

# **Social tract**

**Module on**

# **Adherence counselling**

## **OUTCOMES FOR ALL PARTICIPANTS**

After this module the learner should:

- Have explored the concept of anti-retroviral treatment, the critical value of adherence and its related concepts.
- Understand the various components of pre-ART adherence counselling.
- Be aware of the wide range, and influential impact of, ART side effects and to manage the impact of this in counselling.
- Have considered the various enablers and obstacles to ART adherence, with particular consideration of the South African context.
- Have examined the relevant counselling theories that can be drawn upon in ART adherence counselling.
- Have developed the skills and knowledge for counselling particular client groups with regards to ART adherence.

# 1. GLOSSARY

**Adherence:**

The degree to which a patient exactly follows a prescribed treatment regimen that has been designed in the context of a (consultative) partnership between the client and the health care worker/counsellor. Poor adherence may negatively impact a drug's effectiveness.

**Anti-retroviral therapy (ART):**

Drugs that suppress or prevent the activity of a retrovirus such as HIV. This is done by disrupting the HIV enzyme's ability for genetic copying or for making virus that can infect other cells. Also known as: Anti-retroviral treatment; Antiretrovirals (ARVs); HIV therapy; anti-HIV drugs.

**Compliance:**

The extent to which the patient's behaviour (in terms of taking medications, following diets, or other life style changes) coincides with medical or health advice. This term has been viewed by many as having a value statement and the term 'adherence' is preferred.

**Cross-resistance:**

A mutant version of HIV may develop which is resistant to more than one drug even after a single therapy. For example, people who develop resistance from taking one non-nucleoside reverse transcriptase inhibitor (NNRTI) are likely to be cross resistant to other drugs in the same class.

**Enzyme:**

A cellular protein whose shape allows it to hold together several other molecules in close proximity to each other. Enzymes also induce chemical reactions in other substances.

**Mutation:**

Changes in HIV's genetic structure (RNA) leading to alterations in certain proteins, most commonly enzymes that regulate the production of infectious virus. Mutations are particularly common in HIV as it reproduces at an extraordinary rate and does not contain the proteins needed to correct mistakes made during copying of the genetic material. Some mutations cause the virus to become so weak that it cannot replicate effectively; other mutations may cause the virus to become even more virulent.

**Nucleoside:**

The molecular units that serve as the building blocks of DNA and RNA, the genetic material found in living organisms.

**Replication:**

Reproduction of HIV.

**Resistance:**

A reduction in an organism's (HIV's) sensitivity to a particular drug. The result is that a particular drug or combination of drugs is unable to block reproduction or "replication" of HIV. Some strains of HIV are naturally resistant to the presence of anti-retroviral drugs as a result of random mutations occurring on a daily basis. Resistance can render certain drugs less effective or even completely ineffective, thus significantly reducing treatment options.

## 2. THE ART READINESS ASSESSMENT

Doctors need to make clinical assessments about when it is appropriate to begin ARTs however what has been found to be of utmost importance, though, is:

**The strength of the recommendation for therapy must balance the readiness of the patient for treatment.**

A variety of accepted guidelines (including those proposed by the DoH), recommend that two or three sessions are conducted with the client prior to writing out the first prescription.

The dual aim of these sessions is:

1. To provide the client with the necessary information about ART and its related aspects (i.e. adherence education);
2. To assess the client's "readiness" to take ART medication.

*Antiretroviral therapy should be deferred until patients are prepared to commit themselves to long-term treatment and to maintaining good adherence to the therapy.*

Adherence is an important determinant of early virological response to HAART. In drawing up a recipe for successful ART outcomes, there would be a number of critical ingredients. They are :

<u>RECIPE FOR SUCCESSFUL ART :</u> Key Ingredients	
<ul style="list-style-type: none"><li>•</li><li>•</li><li>•</li><li>•</li><li>•</li></ul>	<ul style="list-style-type: none"><li>Information/education/support prior to ART initiation</li><li>HIV and ART education</li><li>Belief in the need for treatment and adherence</li><li>Information on difficulties of following drug plan, on side effects</li><li>Establish foundation for long-term adherence</li></ul>

### COMPONENTS OF THE ART "READINESS" ASSESSMENT

#### A. Medical Component (usually performed by the doctor)

1. Complete history and physical
2. Complete blood count, chemistry profile
3. CD4+ T lymphocyte cell count
4. Plasma HIV RNA measurement
5. Other routine tests (including gynaecological exam, tests for prevention of Opportunistic Infections)

#### B. Client's HIV History

1. Year of HIV diagnosis
2. The client's reasons for taking the HIV test at the time

3. The client's story (Encourage sharing about the client's history)

C. Disclosure

1. To whom and when has the client disclosed
2. Reactions from others to the disclosure
3. Partner disclosure (previous, current and future partners)
4. Reasons for not disclosing to certain people (if applicable)
5. Household awareness of HIV status (do the people with whom the client lives, know about his/her HIV status?)

D. Factors Influencing Adherence

1. Client's lifestyle (job, travel, routine, sleep patterns)
2. Client's personality traits (levels of self-discipline, organisation, order, responsibility)
3. Prior medication adherence (for example, the contraceptive pill, diabetes, blood pressure, other medication adherence)
4. View towards being on medication again or as well as other medication (if applicable)

E. Holistic Self-Care since HIV Diagnosis

1. Client's attitude towards their HIV status
2. Patterns of sexual behaviours and intimate relationships
3. Treatment and prophylaxis for Opportunistic Infections
4. Substance use or abuse (i.e. drugs and alcohol)
5. Dietary patterns
6. Rest and stress patterns (current life demands, management thereof)

F. ART "readiness"

1. Client's motivation for beginning ART
2. Client's views about whether they can commit to the ART regimen
3. Client's perceived advantages and disadvantages of being on ART
4. Emotional responses to beginning ART (fears, excitement, hopes (realistic/unrealistic))

### 3. PLANNING FOR ART & ADHERENCE:

#### Key Principles

Counsellors, together with the health care team, should encourage or work together with clients to develop personalised plans to ensure adherence to multi-drug regimens.

Here are some key **principles** to assist health care personnel (and thereby the client):

- Encourage the clients to be active participants in their own treatment
- Give clients access to educational materials that describe how to take pills and what the side effects will be
- Provide information about where and how to access physical, social and psychological supports

- Provide practical support (or where to receive these) in the form of pill boxes and charts
- Help clients to identify lifestyle characteristics that could interfere with the treatment plan. See how you could link drug regimens with “established daily routines”
- If the client is interested, the counsellor could assist with doing a “dry run” with dummy pills (smarties, jelly tots etc.). This could help to give a feeling of what it will be like to be on ART, assess the degree of adherence and the potential obstacles.
- Help the client to know when and how to access regular feedback on viral load and T-cell counts.
- Assist the client with developing tools for assessing the treatment plan. For example, medication diaries.

#### **4. WAYS IN WHICH ADHERENCE CAN BE IMPROVED**

There are a number of ways in which adherence to medication can be improved. These centre around ensuring that the patient understands the importance of adhering to medication and the consequences of poor adherence as well as providing medications which minimize changes to the patient's lifestyle.

There are a variety of ways in which adherence can be improved:

- Patient/Physician education
- Patient support systems
- Easy incorporation into patient lifestyle
- Dosing not affected by food/fluid intake
- Convenient and simple dosing
- Good tolerability
- Manageable side-effect profile
- Maintained quality of life
- Few, compact, easy to swallow tablets

Several strategies to improve treatment adherence are listed. Those that should be considered prior to the initiation of HAART include education regarding the disease and antiretroviral therapy (ART) options. Commitment from the physician and patient that adherence is recognized as an important factor in the success of any ART.

Potential life-adjustments required for the ART regimen chosen should be discussed prior to initiation of therapy. Once ART has been initiated, it is important to follow up soon after the initiation of HAART to discuss any side effects or other factors that may be affecting adherence.

#### **5. THE CONTENT OF ADHERENCE COUNSELLING**

- Before ART initiation
  - Patient education on HIV infection and HIV disease stage
  - Risks/benefit of ART
  - Full commitment to therapy and development of trust in the health care team. This may take several visits.

- ART initiation
  - Tailor the regimen to the patient’s lifestyle
  - Start when the patient is ready, when the patient is committed to the selected regimen, including dosing schedules and side effects
  - Follow-up visits soon after initiation are very important: side effects, comfort, convenience?
  - Prompt response to any problems, side effects: adjust, change, stop?
- Treatment-related strategies
  - Simplification of ARV regimen: reduced pill numbers, dose frequency, simplified food requirements\*
  - Avoid drug interactions and minimize side-effects
  - Directly observed therapy: not ideal for the long-term (Costly, time-consuming, not feasible lifelong)
  - Treatment of associated conditions: depression, anxiety, psychotic disorders

*\* ‘ There is evidence that simplified regimens with reduced pills number and dose frequencies improve adherence... .. Fortunately, an increasing number of effective regimens have no specific food requirements. ’*

## **PREDICTORS OF ART ADHERENCE**

### Predictors of poor adherence:

1. Poor clinician-patient relationship
1. Lack of patient understanding and knowledge
2. Low literacy (this should be part of the assessment)
3. Inability of patients to identify their medications
4. Medication side effects
5. Lack of reliable access to primary medical care or medication
6. Domestic violence
7. Discrimination
8. Active mental illness, in particular, depression
9. Active drug and alcohol use
10. Mobile lifestyle

### Predictors of good adherence:

1. Availability of emotional and practical life supports
2. The ability of patients to fit the medications into their daily routine
3. The understanding that poor adherence leads to resistance
4. The recognition that taking all medication doses is important
5. Feeling comfortable taking medications in front of people
6. Optimal viral suppression is associated with keeping clinic appointments
7. Not having to take ART in secret

## **THE CLIENT-COUNSELLOR PARTNERSHIP**

### Involves:

- The client having a say in the kind of drug regimen that he/she goes on
- The client asking for information

- Asking questions
- Making sense of the information
- Deciding when they want to start
- Deciding when/how frequently they would like a consultation

Involves the counsellor

- Providing ALL the necessary information
- Completely disclosing information with regards to side-effects
- Checking the client's understanding
- Responding to and taking account of the client's various emotions
- Addressing the client's doubts about beginning ART
- Anticipating future challenges in the client's life
- Encouraging the client to do independent research/information gathering about the subject

### **DRAWING ON THE PROBLEM-SOLVING MODEL**

In order to facilitate adherence, it is really important that the counsellor spends time with the client weighing up the pros and cons of beginning an ART regimen. This process needs to be client-centred and driven by the client. Whilst the counsellor needs to be supportive, he/she also needs to use challenging skills. These will highlight any contradictions that the client is not consciously aware of as well as anticipate obstacles that may arise later on.

#### Some deterrents against taking ART (DISADVANTAGES):

- Patients must adhere to the timing, frequency and dosage of the drug regimen for a lifelong treatment period
- Dosing regimens may be complex
- There are differing dietary requirements
- Some drugs require refrigeration
- Some require preparation
- Multi-drug regimens require taking numerous pills per day
- Certain drugs may interact
- There is a high possibility of experiencing drug side-effects
- Loss of confidentiality as a result of being seen taking the drugs
- Risk of drug resistance and, therefore, limitations of future ART choices
- Unknown long-term toxicity

#### Some incentives for taking ART (ADVANTAGES):

- Extended life-span
- Delayed onset of opportunistic infections
- Stronger immune system due to delaying progression of disease
- Longer life-span to fulfil dreams and goals
- More time to see children grow up and go through life stages
- Opportunity to convey one's life experience (through writing, talking, other means of communication)
- An opportunity to use the experience of HIV-diagnosis to make life more fulfilling
- The opportunity to continue earning a living (i.e. more productive life years)

- More time to await (and possibly benefit from) the outcomes of scientific HIV/AIDS research – Maybe a cure will be found before I get ill?
- Better quality of life
- More time to do the things you enjoy.

## COUNSELLING AROUND SIDE EFFECTS

The Challenge of side effects:

Do not underestimate the daily challenge of side effects and other symptoms of HIV. It is very important that counsellors are able to EMPATHISE with the difficulties that patients are encountering with regards to their ART regimen.

Never minimise what the patient is experiencing nor label them as difficult patients, such as 'complainers' or 'hypochondriacs'.

Remember (and remind your clients) that being on ART won't necessarily bring them 'normal' lives. Besides the challenges of being adherent, living successfully with HIV does not mean being symptom free. The symptoms may cause psychological distress together with the expectation that successful treatment will engender a 'normal' life.

Counsellors need to create an environment in which clients can speak thoughts that ordinarily remain unspoken. This will open a forum for **validation** and **support** - both of which are crucial for sustaining the perseverance required by ART.

It is crucial for counsellors to assess the functional impact of any side effect on an individual's life. For example, if a client is experiencing a bad bout of diarrhoea, it may be necessary to ask quantitative questions, such as "How often?" and "How bad?" but also qualitative questions, such as "How much of a problem is this for you?" and "Is it manageable or not?". These answers will help the counsellor-client-health care worker team to assess whether medication should be suspended, switched or continued.

Most importantly, counsellors need to remind themselves that people living with HIV and AIDS can benefit from role-players who provide attentive listening and active witnessing.

## DEALING WITH SIDE EFFECTS FROM ART

*Did you know?*

In countries where ART has been available for a long time, about one in three persons stops taking them because of the side effects or inability to maintain the strict drug regimen.

The key to coping with side effects may be knowing what to watch out for and having a plan in place to respond if/when problems occur.

Counsellors should not think that talking about side effects would bring them on. The client may, in fact, feel more confident – “better armed” – to deal with what they know may potentially happen rather than fearing the unexpected. Some practitioners in countries like the USA will even give prescriptions for treatments of side effects

before the client has experienced them. This is seen to reduce the waiting (and suffering) time of the client as well as reduce anxiety about experiencing the possible side effects.

More importantly, some of the side effects caused by ART may be life threatening. For this reason it is essential that clients know what early symptoms to look out for and to monitor for them. In some cases, it is possible to prevent or reduce the seriousness of some side effects by taking certain preventive therapies a few days before or at the same time as starting a new regimen.

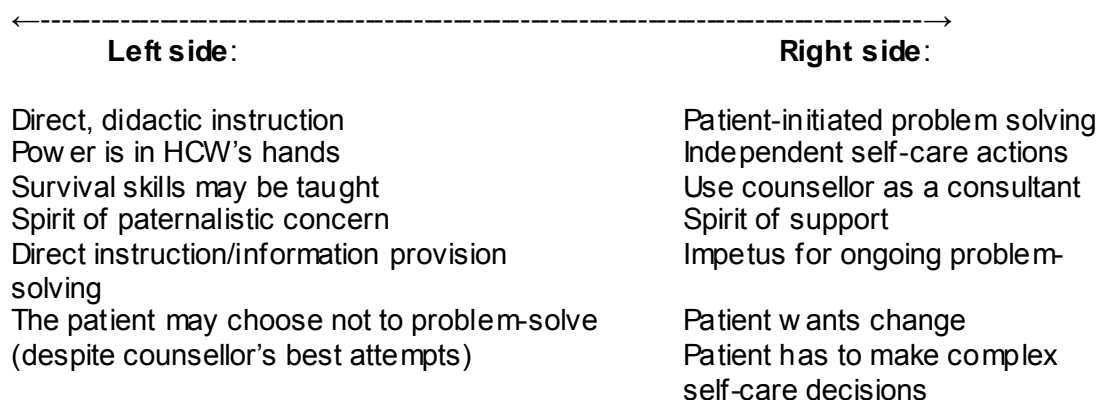
**Bottom Line:**  
Patients must consult their doctor if they suspect that they are experiencing drug side effects. Some of these side effects may be potentially fatal.

## 6. THE EDUCATIONAL CONTINUUM

The requirement of strict adherence to a drug regimen is not being seen for the first time with HIV anti-retroviral treatment. Many life-threatening illnesses have required strict adherence to the prescribed drugs - sometimes for the rest of the patient's life.

Various models have, therefore, been devised to help health care workers understand which is the best approach for achieving maximum adherence. We must also keep in mind the principle of individualisation and that each client has different needs and, therefore, requires a different response from his/her counsellor. The educational continuum takes this into account.

The Educational Continuum:



Many patients may need both direct instruction (for example, "You must take the correct tablets at the same time everyday") as well as engagement in problem solving with their counsellors (for example, "How do you think you can remember to take your pills at the same time every day?"). In order to strike an effective balance, ART counsellors must have skills to move fluidly back and forth along the continuum, ever mindful of their patients' needs and concerns.

The middle of the continuum is therefore characterized by active exchange of ideas, explicitly negotiated goals and objectives, and shared power and influence that serve

patients' interests and foster patient self-management and long-term behaviour change.

## 7. VERBATIM FRAGMENT OF AN ADHERENCE COUNSELLING SESSION

Client: Morning Sister. I've come for my monthly.

Counsellor 1: Morning Mary. It's two months now since you began ART. How are you doing?

Client: Fine thanks, Sister. It's not easy but I'm managing.

Counsellor 1: Do you want to tell me a bit about how it's been going? (Open-ended question)

[Counsellor 2: Have you been taking your medication all the time?]

Client: Well, I've been taking my medication as I'm supposed to... I just feel very tired all the time and then I want to sleep. I can't cook and clean like before. I'm so tired when I wake up that I'm scared that I'll sleep through my morning dose.

Counsellor: It sounds like it's been difficult for you. Do you think your tiredness could be a side effect of the medication?

[Counsellor 2: It's very important that you don't miss any doses. You know that you have to take your medication at the same time every day!]

Client: Yes, I think it is. The doctor told me that I might feel like this. He also said that I might get diarrhoea from the AZT/3TC.

Counsellor: Has knowing this made it any easier for you to cope with – knowing that what you're experiencing is common?

[Counsellor 2: I'm sure it will go away soon. Just keep taking your medication.]

Client: Yes, I guess it has. I probably would have caught a fright if I hadn't expected it. I bought the ingredients for a BRAT diet just in case. So I was prepared.

Counsellor: It sounds like you're being responsible Mary. So you're eating bananas, rice, apple sauce and toast?

Client: (Laughs) Yes!... but, Sister..., some days I'm tempted not to take my medication. I don't like the way it's making me feel.

Counsellor: Perhaps you have days when you wonder if this is worth it. Maybe the side effects make you feel worse than the HIV was making you feel before you started treatment?

[Counsellor 2: You know that it's really important to keep persisting. Everyone feels that way.]

Client: Yes. (Starts crying). I know ... that... it's really important for me to take the drugs – everyday, and I'm scared... that I'll forget and then the drugs won't work anymore and I'll get sick and die. There'll be nothing left for me.

Counsellor: I can see that you realise how important it is to be adherent to your medication, but it seems like you're putting a lot of pressure on yourself too. Would you like to spend some time looking at how you can manage these side effects more easily?

[Counsellor 2: You have to pull yourself together otherwise you'll make yourself sicker than you are now . Do you want that?]

Client: Yes, please. I really need to see if there are things that will help me to get through this.

## 8. PATIENT-RELATED STRATEGIES TO IMPROVE ADHERENCE

- ❖ Multiple education and encounters
- ❖ Establish readiness to take medication first
- ❖ Recruit family and friends
- ❖ Develop support groups
- ❖ Develop concrete plan
  - timing of doses
  - relation to meals
  - daily schedule
  - side effect management
- ❖ Inform patient
- ❖ Provide
  - pill boxes
  - pagers
  - alarm clocks
- ❖ Familiarize patient with pills
- ❖ Selection of regimen
- ❖ Follow-up of patients' perceived symptoms
- ❖ Assisting with management of symptoms

Interventions associated with improved adherence to antiretroviral therapy can include pharmacist-based adherence encounters/clinics; adherence encounters at each visit, which are often multi-disciplinary; medication counselling; behavioural intervention, both before and at the time of treatment initiation, with reinforcement at each visit. Devices that may aid adherence and reinforce education include: reminders, alarms, pagers, timers on pillboxes, patient education aids, including regimen pictures, calendars, stickers, clinician education aids (medication guides, pictures, calendars).

NOTE :

Prevention counselling in the patient with HIV infection must not be forgotten! Adequate counselling about safer sex practices must be provided to encourage prevention of new infections and re-infection.

### HELPING OTHERS LEARN HOW TO TAKE ART

Counsellors and other health care workers must bear in mind that a large portion of the South African population are both illiterate (unable to read due to lack of education) and innumerate (unable to read numbers). There are numerous implications of this for prescribing ART with the expectation of adherence.

Here are some tips for the counsellor:

1. Don't assume that the client can read or understand what is written on their prescription
2. Don't assume that they have already had their medication explained to them by the doctor or that they understood this
3. Don't think that the client will remember what you say. If they (or a family member) are literate, it may be helpful to write down the instructions for taking their medication.
4. If there are family members available, with the client's permission, engage them too in the process of understanding how the medication must be taken. They may be able to serve as "back-up" if the client is confused, doesn't understand or doesn't remember to take his/her medication.
5. Pictures can be very helpful in reminding clients when and how much medication to take. The World Health Organisation has a chart that they recommend. This could be developed to be given to the client. It is also helpful for people who cannot read.

## 9. ART AND CHILDREN

The same anti-retroviral drugs are used with children as with adults except that the dosages are smaller and adjusted according to the age and weight of the child. Children who use ART have normal growth and development and, in fact, these things may be improved and restored together with the child's quality of life. Complicated infections can be prevented and the child's life can be prolonged. (Ref: van Dyk 2001).

Some Tips for ART Adherence Counselling in Children:

- Try to work as closely as possible with at least one parent or the primary caregiver as they are frequently needed to play the role of Treatment Assistant to the child.
- Remember who the client is. It is the child and not the parent/guardian. Be client-centred whilst maintained constructive, inclusive relationship with the parent/guardian as much as possible.
- Depending on the child's age and maturity, believe in the child's ability to act responsibly, be independent and understand the importance of adherence. Do not patronise the child.
- Include the child as much as possible in all consultation/counselling sessions. Talk to them and ask for their thoughts, views and opinions. Don't talk to the adult only.
- During the ART readiness assessment, engage with the child. Remember to make use of counselling skills that facilitate the engagement of the child in the process. These include, asking open-ended questions, summarising, inviting questions and "helping the client to tell his/her story" (Egan).
- During the information provision stage, ensure that you are operating at the child's level of understanding. Provide the facts in a clear, concise and user-friendly manner. If it helps you to use drawings, pictures or analogies to explain certain concepts, then go ahead and be creative.
- Get in touch with the child's feelings. How do they perceive this experience? The child may feel different, afraid, rebellious, uninformed or eager to cooperate. Identify these feelings and reflect them back to the client by means of your empathy skills (Responding to Feelings, Carkhuff).

## TIPS FOR PARENTS OR PRIMARY CAREGIVERS

Here are some tips that counsellors can give to parents or primary caregivers:

- If the child is receiving his/her medicine in syrup form, be clear and accurate as to how much you give;
- For the child, the medicines may be vile (despicable) tasting. Try to find a strategy that will help the child to tolerate this. Perhaps you could follow the syrup with a sweet-tasting drink.
- Your child may go through stages when he/she is tired of having to take the drugs, angry or rebellious. You may need to be patient and continue to explain why the drugs are so important. Try not to become forceful or angry with your child. This may lead to them rebelling even more.
- Never refer to the medicine taking as a “punishment”. The child needs to understand this in a positive light and try to “own” the fact that they are being responsible about taking care of themselves and their health.
- If your child is away from home or might be away at a time when they will have to take their medication, someone needs to be responsible for ensuring that this is planned for and that the regular, required medication is taken with. It is important to consider trying not to disrupt the child’s daily schedule as much as possible.
- When it is time to visit the doctor or nurse, remember to take your child’s medicines with.

## WORKING WITH COUPLES: SOME GUIDELINES



- ⊙ Always remember to **protect and build the relationship of the couple**: By sticking to your beliefs that ‘disclosure is best’, this may, in fact, destroy the relationship AND the only source of support that one partner has.
- ⊙ **Always offer confidentiality**: You can be party to disclosing information, told to you by one partner, to another. This is an abuse of your designated power.
- ⊙ **Accept only informed consent**: It can be very difficult to obtain true consent when one partner is in the same room as a manipulative partner. Rather be sure about the client’s true request, by spending a few minutes with each of them alone.
- ⊙ **Create an environment of free expression** as best as possible: This may be helpful in some relationships and more destructive in others. Although we aim to foster trust, it is sometimes necessary to counsel the couple separately.
- ⊙ **Try not to centralise yourself** as the counsellor: Part of your role is to facilitate communication between the couple. If they are already able to communicate with each other, you are present as a source of support and factual information. Enhance, don’t undermine, the existing strengths of the relationship.
- ⊙ **Actively open communication** between the partners: Is each one ‘hearing’ what the other is saying – both in their verbal and non-verbal

communication? At times you may need to be a voice to amplify or clarify messages directed from one partner to the other.

- ◎ **Remain neutral:** It is not your role to take sides and, in fact, by supporting one partner over the other you may lose their trust, presence and hope in the counselling process. Be aware of a natural tendency to side with the same-sex partner as you.
- ◎ **Make the couple aware of their strengths:** Try to find at least one strength that exists in the relationship, or else focus on each individual's strengths. The couple would not be sitting together with you if they didn't care somewhat about each other and/or the relationship.
- ◎ **Make your role as counsellor clear:** Your role is to support BOTH parties; to remain neutral; NOT to deliver the/a message from one to the other; to clarify misunderstandings; and to provide factual information.

## **GUIDELINES FOR THE COUNSELLOR**

- ♥ Spend time on the relationship
- ♥ Acknowledge the role of race, ethnicity, gender, sexual orientation and age in your own and your client's life
- ♥ Stay up-to-date on HIV risk-related information
- ♥ Be aware of the client's perception of their risk
- ♥ Use the stages of change and harm reduction theory in your work
- ♥ Be curious about the contextual issues in your client's life (whilst also being purposeful)
- ♥ Be aware of the specific impact of HIV in each individual's life
- ♥ Be aware of and support your client's strengths and sources of resiliency
- ♥ Remember that the client has an ultimate right to self-determination
- ♥ Commit to an ongoing self-reflection of your values and judgments.