



Children living with AIDS

Extended family: Mijyasi Gungulou, 82, comforts her great-granddaughter Mdakalira, 9, orphaned by AIDS in Malawi

Martin was referred to the Mildmay Harare Children's Hospital Specialist Clinic in Zimbabwe. He was eleven years old, and had a right sided hemiplegia, the legacy of cryptococcal meningitis. He was very malnourished and depressed, having had to stop school, and move to live with his elderly grandmother who was already overwhelmed with the other orphans for whom she was caring. He had severe oral thrush which made eating difficult and he was losing weight. His grandmother had little hope for him, but she brought him to the clinic as a 'last straw' at which to clutch, having been told that children brought to the clinic usually improved. He was admitted to the Day Care programme, where he received intensive physiotherapy, good nutrition, counselling and daily schooling to his level of ability.

A year later, he has learned to walk again, and can write with his left hand and feed himself. Counselling and spiritual support for Martin and his grandmother has given them both a new outlook on life. A school has been found that is willing to take him in spite of his continuing disability. His grandmother is grateful and has found that the support and help she has received has given her the strength to cope with both Martin and the other children for whom she cares. It is hoped that a sponsor will pay for Martin to start taking antiretroviral drugs very soon.

Children living with HIV infection or AIDS-related illnesses themselves are amongst the most vulnerable of all children. They and their families experience enormous losses as well as stigma and prejudice, which may be felt in their communities, schools, and often, even in church and Sunday school.

The latest estimate from UNAIDS (end of 2004) indicates that there are 2.2 million children worldwide under 15 years of age who are living with HIV themselves, and of these, 640,000 became infected during 2004. The number who died in the same year was just over half a million. The total number of adults and children living with HIV in 2004 is approximately 40 million.

Of the 2.2 million children who are infected with HIV, most are living with recurrent illnesses, many are severely malnourished as a result of persistent or recurrent diarrhoea, or simply because of the family's poverty and lack of nourishing food, and many are disabled as a result of opportunistic infections such as cryptococcal meningitis or toxoplasmosis. As their immune suppression worsens, cancer and HIV related encephalopathy may increase their suffering, and that of their parents or care givers. All of them are suffering emotional stress and trauma, having usually lost one or both parents, or a sibling, and they will often end up as an unwanted burden in the household of a grandmother, auntie or uncle, or in some cases, a child-headed household. Their ill-health may have lost them the ability to go to school, and with that their

normal school life and circle of friends. They need a holistic approach to care which includes the following elements:

- Comprehensive, holistic medical care which offers the whole spectrum of care needed, from antiretroviral drugs (ARV's), when available, to rehabilitation, nutritional support and palliative care as necessary
- Psychological/emotional care and support to the child, the parents or care givers, in particular the grandmothers, and the siblings
- Training to care givers in simple nutritional and nursing care needed by a sick child at home
- Spiritual care and support, appropriate to the child and family background
- Social support and monitoring, including practical help, food aid where needed, training in income generation, and promotion of independence and self-sufficiency
- Sensitisation and mobilisation of community leaders and members to provide on-going support and input to children and families within their own communities identified by them as being especially vulnerable
- Development, through community mobilisation and training, of community support structures, such as children's clubs, work-shops and clubs for grandmothers and other care givers, and training in income generating activities to support families, child headed households and other vulnerable groups
- Training doctors, nurses and other health workers to provide such care, and to communicate effectively with sick children and their care givers

14 million children are estimated to have been orphaned worldwide as a result of HIV and AIDS. There are many programmes that focus on the provision of school fees, food aid and clothing to families who are caring for orphans, but few are taking up the challenge to deal with the most vulnerable children – those who are, themselves, ill as a result of HIV. Mildmay International is one of the few that focus specifically on these children. It is a non-denominational Christian organisation, registered as a charity in the UK, where its work with HIV/AIDS started in 1988 at the Mildmay Mission Hospital in the East End of London. Europe's first hospice programme for people living with AIDS was set up to provide professional and Christian holistic palliative care that led in many instances to rehabilitation of the adults, and later children, for whom they provided care. This work led eventually to the development of a number of care programmes in Uganda, Kenya, Tanzania and Zimbabwe, and to the delivery of training in those and many other countries.

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