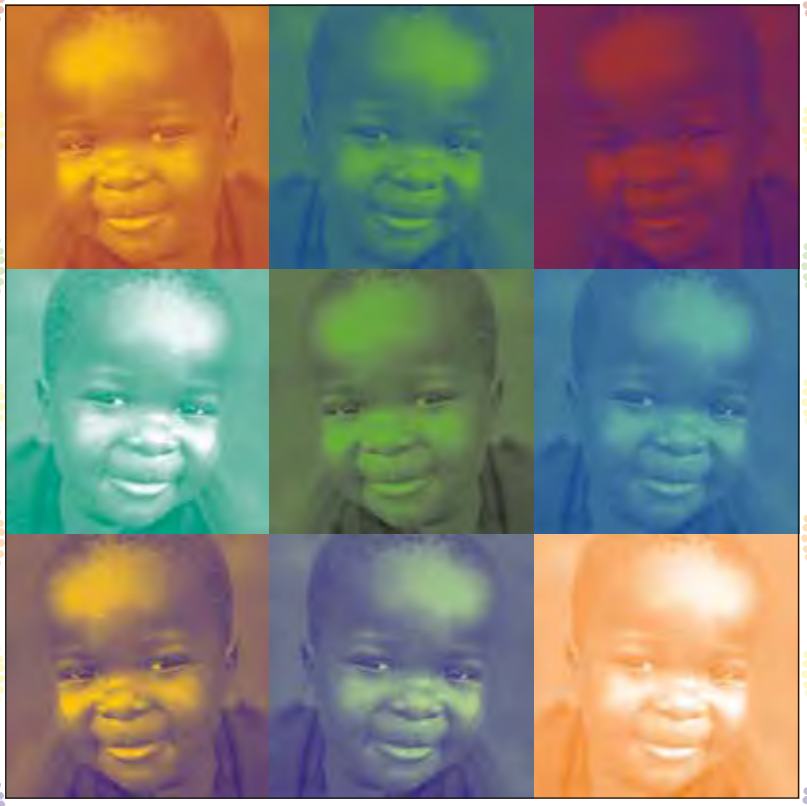
Antiretroviral Treatment Literacy for Caregivers of Children on Treatment

A Counsellor's Guide



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James Nuttall

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A collaborative project between
Red Cross War Memorial Children's Hospital,
the University of Cape Town
and Wola Nani

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Acknowledgements:

For comments on the drafts:
Dr Marco Zampoli
Dr Carol Cowburn
Ms Shenaaz Raiman (Pharmacist)
Dr Simone Honikman

For input during the process of identifying key issues for inclusion in the guidelines, for piloting and implementation:

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This publication is produced under the auspices of Red Cross War Memorial Children's Hospital, Department of Public and Family Medicine, University of Cape Town and Wola Nani.

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First published 2006. Revised edtion 2008.

"This guideline is made possible by funding through the PHRU from the United States Agency for International Development (USAID) and PEPFAR. The contents are the responsibility of the authors and do not necessarily reflect the views of USAID or the United States Government."

Cover photo: www.aidchild.org
Design to print: muhdni@telkomsa.net

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Introduction

Counsellors play a very important role in helping prepare caregivers and families whose children are starting antiretroviral treatment (ARV).

These guidelines have been developed to assist counsellors in this process.

The counsellor's role is to gain the trust of the caregiver, provide information on HIV & AIDS and treatment in children, assess whether the caregiver is likely to be responsible in giving the child treatment, and to build up the confidence of the caregiver in her/his ability to look after and treat the child.

Treatment-readiness counselling includes the practical demonstration of how to prepare and administer the specific antiretroviral medications selected for a particular child. This gives the caregiver an opportunity to practise preparing the medications with the assistance of the counsellor and to discuss any difficulties with this process.

Intshayelelo

Abacebisi ngezempilo badlala indima ebalulekileyo ekuncedeni ekulungiseleleni abagcini-bantwana kunye nosapho elinabantwana abaqalisa amayeza anyanga iNtsholongwane kaGawulayo.

Le migaqo ithi yenziwa ukuncedisa abacebisi ngezempilo kulenkqubo.

Umsebenzi womcebisi kukufumana ukuthembeka kumgcini-mntwana, anike inkcukacha ngoGawulayo kunye nonyango ebantwaneni, ahlole ukuba umgcini-mntwana unako ukunika umntwana amayeza, kwaye ukuzithemba komgcini-mntwana ekumgcineni nasekunyangeni umntwana.

Amacebiso okulungiselela unyango aquka ukubonakalisa indlela yokulungiselela nokunika amayeza akhethelwe lomntwana uthile. Oku kunika umgcini-mntwana ithuba lokufunda ukulungiselela amayeza ngoncedo lomcebisi kunye nokuxoxa malunga nobunzima bokwenza oku.

Counselling session 1

Objectives

In this session the counsellor should aim to establish a friendly and supportive relationship with the caregiver and child. There are three main objectives:

a) To familiarise the caregiver and child with the health care team and their various functions

b) To familiarise herself with the family structure and routine

c) To provide the caregiver with a basic understanding about HIV & AIDS in children including the tests that are used in diagnosis and treatment.

d) To find out about the caregiver's feelings and attitudes to antiretroviral treatment for children.

Iseshoni yesithathu yokucebisa 1

Iinjongo

Kule seshoni ikhansela kufuneka izame ukwakha ubuhlobo kunye nobudlelwane obuyi nkxaso kumgcini womntwana kunye nomntwana. Zintathu ezona njongo:

a) Ukuqhelisa umgcini-mntwana kunye nomntwana neqela labasebenzi bezonyango kunye nemisebenzi yabo eyahlukileyo.

b) Ukuziqhelisa nemo yosapho kunye nendlela abenza izinto ngayo.

c) Ukunika umgcini womntwana ulwazi malunga neNtsholongwane ka Gawulayo/ uGawulayo ebantwaneni kunye novavanyo olusetyenzisiweyo kuxilongo kunye nonyango.

d) Fumanisa indlela abagcini bantwana abaziva nabazibona ngazo iARVs ebantwaneni

Introduction to the Health Care Team and their relationship with the client

- The clerk will receive your folder and prepare it for the nurse/ doctor. The clerk may help with giving your next appointment.
- A nurse will record the child's weight and height and do blood tests on the child if necessary.
- A counsellor will prepare you for giving ARVs to the child, give support, offer advice.
- A doctor/nurse will examine and treat the child for any problems, prescribe the ARV medicines and change them if necessary.
- A pharmacist will give the ARVs and explain how to take them. The pharmacist will also ask you to return all your unused medicine to ensure that the child is being given the correct doses. If you have any questions about the medicines you must always feel free to ask the pharmacist.
- A dietician will give advice about a healthy eating plan for your child and also prescribe supplements if the child needs it.

Ukwaziswa kweqela labasebenzi bonyango kunye nobudlelwane balo kwizigulane

- Uklekhi uyakufumana ifolda aze alungiselele unesi okanye ugqirha. Uklekhi angakunceda ngokuthi akunike usuku lokuza ekliniki.
- Umongikazi uzakubhala phantsi ubukhulu kunye nobude bomntwana kwaye enze novavanyo lwegazi emntwaneni xa kukho imfuneko.
- Ikhansela izakukucebisa ngendlela yokunika umntwana amayeza eNtsholongwane kaGawulayo, anike inkxaso, anike amacebiso.
- Ugqirha uzakukuvavanya aze anyange umntwana nakweziphi na ingxaki, anikezele ngamayeza eNtsholongwane kaGawulayo kwaye abatshintshe ukuba kukho imfuneko.
- Umgcini-mayeza uzakunika amayeza eNtsholongwane kaGawulayo kwaye achaze nendlela asetyenziswa ngayo. Uzakucela ukuba ubuyise onke amayeza angasetyenziswanga ukuqinisekisa ukuba umntwana unikwa imilinganiselo elungileyo. Ukuba unemibuzo malunga nalamayeza, ukhululekile ukubuza usomgcini mayeza.
- Ugqirha onika amacebiso malunga nendlela zokutya uzakucebisa ngendlela ezisempilweni zokutyisa umntwana wakho kwaye akunike uluhlu lwendlela zokutya ukuba kukho imfuneko.

Caregiver & household details

1. Who is the person who looks after the child every day (primary caregiver)?
   E.g.: mother, father, grandmother, aunt, foster parent, other person. If the caregiver is not the mother or father, find out why the child is not being cared for by the parents. If the child is having contact with the parents, find out more about this.

2. Find out the age of the child.
   This will guide you as to whether the child is likely to be completely dependent on the caregiver for taking medication correctly; whether the child can be taught to start swallowing pills; and what the child may understand about illness and medicines.

3. Find out who looks after the child during the day.
   Is it the primary caregiver or someone else? Does the child go to crèche or school? Does the child live with someone else during the week and go home on weekends?

4. Find out who the caregiver will consider as a 'treatment assistant' to help her ensure that the child has the medication and takes it – especially in times when the primary caregiver may not be available (eg. hospitalized). Encourage the caregiver to disclosure to at least one other potential secondary caregiver to ensure that the child always has access to ARVs once the child has started treatment.

Inkcukacha zekhaya nezo mgcini mntwana

1. Ngubani umntu ojongene nomntwana mihla le (Oyena mntu ogcina umntwana)?
   Umzekelo: umama, utata, umhakhulu, uanti, umgcini womntwana ngokomthetho, omnye umntu. Ukuba umgcini womntwana ayingo mama okanye, fumanisa ukuba kutheni umntwana engagcinwanga ngabazali. Ukuba umntwana usa nxulumana nabazali, buza banzi ngoku.

2. Fumanisa iminyaka yomntwana.
   Oku kuzakukhokelela ekubeni wazi ukuba umntwana ingaba uxhomekeke ngokupheleleyo kumgcini wakhe ngokusela amayeza ngendlela elungileyo, okanye umntwana angafundiswa ukuqalisa ukuginya ipilisi, kwaye yintoni umntwana ayiqondayo ngesigulo kwakunye namayeza.

3. Fumanisa ukuba ngubani ojongana nomntwana ngexesha lasemini.
   Ingaba nguyena mntu ogcina umntwana okanye ngomnye umntu? Ingaba umntwana uyasihamba isikolo sabantwana? Ingaba umntwana uhlala nomnye umntu phakathi evekini aze agoduke ngempela veki?

4. Fumanisa ukuba umgcini mntwana ngubani ummtu acinga ukuba angangumncedisi wakhe ekunikeni amayeza uqinisekisa ukuba umntwana uyawafumana amayeza – ingakumbi ngamaxesha xa umgcini mntwana engekho endlini (umzekelo ukulaliswa esibhedlele). Khuthaza umgcini mntwana ukuba axelele noba ngumntu omnye ngesimo somntwana sentsholongwane kagawulayo ozakuba ngumncedisi wakhe emntwaneni ukuqinisekisa ukuba umntwana usoloko ewafumana amayeza rhoqo emveni kokuba ewaqalile.

5. Find out what the household routine is during the week.
What time does the child wake up and have breakfast? Who sees to this? What is the evening routine – supper, bedtime etc?

6. Find out what the caregiver thinks about the child starting ARVs.

- what does she/he believe about the child's illness?
- what does she/he think about ARVs for children?

(Remember: it is important to listen to the caregiver's thoughts, opinions and feelings about the child's illness and potential treatment with ARVs before stating the 'facts' about HIV and ARVs).

7. Find out what the household routine is during the weekends as it affects the child and primary caregiver.

Does the child stay somewhere else at weekends? Who is the primary caregiver on weekends? What time does the child wake up and have breakfast? Who sees to this? What is the evening household routine – supper, bedtime, what time does the child go to bed, etc?

Emphasize the importance of establishing a routine (fixed time) around the daily activities at home in relation to children. It makes children feel safe when things happen at more or less the same time each day and treatment will be easier if there are other routines in place.

5. Fumanisa ukuba injani inkqubo yekhaya phakathi evekini.
Uvuka ngabani ixesha umntwana kwaye isidlo sakusasa usitya nini? Ngubani ojongene noku? Ithini inkqubo yangorhatya – isidlo sasebusuku, ixesha lokulala?

6. Fumanisa ukuba umgcini mntwana ucinga ntoni ngokuqalisa umntwana kumachiza (iARVs)

- Yintoni inkolelo yakhe kwisigulo somntwana?
- Ucinga ntoni ngeARVs ebantwaneni?

(Khumbula: kubalulekile ukumamela ingcinga zomgcini mntwana, imbono kunye nendlela aziva ngayo ngokugula komntwana kunye nonyango lweARVs phambi kokuqalisa "ezonazona" zinto zibalulekileyo ngentsholongwane kagawulayo kunye namachiza).

7. Fumannisa ukuba ithini inkqubo yekhaya ngempela veki kuba ichapazela umntwana kunye noyena mgcini mntwana.

Ingaba umntwana uhlala kwenye indawo ngempela veki? Ngubani oyena mgcini womntwana ngempela veki? Uvuka ngabani ixesha umntwana kwaye isidlo sakusasa usitya nini? Ngubani ojongene noku? Ithini inkqubo yangorhatya – isidlo sasebusuku, ixesha lokulala? Ithini inkqubo yekhaya ngorhatya – ixesha lesidlo sasebusuku – ixesha lokulala, ixesha lokulala komntwana, njalo-njalo?

Gxininisa ukubaluleka ngokwazi inkqubo (ixesha elililo) malunga nezinto ezenziwa ekhaya ngokudibaniselene nomntwana. Ibenza abantwana bazive bekhuselekile xa izinto zisenziwa ngexesha elifanayo qho ngemini, kwaye unyango lubalula xa kukho ezinye inkqubo ekhaya.

General HIV & AIDS knowledge and understanding

1. Explore the caregiver's understanding of how children become infected with HIV, provide correct information and correct any misconceptions.

   HIV infection can pass from a pregnant woman to her child either during pregnancy, birth or breast feeding (including "wet nursing": someone other than the mother of the child who breastfeeds the child). However, children who are sexually abused may be infected this way. Emphasize that HIV is a "germ" and not caused by witchcraft.

2. Discuss what HIV does to the body?

   White blood cells help to fight infections in the body. HIV destroys these white blood cells. The body is then less able to fight infections. This starts happening before a person with HIV actually feels sick. Later, the person will get many infections such as chest infections, skin infections, diarrhoea and TB. Eventually the body becomes so weak that it can no longer fight the infections and the person may die.

Ulwazi kunye nokuqonda malunga neNtsholongwane kaGawulayo

1. Qwalasela uluvo lomgcini mntwana malunga nokuba abantwana bosuleleka njani kwiNtsholongwane kaGawulayo, nikezela ngenkcukacha ezilungileyo kwaye ulungise izinto ezingezizo.

   Intsholongwane kaGawulayo ingagqithela kumama okhulelweyo ukuya elusaneni lakhe ngexesha lokukhulelwa, lokubeleka, ngoku ncancisa (ukudibanisa: nokuncanciswa kosana ngomnye umntu ongenguye umama wakhe). Nangona, abantwana abahlukunyezwa ngezesondo bangosuleleka ngale ndlela. Gxininisa ukuba iNtsholongwane kaGawulayo yintsholongwane kwaye ayibangelwa kukuthakatha.

2. Thetha malunga nokwenziwa yiNtsho-longwane kaGawulayo emzimbeni?

   Amajoni omzimba anceda ukulwa ukosuleleka emzimbeni. Intsholongwane kaGawulayo iyawabulala lama joni omzimba. Umzimba uye usoyisakala ukulwa ukosuleleka. Oku kuqala ukwenzeka phambi kokuba umntu onale-Ntsholongwane kaGawulayo azive engaphilanga. Emva kwexeshana, umntu uye afumane ukosuleleka okuninzi okufana nesifuba, ukosuleleka kwesikhumba, ahambise abenaso nesifo sephepha [TB]. Emva kwethuba, umzimba uye uphelelwe ngamandla kangangokuba ade angakwazi nokulwa izifo kwaye umntu angade asweleke.

3. Discuss the difference between HIV infection & AIDS

Explain that people living with HIV infection may look and feel completely well. HIV infection progresses in the body from stage 1, in which no physical problems are felt by the person, to AIDS, in which there may be repeated serious infections, loss of weight and other illnesses (stage 4). In adults, it may even take 5-10 years for HIV infection to progress to AIDS but children often progress to AIDS much more quickly. Antiretroviral treatment stops HIV infection from progressing to AIDS. HIV infection may be spread from one person to another through unprotected sex, or from mother to child, at any time after HIV infection has occurred.

3. Thetha malunga nomahluko phakathi kweNtsholongane kaGawulayo kunye noGawulayo

Cacisa ukuba abantu abaphila neNtsholongwane kaGawulayo bangakhangeleka kwaye bazive bephilile ngokupheleleyo. Intsholongwane kaGawulayo iqhubekeka emzimbeni ukusuka kwinqanaba lokuqala, apho khona kungekho ngxakiumntu azivayo, ukuya kuGawulayo, apho khona kunokubakho ukuphinda-phindana okukhulu kwezifo, ukuhla komzimba kunye nezinye izifo (inqanaba lesine). Ebantwini abadala, ingathatha iminyaka esuka kwisihlanu ukuya kwishumi ukuba leNtsholongwane kaGawulayo iqhubekeke ukuba nguGawulayo kodwa emaxesheni amaninzi abantwana bayakhawuleza ukuqhubekela kuGawulayo. Unyango lwaleNtsholongwane [Antiretroviral treatment] lunqanda iNtsholongwane kaGawulayo ekukhuleni ukuya kuGawulayo. Intsholongwane kaGawulayo ingasasazeka emntwini omnye ukuya komnye ekwabelaneni ngesondo ungasebenzisi condom, ukusuka kumama ukuya elusaneni, nangaliphi na ixesha xa umntu esulelekile.

4. Discuss testing and diagnosis of HIV infection in children

Children with suspected HIV infection or children born to women who test positive for HIV during their pregnancy can be tested as early as 6 -14 weeks of age. This needs a different test from the one used in older children and adults; it is called a PCR test. Blood is taken from the baby and tested for HIV. If the child tests HIV negative and the mother is still breastfeeding, the child will need to have another HIV test at least 6 weeks after stopping breastfeeding. If the child tests HIV positive, a CD4 count and viral load test can be done.

4.1. Inform the caregiver about the need for routine blood taking once the child starts ARVs. This will only happen every 6 months. Reassure the caregiver that it may be stressful to the child (and caregiver), it does not cause harm.

4. Thetha malunga novavanyo kunye nokufunyaniswa kweNtsholongwane kaGawulayo ebantwaneni

Abantwana abarhanelwa ukuba baneNtsholongwane kaGawulayo okanye abazalwa ngomama abafunyaniswe benale ntsholongwane ngexesha lokukhulelwa, bangavavanywa kwithuba elingane veki ezintandatu ukuya kwezilishumi elinesine ubudala. Oku kufuna uvavanyo olwahlukileyo kolo lwenziwa ebantwaneni nasebantwini abadala; ibizwa ngokuba yiPCR. Igazi lithatyathwa elusaneni luvavanyelwe iNtsholongwane kaGawulayo. Ukuba usana lufunyaniswe lunayo lentsholongwane abe umama esancancisa, umntwana kufuneka aphinde avavanyelwe iNtsholongwane kaGawulayo emva kweveki ezintandathu emva kokuba umntwana eyekile ukuncanca. Ukuba umntwana ufunyaniswe eneNtsholongwane kaGawulayo, kuzakwenziwa uvavanyo lwamajoni omzimba kunye nobungakanani bentsholongwane.

4.1. Chazela umgcini mntwana ngemfuneko yotsalo magazi xa umntwana sele eqalile amachiza iARVs. (Lento izakwenzeka rhoqo kwinyanga ezintandathu). Phinda uqinisekise umgcini mntwana ukuba oku kusemokubangela uxinizelelo lwengqondo (stress) emntwaneni (nakumgcini mntwana); kodwa ayinabungozi.

5. Discuss what a CD4 count is

A CD4 count is a blood test to show the strength of a person's immune system. A high count means that the immune system is still strong enough to fight most common illnesses. A low CD4 count means that the body's defence system is weakened and the body is open to many illnesses. This test will be repeated every 6 months during ARV treatment to check if the immune system is getting stronger again. Explain that the doctor will report the child's CD4 result in percentage. This is different to the result given in adults which is expressed in general numbers.

5. Thetha malunga nokuba yintoni ubalo lwamajoni omzimba

Ubalo lwamajoni omzimba [CD4 Count] luvavanyo lwegazi ukubonakalisa amandla alamajoni omzimba emntwini. Ukuba ubalo luphezulu, oko kuthetha ukuba amajoni omzimba asenamandla ekulweni izifo ezixhaphakileyo. Ukuba ubalo luphantsi, oku kuthetha ukuba amajoni omzimba akanamandla kwaye umzimba ungafunyanwa zizigulo ezinintsi. Oluvavanyo luphindaphindwa rhoqo emva kwenyanga ezintandathu ukujonga ukuba amajoni omzimba aye eqina okanye aye esihla kwakhona. Cacisa ukuba ugqirha uzakuchaza olubalo lamajoni omzimba [CD4 Count] ngokwe percent. Oku kwahlukile kwiziphumo zabantu abadala eziye zithi zibonakaliswe ngamanani.

6. Discuss what a viral load is

A viral load is a blood test to show the amount of virus in the blood of a person with HIV infection. The viral load in children with HIV infection may be very high (millions of copies of virus in each teaspoon of blood) before antiretroviral treatment is started.

Successful treatment is able to bring down the amount of virus in the blood to a very low level - so low that the virus will not show up on the test (less than 50 copies of virus per millilitre of blood).

The treatment does not get rid of the virus completely but can stop the virus from making more copies of itself. This test will be repeated every 6 months during treatment.

6. Thetha malunga nobalo lobungakanani bentsholongwane

Ubalo ngobungakanani bentsholong-wane [viral load] luvavanyo lwegazi ukubonakalisa iqondo lentsholongwane kwigazi lomntu oneNtsholongwane kaGawulayo. Iqondo lobungakanani bentsholongwane ebantwaneni abaneNtsholong-wane kaGawulayo lingaba phezulu kakhulu (izigidi zekopi zentsholongwane kwicetshana ngalinye legazi) phambi kokuba unyango lwentsholongwane luqaliswe.

Unyango oluyimpumelelo lolukwaziyo ukuhlisa izinga lentsholongwane egazini ukuya kutsho kwelona zinga eliphantsi – phantsi kangangokuba intsholongwane ingabonakali kuvavanyo (ngaphantsi kwekopi ezingamashumi amahlanu entsholongwane kwi millilitre zegazi).

Amayeza awakwazi ukuyifunda intshologwane ngokupheleleyo kodwa ayakwazi ukuyenza intshologwane iyeke ukwenza (ukuzala) ezinye intsholong-wane zayo. Uvavanyo luyakuphindwa emva kwe nyanga ezintandathu uthatha amayeza.

7. Explore whether the caregiver understands that the child will be started on antiretroviral treatment and that this treatment is lifelong.

It is very important for the caregiver to understand that antiretroviral treatment does not cure the child of HIV infection but can keep the infection from getting worse and making the child weaker. Unlike many other treatments (such as for TB), ARV treatment must be continued for a person's whole life. If the treatment is given properly, the child can remain healthy for many years. If the treatment is stopped or not given to the child correctly, HIV infection will get worse and the child may become sicker and die.

7. Qwalasela ukuba ingaba umgcini womntwana uyayiqonda into yokuba umntwana uzakuqalisa unyango ngamachiza eNtsholongwane kaGawulayo kwaye olunyango uzakulisebenzisa ubomi bakhe bonke.

Kubaluleke kakhulu ukuba ayazi umgcini womntwana ukuba olunyango aluyiphelisi intsholongwane elusaneni, kodwa lungagcina intsholongwane ekubeni ikhule kwaye yenze usana luphelelwe ngamandla. Ngokwahluka kolunyango kwamanye (njenge sifo sephepha – TB), olunyango lwalentsholongwane [ARVs] kufuneka zisetyenziswe ubomi bomntu bonke. Ukuba unyango lunikezelwa ngendlela elungileyo, umntwana angahlala ephilile iminyaka emininzi. Ukuba unyango luyekisiwe okanye alunikezelwa emntwaneni ngendlela elungileyo, iNstholongwane kaGawulayo iyakhula kwaye umntwana angagula ade asweleke.

COUNSELLOR'S CHECKLIST

Session 1

Date: _____ Counsellor's Name: _____

Introduction to Health Care Team and functions

1. Introduce yourself and explain your role in the team.
2. Establish a basis for beginning to talk about the child starting ARVs.
   a. Ask about the child (name, age etc.)
   b. Enquire what the caregiver knows about the child's condition

Caregiver & household details

3. Who mainly looks after the child? . . . . . ☐
4. Who are all the people involved in caring for the child? . . . . . ☐
5. Who will be responsible for giving the medication? Who else? . . . . . ☐
6. Treatment assistant identified? . . . . . ☐
7. Who looks after the child during the day? . . . . . ☐
8. Household routine during the week . . . . . ☐
9. Household routine during the weekends . . . . . ☐

General HIV & AIDS knowledge and understanding

1. How children get HIV infection . . . . . ☐
2. What HIV does to the body . . . . . ☐
3. Difference between HIV infection & AIDS . . . . . ☐
4. Testing for HIV infection in children . . . . . ☐
5. CD4 counts . . . . . ☐
6. Viral loads . . . . . ☐
7. Lifelong antiretroviral treatment . . . . . ☐

Counselling session 2

Objectives

The two main objectives are:

a) to give the caregiver an understanding about ARV treatment in general

b) to discuss adherence to treatment.

It is important to listen to what the caregiver expects and fears about the treatment.

Iseshoni yesithathu yokucebisa 2

Injongo

Ezona njongo ziphambili zezi:

a) Ukunika umgcini womntwana umqondo malunga nonyango lweNtsholongwane kaGawulayo ngokuphangaleleyo.

b) Ukuxoxa malunga nokusebenzisa unyango ngendlela elungileyo

Kubalulekile kakhulu ukumamela kwizinto ezilindelwe nezoyikwayo ngumgcini womntwana malunga nolunyango.

Antiretroviral treatment

1. Discuss when children with HIV infection will start ARVs.

   Antiretroviral treatment is only used when HIV infection has progressed to stage 3 or 4 or if the CD4 count is low. Some babies and children will already be in stage 3 or 4 when they first get sick and need to start treatment sooner than other children.

Unyango ngamachiza eNtsholongwane kaGawulayo

1. Thetha malunga nokuba abantwana abaneNtsholongwane kaGawulayo baluqala nini unyango

   Unyango ngamachiza eNtsholongwane kaGawulayo lusetyenziswa kuphela xa iNtsholongwane kaGawulayo ikhulile ukuya kutsho kwizinga lesithathu okanye lesihlanu, okanye xa ubalo lwamajoni omzimba luphantsi. Abanye abantwana bathi beqala nje ukugula babe bekwizinga lesithathu okanye lesine kwaye kufuneke beqalise msinyane kunabanye abantwana.

Before starting antiretroviral treatment, doctors and counsellors need to be sure that the caregiver:

- Understands and accepts that the child has HIV infection
- Has shown that they are able to bring the child to the clinic regularly for appointments.
- Is willing to take responsibility for giving medication to the child every day.
- Understands how to give the treatment correctly to the child and that the treatment is life-long.
- Has the opportunity to join a support group.

It is preferable that:

- The caregiver has at least begun the process of disclosure of the HIV status to the child in an age-appropriate manner
- The caregiver has disclosed the HIV status of the child to someone else who is able to take care of the child and give the medicine if necessary (secondary caregiver).
- The caregiver has shown that they can give other medications to the child such as bactrim or TB drugs.
- The caregiver has also been tested for HIV infection. If the caregiver has HIV infection, he/she should know their CD4 count and be attending an HIV clinic.

Phambi kokuba uqalise unyango lweNtsholongwane kaGawulayo, ugqirha kunye nabaniki-ngcebiso kufuneka beqinisekile ukuba umgcini womntwana u:

- Aqonde kwaye amkele into yokuba umntwana uneNtsholongwane kaGawulayo.
- Ebonakalisile ukuba bayakwazi ukusa umntwana ekliniki rhoqo ngamaxesha otyelelo.
- Unomdla wokuthabatha inxaxheba ekunikezeleni amayeza emntwaneni yonke imihla.
- Uyakwazi ukunika amayeza ngendlela elungileyo emntwaneni kwaye unyango bubomi bonke.
- Unethuba lokungena kwiqela elinika inkxaso (support group).

Ingaba kuyinkuthazo ukuba:

- Umgcini-mntwana uqalisile ukuchaza ngesimo seNtsholongwane kaGawulayo emntwaneni ngendlela elungele iminyaka yomntwana.
- Umgcini-mntwana uchazile ngesimo somntwana ngokwe Ntsholongwane kaGawulayo komnye umntu onako ukukhathalela umntwana kwaye amnike amayeza xa kukho imfuneko (umgcini-mntwana wesibini).
- Umgcini-mntwana ubonakalisile ukuba angakwazi ukunika umntwana amanye amayeza afana ne bactrim okanye esifo sephepha (TB).
- Umgcini-mntwana ulwenzile uvavanyo lweNtsholongwane kaGawulayo. Ukuba umgcini-mntwana uneNtsholongwane kaGawulayo, uyalazi izinga wamajoni omzimba kwaye uhamba ikliniki yeNtsholongwane kaGawulayo.

2. Discuss how ARVs works against the virus

Antiretroviral treatment can kill most of the HIV in the body but cannot cure the body from HIV completely. If the treatment is used correctly, the body's immune system becomes strong again and protects the person from most infections and diseases. There are many different ARVs but they work best when three or more ARVs are taken together. The three different ARVs work together so it's better to take all or none rather than some of the treatment. Missing doses of medicine or stopping any of the treatment will allow the HIV to grow in the body again.

2. Thetha malunga nokuba amachiza eNtsholongwane kaGawulayo asebenza njani ukulwa intsholongwane.

Unyango ngamachiza eNtsholongwane kaGawulayo ayayibulala inxalenye yeNtsholongwane kaGawulayo emzimbeni kodwa akakwazi ukuyiphelisa ngokupheleleyo emzimbeni. Ukuba unyango lusetyenziswa ngendlela elungileyo, amajoni omzimba abanamandla aphinde kwaye akhusele umntu kwizifo ezininzi ezosulelayo. Zininzi intlobo zamachiza anyanga iNtsholongwane kaGawulayo kodwa zisebenza ngcono xa intlobo zintathu, okanye ngaphezulu, zithatyathwa ngexesha elinye.
Indidi ezintathu zamachiza eNtsholongwane kaGawulayo zisebenza zonke, kengoko kubalulekile ukuzisebenzisa zonke okanye ungathathi kwanto kunokuthi uthathe nje enye. Ukuphosa ukusela amayeza okanye ukuyeka ukusebenzisa olunyango kunganika ithuba iNtsholongwane kaGawulayo ukuba ikhule kwakhona.

Adherence to treatment

Adherence means ensuring that the child always gets the medication at the right time in the right dose as prescribed

Giving a child medication twice a day every day for months and years is a very big responsibility. At times, it may seem an impossible task and nobody can always achieve perfect adherence. One of the aims of this session is to try to allow caregivers to feel supported in the task of doing the best they can in treating their child.

Ukusebenzisa amayeza ngokuyimfuneko

Ukusebenzisa amayeza ngokufanelekileyo kuthetha ukuba umntwana soloko efumana amayeza ngexesha elililo, nomlinganiselo onguwo njengokuba kubhaliwe.

Ukunika umntwana amayeza kabini ngemini intsuku zonke iinyanga kunye noonyaka ngumsebenzi omkhulu. Emaxesheni, kungakhangeleka kuyinto engakwazi kwenzeka kwaye akukho mntu unokusoloko egqwesile ekunikezeni amayeza ngokulungileyo. Enye yenjongo zale seshoni kukuzama ukuvumela abagcini-bantwana ukuba bazive bexhaswa kumsebenzi wokuzimisela ekunikezeleni abantwana amayeza.

1. Discuss the importance of adherence with the caregiver.

ART does not cure HIV infection but keeps the virus level under control in the body. Therefore it is necessary to continue the treatment for the rest of the child's life. Over time, the virus is able to build up resistance to the ARVs and the treatment may no longer work well. The body may then become weak and develop AIDS. This can happen much more quickly if the medication is not given correctly or if even a few doses of medication are missed. At the moment, there are only two good ARV regimens (first-line and second-line) available to children and adults. The aim is to remain on the first-line regimen for as long as possible while it is able to keep the virus level under control. If the virus level is not under control, it may be necessary to switch to three different ARV medications (second-line treatment).

1. Theha nomgcini-mntwana malunga nokubaluleka kokunika umntwana amayeza ngendlela elungileyo.

Unyango lweNtsholongwane kaGawulayo aluyiphelisi lentsholongwane, kodwa luyigcina lentsholongwane ikwiqondo elilawulekayo emzimbeni. Kengoku, kubalulekile ukuqhubeka nolunyango ebomini bonke bomntwana. Emva kwexesha, intsholongwane iyakwazi ukuwalwa lamachiza [ARVs] kwaye unyango lungasebenzi ngendlela elungileyo. Umzimba ungaphelelwa ngamandla kwaye uvelise uGawulayo. Oku kungenzeka ngokukhawuleza ukuba amayeza akanikezwa ngendlela elungileyo okanye noba umntwana uphose kancinci ukusela amayeza. Okwa ngoku, zimbini kuphela intlobo ezibalaseleyo zamachiza eNtsholongwane kaGawulayo (isihlandlo sokuqala kunye nesihlandlo sesibini) ezikhoyo ebantwaneni nasebantwini abadala. Injongo kukuhlala kwisihlandlo sokuqala kangangoko kunokwenzeka, njengokuba kukwazeka ukugcina intsholongwane ikwiqondo elilawulekayo. Ukuba iqondo lentsholongwane alilawuleki, kungayimfuneko ukutshintshela kumachiza amathathu ahlukeneyo entsholongwane (isihlandlo sesibini sonyango).

2. Discuss things that help adherence

- **Caregiver self-care**: the caregiver should take care of his/ her own health and well-being. Caregivers who are also living with HIV infection should be attending an HIV clinic so that they can receive health care and treatment if necessary. For many caregivers, attending a support group is a helpful way to learn from others.

  Encourage the caregiver to know her/his HIV status. If HIV infected, she/he should go for monitoring of CD4 count if not in care.

- **Keeping a routine**: giving medication to the child should be built into the daily life of the family. It is easier to give it correctly if there is a regular routine at home e.g. the child wakes, eats, sleeps at a similar time each day etc.

2. Thetha ngezinto ezinceda ukusebenzisa amayeza ngendlela elungileyo.

- **Ukuzikhathalela komgcini-mntwana**: Umgcini mntwana kufuneka akhathalele impilo yakhe kunye nendlela aphila ngayo. Abagcini bantwana abaphila neNtsholongwane kaGawulayo kufuneka babe behamba ikliniki enyanga lentsholongwane ukwenzela ukuba bafumane unyango ukuba kukho imfuneko. Kubagcini bantwana abaninzi, ukuhamba amaqela enkxaso kubaluncedo ekufundeni kwabanye abantu.

  Khuthaza umgcini mntwana ngokwazi isimo sakhe sentsholongwane kagawulayo. Ukuba uchaphazelekile, makayokualola amajoni omzimba wakhe ukuba akakho selukhathalelweni.

- **Ukugcina inkqubo**: Ukunikeza amayeza emntwaneni kufuneka kudityaniswe nenkqubo yekhaya. Kubalula ukunika umntwana amayeza kakuhle ukuba kukho inkqubo yekhaya, umzekelo ukuvuka komntwana, ukutya, ukulala ngexesha elinye mihla le, njalo njalo.

- **Disclosure of the child's HIV status:** Disclosure of the child's HIV status to another person who is supportive and helpful is very important for ensuring that the child receives this life-saving medication correctly.

  When the primary caregiver is unavailable, whoever takes care of the child should understand exactly how to give the medication and know the importance of giving the medication.

  If the child is at the age where they can understand about illness and medication, the importance of them taking medication for their illness should be discussed with the child over time. For very young children, telling stories about the virus and taking medicines is one way of allowing a more open discussion of the child's HIV status later when the time is right.

- **Ukuchaza isimo somntwana malunga neNtsholongwane kaGawulayo:** Ukuchaza isimo somntwana malunga neNtsholongwane kaGawulayo komnye umntu onika inxaso noluncedo, kubaluleke kakhulu ekuqinisekiseni ukuba umntwana ufumana olunyango lusindisa ubomi ngendlela elungileyo.

  Xa oyena mgcini-mntwana engekho, nabani na ojongene nomntwana kufuneka azi kakuhle indlela yokunika umntwana amayeza kwaye ayazi indlela ebalulekileyo yokunika umntwana amayeza.

  Ukuba umntwana ukunyaka apho khona anokuqonda malunga nokugula kunye namayeza, ukubaluleka kwabo ekuzithatheleni amayeza esigulo sabo kufuneka kuxoxwe nomntwana ngamaxesha athile. Ebantwaneni bonke abancinci, ukubalisa amabali malunga nentsholongwane nokuthatha amayeza kuyenye yendlela yokuvumela ukuthetha banzi malunga nesimo somntwana malunga neNtsholongwane kaGawulayo emva kwethuba xa ixesha lilungile.

3. Discuss things that interfere with good adherence:

- **Substance or alcohol abuse by the caregiver:** leads to disruption in the daily routine and "forgetting" to give the medication.

- **Physical or mental health problems of the primary caregiver**: the caregiver may be too unwell to remember to give medication or be hospitalised. The child may then be left in the care of those who do not know how to give ART or the importance of giving it. The caregiver may also experience anxiety or depression which may interfere with caring for the child. The caregiver can be encouraged to get assistance from friends or family and be referred for health care.

- **Refusal to take medication by the child**: it may become a very difficult experience for both the caregiver and child. If the caregiver feels stressed by these difficulties, she/he may be tempted to skip doses of the child's medication. This can often be overcome by providing practical advice and counselling on tips for medication administration or a discussion on disclosure of the child's health or HIV status (depending on the age of the child).

3. Thetha ngezinto ezichaphazela ukusebenzisa amayeza ngendlela elungileyo:

- **Ukuzintyintya ngotywala okanye ezinye izinto**: kubangela ukuphazamiseka kwinkqubo yemihla le, kwaye kulibaleke ukunika umntwana amayeza.

- **Ukuthibazeka engqondweni okanye emzimbeni komgcini-mntwana**: umngcini-mntwana angagula kakhulu angakwazi kukhumbula ukunika umntwana amayeza okanye ukumsa esibhedlele. Umntwana angashiywa phantsi kwabo bangazinto ngokunika umntwana amachiza eNtsholongwane kaGawulayo okanye ukubaluleka kokunika umntwana amayeza. Umngcini-mntwana angaphinde afumane ukungaziva kakuhle okanye ephantsi, nto leyo inokuthi ichaphazele ukukhathalelwa komntwana. Umngcini-mntwana angakhuthazwa ekuncedisweni ngumhlobo okanye isizalwane kwaye athunyelwe ukuze afumane uncedo lezempilo.

- **Ukwala komntwana ekuthabatheni amayeza**: kungaba yinto enzima kakhulu kumgcini-mntwana nasemntwaneni. Ukuba umgcini-mntwana uziva edakumbile ngenxa yobunzima, angazifumana ekwimo emenza ukuba atsibe ekunikezeleni umntwana amayeza. Oku ungakohlula ngokunikezela imiyalelo kunye nengcebiso kwindlela zokujongana nalamayeza okanye ingxoxo malunga nokuchaza ngempilo yomntwana okanye ngemo yeNtsho-longwane kaGawulayo (kube kuxhomekeke eminyakeni yomntwana).

- **'Running out of medication'**: this should never happen. The caregiver should learn to recognise when the medication is running low and ensure they get more medication from the clinic BEFORE any one of the medications runs out. This is very important if the child and caregiver are travelling away from home e.g. to the Eastern Cape, and will not easily be able to get hold of medication.

- **Ukuphelelwa ngamayeza**: oku akufunekanga kwenzeke. Umngcini-mntwana kufuneka azifundise xa amayeza esiya ekupheleni kwaye aqinisekise ukuba bafumana amayeza aneleyo PHAMBI kokuba elinye lamayeza liphele. Oku kubaluleke kakhulu ukuba umntwana kunye nomgcini-mntwana baseluhambeni beshiya ikhaya, umzekelo ukuya eMpuma Koloni, kwaye xa kuza kubanzima ukufumana amayeza.

Disclosure of the child's HIV status to another person who is supportive and helpful is very important for ensuring that the child receives this life-saving medication correctly.

Ukuthetha malunga nesimo somntwana seNtsholongwane kaGawulayo komnye umntu oluncedo nokhathalela umntwana kubalulekile ekuqinisekiseni ukuba umntwana uyawanikwa amayeza ngendlela elungileyo.

COUNSELLOR'S CHECKLIST

Session 2

Date: _____

Counsellor's Name: _____

Antiretroviral treatment:

1. When ARVs are started in children . . . . . ☐
2. How ARVs work against the virus . . . . . ☐

Adherence:

1. What adherence means and why it is important . . . . . ☐
2. Things that help adherence . . . . . ☐
3. Things that interfere with good adherence . . . . . ☐

Counselling session 3

Objectives

The session may be done on the day of starting antiretroviral treatment. The caregiver must be equipped with the practical skills and confidence to administer medication to the child. The two main objectives are:

a) To demonstrate how to prepare and administer the medication allowing the caregiver to practice this process.

b) To discuss possible side effects and problems that may arise after starting treatment.

Note: The counsellor should now check with the doctor which anti-retroviral drugs the child will be starting. Use the appropriate demonstration box to teach the caregiver how to prepare the medicines for the child and give time for discussion and questions.

Iseshoni yesithathu yokucebisa 3

Injongo

Le seshoni ingenziwa ngosuku lokuqalisa unyango leNtsholongwane kaGawulayo. Umngcini-womntwana kufuneka anikezwe amava kunye nokuzithemba ekunikeni umntwana amayeza. Injongo ezimbini eziphambili zezi zilandelayo:

a. Ukubonakalisa indlela zokulungiselela kunye nokujongana namayeza kuvumele umngcini-womntwana ukuba afunde lendlela.

b. Ukuxoxa malunga nezinto ezinokuvela ezingalindelekanga (side effects) kunye nengxaki ezinokuvela emva kokuqalisa unyango.

Qapela: Umcebisi kufuneka ngoku ajonge kugqirha ukuba ngawaphi amayeza eNtsholongwane kaGawulayo umntwana azakuwaqalisa. Sebenzisa ibhokisi ecacisayo ekufundiseni umgcini-mntwana ukuba ulungiselelwa njani umntwana amayeza kwaye unike ixesha lokuxoxa kunye nelokubuza.

1. Emphasize the importance of giving the child the correct amount of medication at the right time every day.

Explain that the doctor and pharmacist will show the caregiver the exact dose of each medication to be given to the child and how to draw it up into the syringe. The doctor may change the doses at each clinic visit as the child grows and gains weight.

The caregiver should try to give the medication at the same time every day (morning and evening e.g. 7am and 7pm). If this time is accidentally 'forgotten' or 'missed', the medication should still be given late and not left out altogether. Work out with the caregiver what kind of reminder tool they will use e.g. cell phone alarm, watch, clock.

Allow the caregiver to figure out with you how they plan to fit giving the medication to the child into their daily life:
a) in the morning
b) at night
c) at weekends
d) when they're away from home

1. Gxininisa ukubaluleka kokunika umntwana imilinganiselo elungileyo ngexesha elilungileyo ntsuku zonke.

Cacisa ukuba ugqirha nomgcini-mayeza bazakubonisa umngcini-womntwana imilinganiselo eyiyo eyeza ngalinye ekufuneka liseliswe umntwana nokuba ulitsala njani liye kwisirinji (syringe). Ugqirha angayitshintsha imilinganiselo kutyelelo lasekliniki ngelinye ixesha kuba umntwana ekhula kwaye ebamkhulu ngomzimba.

Umgcini-womntwana makazame ukunika umntwana amayeza ngexesha elinye ntsuku zonke (kusasa nasebusuku, umzekelo 7am kunye 7pm). Ukuba eli xesha kuye kwenzeka ukuba lilibaleke okanye liphosakale, amayeza anganikezwa umntwaneni emva kwexesha kwaye angavelwe ayekwe nje. Bonisana nomgcini womntwana ukuba zeziphi indlela zokuzikhumbuza abanokuzisebenzisa, umzekelo imfono-mfono okanye iwatch.

Nika umgcini-womntwana ithuba lokuba abonisane nawe ukuba zeziphi indlela zokudibanisa ukunika umntwana amayeza kunye nendlela abaphila ngazo mihla le:
a. kusasa
b. ebusuku
c. ngempela-veki
d. xa bekude nekhaya

2. Discuss the importance of the caregiver knowing the child's ARV treatment.

It is important that the caregiver tells the nurse or doctor at the clinic or hospital that the child is taking antiretroviral treatment. The caregiver should be able to give the name of each medicine, and the correct dose for each medicine. All the medicines should always be taken with the child to the hospital or clinic in case the child is admitted to hospital.

3. Discuss possible side-effects of ARVs and what to do

Emphasise to the caregiver that most children will have no side-effects from the medications. Depending on which medications the child is receiving, some children may develop rash, vomiting or diarrhoea. Emphasise that these will usually pass after about 1-2 weeks. These complaints may also result from HIV infection itself. If the child vomits or spits out any of the medications (e.g. Kaletra) the full dose of the medications given must be repeated.

More serious side effects are monitored by blood-tests – to see if there are effects on the liver (hepatitis) or blood (anaemia). This monitoring will be done regularly by the clinic (approx. 3-6 monthly depending on the treatment

2. Thetha malunga nokubaluleka kokuba umgcini-womntwana azi malunga namayeza omntwana eNtsholongwane kaGawulayo.

Kubalulekile ukuba umngcini-womntwana axelele umongikazi okanye ugqirha ekliniki okanye esibhedlele ukuba umtwana usebenzisa amayeza eNtsholongwane kaGawulayo. Umgcini-womntwana kufuneka awazi amagama alamayeza ngalinye, kunye nemilinganiselo eyiyo kwiyeza ngalinye. Onke amayeza kufuneka ahambe nomntwana xa esiya esibhedlele okanye ekliniki ukulungiselela umntwana xa enokulaliswa esibhedlele.

3. Thetha malunga neziphumo ezisecaleni ezinokuvela xa usebenzisa amayenza eNtsholongwane kaGawulayo kunye nokuba kufuneka enze ntoni.

Gxininisa kumgcini-womntwana ukuba abantwana abaninzi abazifumani ezi ziphumelo zivela ekusebenziseni lamayeza. Kuxhomekekile ukuba umntwana ngawaphi amayeza awasebenzisayo, abanye abantwana bangaphuma irhashalala, bakhuphe, okanye bahambise. Gxininisa ukuba oku kuza kugqitha emva kweveki enye okanye ezimbini. Ezi zikhalazo zingabangelwa yiNtsholongwane kaGawulayo buqu. Ukuba umntwana uyakhupha okanye uyalithufa iyeza (umzekelo iKaletra) lonke, kufuneka umntwana aphinde anikwe kwakhona.

Iziphumo ezisecaleni ziyabona-kaliswa kuvavanyo lwegazi – ukubokalisa ukuba kukho ingxaki kwisibindi okanye egazini. Oku kuqwalaselwa kuzakwenziwa rhoqo yikliniki (ukusuka kwinyanga ezintathu ukuya kwezintandathu, kuphinde kuxhomekeke kunyango olo) xa umntwana

regimen) for as long as the child is taking ARVs (life-long). If the caregiver is concerned about the child's condition, they should contact the clinic or bring the child to the hospital.

4. Problems after starting ARV treatment and changing treatment regimens

Some children may become unwell during the first few weeks after starting ARVs and may require further tests (e.g. for TB) or even be admitted to hospital. This can happen even though the child's immune system is getting stronger on the treatment.

The doctor may decide to change the ARVs to a different treatment regimen. Before changing treatment the doctor and counsellor must be sure that the ARVs are being given correctly and doses are not being missed. As there are not many different ARVs available to children we must aim for the first-line treatment to work for the child for as long as possible.

esasebenzisa lamayeza (ubomi bonke). Ukuba umgcini-womntwana uxhalabile malunga nempilo yomntwana, kufuneka aqhakamshelane nekliniki okanye ase umntwana esibhedlele.

4. Ingxaki emva kokuqalisa amayeza eNtsholongwane kaGawulayo kunye nokutshintsha amayeza.

Abanye abantwana bangangaphili kwiveki yokuqala emva kokuba eqalise amayeza, kwaye angafuna olunye uvavanyo (umzekelo, uvavanyo lwesifo sephepha – TB) okanye alaliswe esibhedlele. Oku kungenzeka nokuba amajoni omzimba omntwana aye abanamandla lolunyango.

Ugqirha angafikelela ekubeni atshintshe amayeza eNtsholongwane kaGawulayo ukuya kumanye amayeza. Phambi kokuba atshintshe olunyango ugqirha kunye nomcebisi kufuneka baqiniseke ukuba lamayeza asetyenziswa ngokulungileyo kwaye namaxesha okusela akalityalwa. Kuba engekho maninzi amayeza eNtsholongwane kaGawulayo akhoyo ebantwaneni, kufuneka sizame ukuba isihlandlo sokuqala sonyango siyasebenza emntwaneni kangangoko kunokwenzeka.

What the caregiver should remember once the child starts ARVs

- Learn the names and doses of the ARVs
- Always bring back ARV containers to each clinic or pharmacy visit. (only unopened containers and containers currently being used, empty containers may be thrown away at home)
- Keep appointments for pharmacy repeats and clinic follow-up. Sometimes you may be expected to just collect medicines and not bring the child for a check-up.
- If you think that the medications will run out before the next appointment, you should come to the hospital anyway to collect more medication.
- Do not continue giving some medication if you've run out of any – get to the clinic or hospital for more as soon as possible.
- Always bring ARVs with the child if the child is taken to the clinic or hospital because the child is ill.
- Do not stop the ARVs for any reason without first discussing it with the doctor – your child's life may depend on it!

Yintoni into umgcini-womntwana ekufuneka eyikhumbule xa umntwana eqalisa amayeza eNtsholongwane kaGawulayo

- Ukufunda amagama kunye nemilinganiselo yamayeza
- Kufuneka esoloko esiza nebhotile zamayeza xa esiza ekliniki okanye kwindawo yamayeza (ngamayeza angekavulwa kuphela kunye nebhotile ezisebenzileyo, ibhotile ezingaphethanga zinokulahlwa ekhaya)
- Gcina amasuku otyelelo kwicandelo lamayeza kunye namaxesha otyelelo ekliniki. Ngamanye amaxesha ulindeleke ukuba uzokuthatha amayeza kuphela ungezanga nomntwana.
- Ukuba ucinga ukuba amayeza azakuphela phambi kolunye utyelelo lase kliniki, kufuneka uze esibhedlele uzo kuthatha amayeza.
- Musa ukuqhubekeka unika umntwana amanye amayeza ukuba uphelelwe ngamanye – yiya eklinikio-kanye esibhedlele ufumane amanye.
- Soloko usizisa amayeza nomntwana ukuba umntwana usiwa ekliniki okanye esibhedlele ngenxa yokugula.
- Sukuyeka ukunika umntwana amayeza nokuba kungesiphi na isizathu ungakhange uthethe nogqirha – ubomi bomntwana buxhomekeke kuwo.

COUNSELLOR'S CHECKLIST

Session 3

Date: _____

Counsellor's Name: _____

ARV Regimen: **ARV Start Date:** _____

1. _____

2. _____

3. _____

1. Knowing the child's ARVs . . . . . ☐
2. Correct dosing at regular times . . . . . ☐
3. Any specific food requirements explained . . . . . ☐ N/A ☐
5. Demonstrate opening of child-proof medicine caps . . . . . ☐
6. Demonstrate use of syringes . . . . . ☐
7. Demonstrate mixing of caps with water . . . . . ☐ N/A ☐
8. Discuss refrigeration requirements and practice . . . . . ☐ N/A ☐
9. Discuss swallowing of capsules . . . . . ☐
10. Side-effects of ARVs . . . . . ☐
11. Problems after starting ARVs and changing treatment regimens . . . . ☐
12. What to remember once the child starts ARVs . . . . . ☐

Counselling Guidelines on Medication

First-line regimens

1. Stavudine solution/capsules (D4T) + Lamivudine (3TC) + Kaletra (KLT)
2. Zidovudine solution (AZT) + Lamivudine (3TC) + Kaletra (KLT)
3. Stavudine capsules (D4T) + Lamivudine (3TC) + Efavirenz (EFV)

Second-line regimens

1. Zidovudine (AZT) + Didanosine (DDI) + Efavirenz (EFV)
2. Zidovudine (AZT) + Didanosine (DDI) + Kaletra (KLT)

Points to emphasize

1. Indicate the names of the medications to the caregiver (use "Stavudine", "Lamivudine", "Kaletra", "Ritonavir", "Zidovudine", "Didanosine"), showing where the names appear on the bottles. Explain the colour coding system for the different medications and syringes.

Imigaqo Yokucebisa Malunga Namayeza

Isihlandlo sokuqala sonyango

1. Stavudine solution/capsules (D4T) + Lamivudine (3TC) + Kaletra (KLT)
2. Zidovudine solution (AZT) + Lamivudine (3TC) + Kaletra (KLT)
3. Stavudine capsules (D4T) + Lamivudine (3TC) + Efavirenz (EFV)

Isihlandlo sesibini sonyango

1. Zidovudine (AZT) + Didanosine (DDI) + Efavirenz (EFV)
2. Zidovudine (AZT) + Didanosine (DDI) + Kaletra (KLT)

Izinto ekufuneka zigxininisiwe

1. Chaza amagama amayeza kumgcini-womntwana (sebenzisa "Stavudine", "Lamivudine", "Kaletra", "Ritonavir", "zidovudine", "Didanosine"), ubonakalise apho amagama ebhotile abhalwe khona. Cacisa malunga nemibala-bala esetyenzisiweyo kumayeza ahlukeneyo kunye nesirinji (syringes).

2. All three of the prescribed medications are to be given every day of the week. Efavirenz is given once a day in the evening. All other medications are given twice a day in the morning and in the evening as near to the same time each day as possible (e.g. 7am and 7pm). If the normal time for medication is missed the medications should still be given 'late'.

2. Omathathu amayeza owanikiweyo kufuneka umselise umntwana ntsukuzonke zeveki. IEfavirenz inikwa kanye ngemini ebusuku. Onke amanye amayeza anikwa kabini, kusasa nasebusuku, ngamaxesha afanayo kusasa nasebusuku ukuba ikhona indlela (7am kusasa nango 7pm ngokuhlwa). Ukuba ixesha lesiqhelo lilityelwe, amayeza kusafuneka enikiwe emntwaneni emva kweloxesha.

3. If any of the medications are going to run out before the next clinic appointment is due, the caregiver must come to the clinic before the appointment and get more medication so as to avoid any interruption in treatment.

3. Ukuba elinye lamayeza liphelela esithubeni phambi kokufika kotyelelo oluzayo, umgcini-mntwana kufuneka eze ekliniki phambi kosuku lotyelelo aze afumane amanye amayeza ukunqanda ukuphelelwa ngamayeza.

4. Ensure that the caregiver is able to open the bottles of stavudine and Kaletra (child-proof caps) and can demonstrate this to you.

4. Qinisekisa ukuba umgcini-womntwana uyakwazi ukuvula ibhotile zeStavudine kunye neKaletra (ezinesiciko esenziwe ngendlela yokuba umntwana angakwazi kusivula) kwaye uyakwazi ukubonakalisa.

5. Show the caregiver how to insert and use the syringe adaptors for the lamivudine and zidovudine bottles that allow the dose of medication to be drawn into the syringe directly from the bottle. For stavudine solution, Kaletra and ritonavir it is necessary to carefully pour medication into the small plastic cup and then draw it into the syringe or administer directly from the cup, although this may result in spills. Make sure that the caregiver can read the measurements on the syringe and understands what the lines mean.

5. Bonisa umgcini-womntwana ukuba ifakwa njani, ize isetyenziswe njani isirinji kwibhotile yeLamivudine kunye neZidovudine ukuvumela umlinganiselo weyeza ukuba utsalwe yisirinji ukusuka ebhotileni. Kwi Stavudine, Kaletra kunye neRitonavir, kuyimfuneko ukugalela iyeza ngobulumko kwikomityi yeplastiki encinci, uze ulitsale ngesirinji okanye umselise umntwana ngale komityi, nangona usenokuchitha. Qinisekisa ukuba umgcini-womntwana uyakwazi ukufunda imilinganiselo ekwisirinji kwaye uyayiqonda ukuba imigca imele ntoni.

6. After adding water to the stavudine bottle (up to the mark), the solution requires refrigeration (but should not be placed in the freezer). It should only be removed from the refrigerator for drawing up doses at the time of giving medication to the child (twice daily). If the caregiver is going to be staying in a home with no fridge or if the fridge is not working, she should inform the doctor who will prescribe different medication that does not require refrigeration.

6. Emva kokudibanisa amanzi kwibhotile yestavudine(igcwalisiwe), umxube uza kufuna ukugcinwa ekwisibandisi (kodwa ingabekwa emkhenkceni). Kufuneka ikhutshwe kwisibandisi kuphela ngexesha lokunika umntwana amayeza (kabini ngemini). Ukuba umgcini-mntwana uzakuhlala endlini engenasibandisi okanye apho isibandisi singasebenziyo, kufuneka axelele ugqirha ukuze banikeze ngamayeza ahlukileyo, angafuni sibandisi.

7. Stavudine bottles that have been mixed up with water and are in use should not be brought to the clinic at follow-up visits (except if in a 'cooler-bag' with ice bricks). Unused bottles of stavudine and bottles of lamivudine, zidovudine and Kaletra (opened and unopened) should be brought to each clinic visit.

7. Iibhotile zeStavudine ezithe zaxutywa namanzi zaze zasetyenziswa akufunekanga ziziswe eklinikhi kutyelelo olulandelayo (ngaphandle kokuba isesingxobeni esibandayo esinemikhenkce). Iibhotile ezingekasetyenziswa zeStavudine kunye neebhotile zeLamivudine, Zidovudine kunye neKaletra (zivuliwe kunye nezingavulwanga)kufuneka ziziswe kutyelelo lwekliniki ngalunye.

8. The caregiver should be made aware that Kaletra and ritonavir have a very bitter taste and many children have difficulty swallowing the medication for the first few days or weeks. This may result in refusal to take the medication, crying and conflict around medication times. Offer the caregiver strategies to help with this situation should it arise e.g. giving a sweeter medication such as stavudine followed by Kaletra or ritonavir followed by lamivudine; mixing all three medications together in the plastic cup and giving this in one syringe; giving the child something sweet (e.g. jam, peanut butter) or cold (e.g. ice) in the mouth before and/or after the dose to hide the bitter taste. It helps

8. Umgcini-mntwana kufuneka aziswe ukuba iKaletra kunye neRitonavir zinencasa ekrakra kwaye abantwana abaninzi banobunzima bokuginya amayeza kwintsuku ezimbalwa zokuqala okanye iiveki. Lento inganeziphumo zokungathabathi amayeza, ukulila kunye nengxabano ngamaxesha okunika amayeza. Nika umgcini-mntwana indlela zokunceda kulemeko xa ithe yavela, umzekelo ukunika amayeza anencasa anjengeStavudine ilandelwe yiKaletra okanye iRitonavir ilandelwe yiLamivudine; uxube onke lamayeza mathathu kwikomityi yeplastiki uze unike umntwana ngesirinji enye; unike umntwana into enencasa (umzekelo ijam, peanut butter) okanye into ebandayo (umzekelo umkhenkce)

to give the bad tasting medicine first and ensure that the child has swallowed and is not going to vomit or spit it out before administering the rest.

emlonyeni phambi okanye emva komxube ukufihla incasa ekrakra. Kuyanceda ukunika incasa ekrakra ekuqaleni kwaye uqondisise ukuba umntwana uliginyile kwaye akazukulikhupha okanye alithufe phambi kokuba ajongane namanye.

9. If the child spits out or vomits medication within about 30 minutes of it being given, the full doses of all medications given must be repeated. The caregiver should inform the doctor if the child is having problems with persistent vomiting of medications.

9. Ukuba umntwana uyalithufa okanye aligabhe iyeza kwimizuzu engamashumi amathathu enikiwe, imilinganisela epheleleyo ebeyinikiwe mayiphindwe. Umgcini-womntwana makamxelele uqgirha xa umntwana enengxaki malunga nokungayeki ukugabha amayeza.

10. Kaletra should be given with fat-containing food (e.g. milk or bread & butter) to increase the absorption of the medication into the body. Advise the caregiver to first give the child something to eat and then the Kaletra.

10. Ikaletra kufuneka inikezwe kunye nokutya okunamafutha (umzekelo, ubisi okanye isonka kunye nebhotolo) ukuncedisa ukungena kwamayeza emzimbeni. Cebisa umgcini-mntwana ukuba anike umntwana into yokutya aze alandele ngeKaletra.

11. For children who are not yet able to swallow stavudine or efavirenz capsules, the capsules may be opened and the powder dispersed in 5ml of water in the small plastic cup provided. The mixture should be made up at the time of giving the medication and not stored for later use. This mixture can be administered directly from the cup or drawn up into the syringe.

11. Ebantwaneni abangekakwazi ukuginya ipilisi zeStavudine okanye zeEfavirenz, ezipilisi zingavulwa uze umgubo wazo ugalelwe emanzini angangomlinganiselo oyi 5ml kwikomityi yeplastiki ayinikwayo. Lomxube kufuneka wenziwe ngexesha lokunika umntwana amayeza, hayi ugcinwe ize isetyenziswe emva kwethuba. Lomxube ungenzelwa ekomityini uze utsalwe ngesirinji.

12. From the age of about 5-6 years children should be shown and encouraged to swallow whole capsules with a cup of water. It helps to practice with vitamins or sweets (e.g. Jelly beans). When the child has mastered this, it is useful to practise with empty capsules starting with the smallest (efavirenz 50mg or stavudine capsules) and only allowing the child to swallow full unopened capsules when the caregiver is sure that they are able to swallow the capsules easily.

Make sure the caregiver knows to boil and cool all water that is given to the baby or young child for bottle milk feeds or medicine! This is to ensure that the water is clean.

Note: It is important to advise the caregiver not to be rushed when giving the child medicines but to take the time to feel comfortable with the process. This will help the child feel safe and less anxious about taking bad tasting medicines.

13. For children on didanosine, caregivers need to understand that this medication must be given by itself on an empty stomach, at least 30 minutes before food or drink. Discuss with the caregiver how they will arrange the timing of this in the morning and evening e.g. child wakes up at 06h00, takes didanosine tablets at 06h30 and eats breakfast after 07h00 and

12. Ukususela kwimiyaka emihlanu ukuya kwisithandathu, abantwana kufuneka baboniswe kwaye akhuthazwe ukuba aginye ipilisi epheleleyo ngekomityi yamazi. Kuyanceda ukufunda kwizakhamzimba okanye ilekese (umzekelo, iJelly Beans). Xa umntwana ekwazi ukwenza oku, kuyanceda ukubana afunde ezipilisini, ezingenanto aqalise ngezincinci (ipilisi ze efavirenz 50mg okanye stavudine) kwaye avumele umntwana ukuba aginye ipilisi engavulwanga xa umgcini-womntwana eqinisekile ukuba uyakwazi ukuginya lula.

Qinisekisa ukuba umgcini-womntwana uyazi malunga nokubilisa kunye nokupholiswa kwamanzi anikwa usana okanye umntwana omncinci kwibisi lebhotile okanye iyeza. Oku kukuqinisekisa ukuba amanzi acocekile.

Qwalasela: Kubalulekile ukucebisa umgcini-mntwana ukuba angamngxamisi umntwana xa emnika amayeza kodwa athathe ixesha ukuze azive ezithembile ukwenza oku. Oku kuzakunceda umntwana ukuba azive ekhuselekile kwaye engaxhalabanga ekutyeni amayeza anencasa embi.

13. Ebantwaneni abasebenzisa iDidanosine, abagcini-bantwana kufuneka baqonde ukuba eliyeza kufuneka alinikezwe umntwana engenanto esiswini, phambi kwemizuzu engamashumi amathathu phambi kokutya okanye isiselo. Xoxa nomgcini-mntwana ngendlela abazakulungiselela ixesha lokuselisa umntwana amayeza kusasa nasebusuku, umzekelo umntwana uvuka ngo 6h00, aseliswe ipilisi zeDidanosine ngo 6h30 aze atye isidlo sakusasa emva ko7h00 aze

takes zidovudine and Kaletra with breakfast. Didanosine tablets must be crushed and dissolved in 30ml of water (15ml per tablet), or they may be chewed but many children do not like the taste.

asele iZidovudine kunye neKaletra kunye nesidlo sakusasa. Ipilisi zeDidanosine kufuneka uzicumze uze uzidibanise namanzi angumlinganiselo ongu 30ml (15 ml kwipilisi nganye), okanye zingahlafunwa kodwa abantwana abaninzi abayithandi incasa.

NOTES

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