

CAREGIVERS AND ADOLESCENTS HANDBOOK



**FOR HIV PREVENTION, CARE AND
TREATMENT LITERACY AND DEMAND
CREATION**

Introduction

This is a treatment literacy guide for Caregivers of children and adolescents to provide accurate information on HIV prevention, care and treatment.

As children grow, they face challenges that could expose them to HIV infection. Some children are born with HIV. These equally face challenges when they grow up. It is our responsibility as Caregivers to ensure we provide an environment for both HIV negative and positive children and adolescents that will enable them grow up healthy and achieve their dreams.



During pregnancy

What one should do

- Go to the health facility for Antenatal care checkups as soon as you are aware you are pregnant.
- Ensure you attend at least eight Antenatal care visits. This is intended to protect the unborn child against HIV and monitor their development.
- If you don't know your HIV status, take an HIV test with your partner.
- Men support your partners during and after pregnancy.

If found HIV positive:

- You will be initiated on antiretrovirals (ARVs). Ensure you take them on time as advised by the health worker.
- You will also be given Septrin to prevent other illnesses such as diarrhea, malaria.
- Consider disclosure to the partner/close person and identify a treatment supporter.
- Talk to the health worker about your concerns, worries and fears

However If you are already HIV positive:

- • disclose to the health worker.
- Continue taking your treatment as advised by the health worker.

Danger signs during pregnancy

If you notice any of these symptoms during pregnancy or after delivery go to the health unit immediately.



Any vaginal bleeding



Fever



Mother fitting or having convulsion



Severe abdominal pain



Severe headache



Excessive vomiting



Swelling of face, hands, feet & legs

Care during pregnancy



The provider should check your blood pressure and weight at every antenatal contact. Your weight is expected to increase as pregnancy advances.

The provider should immunize you for tetanus diphtheria (Td). This will prevent your baby getting tetanus.



Avoid heavy workload during pregnancy, rest more.

Care during pregnancy



Immediately contact your health provider when you miss your menstrual period to confirm pregnancy so as to start antenatal on time



The provider should check your pregnancy at every antenatal contact. Your womb gets bigger as pregnancy progresses

Take folic acid for the first 3 months of pregnancy. Continue with folic acid and iron combination for the rest of the pregnancy. Iron tablets will not harm your baby. This will prevent you from getting anaemia and prevent the baby from getting brain and spinal cord abnormality.



During Antenatal care visits, you will be given Three(3) Fansidar tablets once every month starting after three months of pregnancy. This will prevent you and the unborn baby from getting malaria. Test for HIV and syphilis for you and your partner to prevent transmission to your baby.

Husband

- Ensure you take an HIV test.
- If negative and your wife is positive, you will be given PreP (Pre-exposure Prophylaxis) to prevent you from getting HIV. If positive, you will start on ART to keep healthy.

During pregnancy



Birth & Emergency preparedness plan

a. General

- Due date for delivery? :/...../..... Who do you live with? :
.....
- Where do you intend to deliver? :.....
.....
- Who will accompany you to the health unit when labour starts? :
.....
- What means of transport will you use to come to the health facility?
.....
- Who will stay with you at the health unit during labour? :
.....
- Prepare for someone to stay at home for the days you will be in hospital.
- Placenta disposal: To be disposed off at facility Mother to take it home
- Who is the alternative contact in case of an emergency?
.....

b. You MAY need to take these supplies with you to the health unit*

<input type="checkbox"/> 4 Pairs of gloves 	<input type="checkbox"/> 2 Plastic sheet 	<input type="checkbox"/> 3 pieces of string (about 20cm each) 	<input type="checkbox"/> Razor blade 
<input type="checkbox"/> Sanitary pads 	<input type="checkbox"/> Baby Clothing & sheets 	<input type="checkbox"/> Basin 	<input type="checkbox"/> Gauze & cotton: (material for dressing that can be bought from a pharmacy) 
<input type="checkbox"/> Soap 	<input type="checkbox"/> Clean clothing for you 	<input type="checkbox"/> Sugar and tea leaves 	<input type="checkbox"/> Money for emergencies e.g. Transport & other needs 

After delivering your child

What one should do

- Go to health facility and deliver under the care of a skilled health care worker. This will help you have a safe delivery and a healthy baby because the health care workers are trained to address any complication that might come during childbirth.
- continue with Septrin as guided by the health care worker until the child is one and half years or when the baby has stopped breastfeeding.

Role of men

- Support partner to deliver at a health facility.
- Physically escort the partner to a health facility.
- Encourage and provide care to both woman and the pregnancy.
- Provide healthy foods and live a healthy lifestyle to avoid infecting the mother and baby.
- Ensure you sleep under a treated mosquito net, these are given for free at government health facilities.

After delivering your child

What one should do

Mother

- Breast feed your baby exclusively for 6 months.
- Continue to take your ARVs as directed by the health care worker.

Child

After birth, your child will be given a Neverapine (NVP) syrup that will be taken depending on one of the categories below;

- If you tested HIV positive in the first 3 months of pregnancy and started on ARVs or if you were already on ARVs and your viral load is low, your baby will be **given a Neverapine syrup for 6 weeks**
- If you tested HIV positive in the last 3 months of pregnancy, during labour or if you started your ARVs in the last month of pregnancy, your baby will be given a **Neverapine syrup for 12 weeks**
- If you have a high viral load, your baby will be given a **Neverapine syrup for 12 weeks**
- After 1¹/₂ months (6 weeks) your baby will be started septrin. Septrin helps to prevent common childhood diseases.

After delivering your child: Nutrition for the Mother and the Child

FRUITS



CARBOHYDRATES



VEGETABLES



PLANT PROTEIN



ANIMAL PROTEIN



Immunization, infant feeding and testing of the baby

Ensure your child is immunized to protect them against all the Immunizable childhood killer diseases in Uganda

Immunization and HIV testing of the child	
At birth	Baby MUST be immunized and given a syrup (NVP)
6 weeks	Baby MUST be immunized again, given Septrin and also tested for HIV
3 ½ months	Baby MUST be immunized again, given Septrin refill and results from the first HIV test returned
6 months	Baby will be given vitamin A and advise on complimentary feeding
9 months	Baby will be immunized and tested the second time for HIV
1 ½ years	Your baby will be tested for HIV to confirm that he/she did not get HIV during breast feeding

NOTE

At each of the visits, the mother will be given ARV refills and advised on infant feeding.

IF the baby turns HIV, he/she positive will be given ARVs immediately and continue with the immunization schedule. The mother MUST have a viral load test done every 6 months.

As a mother, ask a health worker on how to delay the next pregnancy. this helps you to fully recover and take good care of the baby.

Foods rich in Vitamin C



After delivering your child: Nutrition for the Mother and the Child

Nutrition for the Mother and the Child:

- Proper feeding during pregnancy and after giving birth especially when breastfeeding is important in keeping both the mother and the child healthy.
- Start breast feeding within **30 minutes** after delivery of your child.
- Only feed the baby on breast milk and drugs for the first 6 months without adding anything. Mixing breast milk and other feeds will increase the chances of the mother transmitting HIV to the baby.
- After 6 months, the health worker will advise you on other feeds that can be given to the baby.

Proper nutrition can be observed through _____ ;

- Drinking adequate fluids;
- Eating plenty of fruits and vegetables;
- Using iodized salt to prevent pregnancy complications (stillbirths, fetal growth retardation, and maternal goiter).
- Maintaining high levels of personal and food hygiene and food safety to prevent infections.
- Eating foods rich in vitamin C to enhance iron absorption.

Avoid;

- **Taking tea or coffee within one hour or with meals as this may interfere with absorption of iron.**
- **Taking alcohol, cigarettes and drugs and medicines not prescribed by a trained health care provider.**

Care and treatment of HIV positive children



What I should do if my child turns HIV positive

- Mother should ensure that child is enrolled in care. The health worker will start the child on a combination of 3 drugs.
- Give the child medicine at The Right time, Right dose, Right drug, Right number of times and the Right way.
- Ask your health worker more information about your child's health in case you have not understood.
- Bring the child to health facility at each clinic appointment.

Care and treatment of HIV positive children

What I should do if my child turns HIV positive

- If the child is 0-3 months they will be given a Lopinavir syrup (LPV/r). It tastes bitter but will not be taken for long. As a caregiver ensure you administer the syrup as advised by the health care worker.
- The child's drugs are given basing on the weight. ensure that the weight is taken at each clinic appointment.
- If the child is still under 6 months you will be given Lopinavir capsule/pellet that you will be required to give to your child twice a day.
- You can administer the Lopinavir capsule/pellet with breast milk, mashed foods such as porridge, mashed fruit and food.
- The child will take the Lopinavir capsule/pellet until they are able to swallow tablets as guided by the health care worker.
- If a child is at least 4 weeks and older weighing at least 3kg, can be given a 1 DTG tablet a day. It's easier to take.
- The child **MUST** continue taking ARVs even if the child has low viral load.

Adolescents

Adolescents should appreciate their body changes as they grow. These do not come as a result of ARVs but are biological.

- Disclose your HIV status in case you're beginning a relationship.
- Ask your health care worker about the available peer support groups such as community client led ART delivery (CCLADS) and other treatment support groups.
- Disclose to the school nurse or the school health focal person to keep drugs and support your appointments at the health facility.
- Ensure you ask for a viral load test at health facility every 6 months
- Be a role model.

Have you heard?

A new and improved ARV for young children living with HIV is available.

Paediatric Dolutegravir 10 mg Dispersible Tablet (pDTG)



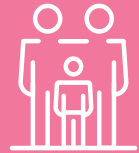
Works fast to control the virus



Safer & has fewer side effects than other ARVs



Taken once daily readily dissolves in water



Same drug as used in adults, in a sweet strawberry flavor









Ask your child's healthcare provider about pDTG today!

Giving Your Child Paediatric Dolutegravir 10 mg Dispersible, Scored Tablets (pDTG)

These are instructions on how to give your child pDTG alongside abacavir and lamivudine (ABC/3TC) 120/60 mg dispersible tablets. If your child is not taking ABC/3TC, there may be changes to these recommendations. Always follow the guidance of your healthcare provider.



1 Add the correct number of pDTG and ABC/3TC tablets to a clean, empty glass based on your child's weight. (See Dosing Table).

Weight	No. of pDTG Daily Tablets	No. of ABC/3TC 120/60 mg Daily Tablets
3 to < 6 kg	0.5 	1 
6 to < 10 kg	1.5 	1.5 
10 to < 14 kg	2 	2 
14 to < 20 kg	2.5 	2.5 



2 Add 2-4 teaspoons (10-20 mL) of clean water into the glass.



Stir until the tablets fully dissolve.



Give the medicine to your child to drink. Make sure they drink all the medicine right away or within 30 minutes.



3 If any medicine remains in the glass, add a little more water to the glass and give to your child. Repeat until no medicine remains in the glass.

Reminders

- Remember to give your child their pDTG (and other ARVs) at the same time everyday
- Use other liquids or foods for mixing if your child is unable to take the tablets in water. Use the same amount of liquid or food as above to avoid spills and to ensure your child takes the full dose
- Only give your child another full dose of pDTG if they vomit within 30 minutes of taking their initial dose

Ask your health provider if you have any questions about administering pDTG!

Care and treatment of HIV positive children

Frequently Asked Questions for Caregivers

1. What is dolutegravir (DTG)?

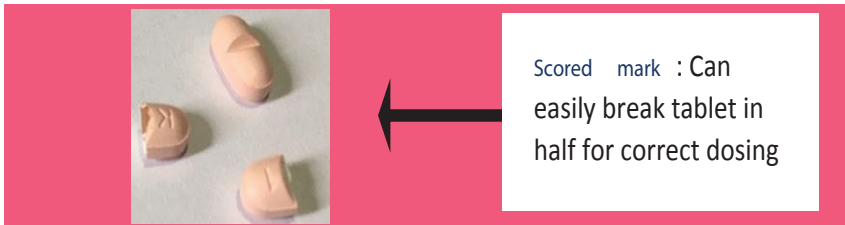
Dolutegravir (DTG) is an antiretroviral (ARV) drug that is safe, very effective at controlling HIV, has few side effects, and, if taken every day, can keep working for a long period of time

What is pDTG?

Paediatric dolutegravir 10 mg dispersible, scored tablets (also known as 'peds DTG' or 'pDTG') is a new DTG product that can be given to children with HIV who are one month and older and weigh between 3 and 20 kg.

2. What does it mean for pDTG to be dispersible and scored?

'Dispersible' means pDTG can be dissolved in clean water. 'Scored' means that pDTG is marked at the centre and can be easily broken in half if needed for the correct dosing.



3. Does pDTG work better than lopinavir capsule/pellets?

A study in children has shown that DTG works better and faster than Lopinavir Capsule in reducing the amount of virus in the body.

4. Does pDTG have fewer side effects than LPV/r? What side effects does pDTG have?

pDTG has less severe side effects than LPV/r. Common side effects of LPV/r include diarrhoea and weakened bones which do not occur with pDTG. Side effects of DTG that happen rarely include insomnia, fatigue, and headache but these usually go away after 1-2 months.

Weight gain has been a common side effect of DTG in adults but does not appear to be a problem in children. Still, you should monitor your child's weight often.

Report to your child's health provider if any concerns come up following your child taking pDTG.

5. Do I need to give my child any other ARVs?

Yes. Remember that HIV treatment is only complete if made up of three ARVs. Your child must take pDTG as well as two other ARVs every day. For many children, these two other ARVs are ABC/3TC (abacavir and lamivudine combined in one tablet).

6. How many tablets of pDTG should I give my child?

When pDTG is taken with ABC/3TC, pDTG only has to be taken once daily. If your child is on something different than ABC/3TC, ask your child's health provider for more information.

Care and treatment of HIV positive children

7. How do I give pDTG to my child?

pDTG can either be swallowed whole or it can be dissolved in a small amount of water to drink. To give pDTG to your child, you should first find the correct number of tablets to give your child based on their weight. If your child can swallow the tablets whole (without crushing), then they can swallow the tablets with some water. If your child cannot swallow tablets, follow the instructions below on how to mix the tablets with a small amount of clean water.

8. Can ABC/3TC 120/60 mg dispersible tablets and pDTG be mixed together?

Yes, to give both medicines together:

1. Determine the correct number of tablets your child should take based on their weight for both pDTG and ABC/3TC.

9. Can I mix pDTG with liquids other than water (such as juice or breast milk) or in food (such as yoghurt or porridge)?

pDTG is recommended to be mixed with clean water. However, if a child is unable to take pDTG with water, it is reasonable to mix pDTG with other liquids or foods such as milk, juice, yoghurt, or porridge. If using other liquids or foods, follow the same small volume recommendations as mentioned in FAQs #10 and #11 to ensure that your child is able to take the full dose of medicine.









10. Can I give my child other medicines in addition to pDTG?

Your child should continue taking any other medications your doctor has prescribed as pDTG is safe to take with the majority of, but not all, other medications. However, please let your child's health provider know what medicines (including local herbs!) that your child is taking before your child starts taking pDTG.

11. Should my child's dose of pDTG be changed if they have TB?

Giving pDTG to your child at the same time as the TB medicine rifampicin (RIF) leads to there being lower amounts of DTG in your child's body than normal. Because of this, if your child is taking RIF for their TB, they should take **double their daily dose of pDTG** for the entire time they are taking RIF. This means you should give your child one full dose of pDTG in the morning and one full dose of pDTG in the evening. Your child's health provider will tell you when your child can go back to their regular dose.

Recommended dosing for DTG 10 mg dispersible, scored tablet for children with TB

Weight	Number of Daily pDTG Tablets When <u>Child is Taking TB Medicine</u>	
	Morning	Evening
3 to < 6 kg	0.5 	0.5 
6 to < 10 kg	1.5 	1.5 
10 to < 14 kg	2 	2 
14 to < 20 kg	2.5 	2.5 

12. If my child is doing well on a different ARV, should they also switch to pDTG?

Because pDTG has so many benefits, Ministry of Health recommends that all children who are eligible for pDTG be switched over to it even if they are doing well on a different ARV. If your child is currently taking other ARVs like LPV/r (lopinavir ritonavir), EFV (efavirenz), or NVP (nevirapine), ask your child's health provider about switching to pDTG.

13. My child weighs 20 kg or more. When should they switch from pDTG to DTG 50 mg?

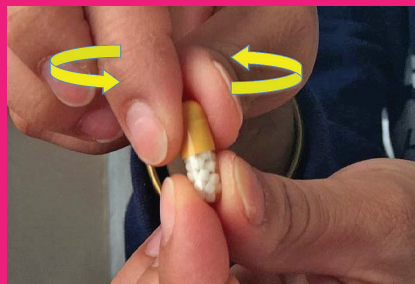
Your child can switch from pDTG to DTG 50 mg once they weigh at least 20 kg and are able to swallow tablets. If you think your child is ready to switch to DTG 50 mg, please talk to your child's health provider

Care and treatment of HIV positive children

How to administer Lopinavir capsule/pellets

How to open Lopinavir capsule/pellet.

Step 1



- Hold the capsule with the yellow side up.
- Twist the yellow half of capsule to loosen it.

Step 2



- Lift the yellow half of the capsule.
- Pellets will be contained in bottom half of capsule.

Step 3



- Carefully pour all pellets on the spoon.

Step 4



- Pour breast milk, porridge or mashed food on top of the pellets on the spoon.
- Give the baby to swallow at once.

Care and treatment of HIV positive children

Don't force your child to try to swallow if they are having difficulty to prevent choking!



Capsules should be opened to administer pellets



Capsules should NOT be swallowed.



Do not let the pellets dissolve



Care and treatment of HIV positive children

Possible side effects of ARVs

Some side effects may include:

- Nausea
- Diarrhea
- Skin rash
- Fatigue

The side effects are usually at the beginning and may take a short while. Continue with ARVs and get advice from health care worker. Ensure that you go with the child to the health facility at each clinic visit.

Effects of not taking your drugs very well.

- High viral load.
- Severe opportunistic infections.
- Possible drug resistance which reduces your options of available treatment.

What is HIV Drug Resistance?

- Is the ability of HIV to mutate/change and reproduce itself in the presence of antiretroviral therapy. The consequences of resistance include treatment failure and further spread of drug resistant HIV. It can come as a result of the two ways below;
- When an individual is infected by a strain of HIV-1 which is already resistant to one or more drugs. They are resistant to HIV therapies before exposure to these drugs.
- Occurs in population during exposure to antiretroviral therapy. HIV makes mistakes during copying and produces variants/types.
- Ask your health worker more information on how to avoid when you're HIV positive.

Care and treatment of HIV positive children



Other key messages for Adolescents, Care givers and their children

Retention

- Remember to take your drugs on time as advised by the health care workers.
- Remember to give your child drugs on time as advised and the right dose.
- Ensure you keep clinic day appointments.
- Ensure you give accurate information on the locator form (phone number or where your home is located and in case you change address or contact, notify your health worker). This will help the health worker to follow-up and check on how you and the child are doing.
- Ask the health worker the most available convenient options of accessing treatment.
- Notify the health worker when you relocate to be given a transfer out letter

Malaria

Ensure you sleep under insecticide treated mosquito net, these are given for free at government hospitals.

Psychosocial support

- HIV positive caregivers and their children need support, listen to them, support their dreams and aspirations.
- Do not stigmatize them because of their HIV status.
- As a child grows they will start asking questions about their status. Find an appropriate time to disclose and continue to have discussions about how they can live a healthy life.

Referral and linkage

- As a caregiver of a HIV positive child find out from your community leaders and health workers about the different services in your community such as livelihoods programs, Gender Based Violence services, Orphan and Vulnerable Children services and ask how you can benefit from them.
- HIV Negative caregivers of positive children and adolescents should support them adhere on treatment and escort them to the facility at each clinic visit.

**Other key messages for Adolescents,
Caregivers and their children**





HIV Testing Eligibility Screening Tool for Children and Adolescents with unknown HIV status (18 months to 14 year)

Is the child's
mother
HIV positive?

NO or
UNKNOWN

Ask the following five questions to the
caregiver or the child:

Has the child/have you been sick in the last three months?	<input type="checkbox"/> NO	<input type="checkbox"/> YES
Has the child/have you had recurring skin problems?	<input type="checkbox"/> NO	<input type="checkbox"/> YES
Has the child/have you lost weight in the last three months?	<input type="checkbox"/> NO	<input type="checkbox"/> YES
Has the child/have you ever had TB?	<input type="checkbox"/> NO	<input type="checkbox"/> YES
Is the child/are you growing well?	<input type="checkbox"/> NO	<input type="checkbox"/> YES

Are TWO or MORE shaded responses selected?

YES

Test the child for HIV using the MoH HTS algorithm

*If child previously tested HIV -negative, only repeat the HIV test if there is a new exposure or risk

