

FEATURES

Two faces of Aids care dilemma

By JULIANA OMALE-ATEMI

At 19, Janet Ngina has just about seen it all. She nursed her mother for five years until she succumbed to Aids in May, last year.

The fourth child of her single mother, Ngina was unable to pursue her education beyond primary school despite having scored 438 points in the Kenya Certificate of Primary Education (KCPE) examination five years ago.

Before that, the family lived in Mbooni, Makueni District, with their grandmother while their mother worked as a nurse aide at a private clinic in Kibera, Nairobi.

"My mother was in poor health by the time she sent for us to join her in Nairobi," says Ngina. "Eventually, she could no longer go to work."

By this time, the eldest daughter had left home to get married, leaving another daughter, son and Ngina to fend for the family, struggling to ensure that the rent was paid on their shack in Lindi village, Kibera, and that the two youngest children stayed in school.

"I stayed home and took care of my mother," says Ngina. "And when she could no longer cope it was I who washed, dressed and fed her."

Cultural taboos about a child seeing her mother's nakedness were set aside since there was no

older female relative nearby.

"She wouldn't let anyone else near her when it was time to be helped to the toilet or when she needed to take her bath," says Ngina. "We were able to overcome the initial embarrassment, and it brought us closer together."

It was Ngina who kept her informed of the goings on in the neighbourhood and beyond, and took her out to the sunshine. She also arranged for her mother's few remaining friends to come and visit, and opened their house to members of their church for prayer sessions.

Ngina says she became her mother's trusted friend and confidant during her long illness, especially through the long nights when sleep eluded her.

The rest of the family has no idea that their mother died of Aids and Ngina would like things to remain that way.

"I must respect her wishes," she says.

For Ngina, living with Aids has been like riding an emotional roller-coaster. Her grief began long before her mother's last breath.

"I was able to see my mother at her best and at her worst as she struggled with Aids," she says.

The worst time was when her mother's skin broke out in sores that refused to heal.

"She was in such terrible pain, it

was driving her out of her mind," she says. "One night she asked me to get her a knife so that she could cut out the source of her pain somewhere in her chest."

Ngina says that was the loneliest moment in her life. It dawned on her that her mother's life was coming to an end.

It was not long before she went into the final stages of Aids; she slipped in and out of consciousness and became delirious. By this time, she had lost control of her bowel movement and other reflexes. Her body was cold most of the time because of poor blood circulation.

But Ngina is eternally grateful to the volunteers at the Kibera Community Self-Help Project at Maina village, who embraced her mother into their support programme and provided a shoulder to lean on when she felt that she could no longer cope.

They arranged for her mother's short admission at Kenyatta National Hospital, where she died.

In a way, Ngina is grateful that her mother's passing on was handled at the hospital.

"There was a certain dignity about it, and I think she would have wanted things that way."

Whereas Ngina has experienced living with Aids from her position as a poor urban slum dweller, the situation in the rural areas is distressing.

According to Arthur Okwemba,



Loud and clear: Aids victims need love, a message from school children during World Aids Day celebration. Aids is a barely understood phenomenon. (File photo)

a recent university graduate, Aids is a barely understood phenomenon in rural Emuhaya Division in Vihiga District where he comes from.

"People here fear death so much and the Aids messages are full of promises of death," he says. "It has a counteractive effect on conventional Aids prevention strategies."

Okwemba says that it is almost impossible for people with Aids to live positively.

They and their families are treated like pariahs. People have the notion that associating with them could put them at risk of contracting the virus.

An incident at a recent funeral left a nasty impression on him. A person with Aids arrived at the venue to fulfill his obligations to the clan. People scattered in his path until someone shouted at him.

"When you got that jigger we were not with you. Don't expect any sympathy from us, just go away!"

When the food was served, his was placed at a distance from everyone else's before he was invited to eat. When he was through with the meal they threw the empty plate into the latrine. His next meal was served on banana leaves.

Although they are materially and financially unprepared, Kenyan families and communities have finally woken up to the fact that they are going to have to shoulder the risks and responsibility.

Caring for an Aids patient at home need not

Home is still the best place for people with Aids. It is often cheaper, comfortable and familiar and gives the victims more control of their lives.

A guide published by the United States Department of Health and Human Services, Public Health Services, Centre for Disease Control and Prevention and the American Red Cross society, *Caring for Someone with Aids at Home*, advises that each person living with Aids is different and is affected by HIV infection and Aids in different ways.

The guide says that many times what is needed is not medical care, but help — with the normal chores of life, shopping, getting the mail, paying bills and cleaning house, among others.

Caring for someone with Aids is a serious responsibility. Aids stresses the victim and the carer. The care giver is advised to work with the person with Aids to decide what needs to be done, how much can be done and when additional help is needed.

"Yet by rising to the challenges of caring for someone with HIV infection and Aids, you can share emotionally satisfying experiences, even joy, with those you love. You can also find new strengths within yourself," the guide says. "But you need to take care of yourself as well as the person with Aids."

People with Aids should take care of themselves as much as they can and as for as long as they can. As a person caring for someone

with Aids, you can do the following to make them comfortable:

- Respect their independence and privacy.
- Give them as much control as possible. Ask to enter their room, ask permission to sit with them.
- Ask them what you can do to make them comfortable. Many people feel shy about asking for help, especially help with things like using the toilet, bathing, shaving, eating and dressing.
- Keep the home clean and looking bright and cheerful.
- Let the person with Aids stay in a room that is near the toilet and bathroom.
- Leave tissues, towels, trash basket, extra blankets and other things the person might need close

by so that they can be reached from the bed or chair.

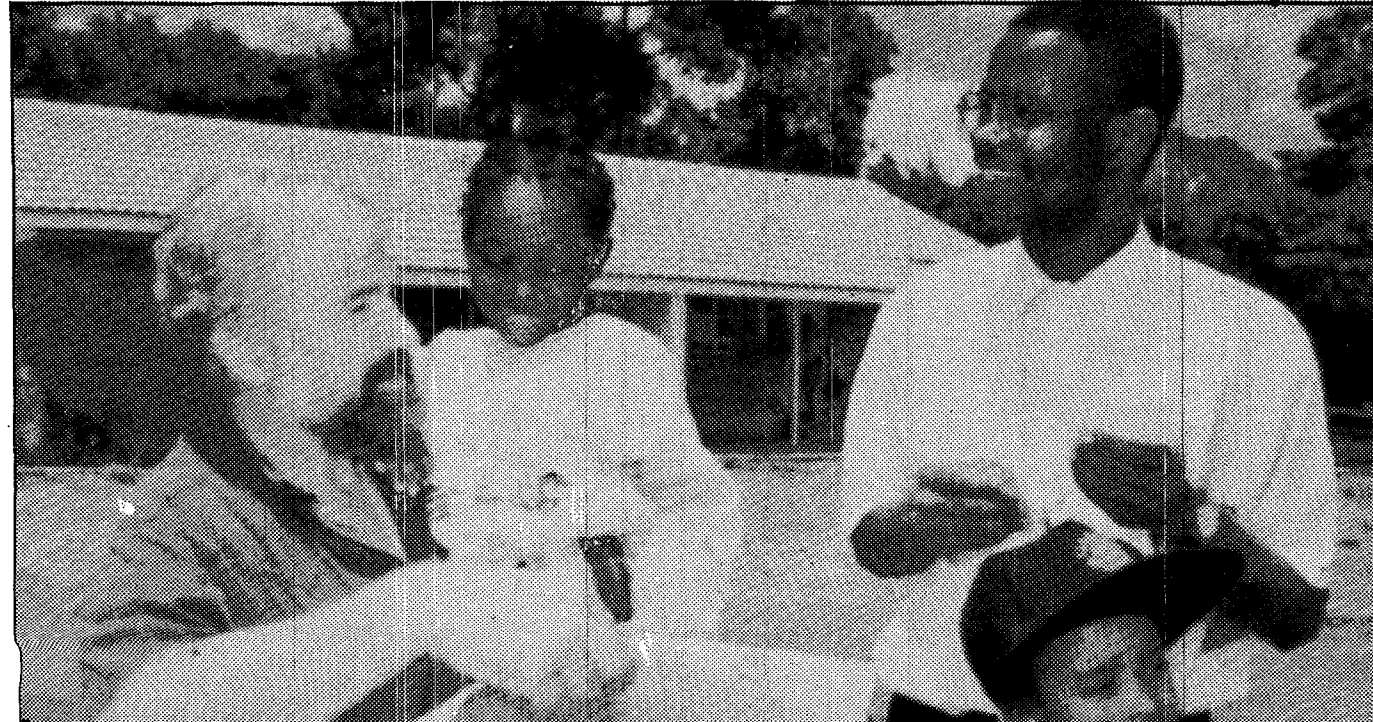
- If the person being cared for is bedridden, be sure to help them change position often. If possible, a person with Aids should get out of bed as often as they can. It prevents stiff joints, bedsores and some kinds of pneumonia. Usually a person in bed needs to change position at least every four hours.
- In caring for a person with Aids, feelings are important. There are no rules about what to do or say, but it is good to keep them involved. The guide gives the following advice.
- Do not do everything for them or make all their decisions. Nobody likes feeling helpless.
- Have them help out around the house if they can. Everybody

likes to feel useful. They want to be part of the group.

- You don't always have to talk, just being there is sometimes enough. A support group of other people with Aids is a good place for dealing with the anger, frustration, depression and loneliness that comes with illness.
- Touching, hugging and kissing is supposed to be good for everyone. But since a person with Aids is vulnerable to germs that would normally be harmless to a healthy individual, clean hands are a must. Washing hands is the single best way to kill germs. Hands should be washed frequently with warm soapy water for at least 15 seconds. Attention should be paid to the area under fingernails and between the fingers.

A person with Aids often cannot fight off colds, flu or other common illness. If the carer is sick and nobody else can do what needs to be done for the person with Aids, it is recommended that a well-fitting surgical-type mask that covers the nose and mouth be worn and that hands be washed before coming near the person with Aids. The carer must also explain to the person they are looking after that these measures are being taken to protect him or her.

Carers are advised that if they have cuts or sores, especially on the hands, they must not touch the person they are caring for or their things. If one has to give care, sores must be covered in bandages and hands washed before touching the other person. Disposable



Airline's crews to for HIV-positive

By a CORRESPONDENT

Nyumbani, the hospice for HIV-positive orphans, will soon have a playground, thanks to a fundraising effort by British Airways' crews. The project will be ready early in 1998.

In a central area surrounded by the children's cottages and classrooms, there will be a miniature football pitch, a play area with a soft sand surface, slides, a scrambling net and other play equipment.

Protus Lumiti (right), the project manager of the Nyumbani Hospice for HIV positive orphans, reviews plans for a playground with Dick McMichael (left), a British Airways Senior Engineer Officer, who presented a cheque of £5,000 to the Home. The money was raised by McMichael, his wife Mira and his colleagues.

Dick McMichael, a senior engineer, backed by his wife Mira and a group of colleagues, has run a campaign to raise money. During a recent stopover in Nairobi, he presented a cheque worth £5,000 (about Sh500,000) to Protus Lumiti, the Nyumbani project manager.

Speaking after the presentation, McMichael said: "For several years members of the British Airways' crews flying to Nairobi have supported Nyumbani with supplies of clothes, medicines and toys. A few months ago, I noticed the need for a playground.

"There is an ideal location in the centre of Nyumbani grounds, but lack of money for such a facility presents a problem. The solution