

# CHILD ART FLIP CHART







## Foreword

The most efficient and cost-effective way to tackle paediatric HIV globally is to reduce mother-to-child transmission (MTCT). According to the World Health Organisation, everyday there are nearly 1500 new infections in children under the age of 15 years most of them associated with MTCT and more than 90% of them occurring in the developing world. HIV in children runs a rapid course with the majority of infected infants frequently presenting with clinical symptoms in the first year of life. An estimated 30% of infected infants will have died before their first birthday and about half by two years of age. There is therefore a critical need to provide antiretroviral therapy (ART) for infants and children who become infected despite the efforts being made to prevent such infections.

Ministry of Health has prioritized pediatric HIV prevention, care, support and treatment and has put in place mechanisms to promote MTCT, early diagnosis and early access to treatment. Where treatment for children has been successfully introduced, ART has substantially changed the face of HIV infection. HIV infected infants and children now survive to adolescence and adulthood. The challenges of providing HIV care have therefore evolved to become those of chronic as well as acute care. Children infected with HIV need greater care and attention because of their low immune status and calls for the involvement of parents and/or caregivers in their management. The flipchart has been developed to facilitate public knowledge and understanding of ART and also act as a step by step for the treatment support workers and counselors involved in the caring of the HIV infected child. It is my sincere hope that the flipchart will be of great use to the service providers and that it will contribute to the improved quality of care given to the children.

**Dr. Victor Mukonka**

**Director Public Health and Research**

**Ministry of Health**





## **Flip Chart for treatment support workers and counsellors to use with parents & young children who are on ART**

### **Introduction:**

This booklet is for use in the first sessions of adherence counselling for the carers of children of 0 to 12 years, at the beginning of antiretroviral (ARV) treatment. It does not include counselling before the child is tested for HIV, although some of the same issues may be discussed at that time. Adherence is a demonstration of commitment and follow through on a plan for treatment that is agreed on by the child and the caregiver (ANECCA).

The booklet can be used by anyone responsible for advising parents and children about ARV treatment (ART). We have used the word 'counsellor' to describe this person, but as well as counsellors trained in HIV and treatment support, the booklet can also be used by trained adherence peer support workers and by health care workers. Ideally, ART adherence counselling is a multidisciplinary team effort involving doctors, nurses, pharmacists, counsellors, peer educators and outreach workers.

The first ARV adherence session will normally be longer but the following ones may be more focused on specific issues. Adherence counsellors must receive basic training on HIV and ARVs before using this flip chart. They should have access to fact sheets or handbooks that they can refer to before or after the session if they need to understand adherence topics in greater depth.

Each page covers one important aspect of treatment which should be covered prior to starting ARV treatment. Individual pages can be referred to again and basic information reinforced at follow up clinic visits. On each page facing the counsellor there is a list of topics to discuss with the clients and a list of important things that the counsellor needs to remember. In addition there are pictures to help with discussion on each page that faces the carer and the child.

The discussion is intended to be between the counsellor, the carer/parent and the child (if the child is old enough to understand and (respond). Even when the child is young, they should be included in the conversation as much as possible. It is important that adherence is discussed with the main carer - this is the person who will be responsible for making sure that the child gets the right treatment at the right times and in the right dose, day after day.

The counsellor must be a person who understands the challenges and benefits of working with children and their carers. They must be able to communicate with respect and openness, and to develop a good relationship that will achieve the best results from adherence support.



## Tips for Working with Children and Carers

- Make sure you are at eye level with the child as well as the adult when you talk to them, so that you are not looking down on them.
- Take time and allow the carer and the child enough time to think and to respond to you.
- Listen to what the carer and the child are saying and watch their body language and how the child plays - these are important for understanding what is happening.
- You will need to ask questions and get some answers, but don't interrogate or ask lots of questions one after another.
- Ask open-ended questions whenever you can - they encourage people to talk.
- Be prepared to wait for an answer, and don't try to force an answer from someone who is not ready to share.
- Help your clients to find their own answers to the challenges they face - don't just tell them what to do.
- You can help a child to talk by encouraging her or him to play or draw pictures. In this way, they can express feelings and show how they see things.
- Adults and children cannot remember too much information at one time. So only provide the information that they really need to know. Ask them to repeat it back to you to make sure they have understood.
- Use simple language and use the language most easily understood by your clients. This might be the vernacular or the type of English that is commonly used in Zambia.
- Avoid using medical or technical words as much as you can. If you have to use one of these words, explain what it means in common language so that the client can understand.
- Let the child and the carer know that they can ask questions. Answer them honestly and appropriately - do not be afraid to say: "I don't know, but I will find out for you."



## Chart 1: Counsellor preparation before seeing carer and child

### Points for the counsellor to discuss with the client:

- Prepare the counselling room so that you, the carer and the child can sit comfortably while you talk.
- Check that you have the necessary record book, a pen and any other materials that you will need during the session.
- Check that you have information ready about available services to refer your clients to, for further support if needed.
- Make sure you are ready to give full attention to the client & the child, and that you will not be distracted by thinking about any thing else or will be interrupted by other health workers.

### Key things to remember:

- You are providing a professional service, so you should have a professional approach, and try to do everything that is within your power for your clients.
- You will be able to help them with adherence support and using the services of the clinic, but you will need to refer them to other services for some of the support they need.
- It will be helpful to have a list that includes contact details for these services, including the name of the service, who to talk to, address, telephone number and times when they are available. The DHMT office will be able to help you with this.
- Good record keeping is essential for keeping track of clients and for reporting how much work you have been able to do.
- Recording referrals and keeping track of what is happening to your clients is a key activity. It will help to ensure that adherence is maintained and that you or the clinic do not lose contact with them.





## Chart 2: Beginning the session

### Points for the counsellor to discuss with the client:

- Welcome the client and child. Introduce yourself. Make sure they are sitting comfortably with you before you start asking question or giving information.
- Ask what they understand about why they are seeing the counsellor.
- Check name, address, clinic number and record if necessary.
- Ask who they have already seen and what they were told.
- Explain how you will help - tell them you will explain more about the ARVs and other medicines, and will tell them about the support they can get for their life with ARV treatment.
- Explain that the ARVs are intended to help the child to live positively with a chronic illness and to grow, play, and go to school like any other child - even growing up to be an adult who can help to look after the rest of the family.

### Key things to remember:

- This first appointment with the treatment counsellor is an opportunity which should not be missed - it is the time to start a positive and encouraging relationship. Clients will value this and it will reassure them that they have found someone they can rely on for the support they need.
- When clients come into the room, they might have had to wait a long time or they might feel dissatisfied with the amount of time they have had with the health care provider or with the attitude of some clinic staff.
- The counsellor should therefore help them to feel at ease and should show from the beginning that they will be listened to and guided according to their needs and priorities.





### Chart 3: Finding out about the child the family and their community

#### Points for the counsellor to discuss with the client:

- Ask about the carer's relationship to the child - are they the main carer, and who else provides care if they are not around? For example, how much time do they spend with the child? are they very busy? do they go out to work?, etc.
- Ask what they understand about HIV - especially how it is transmitted and what it does to the body.
- Ask how HIV has affected the child and the family.
- Ask about the child's general health, appetite, any treatment for other illnesses, immunisations - ask to see the child's clinic card if possible.
- Ask about attitudes in the community. Is there support? Is there stigma?
- Ask if the carer has any worries about the child and provide any reassurance that they need .

#### Key things to remember:

- This part of the session encourages the clients to talk not just about HIV but about their circumstances and worries.
- This is therefore an opportunity for the counsellor to get to know them a bit and to judge for themselves about the relationship between the child, the carer and the community they live in.
- It also allows the counsellor to observe if the child is being well cared for and to get an idea of what support the carer and the child are going to need.
- It also provides an opportunity to correct any misconceptions or myths about HIV and the child.
- Carers often feel that starting ARVs is an emergency; they need to be reassured that it is alright to take time to work out the best treatment for the child and to treat any illnesses as well as giving ARVs.
- Carers sometimes worry also about lab tests and taking blood from the child. Reassure them that only a very small amount of blood is taken and the child will quickly make new blood to replace what is taken in the clinic. Explain that blood tests give the health workers information that they cannot get through looking at the child or asking questions - this information is important for deciding how best to care for the child.





## Chart 4: Finding out what medicines are prescribed and what the carer and child know about them

### Points for the counsellor to discuss with the client:

- Ask the carer to show you all of the child's medicines, not just the ARVs.
- Ask what the carer and the child know about their medicines - ask if they know what they are for and when they should take them. (WHAT, WHEN & WHY)
- Clarify which medicines are ARVs and what the other medicines are for.
- Look together at the ARVs and check if they know what ARV doses have to be taken and when.
- Check what else they have been told about the ARVs and make sure that they have the correct understanding.
- Ask about any traditional medicines that they have used up until now - what they think about using such medicines at the same time as ARVs?

### Key things to remember:

- When people are starting with ARVs, they often receive other medicines as well, such as vitamins, tablets for anaemia, tablets to prevent chest infections, TB or malaria.
- This can be very confusing at a time of stress. If they do not understand what the medicines are and how to use them, there is a serious risk that adherence will be poor from the start of treatment.
- Repeating information and asking questions are helpful to make sure the carer has understood.
- So it is vital for the counsellor to make very sure that they understand which are ARVs and that they know how to take them.
- Asking about traditional medicines is important - they can affect how the ARVs work (see Chart 6). The client might be reluctant to talk about going to a traditional healer, but it is important for them to know that the counsellor is interested and will not be critical about it.



**FREE your MIND  
GO FOR VCT  
TODAY**

**DRUG CHART**  
1) Azt 2) 3tc 3) Nvp  
4) Zidovudine  
Solution  
Orale USP  
5) Triomune Junior  
6) Triomune Baby



## Chart 5: Explaining adherence and why it is important

### Points for the counsellor to discuss with the client:

- Explain that 'adherence' is a word that means sticking to rules about taking ARVs
- Explain that this means taking the ARVs just as they have been told, which means:
  - The right dose
    - At the right times
    - At the same times every day
    - Each and every day
    - For the rest of their life
- Reassure them that if they have very good adherence - nearly 100% - then the treatment should be successful and the child should quickly return to having a healthy, normal life.
- But if adherence is not good enough, the child will become sick again and treatment will become more difficult.
- Explain that treatment is for all of life because ARVs are not able to completely remove HIV from a person's body. ARVs keep HIV under control and if the ARVs are stopped, HIV can start to damage health again.
- Tell them that you are next going to talk with them about:
  - ways to help a child to drink their medicine
  - how to remember the doses
  - what to do if there are any problems with the ARVs
  - what to do about nutrition for the child

### Key things to remember:

- Educating people about adherence takes time - a carer will not be able to remember everything that they are told for the first time. So the counsellor will need to repeat the information at subsequent appointments, and talk in more detail about each topic.
- Continue to maintain an open and trusting relationship with the carer and child - this will make it more easy for them to tell you about any problems with adherence, and to accept your suggestions.



Name.....

Date.....

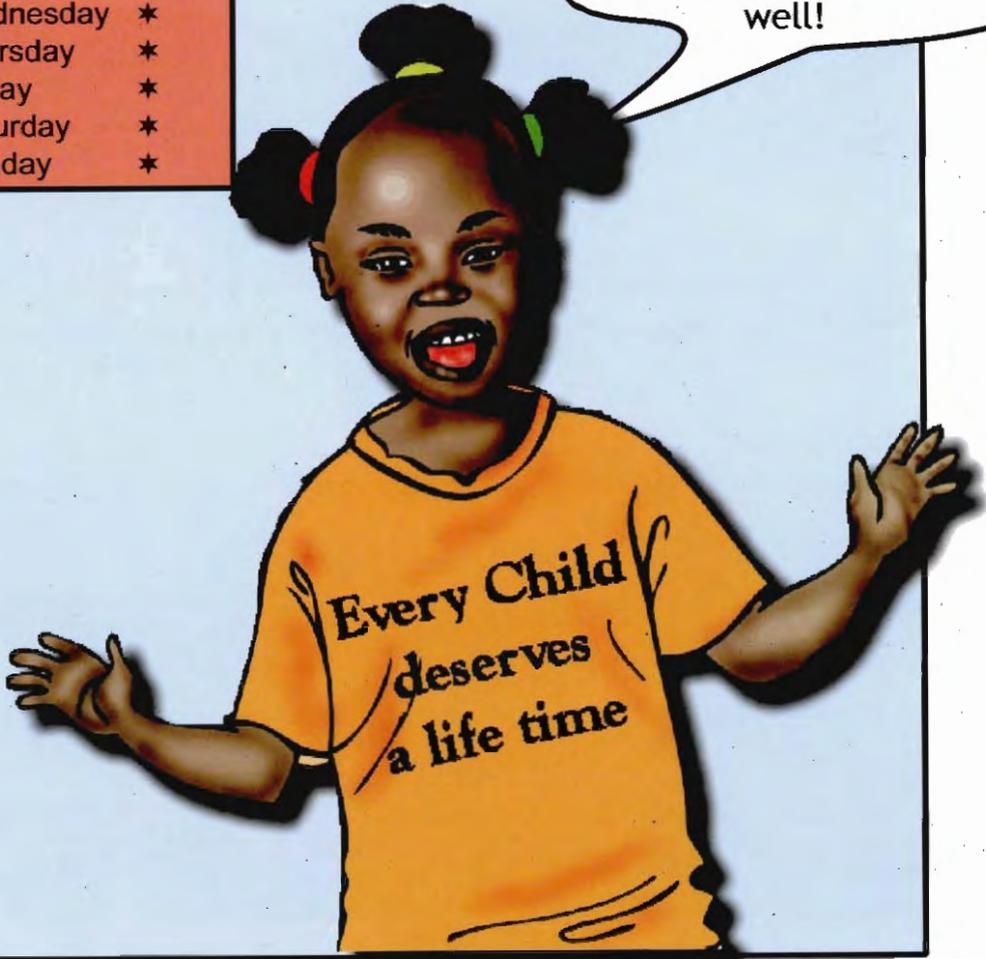
Next Clinic Visit.....

	WEEK 1	WEEK 2	WEEK 3	WEEK 4
M				
T				
W				
TH				
F				
S				
SUN				

**Chanda's Star Chart**

Monday	★ ★
Tuesday	★ ★
Wednesday	★
Thursday	★
Friday	★
Saturday	★
Sunday	★

I take my medicine every day and I'm doing well!





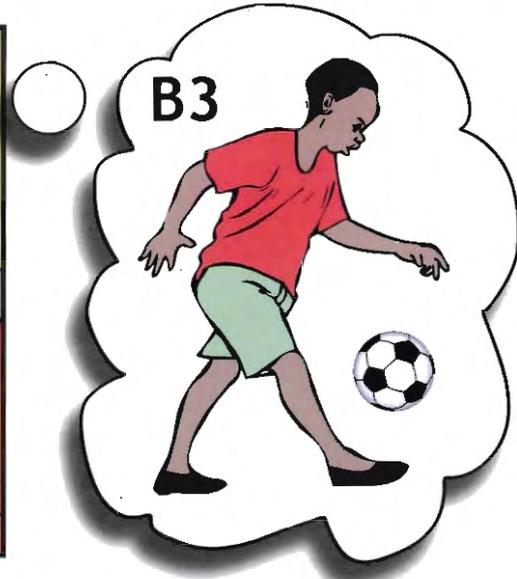
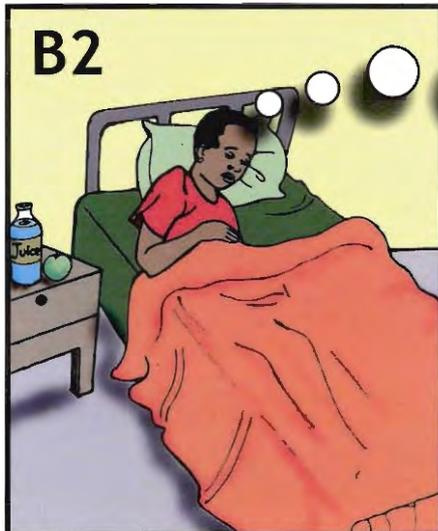
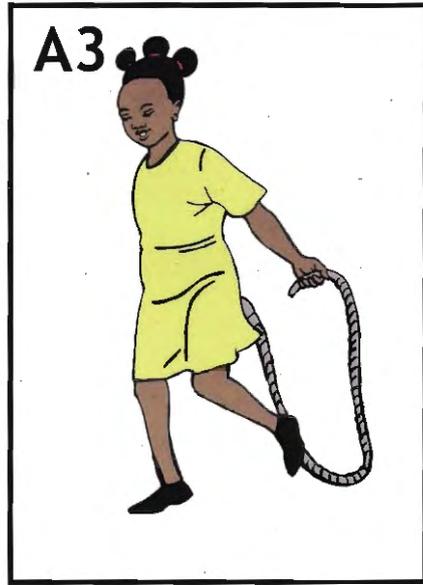
## Chart 6: Non-adherence - what happens?

### Points for the counsellor to discuss with the client:

- Non-adherence means not sticking to all the instructions about taking ARVs.
- There are many reasons why this can happen, such as forgetting, lack of food, side effects, illness, stigma and many others. It is normal for people to forget a dose sometimes, but this should only happen very rarely.
- The effects of non-adherence are that:
  - HIV can start to multiply because there are not enough ARVs in the body to fight it
  - If this continues, the ARVs will lose the ability to fight HIV. This is called resistance, because the virus can resist the effect of the ARVs
  - Resistance means that the child can start to get sick again and the treatment might have to change
  - Changing the treatment because of resistance can be complicated and expensive
- There are other reasons that treatment might be changed which are not caused by non-adherence - the doctor might decide that another combination is better for the child, or the child needs a different dose as he or she grows.

### Key things to remember:

- In Zambia, there are different possible ARV combinations for first-line treatment. If the ARV combination is changed, the child can still be on first-line treatment.
- Changing from one first-line combination to another can be because of side effects, or because the child has to take other medicines (drug interactions) or because of problems with drug supplies.
- A 'drug interaction' is when one drug reduces or increases the effects of another drug - it might be necessary to change ARVs to prevent problems.
- Second-line treatment starts only if all possibilities for first-line treatment have failed to keep the child healthy, especially if there is resistance.
- Reassure the carer that ARVs will only change if it is really necessary for the child's health. Reassure them also that many adults and children have very few problems with ARVs, and continue for many years with the same ARVs.
- Traditional remedies can interact with ARVs, but research has not been done to know if this is dangerous or not. It is best to explain to the client not to use traditional remedies at the same time as ARVs.





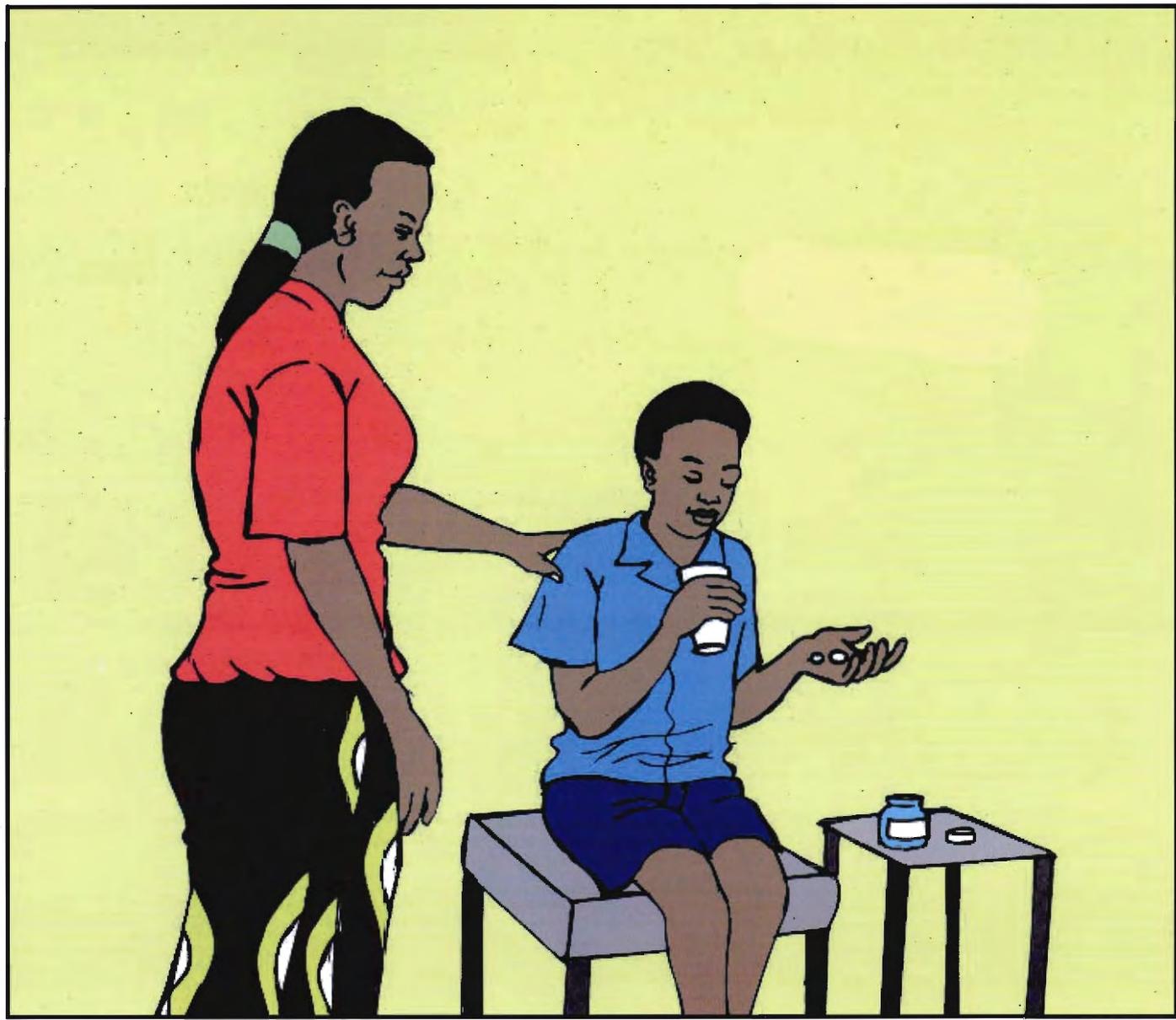
## Chart 7: Ways of giving medicines to a child

### Points for the counsellor to discuss with the client:

- Ask about client's experience with giving medicines to children - what is it like with babies, what is it like with older children?
- Ask what difficulties they have had - for example, unpleasant tasting liquids, difficulty in swallowing pills.
- Discuss ways that they know to help the child to take tablets, and offer suggestions to make this easier.
- Discuss ways that they know to help the child to take liquids (syrups) including how to put them into the mouth, and how to make them taste better.
- Discuss techniques to support and encourage the child to take the medicines and to have a sense of achievement when they have done it.
- Stress the importance of having a good attitude and not threatening the child - 'we can get through it'.
- Remind the carer that the doses of ARVs depend on the weight of the child, so the doses will to be increased from time to time as the child grows bigger.

### Key things to remember:

- If the child vomits more than 30 minutes after the dose, do not give another dose - the drug has already been absorbed into the child's body.
- Some ARV syrups can taste unpleasant. This can be improved by putting something tasting of chocolate on the tongue before giving the ARV.
- Praise and positive encouragement for the child go a long way towards continuing adherence. If a child gets frightened each time, or gets stressed about swallowing, there is a bigger chance that the child might vomit or even refuse to take any more medicines.
- If a child vomits within 30 minutes of being given ARVs, the carer should comfort the child and then give another dose. The next dose should be given at the correct time without delaying it.
- If the child vomits more than 30 minutes after the dose, do not give another dose - the drug has already been absorbed into the child's body.
- Some ARV syrups can taste unpleasant. This can be improved by putting something tasting of chocolate on the tongue before giving the ARV.





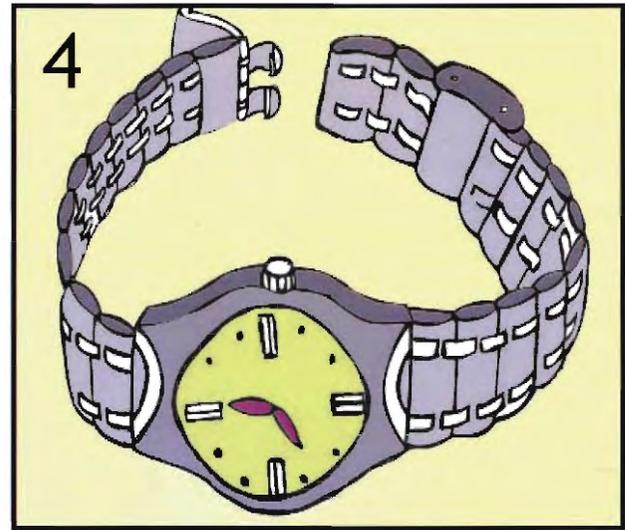
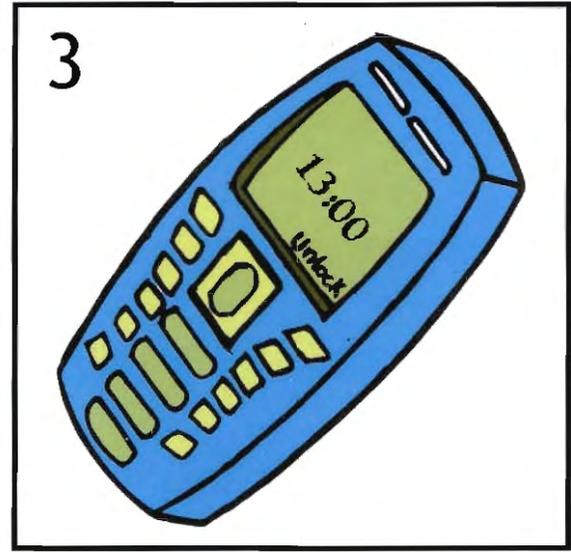
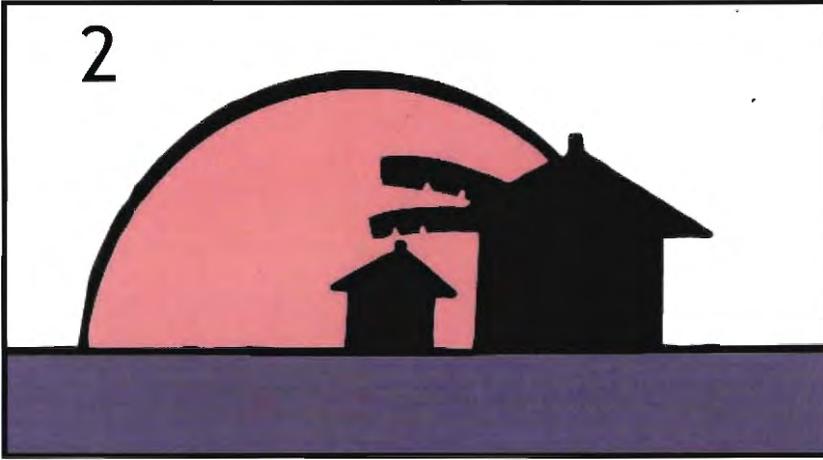
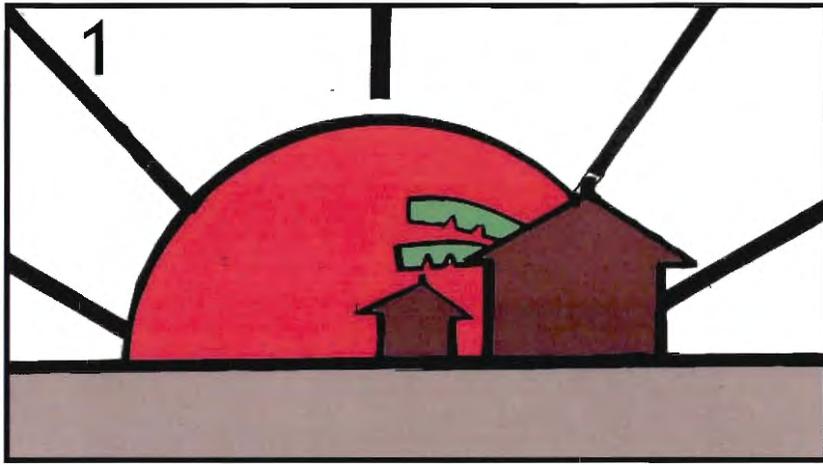
## Chart 8: Ways to support adherence to treatment

### Points for the counsellor to discuss with the client:

- Look together at the ARVs that the child and carer have received.
- Check that they remember how many pills or how much syrup to take and at which times of the day.
- Ask if they have some ideas on how they will try to remember the doses.
- Offer suggestions for helping to remember, for example:
  - sunrise/sunset
  - just before brushing teeth
  - clock alarm
  - regular meal times
  - cell phone alarm
  - family member reminds you
  - joining a support support
- Discuss how to involve the child in remembering when to take the ARVs -this will help to train the child to look after her or himself for the future
- Discuss if other family members are also on ARVs; find out if it is possible for them to remind each other.

### Key things to remember:

- Disclosure to family members or treatment buddies will enable them to take part in reminding a person to take their ARVs at the right time.
- If more than one family member is receiving ARVs, they can get encouragement and support from each other. Many parents on ARVs say that it is their children who remind them every time they need to take a dose.
- The next discussion will be about making a treatment plan, so it is important to clarify first what methods a person normally uses to remember doses.
- A simple chart divided into days and dose times can be used - the child or the carer makes a mark on the chart, for example a star, each time a dose is taken. If the chart stays on the wall in the house where child and carer can always see it, they will be encouraged to remember when the next dose is due.





## Chart 9: Treatment plans and adherence support for child and carer

### Points for the counsellor to discuss with the client:

- Explain that you are going to decide together on a daily ARV plan that includes anyone who might help with adherence - parents, siblings, grandparents or others such as teachers.
- Ask them to tell you exactly who will actually be involved with reminding about doses and helping the child to take their ARVs. This might include more than one person. This is a good time also to find out if the child is likely to be sent to live somewhere else for sometime.
- Discuss what happens each day around the time the doses should be taken - talk through every day of the week, as some days will be different from others. Decide together what the best times for doses are, so that they can happen at the same time every day.
- Discuss what to do if the child becomes ill - stress the importance of not stopping the ARVs and of seeing a health care worker as soon as possible.
- Discuss what needs to happen on days that are different from usual, such as weekends or going away on a visit. Stress the importance of carrying spare ARVs in case of problems about getting back home to take the next dose.
- Discuss adherence strategies for when there is a change in routine e.g., vacation or school holidays. Anticipate any adherence barriers
- Discuss possibilities for getting peer support for the carer and the child to provide encouragement for adherence. For example, support may be given by siblings, grandparents, other adults or children's adherence support groups.

### Key things to remember:

- Agreeing to a daily 'adherence plan' is a good way of helping the carer and child to think through what they need to do. The plan can be used in regular sessions with them, to check how things are going and understand what problems they might be facing.
- Positive encouragement should include giving praise, involving the child by showing how their weight increases on the clinic growth chart and using a daily dose chart so that the child can see their success with taking doses.
- Adherence support can be formal or informal - in many places there are support groups for children and for parents; it is also possible for mothers or fathers to get support from friends in the same position as themselves, for example, between women at the water pump, men meeting for sports.





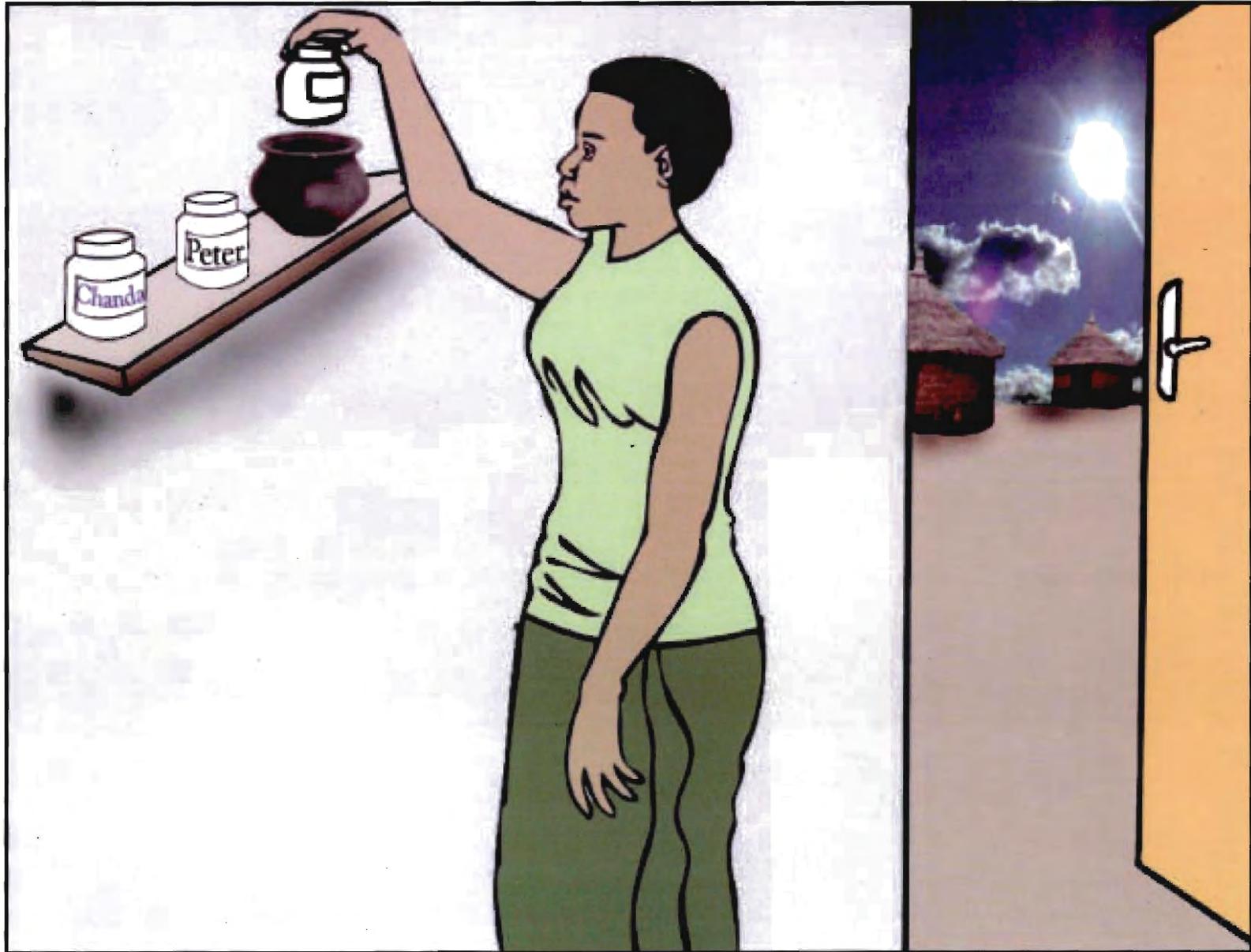
## Chart 10: Looking after your ARVs and other medicines

### Points for the counsellor to discuss with the client:

- Explain to the carer and child that it is very important to look after ARVs carefully because they are essential for the child's life and health.
- Remind the carer and the child that they must always have supplies of ARVs every day, so they must make sure they get new supplies in good time so that there are no interruptions in treatment.
- Emphasize that they must not share ARVs with any other person - each person has treatment chosen specially for them by the health care provider. One person's ARVs will often be different from another person's ARVs.
- Emphasise that they must not borrow ARVs from any other person - they must take only the ARVs that they receive for themselves from the clinic.
- Explain that ARVs and other medicines do not like too much heat or dampness. They should be kept in a cool dry place.
- ARVs should also be kept away from small children who might play with them or might accidentally eat or take them.
- Remind the carer and child that they should always check with their health care worker or doctor before taking any other medicines.

### Key things to remember:

- A 'drug interaction' is when one drug reduces or increases the effects of another drug - it might be necessary to change ARVs to prevent problems.
- Drug interactions can happen between ARVs and other medicines, which means they can change the way that the ARVs work and this can be dangerous. There is the same risk of interactions with traditional medicines and ARVs
- Most ARVs can be stored at 'room temperature', which means temperatures from 4 to 30 degrees centigrade.
- Some ARVs need to be stored in a refrigerator, for example stavudine (d4T) liquid. In Zambia, many people do not have refrigerators. Health care providers will usually find out from the patient or the carer if they have access to a fridge. If not, they try to avoid giving ARVs that need to be stored cold.
- If there is no cupboard or drawer in the house where the ARVs can be stored, an alternative is to keep them away from children in a pot that is kept high on a shelf.





## Chart 11: Importance of 'follow up' appointments and tests

### Points for the counsellor to discuss with the client:

- Ask what the carer has been told about when to go for follow-up appointments and tests.
- Emphasise the importance of always coming on the right day. Explain that the main carer should always come to the appointment so that they can give important information about the child.
- Discuss what follow-up appointments are for, for example making sure everything is going alright, dealing with anything that isn't going right, changing the doses of ARVs as the child is growing bigger.
- Discuss why it is important to see the right people, to get lab tests at the right times and to get new supplies of ARVs before the previous ones run out.
- Discuss risks of not following up and the reasons why it might happen, including 'treatment fatigue'; explain what to do about late or missed appointments.
- Emphasise the importance of getting support from a good relationship with the counsellor & health workers, and of using support in the community for encouragement - buddies, peer group, etc.
- Discuss the reasons for routine tests including blood draws and why it is important to HIV management.
- Emphasise keeping medicines safely stored, out of reach and each person's medicine separate.

### Key things to remember:

- Regular follow-up makes sure that everything is going as it should for the child and family, including the effects of ARVs, growth and emotional health.
- Regular follow-up also reassures the carer and encourages them to continue coping.
- Loss to follow-up, when a patient fails to continue on treatment, is a much bigger problem with ART for children than with ART for adults.
- Reasons for loss to follow-up can include failure to understand the importance of continuing ARVs; fear of criticism for poor adherence; getting tired of giving or taking the medicines (treatment fatigue); poor relationship with clinic staff or counsellor; and sending the child to live in a different place without contacting the clinic. There are many other possibilities.
- Parents and carers sometimes worry about too much blood being taken from children for lab tests. You should reassure them only very small amounts of blood are taken each time and the body quickly makes new blood to replace it. Lab tests give the health worker important information about the child's health - information that cannot be found just by looking at the child or asking questions.





## Chart 12: Side effects

### Points for the counsellor to discuss with the client:

Explain what side effects are - they are unwanted effects of ARVs.

Discuss what side effects can come from ARVs - explain that most are mild but some can be serious so it is important to consult the doctor or health workers about them.

Emphasise that it is important NOT to stop ARVs when there are side effects but to consult the doctor or health worker as soon as possible for advice on how to deal with them.

Discuss when side effects might happen, for example early in treatment, when they are often mild and will go away after a few weeks, or later in treatment. Explain that this is an important reason for follow-up appointments, so that the child can be monitored.

Discuss what can be done to reduce mild side effects.

Emphasise the importance of getting help quickly for severe side effects.

### Key things to remember:

- Any effective medicine can cause some side effects, but they do not happen to everyone, and not everybody will get all the possible side effects.
- ARV side effects are common but most of them can be managed and some people never experience them.
- Common mild ARV side effects can include nausea or vomiting, mild diarrhoea, dizziness (especially with efavirenz), feeling unwell, and discoloured nails.
- Pain or strange feelings in feet or hands should be discussed with your health worker.
- Severe ARV side effects can include high temperature & headache, serious vomiting, diarrhoea or coughing which continues for some time, a skin rash which quickly gets worse, and serious breathing problems.
- All of these side effects can also be signs of other illnesses - they might not be caused by the ARVs.
- So it is important for the carer and child to be in contact with their doctor or health worker so that they can check what is the child's problem and act accordingly.





## Chart 13: Food and ARVs

### Points for the counsellor to discuss with the client:

- Ask the carer what their regular food supply is like:
  - What do they eat and how often? Does the family have any problems with getting enough food or with eating regularly?
  - Can they feed the child every time they are hungry? Are they able to provide the child with 3 main meals and 2 snacks per day?
- Food is important for the child, both for making sure that the child grows properly and because some food can interact with some ARVs.
- Many ARVs can be taken with or without food in the stomach, but ARVs can cause stomach acid or pain. Having food in the stomach protects it at the time of drinking the ARVs.
- Follow medical advice on taking medicine with or without food.
- Too much oil, butter or fat in the food can stop some ARVs from working properly; any food given just before a dose should have very little or no fat or oil in it. It is alright to have fat or oil in food eaten at other times.
- Discuss any needs that the family has for food support and provide information about where they might get help for this.

### Key things to remember:

- In Zambia, it is recommended that young children receive 3 main meals and 2 snacks every day so that they grow and develop in the right way.
- This may be difficult for families that cannot afford to eat more than once or twice a day. There might be difficulties with other family members if the child on ARVs seems to be getting more food than others. The counsellor should explain that both the food and the ARVs are the medicine that will make sure that the child grows up to play their part in the family.
- The Zambian Children's Clinic Card provides advice on which are the best foods to give a child based on age. The counsellor can check this with the carer.
- Some ARVs must be taken at the same time as food but most of these ARVs are only used in second-line treatment for children in Zambia.
- A few ARVs must be taken with an empty stomach, but they are only used in second-line treatment for children in Zambia.
- Taking medicine 'with food' means in the middle of a meal or a snack - but it is not necessary to have a complete meal with every dose.
- Taking medicine 'with an empty stomach' means not having any food for about 2 hours before a dose and not having food for about 30 minutes after a dose.





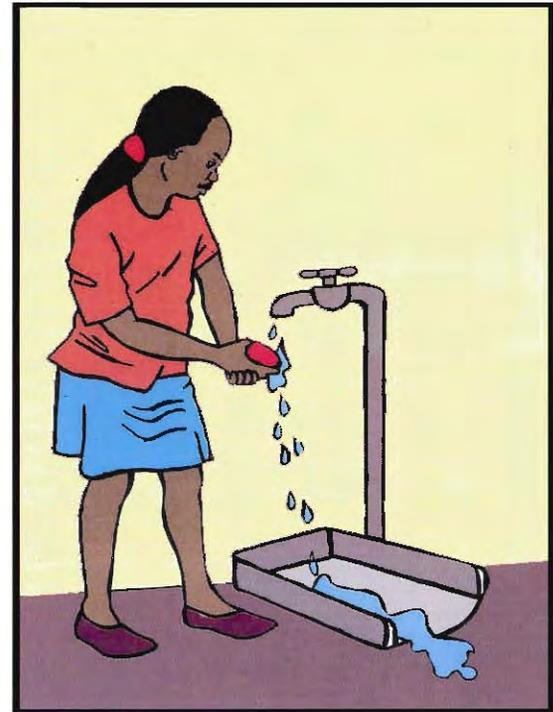
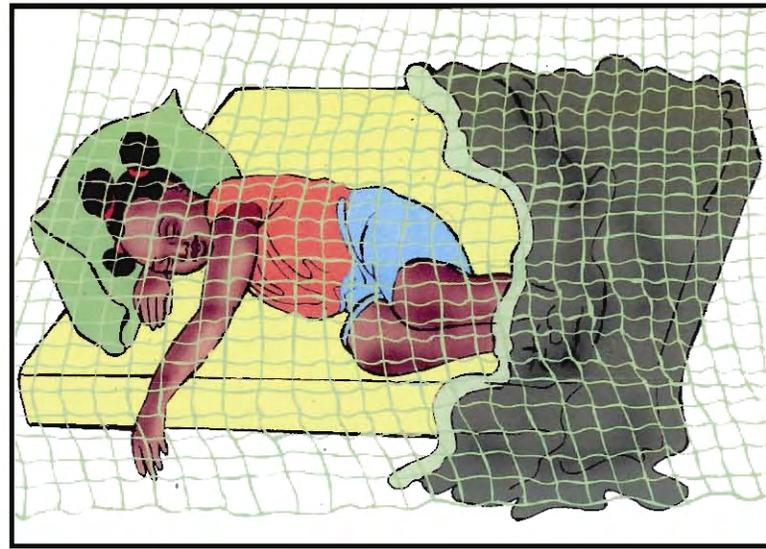
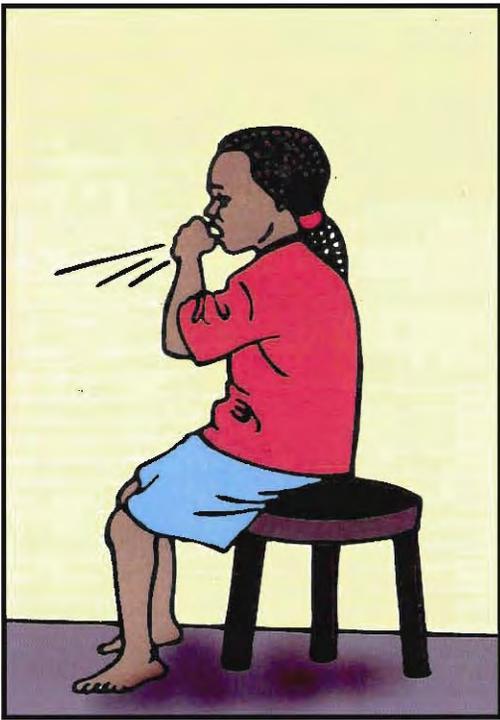
## Chart 14: Positive living – staying healthy and preventing illness

### Points for the counsellor to discuss with the client:

- Emphasise that positive living helps the body to fight HIV. ARVs will work much better if the child and carer live positively and protect their health.
- Remind them that adherence to ARVs and good nutrition will always be important - as discussed in the previous pages.
- Emphasise that if a child or adult on ARVs starts to get ill, they should see a health worker soon - don't wait, especially if there is high temperature and headache; serious vomiting; diarrhoea or coughing which continues for some time; a skin rash which quickly gets worse; serious breathing problems.
- Remind them that it is also important to prevent common childhood illnesses especially malaria, TB, chest infections and diarrhoea.
- If co-trimoxazole has been provided, remind them that it helps to prevent chest infections. Remind them that fresh air and staying away from smoky places and people with persistent cough are also important.
- Check that they have had all the necessary immunisations at the right times, and remind them that malaria can be prevented by using bed nets.
- Emphasise that they should not stop ARVs unless the doctor or health care worker tells them to.

### Key things to remember:

- The points mentioned above are just an introduction to this topic - there will not be time to go into everything, so concentrate on getting the main messages across to the carer and child.
- ARVs themselves provide protection for health. They help to prevent other illnesses because they make the immune system stronger.
- You will need to continue support for positive living each time you see the child and carer. Each time, ask how they are doing and build on their experience to increase their skill and understanding.
- Prevention of illness is essential for positive living. In Zambia, co-trimoxazole preventive treatment (CPT) is prescribed for children with HIV. If the child is at risk from TB, isoniazid (INH) will also be prescribed. The counsellor should support adherence to these medicines, as well as the ARVs.
- Some children or adults can become ill soon after starting ARVs when the immune system starts to fight infections again - it is a sign that the immune system is recovering, but extra care from the doctor or health care worker will be needed. This is called 'immune reconstitution' - ARVs should not be stopped and the person will recover if they get the right support.





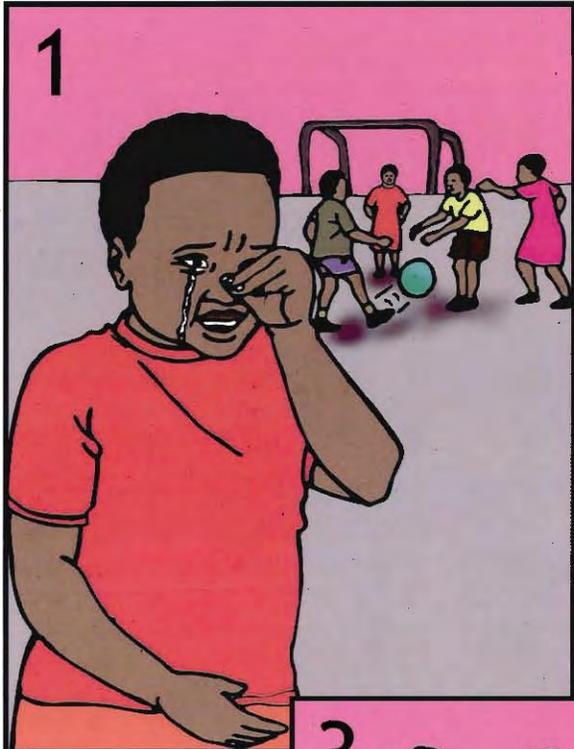
## Chart 15: Positive living – a healthy mind and a healthy body

### Points for the counsellor to discuss with the client:

- Discuss with the carer and the child how a child with HIV might feel about their illness and about their treatment.
- Acknowledge that the child might sometimes have strong feelings and will need someone to talk to.
- Find out who the child normally talks to about happy things and who they talk to about difficult things.
- Try to find out about difficult feelings they might have - for example feeling guilty or angry or depressed. Discuss how they would like to change this, and who they can talk to if they want to.
- It is also useful to talk about dealing with abuse - physical, emotional or sexual. Discuss ways that the child or the carer might be able to prevent it or make it stop.
- Remind them that they will also feel happier if they keep themselves healthy - eating properly and avoiding alcohol, drugs, smoking, glue or anything else which is harmful.

### Key things to remember:

- Children usually decide who they can tell good things to, and who will listen to them when there are difficult things to talk about. These might be different people. Sometimes children only tell their parents the good things because they want to protect them or they fear how the parent will react.
- Parents and carers will also need someone to talk to - this will help them to support adherence and to deal with their own difficult feelings.
- The adherence counsellor should try to help child and carer to communicate with each other about the ARVs and about HIV. They need to be able to trust each other and share thoughts and feelings.
- The adherence support counsellor must be open and ready to listen, but there will not always be enough time to deal with difficult emotions or family situations.
- The carer and child might each need some further counselling support and the adherence counsellor should refer them to an experienced counsellor for further sessions to help them cope with their situation.





## Chart 16: Positive living – prevention of HIV and dealing with stigma

### Points for the counsellor to discuss with the client:

- Revise with the carer and child how HIV can be passed from one person to another and how HIV cannot be passed from one person to another. Make sure that they have the correct understanding.
- Get the child and the carer to tell you in their own words what preventing HIV means in their daily life - home, school, church, with other children, or with adults or older children who might be sexually active.
- Tell a story about stigma e.g, a young girl who told all her friends, what happened.
- Ask about any experiences the child or carer has had in which stigma was a problem - ask how they coped with it.
- Discuss how stigma can affect adherence to ART.
- Ask what they think they can do to deal with stigma and with people's misunderstandings about HIV and ART.
- Discuss how better knowledge and acceptance of people who are HIV positive and receiving ART can change attitudes and make it easier to adhere to treatment.

### Key things to remember:

- Beliefs about witchcraft and other myths and misunderstandings about HIV can cause stigma, discrimination and poor treatment; they can make adherence much more difficult.
- Stigma is also often based on wrong beliefs and fears about how HIV is transmitted.
- If the carer and the child understand how HIV is transmitted and if they are able to explain this to others in a simple way, they can help to correct wrong beliefs and protect themselves from stigma.
- Stigma can make disclosure very difficult. But breaking the silence about HIV can help to reduce stigma because it makes people realise that it is a reality and that it is a disease like any other, which can be treated and can be prevented. A child might need help to decide what they want to tell other people about their HIV status and their ARVs.





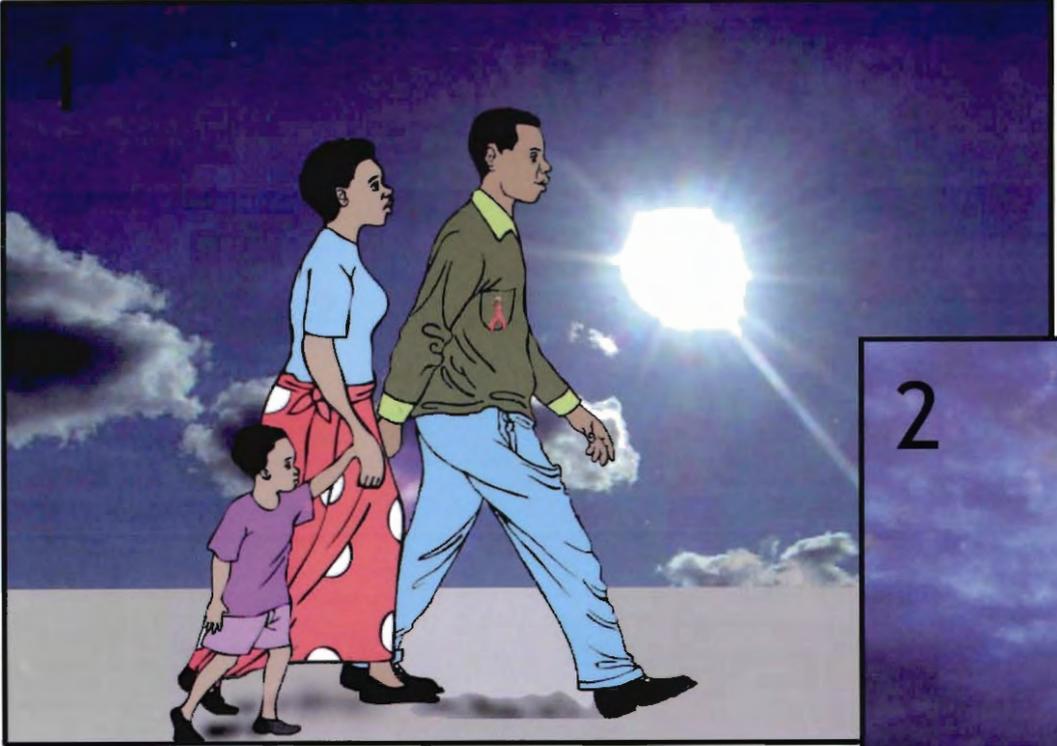
## Chart 17: Where to go for further help

### Points for the counsellor to discuss with the client:

- Check with the carer about what extra support might be needed. Decide together which are the most important priorities at this time.
- Check if they will continue to be at their home address (the one on their clinic card) and where they will be from now until their next ARV appointment.
- Give information about available support services in the area where they live. Use the list of services that you have prepared and note any requests for other help or services that are not on your list.
- Services that might be required could include:
  - Peer support for child and for carers
  - Home-based care
  - Local health centre
  - Food support
  - Social support
  - Counselling support
  - Legal/paralegal services
- Other support will depend on the local context and the family circumstances. If you don't know how they can get this support, tell them you will try to find out and you will let them know as soon as possible or at least by the next appointment.

### Key things to remember:

- Keep your list of available services up to date - add any new services or sources of support that you hear about and include any changes that you hear about such as contact persons or opening times.
- Keep notes of requests from clients so that you can check if they got what they needed.
- If some clients ask for a service that is not available right now, you may be able to advocate with the clinic or a support organisation for someone to start providing it.





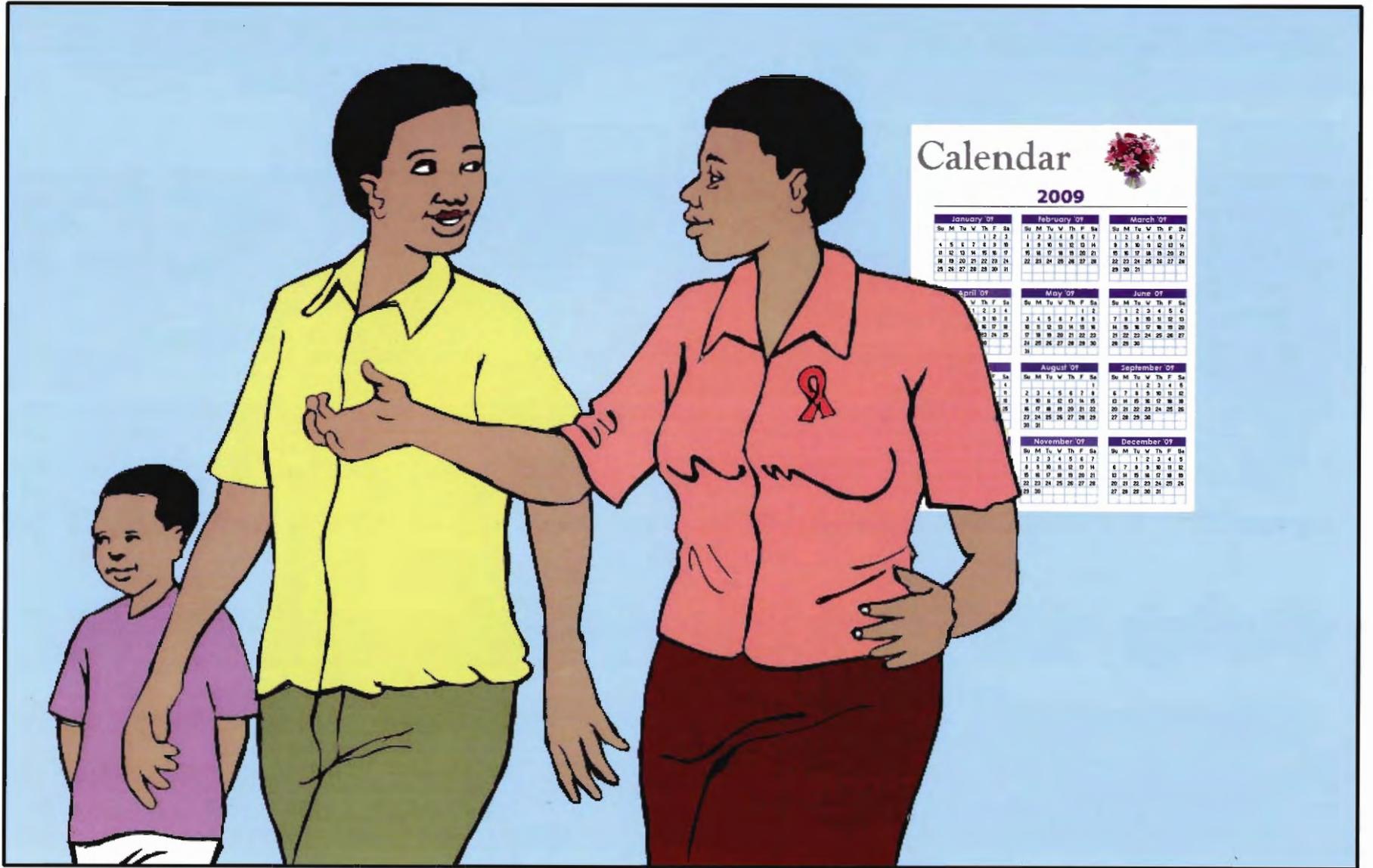
## Chart 18: Conclusion of appointment

### Points for the counsellor to discuss with the client:

- Check that the carer and child remember what to do with their medicines - including the ARVs and any others.
- Check that they know the date and time of their next appointment at the clinic and with the adherence counsellor.
- Remind them what the staff at the clinic will need to know about, for example the child's health and nutrition/growth, adherence and any difficulties with ARVs. If the child has been sick, the staff will want to know:
  - What has happened?
  - How bad has the sickness been?
  - How long has the sickness lasted?
  - How often has it happened?
  - What treatment was given?
- Remind them of the things they should bring to their next appointment, especially any medicines, including ARVs, their clinic card, any messages or letters about the child, and some food and drink and medicine in case of having to wait a long time at the clinic.
- Provide referrals if needed, including information about where to go, who to ask for, and what times the services are available.  
    Make a separate appointment to see the carer if issues of disclosure still need to be discussed.
- Ask if they have any further questions or concerns and remind them that the counsellor and clinic staff will continue to support and encourage them through the coming months and years.

### Key things to remember:

- It is important for the carer and child to go away feeling that they have been listened to and that they understand what they have been told.
- It is also important that they should feel confident that they can try to do everything that they need to do, but that they can ask for help when things don't go right without feeling ashamed or criticised.
- It is important for the counsellor to maintain a supportive and friendly relationship with the carer and the child.



### Calendar 2009



January 09	February 09	March 09
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April 09	May 09	June 09
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August 09	September 09	
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November 09	December 09	
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## Chart 19: Counsellor tasks after seeing carer and child

### Points for the counsellor:

- Take time to complete your record book and any other paper work before you start any other task or see the next client.
- Make a note of anyone that you need to talk to about the client.
- Make sure that you do anything necessary for referrals for the client you have just seen, or schedule a time later in the day to do this.
- Make sure you are ready to give full attention to your next client & child and will not be distracted by continuing to think about those you have just seen.
- Write notes about anything special that happened, any information that you need to find out, or anything that was difficult - keep an 'adherence support diary'.

### Key things to remember:

- You are providing a professional service, so it is important to take a professional approach and do everything that is within your power for your clients.
- Good record keeping is essential for keeping track of clients and for reporting how much work you have been able to do.
- Recording referrals and keeping track of what is happening to your clients is a key activity to ensure that adherence is maintained and that they are not 'lost to follow-up'.
- Keeping an 'adherence support diary' will help to remind you how you have dealt with things and will help you to learn from your experience. When you have mentoring or supervision sessions, it will help you to share your experience and learn from others.





## Chart 20: Disclosure of status to child

Note for counsellor: it is best to discuss this topic just with the carer, and without the child if he or she is old enough to understand what they are talking about. If necessary, ask someone outside the room to look after the child while the discussion takes place, or arrange a separate time to have the discussion. Advising about adherence will become much easier when the carer has agreed with the counsellor on how they will deal with disclosure to the child.

### Points for the counsellor to discuss with the client:

- Tell a story e.g. a child whose parent won't disclose, but she learns her diagnosis for herself.
- Ask if the carer has any plans to disclose to the child, how they intend to do it and what are their concerns about it.
- Discuss the advantages of disclosure for child and carer.
- Discuss ways of disclosure, how to prepare and at what age.
- Discuss how to help the child to choose what to disclose to others.
- Remind the carer that she/he can talk again with counsellor at future appointments and get support when it is time to disclose.

### Key things to remember:

- Children can cope with disclosure just as well as adults.
- Children cope much better with disclosure if they are told at a young age than if you wait until later.
- Choosing the right time for disclosure depends on the child's development and understanding.
- Preparation for disclosure should start as soon as the child starts to ask questions about their illness or their medicines, usually around 6 years of age.
- Disclosure takes time - it should not happen suddenly or without preparation.
- The caregiver is the best person to disclose, but they may find it difficult - they often need encouragement and support.
- The child also needs ongoing support - he or she might become sad or angry and blame him or herself, or the parents, or feel isolated.
- The child will also need some help to understand who they can disclose to and how to deal with people's reactions.
- Advantages of disclosure include: openness between the child and the carer; sharing responsibility for health and adherence; a feeling of more control over their life; preparing the child to be in charge of their own adherence and building trust between the child, care and health care workers.







## Descriptions of Chart Illustrations

### Chart 1

This picture shows the counsellor preparing for the counselling session. Note the calendar and poster, seating arrangement and toys which help to make the room 'welcome' to the child and caregiver (Page 4).

### Chart 2

This picture shows the counsellor greeting a mother and child. Standing and welcoming the family helps them to feel at ease (Page 6).

### Chart 3

This picture shows effective body language. The counsellor is seated, unhurriedly and actively listening. The counsellor has no barrier such as a desk between himself and the caregiver and the child (Page 8).

### Chart 4

This picture shows the counsellor using a visual teaching aid to explain medications (Page 10).

### Chart 5

This page has two pictures. On the left is a sample star chart which can be used to promote treatment adherence. A star is drawn in each box when a dose is taken (Page 12).

### Chart 6

This page shows the consequences of adherence and non adherence. Pictures A1-A3 show a healthy adherent child. Pictures B1, B2 show the result of non adherence (Page 14).

### Chart 7

This picture shows a care giver encouraging and observing a child taking medication (page 16).

### Chart 8

This picture shows the tools to assist with adherence: 1) Using sunrise as a reminder, 2) Using sunset as a reminder, 3) using a cell phone alarm or sms message, 4) Using a clock watch to remember time for the next dose (Page 18).

### Chart 9

This picture shows a mother leaving for while. The child is cared for and given his/her medication by a grandmother (Page 20).

### Chart 10

This picture shows a woman storing medicine on a high shelf away from the children. The medicine is also kept cool by placing it in a clay pot away from direct sunlight (Page 22).



## Descriptions of Illustrations

### Chart 11

This picture shows the counsellor preparing to follow up at the end of the counselling session. The counsellor leaves the chair and discusses the date for the next visit by looking at the calendar with the care giver and child (Page 24).

### Chart 12

This illustration shows three pictures of a child experiencing the side effect of nausea followed by rest and then the caregiver helping the child to eat small amounts of food (Page 26).

### Chart 13

Food groups with common local foods (page 28).

### Chart 14

Positive living practices include frequent hand washing with soap and water (1), covering our mouth while we cough (2), sleeping under an insecticide-treated bed net (Page 30).

### Chart 15

This series of pictures shows a child saddened by being excluded from a game of football (1), followed by talking to and receiving comfort from an adult and (3) the same child now playing with his peers (Page 32).

### Chart 16

“One of us is HIV positive, can you tell which one?” (page 34).

### Chart 17

Further help can be found by for example, visiting a counsellor or other health care worker (1) and joining a support group (2) (Page 36).

### Chart 18

This picture shows the counsellor escorting the family out of the clinic and encouraging them to return (Page 38).

### Chart 19

This picture shows the counsellor completing the counselling session by writing notes on the session. It is important to keep notes on issues including successes and challenges (Page 40).

### Chart 20

Counsellor and caregiver discussing the process of disclosure (Page 42).





