

# SECTION 11: ADHERENCE

## General consideration

Although this section was originally written with adult patients in mind, the difficulties associated with ART for infants and children are highlighted. Adherence to ART is essential to avoid development of drug resistance. It is not possible for health-care providers to reliably predict which caregivers or individuals will be adherent to their treatment plan, as adherence does not correlate with gender, cultural background, socio-economic or education level, or language barriers between provider and patient. It is therefore essential to provide all caregivers with a comprehensive plan to support adherence. Several strategies need to be applied and all members of the health-care team, as well as family and possibly even community-based support groups need to be involved.

## Adherence assessment and monitoring

Experience has shown that adherence decreases as time progresses. Monitoring and support of adherence is essential. See the list below for some factors affecting adherence to paediatric ART. A trusting relationship between the patient and caregiver with members of the health-care team is essential. Optimal adherence requires full participation by the health-care team.

**N.B.**

**Every interaction with the patient and caregiver provides an opportunity for reinforcing the absolute need for adherence.**

### Some important factors diminishing adherence in children

- Drug side effects and adverse events
- Intercurrent illness
- Caregiver illness or otherwise occupied
- Patient resistance to taking medicines – ritonavir alone or in combination with lopinavir has a very bitter taste
- Drug stock-outs
- Change or absence of patient's nurse or doctor
- Frequent daily doses – e.g. twice or three times per day

Supportive and non-judgmental attitudes and behaviours will encourage patient/caregiver honesty about adherence and problems. If adherence problems are noted at a regular follow-up visit, we need to try to contact the family between clinic visits to ensure that there are no problems regarding regular diarising of the treatment. It is also important to remind the caregiver to report any troublesome side effect or illnesses (e.g. investigate new barriers such as transport problems, more frequent visits, get support of family/friends, review counselling).

ARV stock-out should never occur; this is an important disincentive for the patient to continue to collect drugs regularly. If the staff member who normally deals with the child is planning a move or vacation, the caregiver needs to be informed of that and reassured that the therapy will continue.

Sub-optimal adherence calls for intensified support and further counselling. This is best done by means of a home visit.

For all health-care team members, specific training regarding ART and adherence should be offered and updated periodically.

## Adherence to ART

- Success of ART depends on tablet-taking behaviour.
- Ideal adherence means a patient must take more than 95% of their doses (i.e. missing less than 3 doses in a month).
- If a patient is taking less than 95% of their doses, they are at risk of developing viral resistance and ultimately virological failure.

See Table 14 for correlation between adherence and virological response.

**N.B.**

**Patients taking <80% of their doses are unlikely to have any durable virological suppression and should be targeted for adherence improvement urgently. At every follow-up visit this must be reinforced.**

# ADHERENCE

## Strategies to promote adherence

- Spend time and have multiple encounters to explain goals of therapy and need for *life-long* adherence.
- Consider monitoring of medications such as co-trimoxazole or any other drug that is being given prior to ART initiation.
- Negotiate a treatment plan that the caregiver and patient can understand and to which he/she commits.
- Encourage disclosure to the child regarding his/her HIV status.
- Encourage disclosure to family or friends who can support the treatment plan. Adherence is likely to fail if the family is unaware of the problem.
- Inform caregiver and patient of potential side effects – severity, duration and coping mechanisms.
- Establish ‘readiness’ to take medications before ART initiation.
- Provide adherence tools where available: written calendar of medications, pill boxes.
- Encourage use of alarms, pagers or other available mechanical aids for adherence. Link schedules to daily activities such as mealtimes or tooth brushing.
- Avoid adverse drug interactions; there must be full disclosure of over-the-counter drugs and traditional medicines.
- Anticipate, monitor and treat side effects.
- Include adherence discussions in support groups.
- Develop links with community-based organisations to support adherence.
- Encourage links with support groups.
- Create links with patient advocates.

**Table 14: Correlation between adherence and virological response to HAART**

Adherence to HAART*	Viral load <400 copies/ml
>95% adherence	78%
90% to 95% adherence	45%
80% to 90% adherence	33%
70% to 80% adherence	29%
<70% adherence	18%
*(number of doses dispensed minus tablets returned) over (number prescribed) e.g. (30-5)/28=25/28=0.9 (90%)	

## Basic adherence package at initiation

### Pre-treatment

- Pre-treatment information and education as per visit schedule.
- Caregiver and/or patient are introduced to therapeutic counsellor and patient advocate, if available and agreed to or nominated by patient, and home visit is arranged.
- Monitoring co-trimoxazole prophylaxis compliance for one month prior to commencing therapy. (This is not to be used to exclude people from ART. It is meant to reinforce daily medication taking behaviour from the outset, and identify potential problems before starting ART).

### On treatment

At each visit:

- ART pill or syrup returned needs to be counted or estimated (% doses missed). This is the ideal but this depends on the clinic load and capacity to undertake this intensive activity. Adherence goal is >95% doses taken. Patients with adherence <80% require increased adherence support (see following page).
- Tablet/syrup count/estimate may be done before the patient sees the health-care provider, and the count reviewed by the health-care provider during the early/initial visits to evaluate adherence. This does take up time and might not be possible at all sites all the time.

## ADHERENCE

- Missed or late clinic visits should trigger concerns about adherence.
- Routine adherence discussion/education with counsellor is of value. This should be an open-ended discussion, with time for questions and repetition.
- Feedback from therapeutic counsellors to the rest of team is important to get a better profile of patients and their environment.
- Encourage caregiver participation in a support group.
- Continue monthly visit with therapeutic counsellors for first three months and quarterly thereafter.
- Arrange regular community visits by patient advocates.

### **Step-up adherence package for people with reduced adherence or virological failure**

This applies to all those whose adherence is less than 80% at any visit. (See Table 14.)

- The therapeutic counsellor/nurse or doctor needs to re-educate the patient and caregiver (and their ‘buddy’) about the importance of adherence. The long-term benefits need to be re-emphasised.
- Evaluate the support structures in place. Are they appropriate? How can they be improved? What other options are there?
- Consider the use of pillboxes and/or daily dosing diary.
- Insist on participation in a support group or link with a patient advocate.
- Consider doing a psychological profile.
- Check family situation (through social worker and therapeutic counsellor).
- Increase home visits by therapeutic counsellors/patient advocates to daily or weekly at a minimum (spot pill counts to be done at home).
- Consider directly observed therapy for an agreed period.



# SECTION 12: POST-EXPOSURE

Most patient care does not involve any risk of HIV transmission.

Each service requires a senior staff member responsible for universal precautions and handling accidental injuries.

## Universal precautions

Universal precautions are simple infection control practices used at all times in the care of all patients. The aim is to reduce the risk of transmission of blood-borne infections.

## Some preventive measures

- Cuts and sores should always be covered.
- Whenever hands are contaminated with body fluids, they should be washed thoroughly with soap and warm water for at least 10 seconds.
- Gloves should be worn to prevent contact with blood or blood-containing fluids.
- Aprons should be worn in high-exposure areas, e.g. trauma unit, labour ward.
- A solution of household chlorine bleach should be used as a disinfectant for surfaces and other inanimate objects.
- Spills of body fluids should be cleaned immediately with such disinfectant.
- Blood-contaminated material or nappies should be disposed of in a plastic bag with a secure tie.
- Children with ongoing bleeding should be separated from the others until such bleeding has stopped.
- Human bites and sports injuries carry a very low risk for viral transmission, except if there is mixing of blood from both parties.

Precautions need to be taken particularly by all health-care providers to prevent needle-stick injuries.

# PROPHYLAXIS (PEP)

## Procedure for ‘sharps injury’ or other exposure

Each clinic or hospital should ensure that mechanisms to allow the procedure described below are in place before any accident occurs.

- Following a ‘sharps injury’, immediate first aid should be given, such as flushing the site with running water, hand washing with soap and water, and, where there is bleeding, allowing the site to bleed briefly.
- Any exposed mucous membranes should be flushed with large amounts of water.
- Antiseptic solutions can have a caustic effect and have not been proven to be effective. However, in the absence of water, antiseptic solutions can be used.
- Report injury to supervisor.
- Ensure that the Workman’s Compensation Act (WCA) form is filled in.
- Consult a doctor for assessment of injury and initiation of treatment.
- Voluntary confidential counselling should be available immediately, and HIV testing and follow-up counselling made available.
- Post-exposure prophylaxis (PEP) with ART can reduce the risk of becoming infected.
- Starter-pack kits are available at government hospitals on a 24-hour basis, these include a 2-day course of AZT and lamivudine. The rest of the medication can be received at the hospital dispensary, except for indinavir, which must be obtained by the worker at his/her own expense.

The risk of HIV-infection following exposure is outlined in Table 15 on the following page.

**N.B.**

**Many health-care providers find reporting and undergoing voluntary testing and counselling stressful, and some choose to remain silent. This silence is often due to the fear, stigma and discrimination associated with HIV. They will require sensitive support to avoid the very unpleasant consequences.**

## POST-EXPOSURE PROPHYLAXIS (PEP)

**Table 15: Assessment of exposure risk, HIV status of source and recommendations for post-exposure prophylaxis (PEP)**

<b>Percutaneous injury</b>	<b>Risk of exposure</b>	<b>Recommendation for PEP</b>
Superficial injury, solid needle	Some risk	Consider basic regimen
Skin puncture, visible blood on needle, hollow needle	High risk	Recommend basic regimen
Needle used in vein or artery	Highest risk	Recommend basic regimen Consider expanded regimen
Deep intra-muscular injury or injection into body	Highest risk	Recommend basic regimen
<b>Mucosal and skin contact</b>	<b>Risk of exposure</b>	<b>Recommendation for PEP</b>
Unbroken healthy skin	Low risk	Not recommended
Compromised skin, small volume and brief contact	Low risk	Consider basic regimen
Compromised skin, large volume and/or prolonged contact	Increased risk	Recommend basic regimen

(continues on following page.)

HIV status of source	Risk of exposure	Recommendation for PEP
Negative	Very low	Not recommended
HIV positive, AIDS or low CD4 and/or high viral load	Low for small volumes or short duration of skin contact	Consider basic regimen
HIV positive, AIDS or low CD4 and/or high viral load	High risk for percutaneous injury	Recommend basic or expanded regimen depending on the severity of the injury
Unknown		Consider PEP on a case by case basis

## Timing of prophylaxis

- Start as soon as possible, preferably within 1–2 hours of exposure.
- The exposure risk should be considered if there is a delay in obtaining prophylaxis.
- Prophylaxis is of doubtful benefit if started 72 hours after injury.

## Post-exposure prophylaxis

Prophylaxis should continue for 28 days.

Table 16 outlines the recommended drug regimen.

**Table 16: Recommended PEP drug regimen *for adults***

Drug	Dose	Frequency	Duration
Zidovudine (AZT)	300 mg	12 hourly	28 days
Lamivudine (3TC)	150 mg		
Indinavir (IND) in cases of high exposure	800 mg	8 hourly	28 days

### PEP following alleged penetrative sexual abuse

#### Recommended drug regimen

- AZT (suspension 10 mg/ml) (see dosing table, Appendix 3)
- 3TC (suspension 10 mg/ml) (see dosing table, Appendix 3)
- Add Kaletra® if significant exposure has occurred

For adolescents Tanner stage 3–4 (Table 10):

- AZT 300 mg 2 x daily
- 3TC 150 mg 2 x daily
- Kaletra® (optional as above)

Duration of prophylaxis is 28 days.

#### Investigations

- One must be sensitive about taking blood from a child in a post-abuse situation.
- Full blood count.
- HIV ELISA on both victim and exposure source, where available.
- It is useful to know the baseline HIV status; blood for HIV can be taken a few days up to 1 week post-exposure.
- Follow up HIV ELISA at 6 weeks, 3 months and 6 months. Victim can be reassured that the likelihood of sero-converting beyond this period is extremely small.

#### Stop prophylaxis if:

- Victim is HIV DNA PCR positive (baseline HIV test)
- Victim is over 18 months and is HIV ELISA positive
- Perpetrator is HIV ELISA negative



# SECTION 13: LEGAL ISSUES

## Guidelines on HIV testing and treatment of orphans and vulnerable children

### **Explanatory note:**

Currently the law does not permit any person other than a parent or legal guardian to consent to HIV testing and medical treatment in the case of a child below the age of 14 years. In the absence of consent from a parent or legal guardian, consent may be obtained from the Minister of Social Development or an application may be made to the High Court.

The provisions of the Children's Bill have widened the scope of who may provide consent by introducing a definition of caregiver and giving this class of persons certain legal rights, which include the right to consent to medical treatment. The Bill also lowers the age of consent to 12 and in cases where a child has sufficient maturity, a child below the age of 12 may also give consent.

The Children's Bill is currently in the process of being passed into law.

## General statement

HIV and AIDS presents one of the greatest threats to the wellbeing of children and has a catastrophic effect on the lives of children living in poverty.

The loss of many adults to AIDS-related illnesses has meant that children have lost teachers, health-care workers and, most importantly, parents. The lack of an adequate social security net in South Africa means that many children live in informal care settings, without legal guardians to assist them.

## **HIV testing of children**

HIV testing of any child may only take place if it is in the best interest of the child and if a person legally capable of providing informed consent, provides such consent.

The HIV status of an abandoned child needs to be determined as:

- Abandoned children have the same rights as other children.
- HIV-infection must be excluded as soon as possible to institute appropriate medical management.
- Adoptive and foster parents should be aware of the child's health status in order to manage the health needs of the child effectively and to access appropriate support.

## **Informed consent**

Currently, until the Children's Bill becomes enacted, informed consent to HIV testing and treatment may be provided by the following persons:

- The child, if of the age 14 years and of sufficient maturity to understand the benefits, risks, social and other implications of the test
- The parent or legal guardian of the child
- Managers of children's homes if the child has been legally placed in the institution

### **Pre- and post-test counselling**

A child must receive age-appropriate pre- and post-test counselling by a trained person, regardless of whether the child is able to provide consent in terms of the Children's Act.

Where the child is not legally able to provide informed consent, the person providing such consent must also receive appropriate pre- and post-test counselling.

### **Confidentiality**

Children above the age of 12 and who are legally able to provide informed consent to an HIV test are entitled to maintain the confidentiality of their HIV status. Consent to disclose the HIV status of such a child must be given by the child.

The same principle should apply to children below the age of 12, who are of sufficient maturity to understand the benefits, risks, social and other implications of the test. However, a strict interpretation of the law concludes that the parents and legal guardians of children below the age of 12 may have a legal right to have access to the results of the HIV test.

In the case of children below the age of 12 and who cannot consent to HIV testing, consent to disclosure must be given by the persons referred to above.



# SECTION 14: COUNSELLING

The following guidelines are provided to assist health workers for counselling of the mother or other caregiver.

## Pre-test counselling

- Choose a private area for counselling, where you will not be disturbed or overheard.
- Assure the client that everything said is confidential. (You could have a poster on your wall making this clear and showing your commitment.)
- Talk through the reasons for HIV testing of the child and/or the mother.
- Ask questions in a sensitive way to find out about current and previous risk behaviour. Remember that the client may not know about her/his partner's risk behaviour.
- Find out how much the client already knows and how much he/she wants to know.
- Offer information about HIV and AIDS.
- Offer information about the HIV antibody test, including information about the 'window period' of infection.
- Go through the implications of a positive test result for the client and her/his family, and the emotional responses, e.g. fears, anger, loss, etc.
- Discuss the client's possible responses to a positive test result. The client can think about who he/she would tell and where to get support.
- Be aware of what the client's concerns are and let these guide the discussion. For example, if a woman is being counselled and already has children, her major concern may be what will happen to her children if she is HIV positive.
- Go through the implications of a negative test result.
- Provide information about how the test is done, how long before the results will be ready, and how the client could obtain the results.
- Give enough time for the client to consider whether he/she wants to have the test.
- If the client decides to have the test, obtain consent in writing on the clinic card.

## Post-test counselling

- Counselling is essential after the result of the test has become available, irrespective of the result.
- Always meet with the mother or caregiver as soon as possible.
- Before speaking to the client familiarise yourself with the facts about the client.
- Find a private room where you will not be disturbed.
- Allow the client to express emotion.
- Allow for silence; time may be needed to absorb bad news.
- **If an HIV ELISA was done in an infant** this will reflect the mother's status, but not necessarily that of the infant. In such a case the infant's HIV status will be determined by a PCR if <18 months or an ELISA positive result if older (refer to section on infant diagnosis, pages 14–15). The parents must therefore be counselled both about their own status and that of their child.

## If the result is negative

- Deal with the feelings arising from a negative result and explain about the 'window period'.
- Discuss ways to prevent HIV-infection through safer sex and the importance of remaining negative.

## If the result is positive

- Tell the person as clearly and gently as possible. Deal with the immediate feelings.
- Give the client time to understand and discuss the result.
- Provide information in a way that the client can understand, provide emotional support and help the person to discuss how he/she will cope.
- Discuss how the person plans to spend the next few hours and days.
- Identify what support he/she has.

## COUNSELLING

- Discuss with whom the client wants to share the test result. Find out if the client intends to tell his/her partner. Help the person to decide whether or not to tell him/her immediately and, if appropriate, how to tell him/her.
- Go through the ways the client can take care of her/his own health and let her/him know about any available treatment.
- For a pregnant woman, go through the ways she may reduce the risk of MTCT during pregnancy, labour and after the birth.
- Discuss how she will feed the baby and the importance of exclusive feeding – whatever choice she makes. Discussion of co-trimoxazole prophylaxis for the infant and the mother needs to be initiated. Details of this must be discussed at a follow-up session.
- Identify what difficulties or problems the person foresees and discuss how to deal with them.
- Encourage the client to ask questions.
- Where possible and acceptable refer the client to a community organisation for support.
- Encourage the client to return for a follow-up session when he/she has had time to think about some of the information just provided.
- If appropriate, some information could be written down as the person is unlikely to be able to remember everything that was said.
- If the child is HIV-infected, the parent or caregiver must be told what to expect with regard to the health of the child, possible ART and how to care for the child.



# SECTION 15: DISCLOSURE TO

The UN Convention on the Rights of Children (Article 12) states that children have the right to participate in decisions about their own health care.

The decision to disclose the HIV status to the child is a difficult one to make.

## Reasons for disclosing HIV status

- As the age of children living with the disease steadily increases it will result in a population of sexually active young people with HIV-infection.
- Keeping the secret is a burden.
- Disclosure should always be in the best interests of the child. This applies to the disclosure itself as well as the manner of disclosure.
- Benefits of disclosure include recognition of the child's autonomy, increased intimacy with those close to the child, and improved psychological adjustment.
- The child may need to prepare for tasks ahead (sickness, painful procedures etc.).
- The child will need to participate in ART adherence.
- Children often know more than adults think they do.
- Children not told about their disease often have much more anxiety and distress.
- Disclosure needs to take place before adolescence.

## Guidelines for disclosing HIV status

Many parents/caregivers are afraid to tell their children. They will need encouragement and support to do this. However, it is inadvisable to disclose the status to the child against the wishes of the parent/caregiver.

- Where possible get help from trained child counsellors.
- Try to balance the needs of the child and the parents. Disclosure is a process, not a once-off event; plan future visits to answer questions and assess how the child is coping with the information.
- Assess the child's readiness.

- Offer the parents time, support and information.
- Plan in advance the time, place and people who will be present for the disclosure. However, it is best to avoid a formal, solemn occasion.
- It may be an advantage to have a written plan of what should be disclosed to the child.

## **What is the right thing to say?**

- Find out how much the child knows about the illness and what he/she wants to know.
- Children need to know that they are loved and will be cared for.
- Many children believe that sickness is their fault – they need reassurance that their illness or their parent’s illness is not a punishment for a wrongdoing.
- Children need to learn how HIV is transmitted.
- The age of the child suggests what can be told to them, e.g. a 5-year-old may not need to hear the word HIV, while an older child can be given more information.
- Be honest. If you don’t know the answer to the child’s questions say so and then seek help.
- Be led by the child in terms of the amount of information he/she requires.
- Use language appropriate for the child’s insight, understanding, education and emotional readiness.
- Anticipate possible responses by the child and plan for the future; this may include follow-up sessions, counselling and support for the child and parent/family, or education about signs of emotional distress in children.
- Anticipate the impact of the disclosure on other family members, friends, the school and the community and plan for this.
- Once the disclosure has happened, monitor the child’s behaviour (sleeping, school problems and withdrawal). Changes in behaviour can indicate a need for more support and intervention. Despite the best planning, you cannot be certain how a child will respond.
- Be respectful of the child’s needs, feelings and responses.
- Stories and books may be useful.