Caring for Children Living with HIV

“She is my tower of strength”

For more information, visit your nearest health centre or call the National Health Hotline 0312 500 600
Be their key to life

Did you know that children and young people with HIV can live healthy and productive lives? Read this booklet to find out how you can help your child thrive.

Be a tower of strength
You hold the key to your child’s life

- Babies under the age of 2 who are HIV positive should be on ARVs.
- Children with HIV can lead healthy and productive lives when they stick to ART.
- ARVs only work if you take them every day as the health worker tells you.
- Children are better at remembering to take their medicine when they know that they are HIV positive.
- Children who have HIV need to be treated with the same love and affection as other children in the family.
Introduction

Over 150,000 children (under 15) in Uganda currently have HIV, but many are not getting the help they need.

In 2009, around 76,000 children were estimated to need treatment with antiretroviral therapy (ART). Children who receive ART live longer, more healthy lives, yet only 28% of children are on treatment.

*The main reason why children are not getting the help they need is lack of awareness about testing and treatment services available for children.*

This booklet aims to provide information to people who are responsible for children that are at risk of HIV. Caregivers can be parents and close family members, other relatives, friends, teachers, health workers, community leaders and volunteers. As their caregivers, you are the tower of strength for these children and they would not survive without your support. This booklet can help you be their key to life.
How do children become infected with HIV?

- **Mother-to-child:** Most children with HIV get it from their HIV positive mothers. Transmission from mother-to-child can happen during pregnancy, childbirth or breastfeeding. Not all children born to HIV positive mothers will be positive, especially when the mother consults a health worker and takes the medicine that prevents the transmission of HIV to her baby.

- **Unprotected sexual activity:** Sexual abuse often involves unprotected sex, which puts a child of any age at risk of HIV infection. Also, older children or adolescents can get HIV by having unprotected sex (sex without a condom) with an HIV-infected partner.

- **Blood contact:** Anytime that one person’s blood comes in contact with infected blood then there is risk of infection, such as: a blood transfusion with infected blood and a sharp skin piercing or cutting object such as a needle or knife that is shared between two people.

Which children are most likely to be HIV positive?

- Children whose mother or father died of HIV/AIDS.
- Children born to parents who have HIV.
- Children who have been raped or sexually abused.
- Older children or adolescents who are sexually active.
How does HIV affect children?

- HIV weakens the immune system, just as it does in adults.
- Since children are developing, HIV causes children to get sicker much faster than adults.
- HIV can cause a child to grow at a much slower rate than normal.
- HIV causes their immune system to be weak, which can cause them to be at risk for other diseases, and if the child lacks good food and health care, their health can be even worse.

How can I tell if a child has HIV?

The only way to know for sure is to take the child for an HIV test. If you see any of these signs, you should take the child to a health centre for an HIV test and advice. Children should get tested if they:

- Have Tuberculosis (TB)
- Often fall sick with fevers, coughs and diarrhoea
- Do not eat well and stay thin and weak as they grow
- Get skin rashes and growths
- Have wounds and a white coating in their mouth

*HIV testing is now available for babies as well as children at most hospitals and health centres in Uganda.*
Why should children at risk of HIV be tested?

Testing will tell you if a child is HIV positive or not and if positive, the child will need special care:

- The sooner you know that a child is HIV positive, the sooner you can arrange the treatment he or she needs. Even babies as young as 6 weeks old can be tested and treated for HIV.
- Early treatment can save a child’s life and keep him or her healthy.
- Early treatment helps children to develop properly, in both mind and body.

Are there any HIV tests for children under 18 months?

Yes. There is a test called a DNA PCR which is the only test that works for babies less than 18 months. It is different from the test used for adults and older children, and it can be used when a child is as young as 6 weeks old. The DNA PCR test for babies is available in over 600 facilities including hospitals, Health Centre IVs and some Health Centre Ills.
What are antiretrovirals (ARVs)?

ARVs are drugs used to slow down the virus from reproducing. Used correctly, these drugs help a child live a healthy life. However, it is important that children who need the drugs start on them as early as possible. In fact, according to the revised National Paediatric ART Guidelines, all children under 2 years who test positive for HIV need to start ARVs right away since 50% of babies who are HIV positive and are not on treatment will die before 2 years of age.

How do ARVs work?

- ARVs slow down the virus from reproducing, and therefore, prevent someone from becoming sick with AIDS.
- ARVs will not cure an HIV positive child. ARVs help babies and children stay healthy and live longer.
- ARVs help keep the immune system strong so that other infections are less likely.

Do all children who test HIV+ need to start ARVs?

Children above two years might not start ARVs right away. Before starting a child on medication, a health care provider will test the child’s blood to see how far the disease has developed (CD4 count). They will also make a note of any other illness that the child has and assess the amount of social and family support available to the child.
What do I need to know about giving ARVs?

- Follow the health worker’s instructions carefully.
- Take any child on ARVs for a check up every month.
- Make sure the child takes the ARVs every day and at the same time each day.
- Use a calendar or alarm clock to help remind you.
- Store the medicine in a separate pill box in a particular place to help you keep the treatment regular.
- Never share the medicine with other children or adults.
- If you miss giving your child the medication and remember after 4 hours, skip the missed dose and return to the regular schedule.

How will my child react to the ARVs?

When your child starts taking ARVs, they can have different reactions, called ‘side effects’. Side effects usually go away in 4-6 weeks, once the child’s body gets used to the drugs. Tell your doctor, clinical officer or the nurse about any side effects your child has so that they can help you.

What are the common side effects of ARVs?

- Feeling tired
- Headache
- Skin rash
- Dry mouth
- Nausea/vomiting
- Diarrhoea
- Sleep interruptions
- Darkening of toe and finger nails
- Dizziness
- Loss or increase in appetite
What other care does my HIV positive child need?

**Healthy Behaviours**

_Get regular medical check ups:_
- Give all the recommended immunization that any other baby is given. All immunizations should be given at the proper times.
- Measure the child’s height and weight regularly to ensure he/she is growing well.

_Ensure your child gets enough exercise and rest:_
- Encourage your child to play regularly as play and fun are important.
- Your child needs more rest than an adult.
- Send your child to school to play with other children.

_Give emotional support:_
- Be supportive of your child by showing your love and demonstrating that HIV does not mean they are less important than other children.
- Encourage your child to join a group for young HIV positive people.
- Be a tower of strength by being a good listener and providing comfort when your child is sad.

_Challenge stigma:_
- Be an advocate for your child if a teacher or another child treats your child badly, help the child stand up for him/herself.
- Support your child by meeting with a teacher that is mistreating your child and help him/her to understand that a child living with HIV should not be treated differently than other children.
- Educate others about the facts of HIV.
What other care does my HIV positive child need?

Preventing Opportunistic Infections
- Keep the child and everything around the child clean (boiled water, clean food, clean house).
- Drink clean, boiled water.
- Teach everyone in your household to wash hands with clean water and soap after using the toilet or before preparing food or eating.
- If the health worker has given your child Septrin, give it every day to help prevent infections.
- Look out for any new infections and get treatment early.
- Ensure the child sleeps under an insecticide-treated mosquito net
- Take the child to the clinic early when he/she has a fever.
- Give Vitamin A every six months until the child is five years old.
- Regularly de-worm the child.
- If possible, avoid contact with people coughing or with other sicknesses.

Nutrition (for HIV infected infants)
- For the first 6 months the child should have only breast milk.
- From 6 months to 24 months, infants should receive other nutritious and safely-prepared foods while breastfeeding.
- If breastfeeding is not an option for you or if you are having any problems, consult with your health care provider.
What other care does my HIV positive child need?

Nutrition (for HIV exposed infants)

Follow the instructions of your healthcare provider, but here are general guidelines:

• The baby or the mother should be on ARVs to prevent HIV infection.
• For the first 6 months, children of HIV positive mothers should have ONLY breast milk.
• From 6 months to 12 months, infants should receive other nutritious and safely-prepared foods while breastfeeding.
• If breastfeeding is not an option for you or if you are having any problems, such as cracked/bleeding nipples, consult with your healthcare provider so that you can learn about other safe options.
• Before you stop breastfeeding, discuss with your healthcare provider.

Nutrition (for children)

• Feed your child three meals and two nutritious snacks a day.
• Feed your child a variety of foods to achieve a balanced diet. Each day feed your child foods from each category.
  • Energy Foods: flours, potatoes, matooke, yams
  • Body Building Foods: beans, peas, groundnuts, cowpeas, soya beans, meat, chicken, fish, eggs, silver fish
  • Protective Foods: (vegetables) pumpkin leaves, cowpea leaves, cassava leaves, spinach, tomatoes, eggplant, carrot, okra leaves and pods, mushrooms (fruit) passion fruit, mango, pawpaw, orange, banana, watermelon, sweet melon, pineapple, avocado
  • Fats and Oils: Groundnut, sunflower, sesame, palm and shea oils or from animal source (ghee, lard)
When should I tell my child about his/her HIV status?

- Children that are old enough and mature enough to understand should be told about their HIV status. They need to understand why they have to take their medicine every day.
- If children start taking ARVs when they are young, they usually find out about their status when they reach about 10 years. But if they have not, then the caregiver should tell them. However, if your child asks earlier, then you should explain.
- You can use make believe play, storytelling, toys, drawings, games and drama to help explain.
- Never lie to a child about his/her HIV status. Be honest and supportive in explaining that many other children are HIV positive and are healthy and happy.
- If you are a parent living with HIV, telling your child also means talking about your own HIV status. A counselor can help you handle all the issues involved in having these discussions with your child, and let you stay in control of the process.
- Remember that you are not alone. There are counselors and support groups for both you and your child. Ask your doctor if you do not know how to find these services.
What do I need to know about my HIV+ adolescent?

- Children develop at different rates and will enter the stage of adolescence at different ages (10-19 years).
- Adolescence is a challenging stage for all young people. Being an adolescent who is living with HIV can be even more challenging.
- By nature, adolescents want to be in charge of their own lives, so caregivers should embrace this sense of independence and encourage them to take charge of taking their medicine and living a healthy life.
- However, young people will have complicated feelings about their HIV status. If they have not received counseling in the past, it might be a good idea to start at this point.
- If they do not receive support, some young people will turn to destructive habits such as using alcohol or drugs to handle their feelings.
- Some young people, even as young 10, may naturally become curious about love and sex.
- As parents and caregivers, you might find it difficult to talk about these issues with your adolescents. If you do not feel that you can talk to your child about his/her sexual and reproductive health, find a counselor or some other adult that you trust to support your adolescent.
- In many communities or health centres there are support groups for adolescents who are living with HIV. Participating in a group will allow your adolescent to share experiences. Being part of a support group can help boost the self esteem of your child.
What do I need to know about my HIV+ adolescent?

**Key points for your adolescent about HIV and AIDS:**

- Even when on ARVs, they still have HIV in their blood
- HIV can be passed on to any sexual partner, through mother-to-child or by sharing sharp objects or needles
- Even young people can get sexually-transmitted infections (STIs), such as, herpes, syphilis or gonorrhea. When a person has HIV, these STIs are more serious and difficult to treat. STIs can also make the young person sick with AIDS more quickly.
- Unprotected sex could also re-infect the young person with a different type of HIV that the ARVs cannot control.
- Unprotected sex could also mean that your adolescent girl could get pregnant, which would be hard on her health and could infect her baby with the virus.

**Young people can prevent the spread of HIV from Uganda:**

- If possible, delay sexual activity until they are older.
- If in a relationship, show affection in other ways, such as: doing things together, buying gifts, holding hands, kissing and hugging.
- Talk openly about the disease with their partners before becoming sexually involved.
- If sexually involved, they must use a condom correctly every time they have sex, or they risk passing the virus onto their sexual partner and getting re-infected.