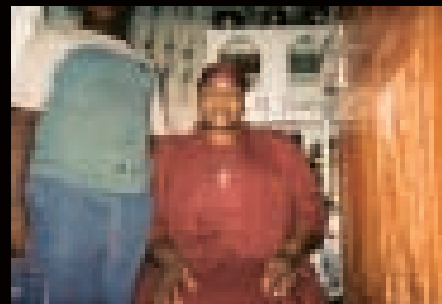
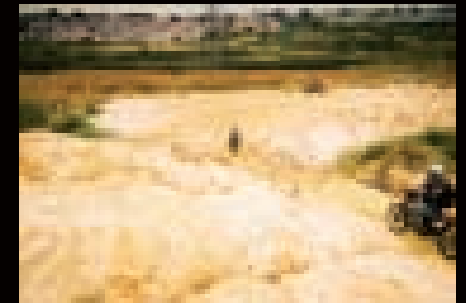
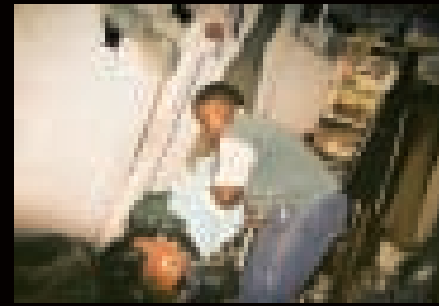
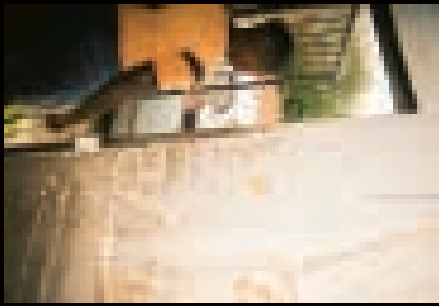


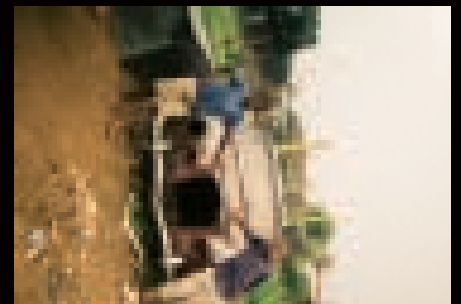
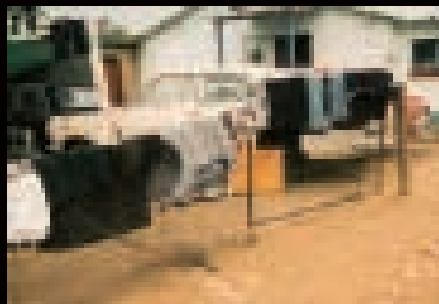
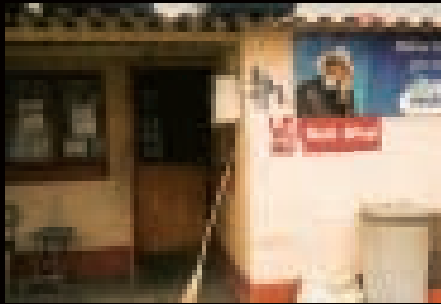
My world: **NONTOBEKO NDLELA (13)**

"I live with my aunt and my aunt does not work. We have help from Sizanani with food and clothes. I wish to have a big home and when I grow up I want to be a doctor. We drink dirty water. It makes me sad when I remember my mother and my father and I love them so much. I wish that Sizanani could have a swimming pool."



My world: **THULEBONE NDLOVU (10)**

“My two big brothers make me happy and I am sad when I fight and when I fall.”



My world: **THEMBA XULU (13)**

“I am an orphan and there is no food and I wish for money so that we will have a big container and a place to live. I have two sisters and Mam Dorothy is my caregiver.”

# sickness

**“When the mother dies the children struggle; they begin to suffer. They don’t become teachers, nurses, or doctors; they just become dead men walking on the streets.”**

*Boitumelo, aged 9*

**It takes a village to raise a child. This African proverb describing the role of the extended family resonates deeply in southern Africa, a region staggering under the growing burden of children orphaned by AIDS. The highest AIDS mortality rates in the world are leaving children to be raised by aged grandparents, extended families and, sometimes, each other. Villages and communities no longer have a choice.**

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But numbers only tell half the story. Long before they are orphaned, children affected by AIDS are thrust into roles they are ill-equipped to handle and poorly prepared for.

## **When parents fall sick**

As parents become ill the normal parent-child roles may be reversed, with older children taking care of the sick parent and assuming household responsibilities, while also looking after younger siblings.

Perhaps because of the shame, fear and rejection attached to people affected by HIV, parents find it difficult to tell their children they are HIV-positive. Although the children may be living with prolonged illness in the home, they are often excluded from discussions about the imminent death because of the prevailing notion that they are “too young to understand”.

But children are often less ignorant than adults imagine: the changes taking place at home can make them feel anxious, depressed and confused; they may not want to upset people by asking questions, or be afraid of the answers.



“Many people have been approaching me for sex and [they] promise to give me money, but I refuse to give in because of what I have heard and seen about AIDS. I want to become a teacher after completing school, so that I can look after my brother and sister - that’s why I don’t even think about any sexual relationship.”

*Memory Kawaya, 16, who has looked after her two younger siblings for the past seven years in Kapiri Mposhi, a commercial hub in central Zambia, with one of the highest levels of HIV prevalence in the country*



Three siblings, ranging from five to 15 years old, mourn for their mother, who has just died of an AIDS-related illness - Kitwe, Zambia

Image: Louise Gubb/Corbis/SABA

Watching and nursing their parents through the final stages of a debilitating sickness, including the loss of control over bodily functions, can have a profound impact on children. The uncertainty surrounding the illness can evoke feelings of fear, anger and resentment, or they may blame themselves. Studies have found, however, that telling the child and talking about death prevents, rather than increases, anxiety and distress.

How does a dying parent say goodbye? Individual counselling and psychosocial support is too expensive and impractical in a region with such high numbers of AIDS-related deaths. Instead, society organisations are helping families affected by AIDS prepare for their children's future through memory work.

Orphans risk growing up without a clear sense of identity and roots, without the traditions and beliefs of their heritage. Memory boxes and books provide a way for parents to create a personal legacy to leave behind as a future source of comfort and a tangible statement of their love. Memory work can also be a way of disclosing their HIV status to children, and discussing plans for the future.

Memory containers come in all shapes and sizes: a discarded shoe box, painted in bright colours with food colouring, can hold the summary of a life in photographs, letters, official identity cards, significant objects like favourite cups or pieces of fabric, and other items that will help children remember their parents.

The purpose of memory work has begun to shift as antiretroviral (ARV) drugs become more widely available in southern Africa - people are living longer and healthier lives, and memory work is now being used to assist HIV-infected people to live positively and even celebrate their lives.

## When parents die

When death eventually arrives, it brings another set of problems to the grieving children, who are forced to adjust to a new life with little or no support. Financial and material needs are usually presented as the most pressing, while their emotional needs are often overlooked.

Admittedly, dealing with emotional trauma or 'hidden wounds' is difficult, but researchers in Botswana have warned that the lack

**Stigma and discrimination can make all these problems worse: stigma may cause children to be denied access to schooling and health care. Without adult protection, children may also be denied their inheritance and property**

of psychosocial support for orphans and other children made vulnerable by HIV and AIDS could be even more damaging. Children are not only wounded by emotional loss, but also because these emotional scars are neglected and buried.

HIV-affected households are more likely to experience food insecurity: they borrow more money and sell more of their productive assets, and those headed by women experience the most severe food shortages. According to the United Nations Food and Agriculture Organisation, women's lack of property and inheritance rights in many African countries have made them and their children even more vulnerable to HIV, poverty and poor nutrition.

Stigma and discrimination can make all these problems worse: stigma may cause children to be denied access to schooling and health care. Without adult protection, children may also be denied their inheritance and property. Children who have lost their parents to AIDS are often assumed to be HIV-positive as well, increasing their likelihood of falling victim to discrimination.



South Africa's KwaZulu-Natal province, the worst affected region in the country, faces a shortage of burial space caused by the growing number of AIDS-related deaths

Image: Paul Weinberg/South Photographs



Sister Gertrude Bobo of the Mother of Peace Community in Mutoko, 150km northeast of Harare, Zimbabwe, reads her Bible as she walks through the community's graveyard. The community was formed in 1994 to provide homes and care for orphans and destitute children affected by HIV and AIDS

Image: Howard Burditt/Reuters



## **Deli Hlongwa**

AIDS activist Deli Hlongwa from Ngwelezana township in northern KwaZulu-Natal, South Africa, has just passed away. Her children get ready for her funeral. South Africa has a rapidly growing HIV crisis, with one in nine people estimated to be living with the virus. According to South Africa's Medical Research Council: "Without significant changes in sexual behaviour or interventions, about 15 percent of all children under the age of 15 are expected to be orphaned by 2015."

**Deli's son irons his clothes before attending his mother's funeral**

Image: Greg Marinovich/South Photographs



The pensioner mother of Deli keeps vigil for her daughter



Deli's children on the day of her funeral

A young mourner weeps at the funeral service



Deli's coffin about to be opened on the day of the funeral

Images : Greg Marinovich/South Photographs





## Doris Witbooi

The Witbooi family lived in Woodlands, a small farming settlement situated in the lush countryside of the Tsitsikamma, in South Africa's Eastern Cape.

Doris Witbooi\* was the mother of Emily (11), Monique (4) and Pukkie (2). Doris was living with AIDS and Pukkie was also HIV-positive, as well as needing treatment for tuberculosis. Neither Doris nor Pukkie were on the antiretroviral drugs that could help prolong their lives, just vitamins and painkillers.

Doris had been very ill and was often confined to her bed, so Emily dropped out of school and took it upon

herself to cook and care for her sisters. The girls were eventually placed in foster care when their mother became too sick. Doris stayed in the house alone and the children would come to visit.

Doris eventually lost her battle against the disease; Pukkie, however, has been placed on antiretroviral therapy, which means she has a chance to live a normal life as long as she takes her medication. Millions of other South African children are not so lucky

*\*Names have been changed.*



(Above) Doris watches two of her daughters. She saw them one more time before she died  
(Left) Pukkie outside the family's government house in Woodlands, Eastern Cape

Images: James Oatway



Emily dropped out of school to help cook, clean and look after her sisters



Doris plaits Monique's hair

Images: James Oatway

Emily and Pukkie



After they were placed  
in foster care, the girls  
became emotional during  
visits to their mother

Images: James Oatway





Doris Witbooi

Image: James Oatway



Emily breaks down at her mother's funeral

Image: James Oatway

## Lineo Makojoa

Lineo Makojoa, 15, lives in Ha Majoro village, about 30km outside Maseru, Lesotho's capital. She lost both her parents to AIDS. Her grandmother has helped capture Lineo's story in a homemade memory book to teach her about her family history and deal with the loss of her mother.

The memory book talks of how Lineo's parents died of AIDS-related illnesses, because her grandmother feels it is important that the children know this, and that they are aware that HIV and AIDS can also affect them.

"The book is also telling her to know and appreciate her status - not only in regard to HIV and AIDS, but also socially, like why she is living without parents, and why she must cook when other children are playing," says Lithapelo Kutlanyane, a project officer for the Lesotho Red Cross Society, as he translates Lineo's explanations of what is in the memory book.

"When I read it, I feel strong," Lineo says. "To be strong enough to live long, even though my parents have died."

Image: Eva-Lotta Jansson

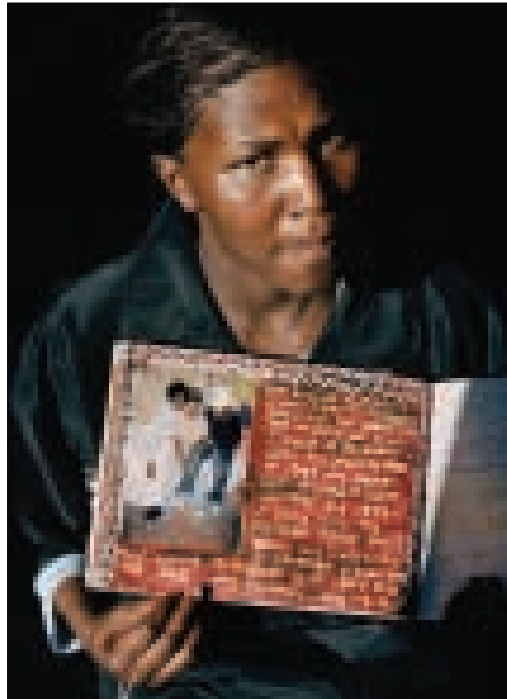


## Memory work

Memory work has traditionally been associated with death – a way for HIV-positive people to say goodbye and leave a legacy for their children and family members. But this innovative form of psychosocial support is evolving, and also caters for HIV-positive people accessing life-prolonging treatment, as well as orphans and vulnerable children.

'Hero books' for example, are a particular kind of memory book, in which a child is invited to be the author, illustrator, main character and editor of a book that is designed to give them power over a specific challenge in their life. At the end of the process, the child will have a handbound storybook, which reinforces their strength and resilience.

The challenges a child might want to take on, using a hero book, could be behavioural problems, such as bedwetting, or social problems, such as being subjected to physical abuse in the home



## Lerato and her memory book

Lerato Motaung, 17, is the only surviving member of her immediate family. In her memory book, she tells her story of how her uncle and his children abused her after the death of her mother and grandmother.

"One day, he and his two children beat me. They poured hot water on me, over my body; they beat me with a whip. He chased me away; he said I must go away from his family. Then I went to a place called Lithabaneng, where another uncle stays, but because that uncle doesn't work, he took me back to the first uncle I was staying with."

Despite her hardships, Lerato is doing well in school. But according to her teacher, Tselisegang Violet Thamae, she is still being mistreated by her uncle: "She is doing a lot more work [at home] than what is right for her age."

Lerato is now in her last year of free education at a government primary school in Lenono, Lesotho. "I want to become a teacher, I am going to work hard," she says. "I want to improve the children of this country as teachers have done for me."

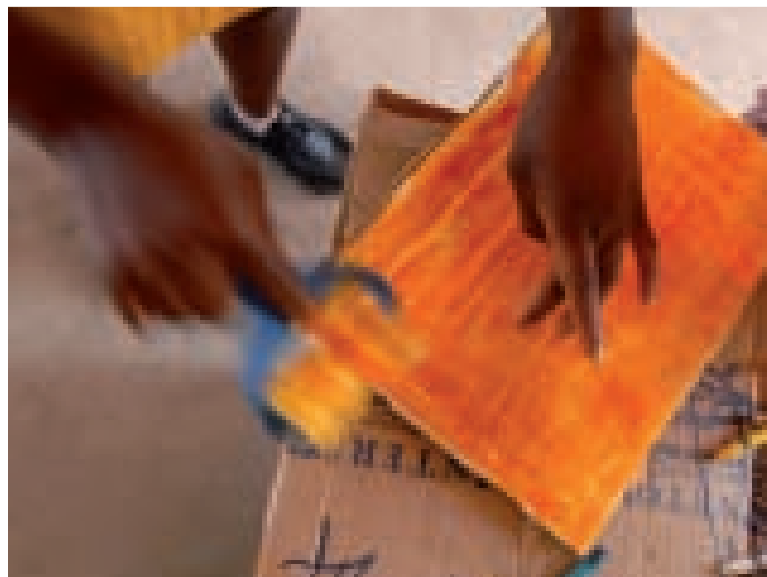
Care facilitator Ikaneng Sentje explains that there is nobody to pay for Lerato's secondary school education, but the government has a few bursaries for gifted students without means, and the principal says there is a chance the school will recommend her for one of them.

Thamae adds: "But if she doesn't get a bursary, that's the end of her life here [at school]."

Images: (Right) Eva-Lotta Jansson

(Left) Liziwe Kweyama is a young unemployed HIV-positive woman. Her ambition is to become a counsellor. She holds some pages from her memory 'tracing' book. Masiphumelele, Cape Town, South Africa

Image: Gideon Mendel/Corbis





## Nestor Uiras

Elizabeth Uiras's two-year-old son, Nestor, looked as if he was asleep in his tiny white coffin when it arrived at her house. She glanced at the face, screamed, slapped a hand to her mouth and collapsed in agony on the floor.

He had been gravely ill for some time and died less than a month after the doctors diagnosed him as being HIV-positive. But how did he acquire the disease? The possible answer is almost too much for his grieving mother to contemplate.

"I was working almost every day and had to leave the house early in the morning, and I wouldn't come home until late at night," says Elizabeth, 32, who has five other healthy children, the youngest only seven months old. "I had to leave Nestor with relatives and sometimes friends. Nestor would go from one house to another house to another house. Everybody helped take care of him."

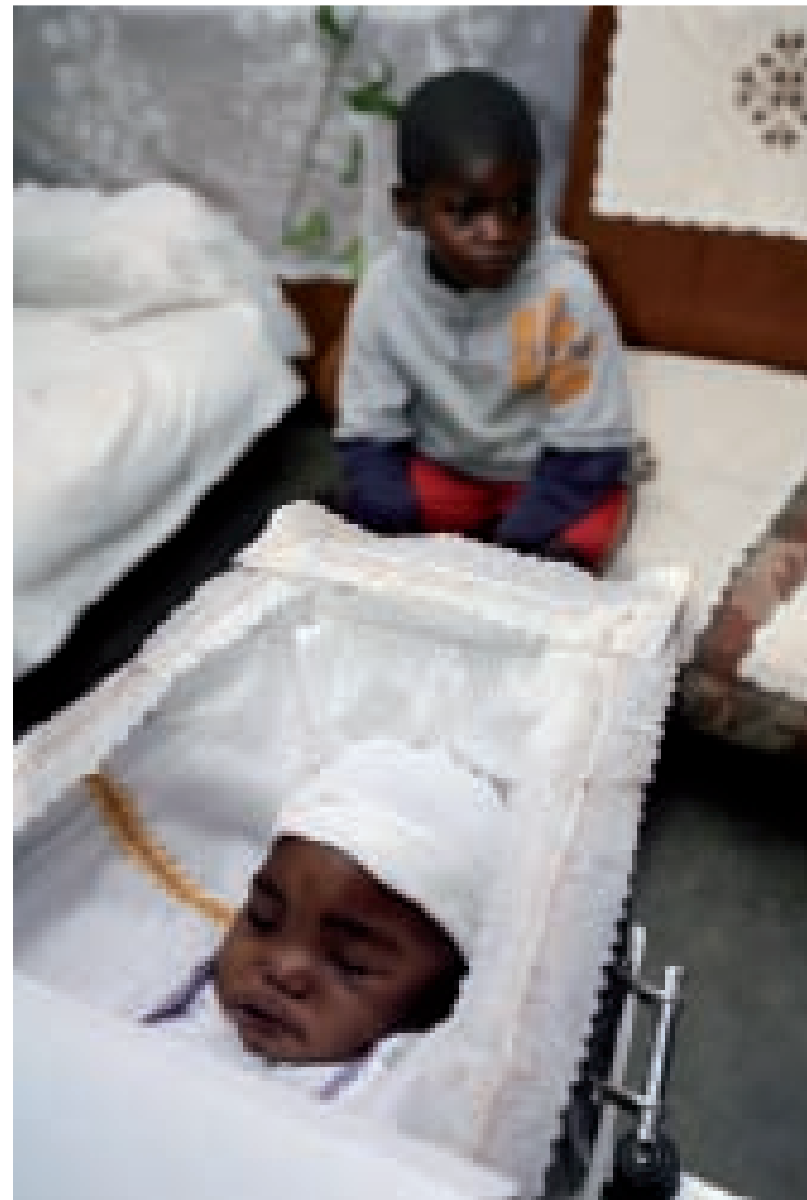
But the generosity of friends and neighbours turned into Elizabeth's worst nightmare. One day, Nestor simply stopped eating.

"He was a happy baby, and then he wasn't happy any more. A doctor said he wasn't getting nutrients, but then we had tests and found he had the HIV," Elizabeth says, struggling with the words.

Elizabeth and her boyfriend, Nestor's father, were tested for the virus, but they were both negative. A health care worker said Nestor was most likely sexually abused by an HIV-positive relative or neighbour while Elizabeth was out working to feed and clothe him.

"It was very hard when Nestor was getting sicker and sicker, I wanted to fight it and beat it and not be sad," Elizabeth says. "I feel no anger now that he's gone. I don't want to blame anyone, but it is too hard when a baby dies. It is too hard for me."

Images: Juda Ngwenya





A child with her memory box in Port Shepstone, South Africa. Memory boxes give HIV-positive parents a way of creating a personal legacy for their children

Image: Paul Weinberg/South Photographs



Nosipho Madlala, a social worker, visits Vusi, 5, an orphan in South Africa

Image: Louise Gubb/Corbis/SABA





(Opposite) Amelia, 13, and her sister Mamdiuana, 7, in their hut in a small village near Mombane, Mozambique. The sisters were orphaned after their parents died of an AIDS-related illness, but are supported by other villagers. According to UNAIDS, about 510,000 children have been orphaned by AIDS in Mozambique

Image: Andy Clark/Reuters/Photosensitive

(Above) Three children, too sick to play outside, at the Salvation Army's Ethembeni Home in Doornfontein, South Africa

Image: Graeme Williams/South Photographs

A friend comforts a child after his volunteer caretaker was unable to get away from work to visit him. The psychosocial needs of orphans and vulnerable children are often neglected, with most programmes focusing on their material needs

Image: Graeme Williams/South Photographs





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South Africa's eastern coastal province of KwaZulu-Natal has the highest HIV infection rate in the country

Image: Paul Weinberg/South Photographs



A young child in an orphan-run household in Lesotho. Many child-headed households may exist for a limited period after the death of an adult, prior to other arrangements being made to care for the children. Most children who have been orphaned are growing up in households where adults are also resident

Image: Graeme Williams/South Photographs

**Mamaribe Hata-Hata, 17, and her father Ramarumo Hata-Hata, who has just tested HIV-positive in Lesotho. Mamaribe's mother died, and two years ago her father's new partner passed away. Mamaribe is the only one left to take care of Ramarumo**

Image: Eva-Lotta Jansson

