HIV affects children in many different ways.

Many children around the world are affected by HIV – either they have HIV themselves or a close family member is HIV-positive. Children can be infected with HIV through mother-to-child transmission, infected blood transfusions, unsterile medical equipment or sexual abuse. More than one million children around the world are estimated to have HIV. About four out of every ten HIV-positive children die before they are one year old. However, with good preventive care and early treatment of common infections, many children with HIV can live well beyond their first year. In order to achieve this, their carers need information on how to prevent infections, help on coming to terms with HIV and a supportive environment where people with HIV are not discriminated against.

Dealing with children affected by HIV can be difficult for many health workers due to lack of information or lack of resources to care for sick children and to support their carers. This special joint issue of Child Health Dialogue and AIDS Action suggests ways of supporting children and families affected by HIV. In addition, it contains information for health workers and carers on how to diagnose and treat illnesses in HIV-positive children.

HIV has raised many difficult questions. In this issue, a story is used to highlight some of the problems mothers, fathers and carers face when a child is diagnosed with HIV. One of the most difficult questions is deciding what to do about breastfeeding. An article on infant feeding looks at options to reduce the risk of HIV transmission through breastmilk.

Talking and listening to children is an important aspect of working with children affected by HIV. Different ways of encouraging families to talk to children and prepare for the future are described. We hope readers will use this joint issue to share ideas about how they are responding to the HIV epidemic and involving children and families in their work.

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HIV and children

What is HIV?
HIV stands for Human Immunodeficiency Virus. The virus attacks the body’s immune system which protects the body against illness.

What is AIDS?
AIDS stands for Acquired Immune Deficiency Syndrome. Getting (acquiring) HIV infection leads to a weakened (deficient) immune system. This makes a person with HIV vulnerable to a group of illnesses (syndrome) that a healthy person without the virus would be unlikely to be affected by.

How do children get HIV?
Children and young infants can be infected with HIV through:
- pregnancy, delivery or breastfeeding if the mother has HIV
- receiving infected blood transfusions
- receiving treatment with unsterile medical equipment such as needles, syringes or surgical instruments
- suffering sexual abuse involving penetrative vaginal or anal sex.

How can HIV in children be prevented?
The best way to prevent HIV in children is to prevent HIV infection in men and women. Promoting safer sex, condom (male and female) use and better detection and treatment of sexually transmitted diseases can help reduce infection in men and women and, consequently, reduce transmission of HIV to children. Antiretroviral drugs, taken by the mother before and during delivery, can reduce the risk of HIV being passed to the child. HIV is transmitted through breastmilk, with about one in seven breastfed infants born to HIV-positive women, acquiring HIV in this way. Women face difficult choices about whether to continue breastfeeding to protect their infants from other illnesses or provide alternatives to breastmilk.

What is an HIV test?
An HIV test detects antibodies to the virus in the blood. Antibodies are produced by the immune system in response to infection with the virus. If there are no antibodies, the person is antibody negative (seronegative or HIV negative). The test result may be negative if the person has been infected only recently. It can take up to three months from the time of infection for antibodies to develop. This is called the window period. Anyone who might have become infected in the last three months should take a second test three months after the first test.

Young children and testing
When infants are born, they often have their mother’s antibodies. An infant may have a positive HIV antibody test but not have the virus. The mother’s antibodies disappear when the infant is approximately 15 months old. There are tests which can detect the virus earlier (called PCR tests) but these are expensive and not usually available in developing countries.

What is antiretroviral therapy (ART)?
ART is the use of a number of drugs that can slow down the growth of the virus in the body. Drugs are taken singly or in combination. Zidovudine (often known by its brand name, AZT) has been shown to reduce mother-to-child transmission. However it is expensive and currently not easily available.
During the next 10 years, over 40 million children will lose one or both parents as a result of AIDS, mostly in sub-Saharan Africa. In countries with a high rate of HIV, over one-third of children will be orphaned.

Many children are first affected by HIV when their parents develop HIV-related illnesses. Parents may be too sick to work or they may be too ill to bring their children for immunisation and growth monitoring. Older children often take over caring for younger brothers and sisters at this time, which means that they start to miss school. Children in households affected by HIV face a number of problems:

**Poverty** The AIDS epidemic is leading to increasing poverty and wherever poverty increases, children’s health gets worse. When poor children get sick they may not get adequate treatment because their carers cannot afford transport charges, user fees or medicine costs, or because they cannot spare time away from work and family commitments.

Poverty is also associated with increased risk of HIV infection. Orphaned girls from poor households are vulnerable to HIV because of sugar daddies or sexual exploitation by relatives. They may have to work as prostitutes to earn money to feed or educate children in their care. Many orphaned children (boys and girls) end up living on the street.

**Nutrition** Children from HIV-affected families are often at risk of malnutrition. A sick mother will find it hard to provide nutritious food for her children. In Tanzania, in poor families where an adult had died, food consumption fell by 15 per cent. Malnutrition is especially likely when young children are cared for by elderly or adolescent carers who may not be aware of good feeding practices.

**Substitute parenting**

Mothers are important primary care workers. Health workers spend time educating mothers about good child health practices. If a young child has no mother, the child’s health is often worse. As a result of AIDS, increasing numbers of children are being looked after by grandparents. Often grandparents are unable to care for children adequately. They may be poor, elderly and expected to care for large numbers of grandchildren.

Orphans are often moved from one household to another, sometimes with relatives who neglect, maltreat or abuse them. Increasingly in AIDS-affected communities, relatives are unwilling to foster children, so they are left living alone in child-headed households.

**How to help**

Health workers and community-based workers can help protect the health of children affected by HIV by:

- encouraging the establishment of community-based orphan programmes

Grandparents often care for children orphaned by AIDS.

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<td>The Families, Orphans and Children Under Stress (FOCUS) programme in Mutare, Zimbabwe, is supported by the Family AIDS Caring Trust (FACT). FOCUS supports community-based orphan programmes in four areas through volunteers from rural churches. Orphans needing help are identified, regular visits are made and material support is provided to enable children to stay in their homes and communities. In the last six months of 1996, 90 volunteers made nearly 10,000 visits to over 3,000 orphans in 800 families. Practical help provided by volunteers has included: providing food, blankets and primary school fees and helping children to rebuild their homes. One family, with an older sister looking after several younger siblings, had been ignored by the community – ‘we had no visitors because we are so poor, we had nothing to give them’ – until community leaders became involved in helping repair the house. The family now receives support from neighbours.</td>
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Managing illness

Dr Grace Ndeezi explains how to manage illness in children with HIV/AIDS.

Most infants infected with HIV show no symptoms at birth. However, children usually develop clinical signs of the disease much sooner after infection than adults. Infants who show symptoms of HIV-related illnesses in the first six months of life are most likely to get sick and die young. Those who show symptoms later (after two to three years), have a better chance of staying healthy for longer. A few children do not show signs of HIV-related illness until they are ten years or older.

Preventative care such as immunisation is important for all children regardless of HIV status.

Keeping children well

More than half of all children with HIV live beyond five years. It is extremely important that children with HIV lead normal lives. They should be allowed to play with friends, go to school and play sports. Children with HIV infection cannot pass the infection on to others through everyday activities.

In many areas, it is not possible to diagnose a child’s HIV status because of lack of counselling and testing facilities. It is not necessary to know HIV status for most infections the child is likely to have. HIV-positive children need the same preventative care as all children including:

- routine immunisation – except BCG (the vaccine against tuberculosis) if an infant or child is already showing signs of advanced HIV infection
- good nutrition – this is especially important for children with HIV infection. If an HIV-positive mother chooses not to breastfeed this means ensuring adequate and safe replacement feeding for the first six months (see pages 6-7). Appropriate family foods should be started between four to six months (see CHD9). Children with HIV often have a sore mouth due to thrush or other infections such as herpes. This may reduce the amount of food a child takes because it is painful and uncomfortable to eat
- basic hygiene, both personal and environmental, helps prevent illness. Advise parents how to prepare the child’s food safely and how to dispose of faeces hygienically
- prompt treatment of illnesses
- regular growth monitoring.

Common illnesses

Infections in children with HIV are similar to the usual common childhood illnesses: acute respiratory infection, diarrhoeal diseases, malaria, measles and malnutrition. The only difference is that these illnesses occur more often and are likely to be more severe or difficult to treat.

The management of illness in HIV-infected children is similar to that in other children. However, if an HIV-positive child does not respond to treatment, he or she needs urgent referral to a hospital. Common illnesses in children with HIV infection include:

Candidiasis (oral thrush)

If a young child has oral thrush (white patches inside the mouth) for more than 30 days and is not having antibiotic treatment, he or she may have HIV infection. Apply 0.25% gentian violet solution (water-based) once a day for seven days or treat with Nystatin oral suspension 100,000 I.U (1ml) four to six hourly for seven days. If there is no response use miconazole oral gel (Daktarin) four hourly for seven days. If there is still no response, use ketoconazole (nizoral).

In children with HIV, thrush sometimes spreads into the child’s
Encourage sick children to eat and drink.

thirst and oesophagus (gullet), causing difficulty or pain on swallowing, reluctance to eat, crying during feeding and weight loss. Oesophageal thrush may occur without signs of oral thrush. Treat with ketoconazole 5mg/kg orally for seven days. If no response, use fluconazole 3mg/kg/day orally for seven days.

Recurrent fever
In endemic areas, malaria is the major cause of fever for all children. If malaria is confirmed by a positive blood slide, treat the child according to national malaria guidelines. If the blood slide is negative for malaria, consider the possibility of a bacterial infection. Encourage the use of insecticide-treated bednets.

Recurrent bacterial infections, such as otitis media (middle ear infection), pneumonia and meningitis, are usually caused by the same organisms that cause infections in children without HIV. Treat with antibiotics according to standard guidelines.

Persistent diarrhoea
If the child is dehydrated, give oral rehydration solution, then refer for further care. If there is no dehydration, advise the carer to give the child a diet which contains less animal milk until the diarrhoea stops:
- if the child is still exclusively breastfed, give more frequent, longer breastfeeds, day and night
- if the child is taking other milk – replace the milk with fermented milk products such as yoghurt OR – reduce the amount of other milk given by half and replace with nutrient-rich semi-solid foods.

The child should continue to take an appropriate diet for his or her age. Treat children with dysentery (blood in the stool) with the appropriate antibiotic recommended for Shigella in the area.

Chronic cough
If the child has fast breathing and/or chest indrawing, he or she will need antibiotic treatment for pneumonia. Younger children are particularly at risk from severe pneumonia and should be treated in hospital where possible.

A child who has a cough lasting for more than 30 days needs referral. Tuberculosis is difficult to diagnose in children, particularly if they have HIV. Consider TB if the child has:
- failure to thrive or weight loss
- fever or persistent cough for more than one month
- an abnormal chest X-ray that persists despite adequate antibiotic treatment for two weeks or more
- history of household contact with a person with TB.

Treatment should follow national guidelines. NEVER treat HIV-positive children with thiacetazone because this drug can cause severe and sometimes fatal side effects in people with HIV.

Skin diseases
In many children skin diseases may be the first sign of HIV. It is often difficult to identify the cause of the sore or blister (lesion). Suspect herpes zoster (shingles) if the child has painful blisters spreading over a specific area of skin. Keep the area clean and dry and apply calamine lotion (15% solution). Give paracetamol (10-15mg/kg orally every 4-6 hours) to relieve pain.

If the lesions are scaly or itchy, treat for a fungal infection with miconazole (Daktarin) cream (2%). If not available, apply 1% gentian violet solution or nystatin ointment two times a day for seven days.

If there is pus on the lesions, treat with oral clavulaxillin, 50mg/kg every 6 hours until the lesions heal. If not available use erythromycin or trimethoprim-sulfamethoxazole (cotrimoxazole). Creams applied directly to the skin are not effective. For dry lesions provide calamine lotion. Treat scabies with benzyl benzoate 12.5% lotion (see CHD10 p.6).

HIV-specific illnesses
Some infections are more common in HIV-positive children than HIV-negative children. These include:
- Pneumocystis carinii pneumonia (PCP) – suspect if a child presents with fever, fast breathing (which is often severe) and difficulty in breathing; particularly if there is no response to initial antibiotic treatment. It is more common in infants under six months of age, but can occur at any age.
- Cerebral toxoplasmosis – suspect in a child who is unconscious, has convulsions or weakness down one side of the body
- Cryptococcal meningitis – suspect if a child fails to respond to standard antibiotic treatment for meningitis. If facilities are available, diagnosis can be made following lumbar puncture, if cryptococcal organisms are found in the child's cerebrospinal fluid.

These conditions are all serious and often difficult to treat. If suspected, the child must be referred to a hospital.

Supportive care
Sick children need supportive care to help relieve symptoms and reduce pain. This includes:
- keeping the child comfortable, warm and dry
- giving plenty of drinks and small, frequent, nourishing meals
- reducing high fever (38.5°C or above) by removing layers of clothing and giving paracetamol
- giving the child love and attention.

Children with HIV who are very sick may also need pain relief. Management of pain follows the same principles as other chronic diseases such as cancer or sickle cell disease. Paracetamol can be used for mild and moderate pain. Stronger drugs such as morphine and codeine are used for moderate and severe pain not responding to paracetamol. They should be given under the supervision of a properly trained health worker. Health workers should find out about local organisations which offer support to HIV-affected families so they can refer families to them.

Dr Grace Ndeezi, Paediatrician and Lecturer, Makerere University Medical School, PO Box 7072, Kampala, Uganda
Mother-to-child transmission of HIV is the main cause of HIV infection in children. About two thirds of these children are infected during pregnancy and around the time of delivery. The other third are infected during breastfeeding.

Breastfeeding is usually the best way to feed an infant, but if a mother is HIV-positive, replacing breastfeeding can reduce the risk of HIV transmission to her infant. However, alternative methods of feeding also have risks. When breastmilk substitutes are used, infants are five times more likely to have bacterial infections than breastfed infants, even where hygiene is good. Where hygiene is poor, artificially-fed infants may be 20 times more likely to die from diarrhoea than breastfed infants.

HIV-positive women need information about the risks and benefits of breastfeeding and of the various alternatives, and support in deciding which method is best. Helping a mother who is HIV-positive decide whether to replace breastfeeding means discussing with her:

- the risk of transmitting HIV to her child through breastfeeding
- all infant feeding options – their risks and benefits
- how she might approach her family, especially her husband and mother, to get their support rather than rejection
- how to get support from other women who have been in her position
- whether she has the resources – water, fuel, utensils, skills and time – to safely prepare replacement feeds
- what effect the cost of buying breastmilk substitutes might have on the rest of the family, if these cannot be subsidised by the health service
- the importance of regular growth monitoring and follow up for her child.

It is also important to remind women that breastfeeding is a natural form of contraception, effective for as long as women continue to practice exclusive breastfeeding and not have periods. Women and their partners should have information about, and access to, family planning methods especially if their child is not breastfeeding.

Some HIV-positive women may decide not to breastfeed. Others may decide to breastfeed. Whatever her choice, a woman needs support and information about the safest way to feed her baby.

**INFANT FEEDING OPTIONS**

Health workers should continue to encourage breastfeeding by women who are HIV-negative and those who do not know if they have HIV. While it is good to be able to offer access to HIV counselling, and to confidential voluntary testing, in many areas this is not yet available. Women who do not know their status may choose not to breastfeed for fear they are infected. It is important to listen to the woman's reasons why she is choosing not to breastfeed and to explain the value of breastfeeding, whilst supporting the woman's choice.

**Infants of HIV-positive mothers**

**The first six months**

Up to about six months, milk in some form is essential. If not breastfed, an infant needs about 150ml of milk per kg of body weight a day. So, for example, an infant weighing 5kg needs about 750 ml per day, which can be given as five 150ml feeds a day. Up to about six months of age, infants do not need other foods if they are gaining weight adequately.

This milk can be supplied by:

- **commercial infant formula** – feeding an infant for six months requires on average 40 x 500g tins of formula. This provides the best mix of nutrients for infants who cannot have breastmilk but is expensive if bought commercially and therefore not an option for many mothers.

- **home-prepared formula** – made with fresh animal milks, dried whole milk or unsweetened evaporated milk. These milks must be modified to make them suitable for infants. For example, to prepare fresh cow's milk: mix 100mls milk with 50mls of water and two level teaspoons of sugar and boil. Micronutrient supplements should be given because animal milks contain...
Infant Feeding and HIV

Breastfeeding as soon as she is able to prepare and give her infant adequate and safe replacement feeding.

Stopping breastfeeding early is advisable if an HIV-positive mother develops severe HIV-related illnesses.

After six months

Between 6-12 months infants who are not breastfed should have:

- undiluted cows milk (or a suitable alternative) at least five times a day
- suitably prepared family foods three to four times a day. If milk is not available, give family foods five times a day. Good meals are those which provide a variety of food. During a day, a child's food should include:
  - cereal or starchy roots such as maize, rice or sweet potato
  - legumes (beans, peas, lentils or groundnuts)
  - small amounts of energy-rich food such as oil, fat, honey or sugar to provide extra calories (energy)
  - fruit and vegetables to give extra micronutrients such as vitamins A and C

Where possible include:

- a blood containing food (such as fish or meat) to provide easy-to-absorb iron and zinc
- other animal foods such as eggs to provide more protein and calcium.

Give micronutrient supplements if the child's diet is likely to be low in iron, vitamin A or other micronutrients.

Safe feeding

To prepare and give milk feeds, carers should:

- wash their hands with soap and water
- wash the mixing and feeding utensils with boiled water or boil to sterilise them before preparing the milk
- carefully measure and prepare the milk. Keep covered until used
- use a cup to feed the infant. Cups are easier to sterilise than bottles and reduce the risk of diarrhoea
- not keep left over milk. Give it to older children.

Other food must also be hygienically prepared and given using a clean bowl and spoon.

Thanks to Caroline Maposhere, Zimbabwe AIDS Prevention Project, 103 Rotten Row, Harare, Zimbabwe, for contributing to this article.

HIV Counselling and Testing

- Women need access to HIV counselling and testing to be able to make informed decisions about infant feeding. Counselling is not the same as giving advice or telling people what they should do.
- Counselling aims to enable an individual to take decisions that he or she feels are most appropriate and to find realistic ways of coping. A counsellor's role is to listen to an individual's concerns, ask questions, and provide information and emotional support.
- HIV testing must be voluntary and carried out with informed consent. Testing must always be accompanied by pre-test and post-test counselling. Ongoing counselling on infant feeding is important.
- Counselling and testing must be confidential. Confidentiality is a right. Only the person concerned has the right to know his or her HIV status and decide who else to tell.
Stories can help health workers and other carers learn more about HIV/AIDS and think about ways to improve the care and support they give to families.

The following story can be used and adapted as a training exercise for health workers, counsellors and home-based care workers. Tell the story (or your own variation of it) and then go through it again slowly, asking questions and providing information. You can tell the story in parts (as suggested here), discussing each part in detail before moving on, or you might prefer to tell the whole story right through first. Always change the story to make it familiar to the people you are talking to. For example, change the names to ones that are common in your area.

With thanks to Dr Connie Osborne, Consultant Paediatrician, University Teaching Hospital, Private Bag RW1X, Lusaka, Zambia, for providing this case study.

Editors' note: The resources on page 12 give you more information to help answer the questions that this story raises.

Ilinangás story

**Discussion points**
- Most women do not know their HIV status when they get pregnant. Health workers often find it difficult to talk to pregnant women about HIV. In Nakala’s case, should the nurse have talked to her about HIV during her clinic visits? Should health talks on HIV and STDs be given routinely at antenatal clinics?
- What information do women like Nakala need about HIV and breastfeeding? How and when should this information be given? For example, is it best to talk to women individually or in a group?

1992

**Ilinanga is born**

When Nakala became pregnant for the fourth time, she crossed her fingers that it would be a boy, because that is what her husband wanted. She already had three lovely girls aged 8, 6 and 3 years. She went to the clinic early on in her pregnancy and, as usual, her blood was checked. Nakala had read a lot about HIV in the newspapers and knew that it could be passed on from a woman to her child. She, like most people, had absorbed the facts about HIV but never thought it would affect her family. While waiting to be examined at the clinic Nakala and the other women all agreed that it would be too depressing to discover one was positive when already pregnant.

Ilinanga, a girl, was born healthy and strong. The whole family was happy with the new baby. Nakala happily breastfed her baby. She knew that not only was this best for Ilinanga, but that it would help her not to get pregnant again too soon.

1993

**Something is wrong**

During her first year Ilinanga had many infections. When she was nine months old Ilinanga stopped gaining weight properly. Nakala was surprised and upset as this had not happened with any of her other children. When Ilinanga was 16 months old she developed a bad cough that did not go away. The nurse proposed a HIV test which Nakala and her husband agreed to. They did not think Ilinanga had HIV, but thought that once the nurse knew that their baby was HIV negative, she could start looking for other causes for Ilinanga’s frequent infections.
The results came back – Ilinanga tested HIV-positive. Nakala and Samson were shocked. They felt angry and didn’t believe it was true. They then both had an HIV test and were also found to be infected with the virus. Nakala asked herself – when did she get infected? Was it before or after her marriage? During her last pregnancy? Or during the time she breastfed Ilinanga? She and Samson had never used condoms in their marriage. Like most couples in their community they started to have sex again one month after the birth of a child. She had not slept with anyone else, but could not say the same for Samson. And when did Ilinanga get HIV? Was this before or during her birth, or from breastmilk?

Nakala worried about Ilinanga’s health, her own health and that of her husband and other children. She worried about how she was going to tell the other children about Ilinanga’s illness. Nakala and Samson agreed not to have them tested but they worried that they might get infected through close contact.

For many of their concerns there seemed to be no right or wrong answer. The nurse could only give them the facts about HIV infection and what could be done locally to help them. Nakala and Samson had to make their own decisions. The challenge for the nurse was how to encourage Nakala and Samson to keep Ilinanga and themselves as healthy as possible. This meant healthy eating, exercise, preventing infections or treating them early and, because they were religious, “putting God first”.

Discussion points

♦ Samson passed HIV to Nakala during sex. What could Nakala have done to prevent herself becoming infected? What could she have done to prevent Ilinanga from getting the infection?

♦ What do health workers need to consider before they suggest an HIV test to parents? Discuss what facilities for testing there are in your area.

♦ When Ilinanga tested positive this meant probably either one or both of her parents had the virus too. How might a parent feel knowing she or he has infected his or her child? How can parents be helped to come to terms with this?

♦ Nakala worried about HIV transmission to her other children through close contact. What do health workers need to do to overcome this fear?

1998

Ilinanga goes to school

Ilinanga became healthier after she completed treatment for tuberculosis which was the cause of her chronic cough. She started to grow well again. In November last year, Ilinanga had her sixth birthday. She is a happy, healthy child doing her first year at the local school. The nurse wrote to Ilinanga’s teachers explaining that Ilinanga has a chronic medical problem and may sometimes miss school. Ilinanga’s sisters now know why Ilinanga was always sick. They asked many questions until Samson and Nakala told them the truth. They are at the same school as Ilinanga and go to the school anti-AIDS club, except the second oldest girl. She will not join the club and avoids any mention of HIV.

So far Ilinanga has not asked any questions about her illness. Everyone in the family is waiting and so is her nurse. No one is sure what they will say to her when the time comes. Nakala reads whatever she can get hold of about HIV and knows about antiretroviral therapy. She also listens for news of traditional remedies. She and Ilinanga’s nurse often discuss the different western and traditional therapies. But Nakala, Samson and the nurse all agree that the cost of antiretroviral therapy is too much. They realise as Samson begins to complain that he is tired all the time, that soon they must start thinking more about the future of the family. In the meantime they thank God for each year that passes.

Discussion points

♦ Who needs to know that a child has HIV infection? Should the teachers be told the real reason why Ilinanga might be sick more often than other children?

♦ One of Ilinanga’s sisters does not want to talk about HIV. Why might this be?

♦ Ilinanga’s three sisters all remain uninfected even though they are living with three other family members who are infected with HIV. Think of all the things they do together but still remain free of the virus.

♦ When Ilinanga starts to ask about her illness what does she need to know and how should she be told?

♦ Where do people in the community get information about HIV/AIDS? How can health workers, carers and families find out about the latest information?
Living positively

Care and support to young children with HIV, and their families, are necessary to help children live positively.

HIV-positive children can have happy and fulfilling lives, especially if families are given emotional and social support, information about HIV, access to health care and protection from discrimination and stigma.

In our project, we have found that giving the time to supporting families at home can make HIV easier to deal with for both the children and for their parents, family and friends:

'If I have a problem, I can talk to her. There's time to talk.'

'The children are better since the home carers are visiting us.'

Memories help

When children become separated from their families, important memories quickly fade. Before it is too late they need truthful answers to their urgent questions: Who am I? Where do I belong? Who will take care of me in the future?

In many different countries, parents have helped their children by making memory books which record information about each child. The memory book has pages covering different topics which parents and children can fill in together, such as:

- My home – where I grew up
- Important family traditions
- Family trees to show where different relatives are living
- Outline maps to show where the family is from.

Some families have covered the same ideas by making a memory basket for each child. They collect small personal objects from the home which will help children remember the family's life together. Others have made tape recordings of favourite songs and hymns along with spoken messages from individual parents.

Parents say that as well as providing valuable information for their children, these activities have also helped them to remember happier times. When children get involved in helping their parents collect the 'memories' it has been an easy step to go on to talk about the loss and changes ahead. Many parents said this has helped them to talk for the first time about HIV in the family.

Once they broke through the wall of silence, many parents found it was easier to start talking to relatives or friends about plans for their children's future. Open discussion has helped the children to be less afraid of HIV and to learn from their parents about how to avoid risks to their own health in the future.

Many parents have said that by preparing for their children's future, they feel both physically and emotionally stronger. They are no longer wasting energy on hiding the truth.

'You don't need to have AIDS before you start a memory book. We all need to know about our origins. We should all be doing it for our children and for ourselves'.

Carol Lindsay Smith, CLS Development Services, PO Box 4385, Colchester CO6 4UA, UK

HIV can cause children stress and distress in a similar way to cancer and other potentially fatal illnesses. However, a number of circumstances make AIDS unique:

- most children with HIV have HIV-positive parents too, and parents and children are often ill at the same time
- the stigma of the disease results in families not asking for help because of fear of disclosure
- many families affected by HIV are poor, and the disease makes them poorer still. Parents may be too sick to work or women may lose their jobs because their children are often ill and they have to stay away from work to look after them.

In many families we work with it is the mother who cares for her HIV-positive child. She is often abandoned by her partner, family and friends. It is not easy looking after a sick child, especially if a mother is unwell herself. She needs both emotional support, such as someone to listen to her and understand her, and social support, such as food, employment or child care.

Early treatment of illness

Parents need information and advice about how to manage common illnesses in children with HIV including simple practical home-based remedies, such as oral rehydration fluids for diarrhoea or ways of reducing a child's fever. In addition, they should be able to recognise danger signs in a sick child that need urgent treatment by a health worker.

HIV positive children have rights!

Like all children, a child with HIV infection has a right to love, protection, food, shelter, education, health care and play. HIV cannot be transmitted by direct contact such as hugging or kissing or through routine activities, such as changing nappies or bathing. They should not be excluded from play groups, creches or schools. Children living with HIV need to feel valued and secure. This means knowing who will care for them in the future if one or both of their parents dies.

Desiré Fransman, Project Coordinator, Thuthuzela Abantwana, c/o Child Health Unit, 46 Sawkins Road, Rondebosch, 7700 Cape Town, South Africa
Helping children talk

**Story telling and play can help children affected by HIV talk about changes happening in their families.**

Many children and young people living in our area of London are affected by HIV. Most of the families are from sub-Saharan Africa. Some HIV-positive parents have died, some are ill and some are well. Some older children know that their parents have HIV, but most of the children do not. We felt that these children needed opportunities to understand some of the changes affecting their lives.

Children with a parent or parents who have died or are very sick are invited to six half-days of story telling and play. The sessions are led by a family counsellor and someone who uses drama. Trained volunteers come from local AIDS organisations.

The sessions vary, depending on what the children choose to talk about. The adults’ role is to help the children to begin to reflect about their own feelings in a way that is easy for them to express. This allows each child to work at the level that is right for them. The children create the stories, bringing images and themes from their own cultural and spiritual contexts. They know that they share a similar experience of loss, but most do not know that HIV is the cause. Whether, or how, HIV is spoken about depends on the age and understanding of the children, and the wishes of their families and the community.

A session usually begins by making up a story using a toy animal. We all sit in a circle, pass the toy from one child to the next, talking about it. Then we make a story. Everyone in the circle takes it in turn to tell a bit of the story. We go round the circle as many times as the story takes. Anyone who doesn’t feel like speaking can say “pass”. If it seems appropriate, the adults may use their turn in the story to introduce ideas of family, support, separation, loss and change.

The story in the box was developed by a group of children aged 5-8 years. After we have made the story together, the children act out the imaginary family in different ways. One example is described below, but there are many other ways that adults can tell stories with children, depending on local traditions.

The children chose to build baby cheetah’s home out of chairs, branches or bits of cardboard. The adults then ask questions which help the children develop the story. *Where does baby cheetah sleep? Who else is part of her family? What does she like to eat? Who does she play with?* Children weave their own experiences into the story, for example baby cheetah wetting the bed, feeling alone and being comforted by an older animal. Because these experiences happen to baby cheetah and not the child, this sometimes make it easier for the child to talk about problems like bed wetting. The story helps children talk about change and the future.

At the end of the sessions, time is set aside for the children to talk freely about what they have been doing and make connections with their own lives. The children say the sessions have helped them feel more confident. They make friends with other children and they give and get support from each other. Families say that their children seem more settled.

**Liz Day, HIV Coordinator, Bexley Council, Howbury Centre, Slade Green Road, Kent DA8 2HX, UK and Roya Doorman, Drama Therapist, 8 Harraden Road, London SE3 8BZ, UK**

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**MUMMY CHEETAH AND HER BABY**

Mummy cheetah and her baby lived in the plain. Mummy cheetah hunted for food for her baby and sang to her to keep her safe at night. One day mummy cheetah became sick. She was sad and worried about who would look after her baby if she did not get better. Baby cheetah played with her friends in the sun, but sometimes she worried about her mummy. Mummy cheetah became so sick she could not sing any more and after a time she died. Auntie took baby cheetah to live with her and her own children. They had lots of fun together, but sometimes baby cheetah felt sad. When she felt sad, baby cheetah sang the song her mummy used to sing and she felt comforted.
Using new information

There are lots of ways you can share and use the information in this newsletter. For example you could:

- make contact with the AIDS organisations in your area and talk about their experiences of working with children and families, especially orphans. Perhaps the memory book idea would be useful to them.
- set up a meeting with colleagues involved in health education, antenatal care and counselling and use Ilinanga’s story to discuss how you could include some of the lessons learned in your work.

Editors’ note: write and tell us how you have used the information in this issue. We will print readers’ experiences in future issues.

Useful resources for HIV and children

From Healthlink Worldwide

The following back copies of AIDS Action and Child Health Dialogue are relevant to this joint issue. If you would like to receive one or more of these issues, please write to Healthlink Worldwide stating the newsletter and issue number you would like.

**AIDS Action**
- Issue 28 Home and hospital
- Issue 31 Tackling TB and HIV
- Issue 41 Caring for people who are very sick

**Child Health Dialogue**
- Issue 5 Parents as partners
- Issue 9 Promoting good nutrition
- Issue 10 Common childhood illnesses

**Tuberculosis and children:** The missing diagnosis provides detailed information on diagnosis and management. Special supplement to Child Health Dialogue April–June 1996. Price: Free.


Other resources

- **AIDS home care manual** a practical handbook for families and communities to provide practical and compassionate AIDS care at home. Price: US$10 developing countries, US$14 elsewhere. Available from: UNAIDS, CH-1211 Geneva 27, Switzerland. E-mail: info@unaids.org (WHO/GPA/IDS/HCS/93.2)

- **Child Health, a manual for health workers in health centres and rural hospitals** covering all aspects of child health. Price: £8 plus postage. Available from: TALC, PO Box 49, St Albans, Herts AL1 5TX, UK. E-mail: taluk@binternet.com


- **Memory book** a photocopiable resource useful for NGOs, parents’ or church groups working with families affected by HIV/AIDS or other terminal illnesses. Price: £15. Available in English, Luganda and Swahili from: CLS Development Services, PO Box 4385, Colchester CO6 4UA, UK

- **The Prescriber** newsletter promotes rational drug use and correct case management of illness in basic health services. Issue number 16-17 (September 1998) focuses on the prevention, treatment and care of adults and children with HIV/AIDS. Price: Free. Available in English, French, Portuguese and Spanish from: UNICEF, 3 UN Plaza, New York 10017, USA

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**Resources**

**Healthlink Worldwide (formerly AHRTAG)** aims to promote policies and practices in health which are appropriate, sustainable and cost-effective. Healthlink Worldwide provides information on health and disability issues in developing countries, and provides technical support and training to partner organisations.