premises consist of donations. The organisation is not for profit and relied entirely on bequests and donations. They do not even receive government funding. It is solely the support of the community that keeps them functioning - they do not even charge for their services.

Even so, a number of staff members are employed full time. In addition to a doctor, matron and professional nurses and assistants, administration and fund-raising functions are carried out. Hospice also employs three social workers, 13 domiciliary sisters who offer home care, cooks and domestic workers. A vital part of their service is provided by volunteer caregivers, who include a therapist, hairdresser and aromatherapist.

It's been no mean feat to keep Hospice functioning and growing for almost 20 years. The Hospice Association of KwaZulu-Natal held its inaugural meeting in April 1982 and less than three months later the first patients were admitted to founder Greta Schoeman's house. More than 180 patients were cared for in the first year. The Sherwood premises were subsequently bought and have remained throughout the years, although much extended. The association grew and branches were started across KwaZulu-Natal.

The HIV/Aids epidemic has had a great impact on Hospice. All domiciliary sisters are involved in educating people on how to care for those who are dying and tell terminally ill patients about the processes they are going through. Walker says that this type of assistance is not provided by doctors, but helps family members who are "horrified by death when they are not prepared for it".

Such work takes its toll on the domiciliary sisters who sometimes "come back to the office in tears", according to Walker. She says that they see patients who cannot be given pain-relieving medication because they have not eaten for days. Sometimes they find patients who have been abandoned by family members and left on the streets of informal settlements because of their illness. Walker says increasing support is given to young children who, particularly as a result of Aids-related deaths, are abandoned.

The emotional and psychological aspects of assisting Aids patients are important to Sibongile. She says that at first her brother's emotions had made him suffer more than the terrible physical aspects of dying from Aids. "Once the church group could come

Perspectives on KwaZulu-Natal was published by Profile KwaZulu-Natal cc in 2001 and 2002. All rights reserved. No editorial material published in Perspectives on KwaZulu-Natal may be reproduced in any form without prior written permission from, and acknowledgement to, Cheryl Goodenough.

Perspectives on KwaZulu-Natal was proofread by Donna Hornby from Absolute Proof.

Copyright Profile KwaZulu-Natal cc, 2001, 2002

back into his room and pray for him, my brother understood our forgiveness and was able to accept his own death. Even though he was very angry at himself for allowing AIDS to rob him, he was given more dignity by, for example, the adult nappies that Hospice advised us to buy." Sibongile is grateful that the Hospice sister, who was available to give advice by phone at all hours of the day, lessened the worries of her family and her brother.

In the last week of his life, Sibongile's family struggled to feed their son and brother. The Hospice sister said that this was a sure sign that he was soon going to die. The family physician prescribed morphine drops that eased his death. With the support and assistance of his family and Hospice, the death of Sibongile's brother was dignified and as pain free as possible.

Susanna Coleman is a writer specialising in medical issues.