The Lotus Project

Women's Peer Education Training

A Collaboration Between:

Center for Health Training

You are not alone!

WORLD

Women **O**rganized to **R**espond
to **L**ife-threatening **D**iseases

Funded by Health Services and Resources Administration

The Lotus Project

Women's Peer Education Training

Each day the beautiful Lotus flower
enacts rebirth and renewal of life
as it dips below the surface of the water at night
only to be reborn with the sun
at the dawn of the new day.

Day 1:
What Does It Mean To Be a Peer Educator/Advocate?

1 Registration, Evaluation

2 Introductions

3 Group Agreements & Parking Lot

4 Lotus, a Symbol of Peer Advocacy

5 Stages of Change

6 Peer Educator Code of Ethics

7 HIV/STD 101 Jeopardy Game

8 Closing & Homework

Peer Education/Advocacy

A **peer** is a person who belongs to the same social group as another person or group. The social group can be based on age, sex, sexual orientation, occupation, health status, or other factors.

Education/Advocacy refers to the development of a person's knowledge, attitudes, beliefs or behaviors as a result of the learning process.

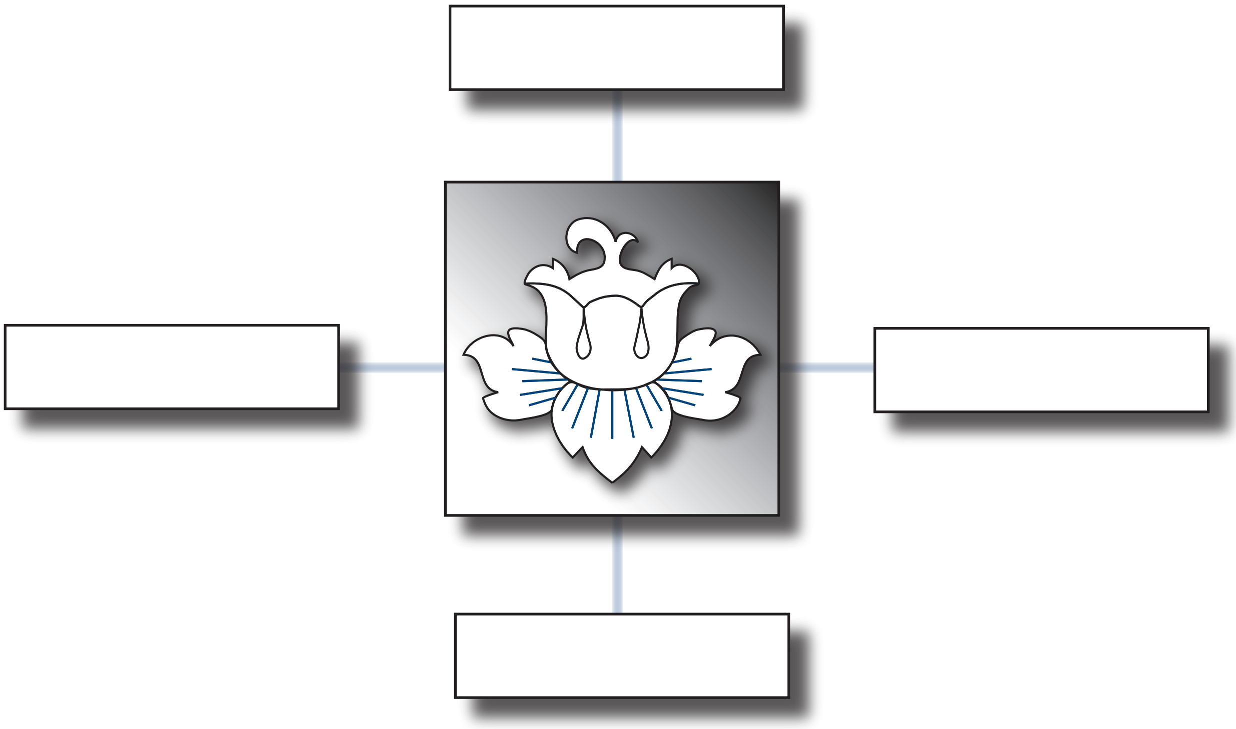
What are the **advantages** of Peer Education? ______________________________

____

What does Peer Education/Advocacy mean to you? _________________________

____

What are the various roles of Peer Educators?



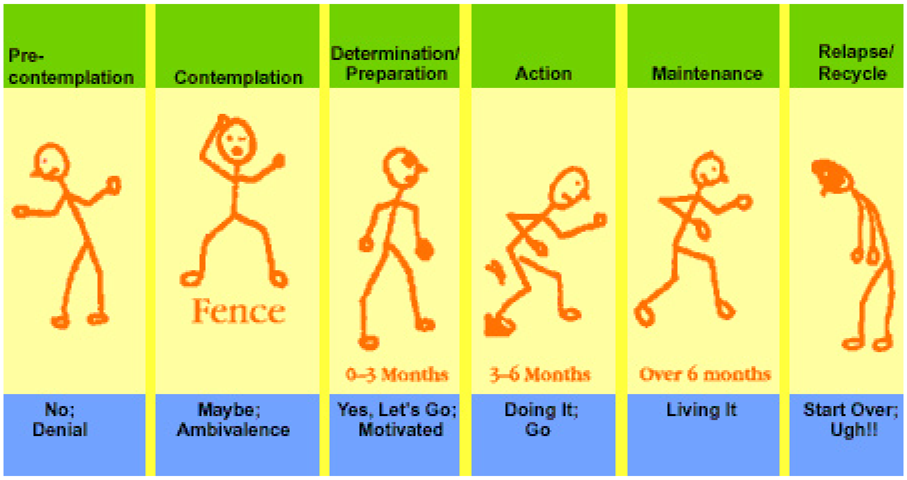
A Peer Advocate is NOT a ...... ______________________________________

Stages of Change Model of Peer Advocacy…

One model we can use to understand better how we deal with change is the Stages of Change model. This theory proposes that we typically progress through six stages as we incorporate a new behavior, attitude, or skill into our lives. We can learn to identify at what stage a client, family member or friend is in, and offer support to help them move forward.

STAGE	BEHAVIOR	WHAT YOU CAN SAY/DO TO HELP
Pre-contemplation	• Doesn't intend to change, feels no need to change. • May feel hopeless, defensive, ashamed or angry.	• Support feelings: You seem sad/scared/nervous. • Ask non-threatening questions: What do you think about . . .? How would you handle this? • Listen. • Provide limited information, increase awareness of risks.
Contemplation	• Growing awareness of need to change. • More open to feedback. • Thinking about change, not taking action. • Indecisive, not ready to commit to change.	• Support feelings: This seems scary to you. • Ask open questions: What would happen if...? How would it be to...? • Weigh pros/cons of change: On the one hand…, but on the other…
Preparation	• Intent to take action in near future. • May have already begun taking some steps toward change. • 0-3 months	• Show understanding and support: Other women feel the way you do. This is a really tough decision. You're making a great start. • I like what you've already done. • Examine alternatives: Some women have tried...
Action	• In process of changing. • Practices new behavior consistently. • 3-6 months	• Ask supportive questions: Who can help you stick with this? • Support small steps: I'm so impressed you've tried this.
Maintenance	• Feels confident and comfortable with new behavior. • 6 months or more	• Show support: What an accomplishment! Look how far we've come. • Identify strategies: What's one thing that will keep you going?
Relapse	• Falls back to any former stage.	• Support feelings: You seem frustrated/sad. • Ask non-threatening questions: What helped you…? What do you think about…? • Provide reassurance: Most people go through this.

Meeting Your Client Where They Are At



This model suggests that individuals or groups pass through six stages when changing behavior:

For example, when people change their behavior by using condoms to protect themselves from infection, the stages they pass through could be described as:

1. **Pre-contemplation:** Have not considered that they are at risk and need to use condoms
2. **Contemplation:** Become aware of their risk and subsequent need to use condoms
3. **Preparation:** Begin to think about using condoms in the next months
4. **Action:** Use condoms consistently for fewer than six months
5. **Maintenance:** Use condoms consistently for six months or more
6. **Relapse:** May begin to use condoms less consistently or discontinue use

People tend to move back and forth between stages, and relapse to a prior stage is always possible. In fact, people can relapse to any stage, but a return to pre-contemplation is least likely.

It is important to remember that changing behaviors, especially intimate and private behaviors, is a complex process.

Peer Educator Code of Ethics

I value my role as a peer educator and in order to best fulfill that role, I will:

1. **Respect** individual differences, including choices people make that may not be my own.
2. Act as a **role model,** making healthy choices and being true to myself.
3. **Honor diversity** in all its forms.
4. Maintain **confidentiality.**
5. **Learn** as much as possible about the issues that affect my peers.
6. Only **offer information** that I am qualified to offer and with the greatest accuracy possible.
7. **Follow through** on my word and promises.
8. **Meet clients where they are at** in their journey towards healing and positive change.
9. **Accept supervision and support** from others.
10. Not allow my peer educator duties to put my emotional or physical well-being at risk.

I value and know who I am...

I am an individual, a caring helper, an educator, a role model.

I am a Peer Educator.

My Plan Worksheet

My **Strength** comes from …

Pluses "+s": list some of the wonderful things you do or qualities that you have that will help you in your work as a peer educator.

Wishes: list a few things you would like to start working on to improve your weaknesses.

Choose **one thing** you would like to start doing within the next few weeks.

What is that one thing you want to work on?

What will be your first step?

When will you take this first step?

Who can help you do this new thing?

How will you reward yourself once you've gotten started?

And Still I Rise
by Maya Angelou

You may write me down in history
with your bitter, twisted lies,
you may trod me in the very dirt
But still, like dust, I'll rise.

Does my sassiness upset you?
Why are you beset with gloom?
'Cause I walk like I've got oil wells
pumping in my living room.

Just like moons and like suns,
with the certainty of tides,
just like hopes springing high,
still I'll rise.

Did you want to see me broken?
Bowed head and lowered eyes?
Shoulders falling down like teardrops.
Weakened by my soulful cries.

Does my haughtiness offend you?
Don't you take it awful hard
'Cause I laugh like I've got gold mines
Diggin' in my own back yard.

You may shoot me with your words,
You may cut me with your eyes,
You may kill me with your hatefulness,
But still, like air, I'll rise.

Does my sexiness upset you?
Does it come as a surprise
that I dance like I've got diamonds
at the meeting of my thighs?

Out of the huts of history's shame
I rise
up from a past that's rooted in pain
I rise

I'm a black ocean, leaping and wide,
welling and swelling I bear in the tide.
Leaving behind nights of terror and fear
I rise

Into a daybreak that's wondrously clear
I rise

Bringing the gifts that my ancestors gave,
I am the dream and the hope of the slave.
I rise
I rise
I rise.

Day 2:
The abC's of Peer Advocacy

1 Warm-Up, Review Homework

2 4 C's of Peer Education

3 Communication Skills

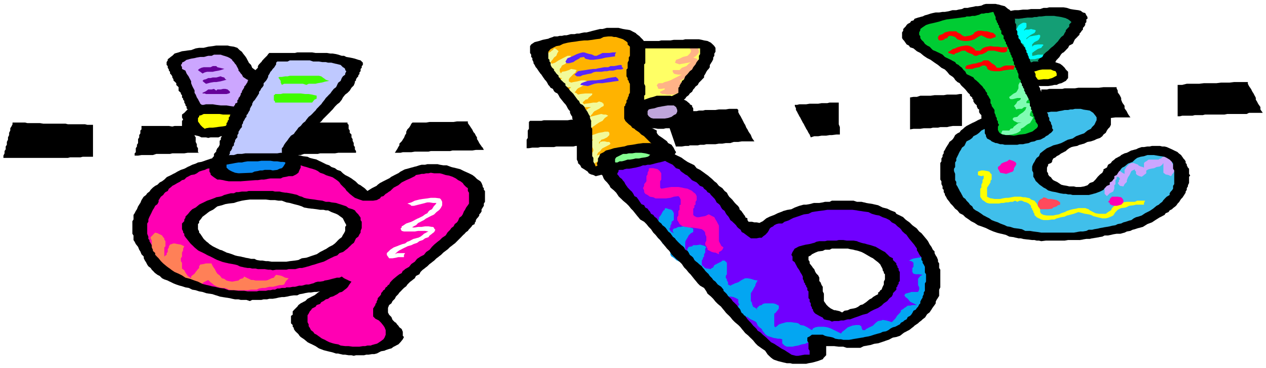
4 Confidentiality

5 Countertransference

6 Creating Boundaries

7 Working with Grief

8 Closing Candle Activity, Homework



4 Concepts of Peer Education to address Challenges

Communication

Confidentiality

Countertransference

Creating Boundaries

Barbara's Case Study

Barbara is a peer advocate living with HIV.

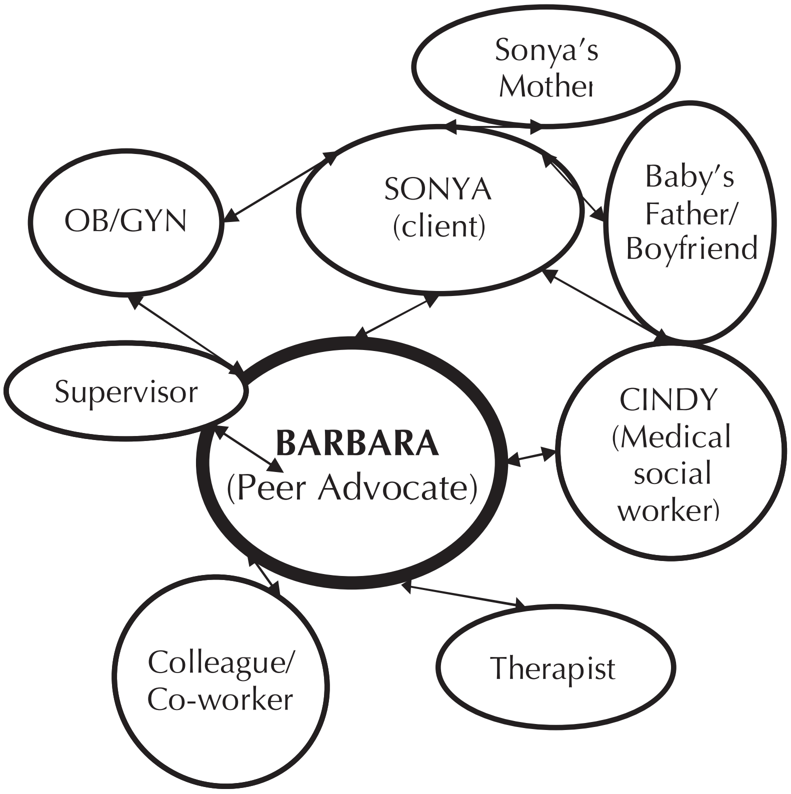
Sonya has recently tested positive for HIV (not an AIDS diagnosis) and was referred to Barbara by a social worker at a local medical clinic.

Cindy, the social worker is Sonya's social worker and refers her clients to Barbara when they need a peer advocate and the two of them sometimes coordinate care for their mutual clients. Cindy is also Barbara's personal social worker—and to this day helps Barbara with some matters. Barbara and Cindy are therefore, in two different kinds of relationships. Cindy is Barbara's social worker, and the two of them are also colleagues.


Barbara – Peer Advocate **Sonya (client)** **Cindy – Social Worker**

Cindy referred Sonya to Barbara when Sonya was a few months pregnant. Sonya had recently tested positive for HIV (not an AIDS diagnosis). Barbara and Sonya met for the first time after Sonya's initial HIV clinic appointment. While they were meeting privately, Barbara explained peer advocacy to Sonya, and disclosed her own HIV status. As soon as Sonya found out Barbara was also living with HIV, she burst out crying. Barbara empathized with Sonya's feelings because she has been there herself. She also re-assured her that she wasn't alone, and that many women were living full lives after this diagnosis.

During the first meeting, Barbara learned that Sonya needed: 1) emotional support; 2) education and information; and 3) support attending appointments. Barbara shared with Sonya what she could provide. Sonya said she would



like to get this help from Barbara. Barbara suggested that they talk and/or meet at least once per week. Sonya agreed. Barbara filled out an intake and consent form with Sonya. Sonya agreed in writing that Barbara could speak with Cindy and Sonya's physician in order to better coordinate care for her. They set a follow up meeting for a week later. The two of them decided that Sonya would come by Barbara's office before an OB/GYN appointment to talk. Then, Barbara would accompany Sonya to her OB/GYN appointment for moral support and help with asking questions of the doctor.

After meeting with Sonya, Barbara touched base with Cindy the social worker to let her know that the meeting went well and she would be helping Sonya with emotional support, information, and medical appointments. Cindy thanked her and asked if Sonya had also mentioned her unstable living situation. Barbara said no. Cindy told Barbara that Sonya might require help finding housing resources if she was kicked out of the house where she stays with her mother, grandmother, and siblings. Cindy explained that Sonya and her mother fight and there have been threats by her mother for her to leave. Cindy was thinking of having a meeting with Sonya and her mother, hoping to mediate the conflict and encourage the mother to allow Barbara to stay until the birth of the baby. At that point Cindy could find a transitional housing situation for Sonya and her baby. Barbara, suddenly wondering about the father of the baby, asked Cindy about the father. Cindy replied that Sonya told her the father was "out of the picture." Barbara is now feeling very overwhelmed about her client and everything she has to do to help the client.

In their next meeting, Barbara and Sonya talked more about HIV, pregnancy and Sonya's fears. Barbara mentioned to Sonya that Cindy let her know that her living situation was problematic. Sonya said, "She told you that?" Barbara said, "She wanted me to know in case you needed me to help you find housing resources." Sonya seemed to relax, and said, "Oh, okay." Then Sonya asked Barbara if Barbara "tells Cindy everything." Barbara said, "I don't tell her everything, and she doesn't tell me everything either. What you and I talk about is confidential. Sonya replied, "Honest?" Barbara replied, "Honest."

Then Sonya began to tell Barbara about her on-and-off boyfriend (who is the father) who is very possessive and sometimes "beats her up". She said that her mother "hates" him and has banned him from the house. She fights with her mom because her mom hears them talking on the phone a lot, and Sonya has "snuck" him over a few times. Barbara feels her emotions rising but remains calm with Sonya. She always gets protective towards her client when a client mentions domestic violence because she herself had a lot of trouble leaving a husband who was abusive. She makes a mental note to talk to her close colleague, supervisor, and therapist for her own emotional support.

Cash Register Worksheet

THE STORY

A businessman has just turned off the lights in the store when a man appeared and demanded money. The owner opened a cash register. The contents of the cash register were scooped up, and the man sped away. A member of the police force was notified promptly.

Statements About the Story:

1. A man appeared after the owner turned off his store lights. **T F ?**
2. The robber was a man. T or F ? **T F ?**
3. The mans did not demand money. **T F ?**
4. The man who opened the cash register was the owner. **T F ?**
5. The storeowner scooped up the contents of the cash register and sped away. **T F ?**
6. Someone opened a cash register. **T F ?**
7. After the man who demander the money scooped up the contents of the cash register, he ran away. **T F ?**
8. While the cash register contained money, the story does not state how much. **T F ?**
9. The robber demanded money of the owner. **T F ?**
10. The story concerns a series of events in which only three persons are referred to: the owner of the store, a man who demanded money, and a member of the police force. **T F ?**

Communication Skills

SKILL	WHAT IS IT?	EXAMPLES
Affirming		
Open-Ended Questions		
Active Listening		
Nonverbal Messages		
Express Thoughts and Feelings		
Communicate Without Making Others Feel "Wrong"		

Confidentiality Worksheet

What is confidentiality?

Why is it important for a peer advocate to maintain confidentiality with her client:

What types of things may a client want to keep confidential:

When is it OK to break confidentiality? What are steps to follow?

1. If the client is **suicidal:**

   - It is very appropriate and OK to ask the client:
     Are you suicidal or have you thought about hurting yourself?
     Do you have a plan on how you would do it?
   - Immediately seek assistance from supervisor or higher authority at the agency you are working with.
   - Call 911 if client needs immediate assistance even if you have a doubt.
   - Call 1-800-273-TALK (8255) and make sure client has this phone number to call if they need to talk.

2. If the client threatens **homicide** or plans to seriously hurt someone.

   - Immediately seek assistance from supervisor or higher authority at the agency you are working with.

3. If a client shares that they are **physically abusing** a child or dependant adult

   - Immediately seek assistance from supervisor or higher authority at the agency you are working with.

Sample Confidentiality Agreement

As a client of ____________ and a participant in the ___________ Peer Advocate Program, you can expect to receive peer support that is professional, respectful, and trustworthy.

Professional peer support means that you can expect your Peer Advocate to maintain a confidential relationship with you. She will not share information about you with anyone outside of WORLD without your consent. There is, however, an exception to this rule. Confidentiality may be waived if your safety or the safety of someone close to you is in question. If questions of safety arise, she will contact either your FCN case manager or another professional for assistance. In most cases, the peer advocate will let you know if she plans to speak with your case manager.

Respectful peer support means that you can expect your Peer Advocate to honor your privacy. You may choose to share many personal topics with your Peer Advocate; however, you need only to share personal information if and when you feel comfortable. At times, she may offer advice or suggestions, but she will keep in mind that you know what is best for you.

Trustworthy peer support means that you can expect your Peer Advocate to follow through with the support that she offers to you. She will be on time and listen to you during your time together. Time spent together may include peer counseling, accompaniment to doctor visits, visits to your home, phone check-ins, and other activities as decided upon by you and your Peer Advocate.

<u>As a client of our organization, you are encouraged to speak with your Peer Advocate if you have questions, concerns or complaints about the program</u>.

By signing below, you and your Peer Advocate are agreeing to the above guidelines. You also are indicating your understanding of the standards inherent in the peer advocate/client relationship:

Client:

Print Name ______________________________

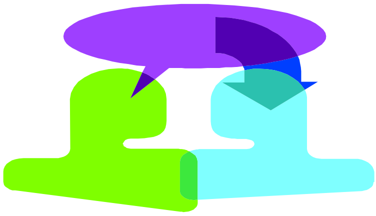
Signature _______________________________ Date __________

Peer Advocate:

Print Name ______________________________

Signature _______________________________ Date __________

Countertransference:
How Can You Recognize It?



You could be experiencing countertransference if one or more of the following is true:

1. You think you know exactly what a client needs to do.
2. You are making assumptions about a client without checking them out with her.
3. You are going out of your way for a client, even though she is not working very hard for herself.
4. You are avoiding a client(s).
5. You feel you are being manipulated.
6. You begin to ignore or forget your boundaries, or the boundaries of your organization.
7. You are spending too much time with one client for an extended period of time.
8. You worry about a client(s) excessively.
9. You begin to use your client for your own stress relief.
10. You are feeling confused about your role with a client(s).
11. You feel angry, sad or judgmental about a client(s) a lot of the time.
12. You find yourself being late consistently with a client.
13. While meeting with a client, an intense feeling suddenly arises—could be anger, sadness, or any other feeling, even a "positive" one. The feeling distracts you from your normal ability to listen well.

What can you do to address your countertransference?

1. Take some time to consider your feelings about the client(s) who are triggering you.

2. Check to see if you are over-identifying with your client (perhaps she and you have some similarities that trigger feelings for you). Remember that sometimes these similarities are hard to acknowledge.

3. Talk to a trusted colleague, supervisor, counselor, or other supportive person.

4. Engage in a stress reduction technique of any sort.

5. Re-assess your boundaries with a client(s). Do you need to spend more or less energy on this person(s)?

6. Question your assumptions.

7. Remember your limits.

8. Remember that you do not have to be perfect.

9. Remember that your job is not to fix people—people are ultimately responsible for themselves.

10. Remember to get help if you need it.

11. Get feedback from someone who will remind you of your strengths.

12. Remember that one of your most important jobs is to role model self-care.

Creating Boundaries

HOW TO CREATE BOUNDARIES	HOW WILL I DO THIS
1. Open communication with clients	
2. Follow through with your promises in a timely manner	
3. Address your limitations	
4. Seek support from your supervisor	
5. Refer, refer, refer	
6. It is OK to not know	
7. Don't feel pressured to share your story each and every time	
8. Being professional	
9. Putting your personal values aside	

My Personal Story Worksheet

1. In what context will you be sharing you story (i.e., prevention education, family planning, issue awareness, public at large)?

2. Why are you telling your story? What is the purpose? What do you want people to get out of it?

3. Who is your audience? How might your audience affect the way you tell your story (i.e., language, level of formality, personal appearance)?

4. How will you structure questions and comments from the audience?

5. What is your story?

    - Main events/experiences relevant to your story.

    - Identify 3-5 main points/messages to be included.

    - How can you make it interactive? What questions do you want the audience to answer?

    - What questions do you expect the audience to ask?

Values

Value Statements

1. Sexual intercourse is appropriate only between married people.
2. Birth control should be available to youth without parental consent.
3. Men who have sex with other men are responsible for the HIV/AIDS epidemic.
4. It should be a crime for anyone infected with HIV to have sexual intercourse without telling her/his sexual partner.
5. Postponing sexual intercourse is the only message we should give youth about sexual behavior.
6. When a man and a woman have sexual intercourse, contraception should be the womanís responsibility.
7. Young woman/man who carries condoms or has them readily available are easy.
8. A young woman walking alone at night in tight sexy clothing is asking to be harassed.
9. People living with HIV/AIDS should be allowed to work in restaurants and prepare food.
10. People who use drugs and get HIV should not receive medical benefits and services.
11. Sex education and disease prevention messages should not include gay/lesbian sex since it is against most peopleís religion.

Discussion Questions

1. What did you learn about yourself and others?
2. What values informed your choices?
3. Was it hard to express disagreement with another personís value(s)? Why or why not?
4. Were there times when you felt uncomfortable or unsafe? What helped you stand by your values at that time?
5. Were there any times when you felt unable to stand for your values? When and why do you think that was so?
6. What would support people at times when they feel unable to stand up for a value they believe in?

Working with Grief

When do we Grieve?

We grieve when we have suffered a loss that is somehow permanent:

- Loss of one's health status (e.g. an HIV diagnosis)
- Freedom
- Break up, divorce
- Friend who moved away
- Death
- Loss of a pet
- Child who got married and moved away
- Place in our life we had to leave behind

Stages of Grief

Early Stages of Grief:

- Shock
- Denial/Unreality
- Fear
- Bargaining
- Loneliness
- Anger
- Shame
- Sadness

Later Stages of Grief:

- Understanding – growth and positive change
- Acceptance
- Sense of meaning/purpose
- Wholeness

Role of a Peer: *As a peer advocate you can help clients move through various stages of initial crisis to the later stages of grief!*

Grief vs. Depression

Grief:	Depression:
Range of emotions	Only sadness, despair
Life will go on	Sense of hopelessness
Sense of purpose for future	Feel a lack of purpose
Need time alone and with others	Only want to be alone
Usually temporary	Can be long-term feeling
Many times can work through on their own	Needs professional support to work through

Grief vs. Depression

Determining if a client is depressed or sad with grief…

1. Do your feelings change throughout the day or the week? For example, are you sometimes sad, happy and/or angry? What are some of the feelings that you have throughout the week?

   Someone who is grieving will experience a range of emotions at any given time. Someone who is depressed may not experience a range of emotions; rather she may feel only deep sadness, despair or numbness.

   A follow up question would be: ______________________________________

   ____

2. Do you have hope that you will be able to heal from the loss? What can you imagine the future to be like?

   Someone who is grieving will probably indicate that they know that life will go on despite the loss. People who are depressed often feel a sense of hopelessness.

   If a person's answer is no or not sure or that they imagine it to be hopeless, you may want to ask:

   ____

3. Do you feel a sense of purpose even though you have suffered a loss?

   People who are grieving usually feel a sense of purpose; as a matter of fact, the loss may cause them to strengthen or re-assess what is important. Someone who is depressed may feel a lack of purpose, or unenthusiastic about her life's purpose.

   If the answer is no or not sure, you may want to ask her: ______________________

   ____

4. Do you sometimes feel like being alone, and other times feel like being with other people? How is it to be alone? To be with others?

   While grieving, people need time alone as well as support and company from other people. If the person only wants to be alone, or only with others, she may be experiencing depression or anxiety.

   If she indicates one or the other only, you may want to ask her: ________________

   ____

Day 2 – Working With Grief, Case Scenario 1

You have a client who found out that she has HIV about 2 months ago from her OB/GYN who decided to test her after she had several severe yeast infections and was complaining of feeling tired. Her CD4+T cell count came back at 125, so she started medication. Her partner of 5 years broke up with her when he found out about her status. She found your agency through a referral from her doctor and has been coming to see you for about a month. She has seemed very sad about her situation and today when you see her and ask her how she is doing, she says fine but as she is checking in with you she begins to cry.

For each scenario Answer the Following Questions:

1. In your opinion – what is happening in the scenario?

   ____

2. What state of grief process do you think she is experiencing?

   ____

3. List the information that supports your conclusion.

   ____

4. List at least three questions might you ask her to figure out if she is depressed or grieving?

   ____

5. What thoughts, concerns, or feelings might come up for her? For you?

   ____

6. What support and/or information could you offer her?

   ____

7. What action steps might your client, you or both of you consider taking?

   ____

Day 2 – Working With Grief, Case Scenario 2

You have a client who has known about her HIV status for several years. She has been taking medication, but after getting the flu, she ended up in the emergency room with pneumonia. When she was in the ER getting her lungs checked, the doctor found a lump on her neck and under her arm. The biopsies determined that she has cancer and she has started treatment for that. When you call to check-in on how she is doing, she sounds angry that her regular doctor did not find the lumps and can't seem to talk about anything else.

For each scenario Answer the Following Questions:

1. In your opinion – what is happening in the scenario?

   ____

2. What state of grief process do you think she is experiencing?

   ____

3. List the information that supports your conclusion.

   ____

4. List at least three questions might you ask her to figure out if she is depressed or grieving?

   ____

5. What thoughts, concerns, or feelings might come up for her? For you?

   ____

6. What support and/or information could you offer her?

   ____

7. What action steps might your client, you or both of you consider taking?

   ____

101 Ways to Take Care of Yourself and to Reduce Stress

1. Get up 15 minutes earlier
2. Prepare for the morning the night before
3. Avoid tight fitting clothes
4. Avoid relying on chemical aids
5. Set appointments ahead
6. Don't rely on your memory...write it down
7. Practice preventative maintenance
8. Make duplicate keys
9. Say no more often
10. Set priorities in your life
11. Avoid negative people
12. Use time wisely
13. Simplify meal times
14. Always make copies of important papers
15. Anticipate your needs
16. Repair anything that doesn't work properly
17. Ask for help with the jobs you dislike
18. Break large tasks into bite size portions
19. Look at problems as challenges
20. Look at challenges differently
21. Unclutter your life
22. Smile
23. Be prepared for rain
24. Tickle a baby
25. Pet a friendly dog or cat
26. Don't know all the answers
27. Look for the silver lining
28. Say something nice to someone
29. Teach a kid to fly a kite
30. Walk in the rain
31. Schedule play time into every day
32. Take a bubble bath
33. Be aware of the decisions you make
34. Believe in yourself
35. Stop saying negative things to yourself
36. Visualize yourself winning
37. Develop your sense of humor
38. Stop thinking tomorrow will be a better today

#3 - Avoid tight fitting clothes

#8 - Make duplicate keys

#12 - Use time wisely

39. Have goals for yourself
40. Dance a jig
41. Say hello to a stranger
42. Ask a friend for a hug
43. Look up at the stars
44. Practice breathing slowly
45. Learn to whistle a tune
46. Read a poem
47. Listen to a symphony
48. Watch a ballet
49. Read a story curled up in bed
50. Do a brand new thing
51. Stop a bad habit
52. Buy yourself a flower
53. Take time to smell the flower
54. Find support from others
55. Ask someone to be your "vent partner"
56. Do it today
57. Work at being cheerful and optimistic
58. Put safety first
59. Do everything in moderation
60. Pay attention to your appearance
61. Strive for excellence NOT perfection
62. Stretch your limits a little each day
63. Look at a work of art
64. Hum a jingle
65. Maintain your weight
66. Plant a tree
67. Feed the birds
68. Practice grace under pressure
69. Stand up and stretch
70. Always have a plan "B"
71. Learn a new doodle
72. Memorize a joke
73. Be responsible for your feelings
74. Learn to meet your own needs
75. Become a better listener
76. Know your limitations and let others know them too
77. Tell someone to have a good day in pig Latin
78. Throw a paper airplane
79. Exercise every day
80. Learn the words to a new song


#25 - Pet a dog!


#30 - Walk in the rain!


#36 - Visualize yourself winning

81. Get to work early
82. Clean out one closet
83. Play patty cake with a toddler
84. Go on a picnic
85. Take a different route to work
86. Leave work early (with permission)
87. Put air freshener in your car
88. Watch a movie and eat popcorn
89. Write a note to a far away friend
90. Go to a ball game and scream
91. Cook a meal and eat it by candlelight
92. Recognize the importance of unconditional love
93. Remember that stress is an attitude
94. Keep a journal
95. Practice a monster smile
96. Remember you always have options
97. Have a support network of people, places and things
98. Quit trying to "fix" other people
99. Get enough sleep
100. Talk less and listen more
101. Freely praise other people

#63 - Look at a work of art

P.S. Relax, take each day one at a time...
You have the rest of your life to live.

Examples of Rational Self-Talk

I'll just relax and do the best that I can.

I've had to deal with this before and I managed pretty well.

This is really a pain in the neck and I sure don't like it, but I won't panic.

I'll just take one thing at a time, stay calm, and see it through.

I know it won't help to get upset. I can't control what someone else does.

Examples of Coping Self-Talk

I'll take one step at a time.

I'll just think calmly about what I can do.

I'm in control; I can handle this.

Relax. Take a deep, slow breath.

It's okay to be a little anxious; it doesn't mean I can't handle it.

These feelings will pass.

Examples of Reinforcing Self-Talk

I did it, and it worked.

That wasn't so bad.

I'm really getting better at dealing with this stress.

I've learned more about myself and these feelings.

I like how I handled this.

Next time, I'll know what works for me.

Don't worry about things that you have no control over, because you have no control over them.
Don't worry about things that you have control over, because you have control over them.
— Mickey Rivers

Changing Negative Thinking Into Positive

Rewrite the negative messages below, using more powerful and positive words. Look for messages that are realistic, that you have control over, and that are helpful.

1. I know I'm going to be so nervous I'll blow it.

   Even though I'll be nervous, I'll try my hardest.

2. There's no way I can get this done! No way!

3. I can't stand her; she makes me sick.

4. I can't believe I screwed that up so badly! I'm so stupid!

5. He just has it in for me; there's nothing I can do.

6. It's not even worth trying. Everyone else is so much better than I am.

7. I've tried this a million times. It's just not worth it. I can't do it and I know it.

8. No one cares if I'm there or not! Why should I go?

9. I'm always late. I just can't help it!

10. I'm so ugly (or fat, or???). I can't stand the way I look!

Practicing Self-Care

Excerpted from: Saakvitne, K. W., & Pearlman, L. A. (Eds.). 1996. *Transforming the pain: A workbook on vicarious traumatization*. New York: Norton

Physical Self-Care

- Eat regularly (e.g. breakfast, lunch, dinner)
- Eat healthily
- Exercise
- Get regular medical care for prevention
- Take time off when sick
- Get massages
- Dance, swim, walk, run, play sports, sing, or do some other physical activity that is fun
- Take time to be sexual—with yourself, with a partner
- Get enough sleep
- Wear clothes you like
- Take vacations
- Take day trips or mini-vacations
- Make time away from telephones

Psychological Self-Care

- Make time for self-reflection
- Have your own personal psychotherapy
- Write in a journal
- Read literature that is unrelated to work
- Do something at which you are not expert or in charge
- Decrease stress in your life
- Notice your inner experiences• Let others know different aspects of you
- Engage your intelligence in a new area, e.g., go to an art museum, history exhibit, sports event, auction, theater performance
- Practice receiving from others
- Say no to extra responsibilities sometimes

Emotional Self-Care

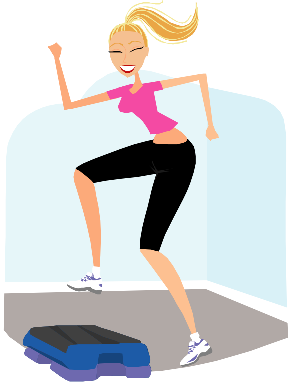
- Spend time with others whose company you enjoy
- Stay in contact with important people in your life
- Give yourself affirmations, praise yourself
- Find ways to increase your sense of self-esteem
- Reread favorite books, re-view favorite movies
- Identify comforting activities, people, relationships, places, and seek them out
- Allow yourself to cry
- Find things to make you laugh
- Express your outrage in social action, letters, donations, marches, protests
- Play with children

Spiritual Self-Care

- Make time for reflection
- Spend time with nature
- Find a spiritual connection or community
- Be open to inspiration
- Cherish your optimism and hope
- Be aware of nonmaterial aspects of life
- Try at times not to be in charge or the expert
- Be open to not knowing
- Meditate, Pray
- Sing
- Spend time with children
- Have experiences of awe
- Contribute to causes in which you believe

Ten Things You Can Do to Enhance Your Emotional Well-Being if you are HIV +

By J. Buzz von Ornsteiner, Ph.D.



1. **Build a strong, supportive, trusting relationship with an HIV/AIDS doctor.** You should be able to freely discuss everything and anything and, if needed, to challenge your doctor's advice.
2. **Develop consistent contact with a health care case manager** who can help to make the rocky road to benefits and services easier for you. One mold does not fit all, so try to find a case manager that you trust, even if you have to switch to a new one.
3. **Join an HIV/AIDS support group.** Find out if they use an ongoing, drop-in format or if they are time-limited and require pre-enrollment. Also find out about the training and qualifications of the group leaders.
4. **Get a therapist,** preferably a good licensed psychologist or certified social worker. Remember anyone can state they are a "therapist"; request more information about their background and experience. Keep looking until your instincts tell you that you have found a good match.
5. **Attend workshops or other HIV/AIDS events** so that you can find out as much as you can about HIV/AIDS. You must be the expert on this disease and be on top of any new developments and programs.
6. **Stay informed about your HIV/AIDS medications** by seeking out information from any and all sources, including people, Web sites, and periodicals. The more you know about the medication you are taking and its potential side effects, the more you know what to expect about your emotions and mental well-being.
7. **Address any substance use issues you may have** by looking into substance use programs and groups. Consider working towards being clean and sober.
8. **Exercise regularly and maintain good nutrition** because the mind and the body are closely linked, and physical health enhances mental health.
9. **Work if you can** for income but also work for the structure and well being that employment can provide. Everyone can benefit from structure, and we all need to feel we are productive members of this world.
10. **Seek a sense of belonging outside of HIV/AIDS** such as by starting a hobby, traveling and exploring, getting a pet, starting or finishing school, or volunteering. The bottom line is to keep your stress low; keeping your stress low will help you to keep your immune system high.

My Self-Care Contract

I, ______________________________, do hereby agree to begin to focus on my health and to take better care of myself as of ________________________, and to continue it for a period of ____________________________________.

What I plan to do is: ____

____.

The barriers/challenges I think I may have in meeting my goal are: __________

____.

The people who support me and what I want of them are: ________________

____.

My short-term (daily) rewards will be: ________________________________.

My long-term reward(s) will be: _____________________________________.

_____________________________ _____________________________

Signature Witness

Day 3
HIV/AIDS – Part 1

1 Sex Talk

2 Female Reproductive System

3 Immune System & HIV Life Cycle

4 HIV Medication 101
(Side Effects, Adherence & Goals of Medication)

5 Panel of Providers

6 Review

7 Closing & Homework

HIV & STDS

What does HIV stand for?

H ______________________________

I ______________________________

V ______________________________

What does AIDS stand for?

A ______________________________

I ______________________________

D ______________________________

S ______________________________

Two Types of STDS:

Bacterial STDS – are curable infections caused by bacteria.

- These diseases can be transmitted during vaginal, anal, oral sex, and sometimes during the skin-to-skin contact if sores and bumps are present.
- Most women and some men do not experience symptoms. If symptoms do occur, they usually appear within 1 to 3 weeks after infection.
- Since symptoms may not be present, the only way for a person who has been exposed to tell whether they're infected is to be tested.
- If left untreated, many STDS can cause complications such as PID and infertility.

Viral STDS – are STDS, which are caused by viruses. As with all viruses, there is no cure for these diseases, but treatment may be available.

- Many viruses, once they are in the body, they live in the body over a lifetime, often without symptoms or only with periodic symptoms.
- To decrease the symptoms of the viral infection medications should be taken.

Bacterial (curable) STDS	**Viral** (no cure) STDS

What are the 4 body fluids that CAN transmit HIV?

1.____
2.____
3.____
4.____

What are the body fluids that CAN NOT transmit HIV?

1.____
2.____
3.____
4.____

What are some signs and symptoms of STDS/HIV…how do we know we may have something?

1.____
2.____
3.____
4.____

What are some of the behaviors (things that we do) that put us at risk for getting or giving STDS and HIV?

1.____
2.____
3.____
4.____
5.____
6.____

Risk Meter (highest risk to the lowest risk) for passing HIV:

1. Sharing needles for drugs, medicine, hormones. – very high risk.
2. Receptive (receiving) anal sex without condom – very high risk. The lining of the rectum is very thin. It is damaged very easily during sexual activity. This makes it easier to HIV for HIV to enter the body.
3. Receptive (receiving) vaginal sex without condom – very high risk. The lining of the vagina is stronger than in the rectum, but it can still be damaged by sexual activity. All it takes is a tiny scrape that can be too small to see. The risk of infection is increased if there is any inflammation or infection in the vagina.
4. Insertive (giving) anal sex without condom – high risk. It's possible for HIV to enter the penis through any open sores, or through the moist lining of the opening of the penis.
5. Insertive (giving) vaginal sex without condom – high risk. It's possible for HIV to enter the penis through any open sores, or through the moist lining of the opening of the penis.
6. Oral sex – low risk. Risk is increased if there are bleeding gums, cuts, sores, lesions, ulcers or burns in the mouth. Other diseases such as syphilis can be transmitted through oral sex.
7. Sharing sex toys – low risk. It is recommended that toys be cleaned between users.

HIV Cannot Be Caught:

- through the air or by coughing and sneezing.
- by kissing, touching or shaking hands.
- by sharing pots, pans, plates, and spoons.
- through contact with toilet seats.
- through insect or animal bites (HIV only lives in humans and will die in other animals).
- through swimming pools.
- by eating food prepared by someone with HIV.

STD Signs & Symptoms

Chlamydia: Show up 7-21 days after having sex.

- Discharge from the vagina
- Bleeding from the vagina between periods
- Burning or pain when you urinate (pee)
- Pain in belly, sometimes with fever and nausea

Gonorrhea (Clap, Drip, GC): Show up 2-21 days after having sex.

- Thick yellow or white discharge from the vagina
- Burning or pain when you pee or have a bowel movement
- More pain than usual during your period
- Cramps and pain in the belly

Vaginitis (trich, yeast infection): Some have no symptoms.

- Itching, burning or pain in the vagina
- More discharge from the vagina than normal
- Discharge smells and/or looks different

Genital Warts (HPV): Show up 1-6 months after having sex.

- Small, bumpy warts on the sex organs and anus
- The warts usually do not go away
- Itching or burning around the sex organs
- Even if warts do go away, you are still infected

Herpes: Show up 2-30 days after having sex.

- Some have no symptoms
- Flu-like feelings
- Small, painful blisters on the sex organs and/or mouth
- Itching or burning before the blisters appear
- Blisters last 1-3 weeks
- Blisters go away, but you still have herpes. Blisters can come back.

Pelvic Inflammatory Disease: (PID)-Not an infection itself, but caused when Chlamydia or Gonorrhea are untreated.

- Irregular menstrual periods
- Constant lower belly pain
- Fever, Nausea, Vomiting
- Headaches
- Can lead to infertility

Syphilis (syph, the pox):

1st Stage

- Show up 1-12 weeks after having sex.
- A painless, reddish brown sore called chancres. They can be seen on the part of the body that was exposed to the syphilis bacteria, such as the penis, vagina, cervix (opening to the uterus, or womb), tongue, or mouth. Sores last 1-6 weeks and heal on their own. If the infection is not treated during this early stage, it moves on to the next stage.
- The disease can easily be passed to another person when sores are present.

2nd Stage

- Symptoms show up 6 weeks to 6 months after sore appears.
- A rash anywhere on the body and the rash does not itch. The rash may show up as the chancre is fading or up to several weeks later. The rash may appear as rough, reddish-brown spots the size of a penny on the palms of the hands and the soles of the feet. It may also appear elsewhere on the body and be faint or look like another kind of rash. The rash will clear up on its own even without treatment.
- Other symptoms may include mild fever, fatigue, headache, sore throat, as well as patchy hair loss, and swollen lymph glands throughout the body.
- Rash and flu-like feelings go away, but you still have syphilis.

Later Stages of Syphilis

- If syphilis remains untreated, the disease progresses to a latent (hidden) stage. Some people will have no further symptoms, even though they still have syphilis.
- Untreated syphilis can damage body organs, including the brain, nerves, eyes, heart, blood vessels, liver, bones, and joints. This damage may show up many years later as heart disease, mental illness, blindness, or other health problems, and cause death.

Hepatitis A, B, C

There are 5 types of hepatitis - A, B, C, D, and E - each caused by a different hepatitis virus. A, B, C are most common. Hepatitis can live outside the body for a long time so it is easier to contract then HIV.

- Can have no symptoms many times
- Flu-like symptoms-nausea/vomiting
- Loss of appetite
- Fatigue
- Pain in belly
- Yellow skin or eyes
- Muscle and joint aches
- Dark color in urine (pee) or pale feces (poop)
- Itching skin

Hepatitis A is caused by eating food and drinking water infected with a virus called HAV. It can also be caused by anal-oral contact during sex. While it can cause swelling and inflammation in the liver, it doesn't lead to chronic, or life long, disease. Almost everyone who gets hepatitis A has a full recovery.

Hepatitis B is caused by the virus HBV. It is spread by contact with an infected person's blood, semen, or other body fluid. And, it is a sexually transmitted disease (STD). You can get hepatitis B by:

- Having unprotected sex (not using a condom) with an infected person.
- Sharing drug needles and other drug equipment (straws, dollar bills, pipes) for illegal drugs like heroin and cocaine.
- Getting a tattoo or body piercing with dirty (unsterile) needles and tools that were used on some one else.
- Sharing a toothbrush, razor, or other personal items with an infected person.
- An infected woman can give hepatitis B to her baby at birth or through her breast milk.
- Through a bite from another person.

With hepatitis B, the liver also swells. Hepatitis B can be a serious infection that can cause liver damage, which may result in cancer. Some people are not able to get rid of the virus, which makes the infection chronic, or life long.

Hepatitis A and B have vaccines to prevent (so you never get) the disease!

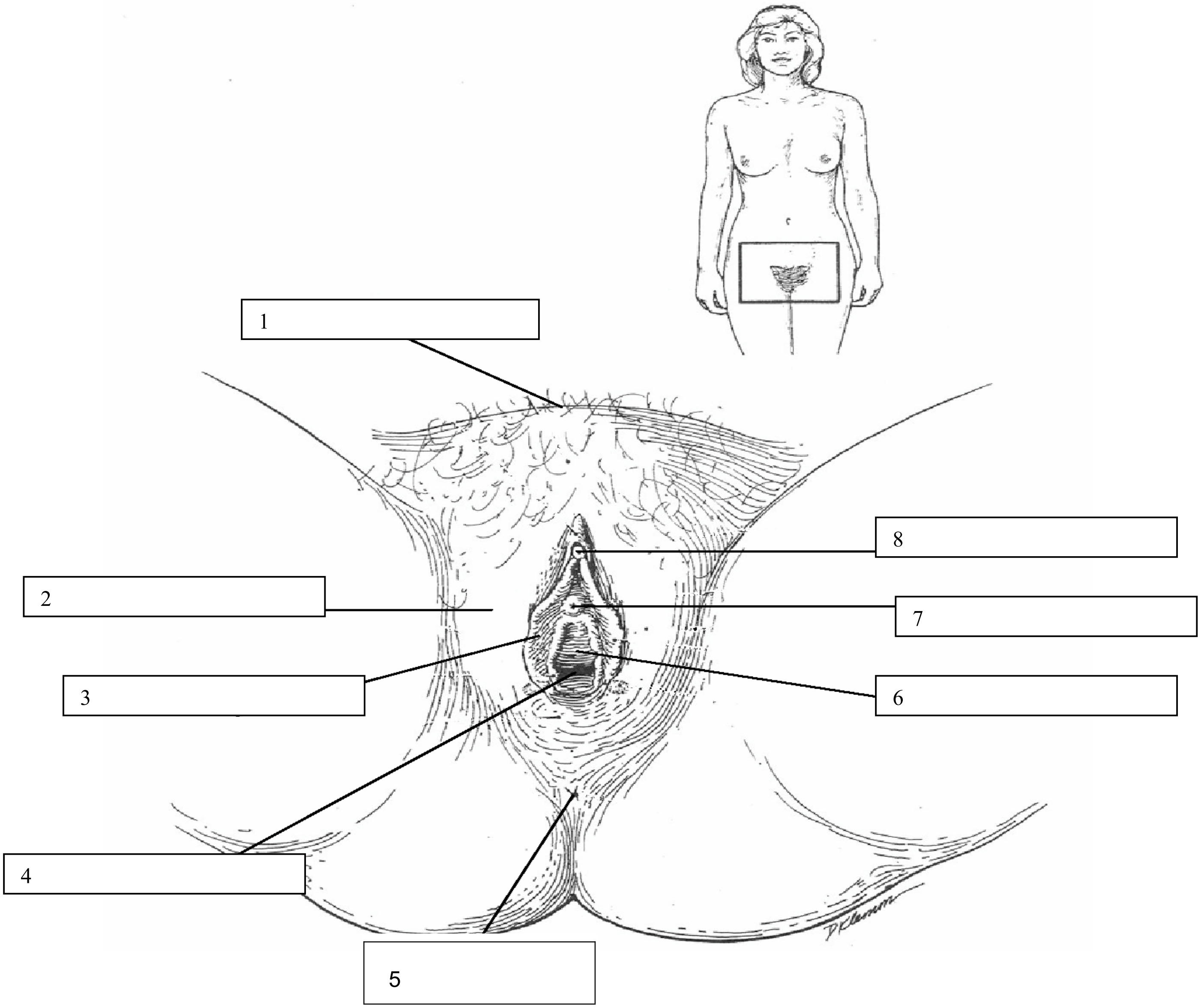
Hepatitis C is caused by the virus HCV. It is spread the same way as hepatitis B, through contact with an infected person's blood, semen, or body fluid (see above). Like hepatitis B, hepatitis C causes swelling of the liver and can cause liver damage that can lead to cancer. Most people who have hepatitis C develop a chronic infection. This may lead to a scarring of the liver, called cirrhosis.

There is no vaccine to prevent Hepatitis C but treatment is available.

Female Reproductive System

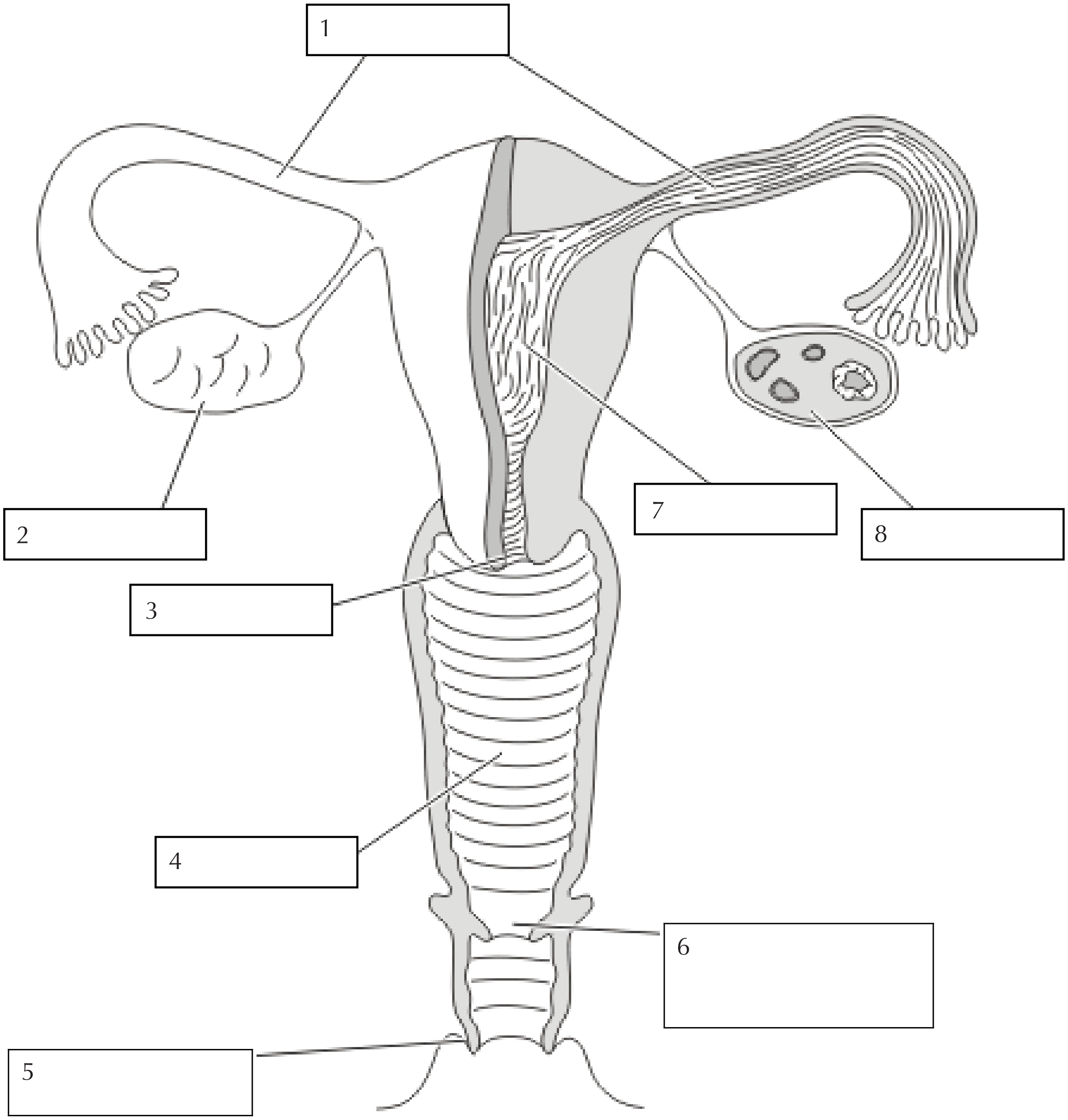
How many holes do we have down there (by down there, we mean female reproductive system)? ________

Note: *clitoris is not a hole. Nothing can go into it and nothing can come out of it. It is an area that is connected to lots of nerves which, when aroused, create sensation.*



FEMALE REPRODUCTIVE ANATOMY

(INTERNAL, FRONT VIEW)



4 Essential Stages of Female Reproduction:

1. **Puberty**
    - Age
    - Changes that occur
2. **Reproduction**
    - Age
    - Changes that occur
3. **Perimenopause**
    - Age
    - Changes that occur
4. **Menopause**
    - Age
    - Changes that occur

What Happens During the 4 Stages:

1. Most women have two ovaries; one on each side of the uterus and are connected by fallopian tubes.

2. Our ovaries contain a set number of eggs. Ovaries at birth contain 300,000-400,000 follicles, which are balls of cells with an immature egg in the center. This is the maximum number of follicles a female will ever have. However, only approximately 400 of these eggs will actually mature and ovulate while the rest degenerate.

3. One by one, the eggs in a woman's ovaries get used up. When there are no more eggs, she does not have a period. This is called menopause. Once they run out, we cannot make anymore. Men (most) on the other hand can produce sperm until they are very old. Women can also damage or loose our eggs over our lifetime by drinking, smoking, substance abuse, medications such HIV medications, stress, cancer treatments and other health issues.

4. For women on a normal cycle, each month ONE egg is released by one of the ovaries. As soon as the egg is released, a lining of tissue and blood is also formed in the uterus.

5. The purpose of the lining is so that the woman can hold the baby in her womb if she were to get pregnant.

6. Ovarian Hormones are also released when the eggs is released.
    - **Estrogen** – Prepares the body for pregnancy. Secreted by the follicle and causes the following changes:

Uterine lining thickens (endometrial cells multiply and "proliferate")
Cervical secretions become slippery and nourish the sperm
Cervix softens, lifts and opens
Resting body temperature is low

- **Progesterone** – Sustains pregnancy. Secreted by the corpus luteum and causes the following changes:
  Uterine lining thickens (endometrial cells grow and store nutrients to offer an appropriate condition for implantation of fertilized egg)
  Cervical secretions thicken to keep bacteria and other sperm out
  Cervix firms, lowers and closes
  Resting body temperature is higher

7. The egg travels through the fallopian tube. The egg takes approximately 2 weeks to travel from the ovary to the uterus. This period is called ovulation.

8. In a woman (with a fairly regular menstrual cycle), ovulation occurs in approximately 14-15 days before her next menstrual period is due. Some women do not have a regular cycle due to various changes in their lives, including emotional stress, drug use, HIV, etc. If you have an irregular cycle, ovulation will also be irregular and unpredictable.

9. Ovulation is the time that a woman is most likely to get pregnant. You can get pregnant if you have sex during or near the time of ovulation.

10. During sex, sperm are released into the vagina. They travel up through the cervix, through the uterus, and out up to the tubes.

11. Around the time of ovulation, there is thin mucus in the cervix that helps the sperm move.

12. If a sperm meets an egg in the tube, fertilization (the joining of egg and sperm) can occur. The fertilized egg then moves through the tube into the uterus and becomes attached there to grow into a fetus.

13. If the egg and the sperm do not meet during the ovulation period, the egg is absorbed into the body and the lining in the uterus break apart and come out of the vaginal canal. This is called menstruation. Cramps, changes in mood, breast tenderness, etc may also result during this period due to menstruation.

14. In her period a woman may notice clumps as well as blood. The clumps are not blood clots. They are pieces of the tissue that was in the uterus lining. It is very normal to see these clumps.

15. If a woman has her “tubes tied”, the sperm and egg cannot join to form a fetus but she will continue to have her periods.

16. If a man has a vasectomy, he cannot impregnate (get a woman pregnant) BUT he can still transmit STDS and HIV through the semen. Vasectomy is a simple procedure. It makes men sterile by keeping sperm (the reproductive cells in men) out of semen — the fluid that spurts from the penis during sex.

    Sperm are made in the testes. They pass through two tubes called the vasa deferentia to other glands and mix with seminal fluids to form semen. Vasectomy blocks each vas deferens and keeps sperm out of the seminal fluid. The sperm are absorbed by the body instead of being ejaculated. Without sperm, your “cum” (ejaculate) cannot cause pregnancy.

    Vasectomy does not affect masculinity. And it will not affect your ability to get hard and stay hard. It also will not affect your sex organs, sexuality, and sexual pleasure. No glands or organs are removed or altered. Your hormones and sperm continue being produced. Your ejaculate will look just like it always did. And there will be about as much of it as before.

17. Remember that pre-ejaculation or pre-cum can get a woman pregnant as well as transmit STDS and HIV.

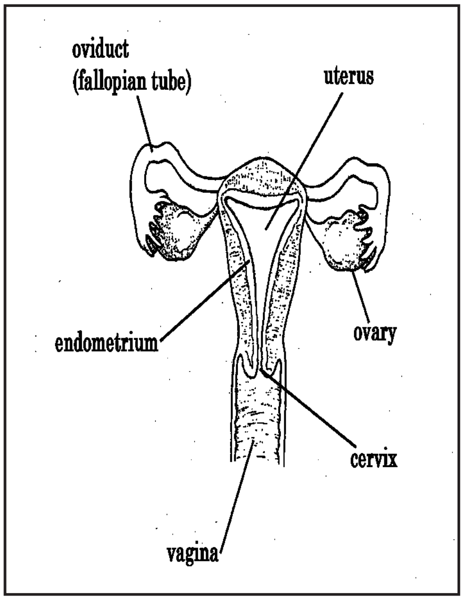
18. A woman cannot get pregnant if the semen/sperm enters the woman’s body through the mouth during oral sex BUT she can get certain STDs in her mouth as we will talk about in the next section.

19. Some women because of complications, cancer, diseases or even naturally have less eggs or no eggs at all in their ovaries. They women reach menopause at a much earlier age then what the age an average woman does at 40-60 years of age.

20. Some women for health and personal reasons may have a surgical procedure called a hysterectomy. There are several types of hysterectomies.
    - A complete hysterectomy is the removal of the uterus, cervix, fallopian tubes and ovaries leads to menopause.
    - A partial hysterectomy is the removal of the uterus and the cervix. A woman will continue to ovulate but will have no menstrual periods.
    - An oophorectomy is the removal of the ovaries and is usually done in connection with a hysterectomy.

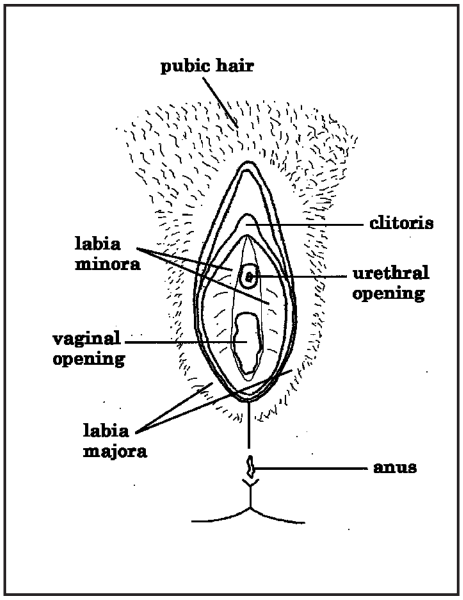
Female Reproductive System

Vagina: The canal in the female is used for 3 purposes. It is used for sex, birthing (baby comes out of this canal) and menstrual period is released from the body through this canal.



Clitoris: The center of sexual arousal for women. The area is made of many nerves and it is sensitive to stimulation the women. The clitoris is not a hole or an opening but an area with nerves.

Uterus: The pear-shaped female organ, which houses the fertilized egg and the developing fetus (baby). The uterus is also known as the "womb".



Cervix: The cervix is the base of the uterus. It is located at the end of the vagina. In the cervix thin mucus forms that help sperm travel through for the fertilization of the egg. The cervix is very sensitive to infection. This is also the area which the doctor checks (for infections) when doing a pap smear. The younger we are, the more sensitive the cervix is to developing infections.

Ovaries: The primary organ of the reproductive system. We have two ovaries which are sexual glands that hold our eggs. The ovaries also produce the female hormones estrogen and progesterone. Hormones provide essential signals and functions for the body to operate properly.

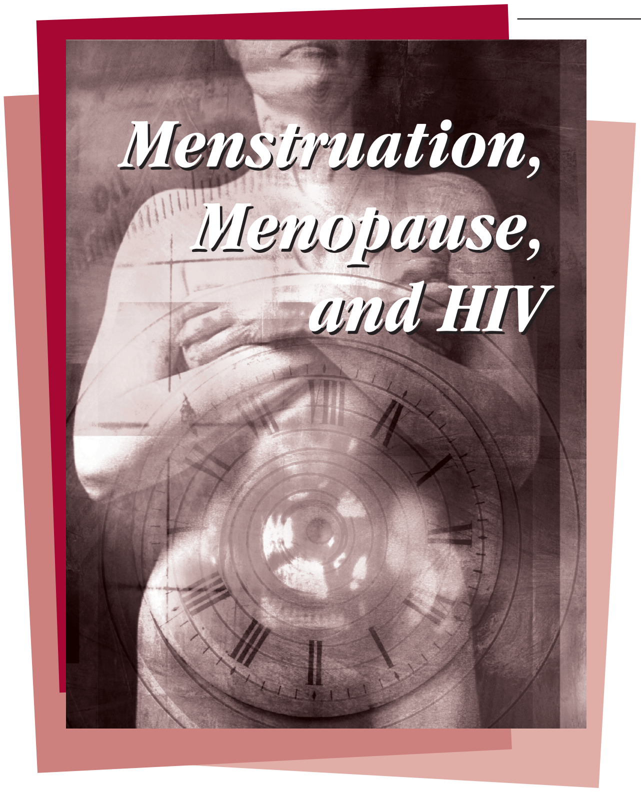
Egg: The female reproductive cell released by the ovaries, which after fertilization (meeting with the sperm) develops into the beginning of human life (a baby).

Fallopian tube: Tubes or branches connected to the uterus. After the egg is released by the ovaries it moves through the fallopian tube and then goes to the uterus.

Urethra: A canal that transfers urine from the bladder to the outside.

The G-Spot (Gafenberg spot): An area that has brought much controversy. The G-spot is located on the front wall of the vagina. It is described as being about the size of a small bean during its unaroused state and growing to the size of a dime during arousal. Stimulation may lead to orgasm and sometimes resulting in the ejaculation of a clear fluid from the urethra.

Anus: The opening of the large intestine that carries waste to the outside.



Menstruation, Menopause, and HIV

Anne Monroe, MD

There is a growing need for research about the effects of HIV on the menstrual cycle and menopause. HIV positive women and their care providers need to know what to expect at all life stages, and need strategies for optimal long-term care in the HAART era. Once the impact of HIV on menopause is better understood, clinical management can be individually tailored to avoid long-term complications such as osteoporosis and cardiovascular disease.

The Menstrual Cycle

There is a wide range of "normal" with regard to menstruation. A normal menstrual period ranges from two to six days, with an average length of four days. A mentrual cycle generally concludes in a period every 21 to 35 days, with an average loss of 40 mL of blood per period.

Normal menstruation is characterized by cyclic changes in the levels of hormones produced by the pituitary gland (luteinizing hormone [LH] and follicle stimulating hormone [FSH]) and by the ovaries (estrogen and progesterone). (See "HIV and Hormones" in the Summer 2004 issue of *BETA*.)

Menstrual irregularities are common in both HIV positive and HIV negative women. Amenorrhea is the absence of menstruation. Primary amenorrhea refers to a woman older than 16 years who has never menstruated, while secondary amenorrhea is the absence of menses for three to six months or longer in a woman who previously menstruated.

Menorrhagia refers to the loss of more than 80 mL of blood during each cycle of regular length, whereas dysfunctional uterine bleeding (DUB) is defined as loss of more than 80 mL of blood during irregular cycles; both menorrhagia and DUB may result in anemia, or reduced number of red blood cells. Dysmenorrhea refers to pain during menses, which may be a crampy discomfort with no underlying gynecologic condition, or may stem from endometriosis (growth of endometrium, or uterine lining tissue, outside of the uterus) or pelvic inflammatory disease (PID).

Many conditions can cause abnormal menstrual bleeding. Uterine fibroids may cause heavy or prolonged periods. Genital tract infections may cause abnormal bleeding, usually accompanied by other signs of infection, such as pain, vaginal discharge, or fever. Cancer in the genital tract (cervical cancer, endometrial cancer) may also cause bleeding. Other medical conditions, including thyroid abnormalities and low platelet counts, can interfere with regular menstrual cycles. Extreme weight loss or being underweight can cause acquired gonadotropin releasing hormone deficiency, eliminating the stimulus for LH and FSH release and resulting in amenorrhea. Hormonal dysfunction that disrupts ovulation can also lead to abnormal bleeding, which may be more common in HIV positive women, although studies are inconclusive.

Use of drugs (including methadone) may interfere with hormonal regulation and cause abnormal bleeding. Some medications commonly used by HIV positive women, such as contraceptives and megestrol acetate (Megace), may also interfere with normal menstruation. Antiretroviral agents may also contribute to abnormal bleeding; for example, one case series reported heavy menstrual bleeding associated with full-dose ritonavir (Norvir) in a small sample of young women.

Menstrual Irregularities in Women with HIV

HIV positive women and their care providers should be aware of changes in the menstrual cycle that may be related to HIV and its treatment. Many studies have tried to sort out the effects of HIV on the menstrual cycle, with contradictory results. Much of the research on menstrual abnormalities in women with HIV/AIDS was conducted during the early years of the epidemic, when women more often had advanced disease accompanied by wasting. Menstrual irregularities in women on antiretroviral therapy with well-controlled HIV are less well understood.

In a study of the effect of HIV infection on menstrual cycle length, published in the May 2000 issue of the *Journal of Acquired Immune Deficiency Syndromes,* Sioban Harlow, PhD, and colleagues collected data from 802 HIV positive and 273 HIV negative women. The women completed monthly menstrual calendars and answered questions regarding antiretroviral therapy and recreational drug use. The researchers examined relationships between viral load and CD4 cell count and menstrual cycle length. Overall, HIV infection did not increase the likelihood of having a cycle longer than 40 days (i.e., a longer interval between periods). However, HIV positive women with more advanced immunosuppression (CD4 counts less than 200 cells/mm^3) were more likely to have long cycles. The researchers concluded that HIV serostatus had little effect on menstrual cycle length, and that other factors—for example, advanced disease, age, race, malnutrition, wasting, and substance use—were more important.

In an earlier study, Keith Chirgwin, MD, and colleagues evaluated 248 HIV positive and 82 demographically similar HIV negative women, and found that women with HIV were more likely to experience amenorrhea for more than three months and had intervals greater than six weeks between menstrual cycles. However, menstrual irregularities were not found to be significantly associated with HIV disease status in this study.

Tedd Ellerbrock, MD, and colleagues interviewed 197 HIV positive and 189 HIV negative women to assess the effect of HIV on menstruation. The researchers collected data retrospectively to identify trends in menstrual cycles over the previous year. The study found no major differences between the two groups, and no relationship between degree of immunosuppression and menstrual irregularities. However, the design of this study was not ideal, as it required that women recall characteristics

Tests for Diagnosing Menstrual Abnormalities

A full history and physical give the health-care practitioner clues to the underlying cause(s) of abnormal menstrual bleeding and directs all additional testing. These tests and screenings may include:

Blood tests

- Complete blood count (CBC) to screen for anemia, low platelet count
- Endocrine studies to check various hormone levels for abnormalities
- Coagulation studies to check blood clotting

Pelvic exam

- Collection of samples for sexually transmitted infection testing
- Pap smear to screen for cervical cancer
- Palpation of uterus and ovaries to check for abnormalities

Pelvic ultrasound (if indicated)

An ultrasound probe is inserted in the vagina to assess uterus size, presence of fibroids, thickness of the uterine lining, ovarian abnormalities, and presence of endometriosis.

Endometrial biopsy (if indicated)

A thin tube is inserted through the cervix into the uterus and samples from the endometrium (uterine lining) are collected to test for abnormalities, such as inflammation or cancer.

of their menstrual cycles for the entire year prior to the interview.

Wasting syndrome associated with HIV is known to affect the menstrual cycle, as also occurs in HIV negative women—such as athletes and malnourished women—who lose a significant percentage of body fat or lean body mass. For example, a small study by Steven Grinspoon, MD, and colleagues found that among 31 HIV positive women with varying degrees of wasting, 20% overall had experienced amenorrhea. Among the women with amenorrhea, muscle mass was significantly lower, as was the total level of estradiol (a form of estrogen). The study revealed a higher rate of amenorrhea in women with less than 90% of ideal body weight.

Menopause

Menopause is a natural, normal life stage. It is defined as the end of menses and is characterized by 12 months without a menstrual period. The hormonal changes associated with menopause include elevation of FSH and LH levels and decreased estrogen levels. In the United States, the final menstrual period occurs at an average age of 51 years. There is evidence supporting a younger age of menopause onset (48 years) in African-American women.

A diagnosis of menopause can be made in women over the age of 45 years who have stopped menstruating for at least one year. Menopause is a clinical diagnosis; no diagnostic tests are necessary. However, in younger women who stop menstruating and are not pregnant, hormone testing for premature ovarian failure should be performed.

Women beginning the menopausal transition (perimenopause) may have irregular cycles with either light or heavy bleeding. They may also experience hot flashes, a heat sensation that starts on the upper face or chest and can spread throughout the entire body. Hot flashes at night may be particularly troublesome if they disturb sleep. Another common symptom of menopause resulting from decreased estrogen production is vaginal thinning and dryness, which increase in prevalence as women age. Thinning of the vaginal wall may cause pain during sexual intercourse.

Other menopausal symptoms include breast pain or tenderness—more common during the early menopausal transition than in late menopause—and mood changes, such as depression. Other mood-related symptoms may include nervousness, irritability, and frequent mood fluctuations. Some women experience forgetfulness and impaired concentration. Long-term physiological changes associated with menopause include a higher risk of osteoporosis (bone thinning) and cardiovascular disease.

HIV and Menopause

As women with HIV live longer thanks to effective treatment, more research is needed on the interactions between HIV disease, antiretroviral therapy, and menopause. More than ever, HIV positive women need support and strategies for dealing with the changes of menopause. Considerable research has explored the relationship between menopause and HIV, but this too has yielded inconsistent results.

One large study examined the relationship between HIV disease and onset of menopause. Ellie Schoenbaum, MD, and colleagues examined the effects of HIV infection, HAART, street drug use, and immune status on age of onset of menopause. Their study group included 571 women, half of whom were HIV positive. Half the women in both the HIV positive and HIV negative groups used recreational drugs, and 90% were current or former smokers. About half were African-American, 40% were Latina, and 10% were white. In this population with high rates of drug use, the average age of menopause onset was 46 years in the HIV positive group and 47 years in the HIV negative group.

The likelihood of early menopause rose with increasing degree of immunosuppression. In women with CD4 counts less than 200 cells/mm^3, the mean age of onset of menopause was 42.5 years. Women with low levels of physical activity were also at risk for earlier onset of menopause. This study showed no association between low body mass index (BMI) or cigarette smoking and early onset of menopause, contrary to some other epidemiological studies. There was also no association observed in this study between HAART use and earlier onset of menopause.

Clearly, more research into the effect of HIV on onset of menopause is necessary. The HIV Menopause Clinic—the first of its kind in the U.S.—was founded by Susan Cu-Uvin, MD, director of the Miriam Hospital's Immunology Center in Providence, Rhode Island. The

Medications Used to Prevent or Reverse Osteoporosis

Bisphosphonates: alendronate (Fosamax), risedronate (Actonel), ibandronate (Boniva)

Selective estrogen receptor modulators (SERMs): raloxifene (Evista), tamoxifen (Nolvadex) clinic is currently collecting observational data as a first step toward large-scale research on menopause in HIV positive women.

In addition, numerous studies are underway to determine the effects of HIV infection and antiretroviral therapy on the risk of developing cardiovascular disease and osteoporosis. These effects may be compounded in HIV positive menopausal women on HAART.

Osteopenia and Osteoporosis

In the February 20, 2004, issue of *Acquired Immune Deficiency Syndromes,* Sara Dolan, NP, and colleagues report on a study comparing the risk of osteopenia—bone thinning, a precursor to osteoporosis (more severe bone atrophy)—in HIV positive and HIV negative women. They found that women with HIV were more likely to have osteopenia, even after controlling for age and BMI. Prior exposure to antiretroviral therapy did not appear to have any significant effect on bone density. The study also found that abnormal menstrual function was associated with lower bone density, and that women who maintained their baseline weight were more likely to maintain their bone mass, compared with those who had HIV-related wasting.

A study by Julia Arnsten, MD, and colleagues with the U.S. Menopause Study, published in the April 1, 2006, issue of *Clinical Infectious Diseases,* analyzed data from 263 HIV positive and 232 HIV negative women; the median age was 44, most were pre-menopausal, and roughly three-quarters were on HAART. Overall, the HIV positive women had lower bone mineral density (BMD) in their hips and lumbar spines: 27% of the HIV positive women had low BMD, versus 19% of the HIV negative participants.

Cardiovascular Risk

Post-menopausal women have an increased risk of cardiovascular disease as estrogen levels decrease. HIV positive people on antiretroviral therapy are also at increased risk of cardiovascular disease, as certain antiretroviral medications (especially protease inhibitors) can lead to elevations in low-density lipoprotein (LDL, or “bad”) cholesterol and triglycerides. This side effect is quite common: multiple studies have shown that up to 20% of patients on HAART develop hyperlipidemia. Antiretroviral drugs may also cause insulin resistance and diabetes mellitus (impaired glucose tolerance), which in turn increase the risk of heart disease.

Management of Menopause

Although menopause is a natural process, many women seek medical assistance to manage the symptoms of menopause, both short-term symptoms such as hot flashes and vaginal dryness and more serious long-term complications such as elevated risk of osteoporosis and cardiovascular disease.

Not long ago, it was widely believed that hormone replacement therapy (HRT)—replacing estrogen, with or without the addition of progesterone—could safely alleviate

HEALTH SCREENING

Mammograms (breast cancer screening):

A mammogram is recommended every 1 to 2 years starting at age 40, then yearly after age 50. Monthly self-breast-exams are also advised.

Pap smears (cervical cancer screening):

HIV positive women should have two Pap smears during the first year following HIV diagnosis, then one per year thereafter.

Cholesterol checks:

For HIV positive people not on HAART, regular cholesterol checks should begin at age 45. Individuals at higher risk of heart disease (smokers, diabetics, or people with a family history of heart disease) should start cholesterol checks at age 20. Cholesterol should be checked before starting antiretroviral therapy, three to six months after starting therapy, and at least annually while on HAART.

Blood pressure checks:

Blood pressure checks are recommended at least once every two years.

menopausal symptoms while at the same time helping women avoid the detrimental long-term effects of reduced estrogen levels.

In recent years, however, data from large longitudinal studies have shown that the risks of HRT outweigh the benefits for many women. The Women's Health Initiative (WHI) is a group of studies designed to investigate long-term HRT. One study evaluated combined estrogen/progestin (synthetic progesterone) therapy versus placebo in more than 160,000 menopausal women, with an average follow-up period of more than five years.

In 2002, the estrogen/progestin arm of the study was discontinued after it was shown that women receiving long-term combination HRT had an increased risk of cardiovascular disease, cerebrovascular disease (stroke), deep vein thrombosis (blood clots), and breast cancer. The study did, however, reveal some beneficial effects associated with HRT: decreased rates of bone fractures and colon cancer. The estrogen-only arm of the study (which included women who had received hysterectomies and therefore were not at risk for uterine cancer) was later stopped after data showed that estrogen replacement did not reduce the risk of heart attack and slightly raised the risk of stroke.

Symptom Management

Acute symptoms often improve spontaneously as the hormonal fluctuations of perimenopause and early menopause level out. Women with severe hot flashes may find relief through short-term, low-dose estrogen/progestin HRT.

Alternatives to HRT for hot flashes include using a selective seratonin reuptake inhibitor (SSRI) antidepressant, most commonly venlafaxine (Effexor). Some women use soy products or herbal remedies such as black cohosh (*Cimicifuga racemosa*) or evening primrose (*Oenothera biennis*)—which contain estrogen-like compounds known as phytoestrogens—to alleviate hot flashes, bloating, and mood swings. Dr. Cu-Uvin notes that there is conflicting evidence from clinical trials about the effectiveness of herbal therapies, but for her patients who wish to try soy products, she recommends 40–80 mg of isoflavones taken daily for up to six months. (It is essential, however, for an HIV positive woman to consult with her own health-care provider before beginning a supplement regimen, as some herbal and dietary supplements can interact with antiretroviral medications and other drugs.)

One solution for vaginal dryness and thinning is the use of topical estrogen creams or lubricants during sexual intercourse. There is also an estrogen-releasing silicone ring (Estring) that can be inserted in the vagina and worn for three months at a time to alleviate the symptoms of vaginal atrophy. Local administration of estrogen is not associated with the same risks as systemic HRT.

Avoiding Long-Term Complications

One of the beneficial effects of HRT demonstrated in the WHI study was a decrease in the risk of bone fractures. However, there are other interventions that can decrease

TESTS FOR WOMEN

Colorectal cancer screening:

Testing for colorectal cancer (colonoscopy or flexible sigmoidoscopy) should start at age 50. If colonoscopy results are normal, repeat every ten years; if sigmoidoscopy results are normal, repeat every 5 years.

Diabetes tests:

A blood sugar test screens for diabetes. Patients on HAART should have a blood sugar test one to three months after starting therapy and then at least every three to six months.

Osteoporosis screening:

A bone density test to screen for osteoporosis is recommended for all women at age 65. Women may need to be tested earlier if they weigh less than 154 pounds, take chronic steroid therapy, are white or Asian, or smoke. There are currently no changes to these recommendations based on HIV status or HAART use; patients on HAART should talk to their health-care providers to determine whether an earlier test is indicated.

Sexually transmitted infection screening:

HIV positive women with multiple sex partners are advised to receive biannual screenings for syphilis, gonorrhea, and chlamydia, as these infections may be more serious for people with immunosuppression.

the danger of osteopenia and osteoporosis without the risks associated with HRT. Adequate dietary intake of calcium and vitamin D is extremely important—postmenopausal women need 1500 mg of calcium daily in addition to 400 units of vitamin D (800 units for women over age 70). Weight-bearing exercise also helps maintain bone mass. In addition, several medications can prevent and even reverse osteoporosis (see sidebar, page 41).

Similarly, there are many ways to reduce the risk of cardiovascular disease. The first step is lifestyle modification, including exercising, eating a low-fat diet, and quitting smoking. Statins—drugs such as atorvastatin (Lipitor) and simvastatin (Zocor)—reduce LDL cholesterol and triglyceride levels and can help lower the risk of heart disease. Other strategies include diabetes management and, for some people (and under their doctor's orders), taking a daily aspirin.

Conclusion

Knowledge regarding the menstrual cycle and menopause in HIV positive women has advanced since the beginning of the epidemic, but much remains to be learned. As women live longer with HIV, it is increasingly important to determine optimal care for a healthy menopause.

As with many aspects of HIV care, management of menopausal symptoms and complications should be tailored to the individual patient. Dr. Cu-Uvin notes that many of her patients have refused even short-term HRT due to their fear of complications, but estrogen replacement remains a viable option for some women, and the absolute risk of complications such as heart attacks and strokes remains small.

Until more is known, HIV positive women are advised to receive the recommended regular health check-ups for their age group (see sidebar, pages 42–43). Women should also discuss bothersome menstrual irregularities or menopause symptoms with their health-care providers and together explore individualized management strategies.

Anne Monroe, MD, is a resident in Internal Medicine at Jackson Memorial Hospital in Miami, Florida. She has a longstanding interest in HIV clinical trials and women's health.

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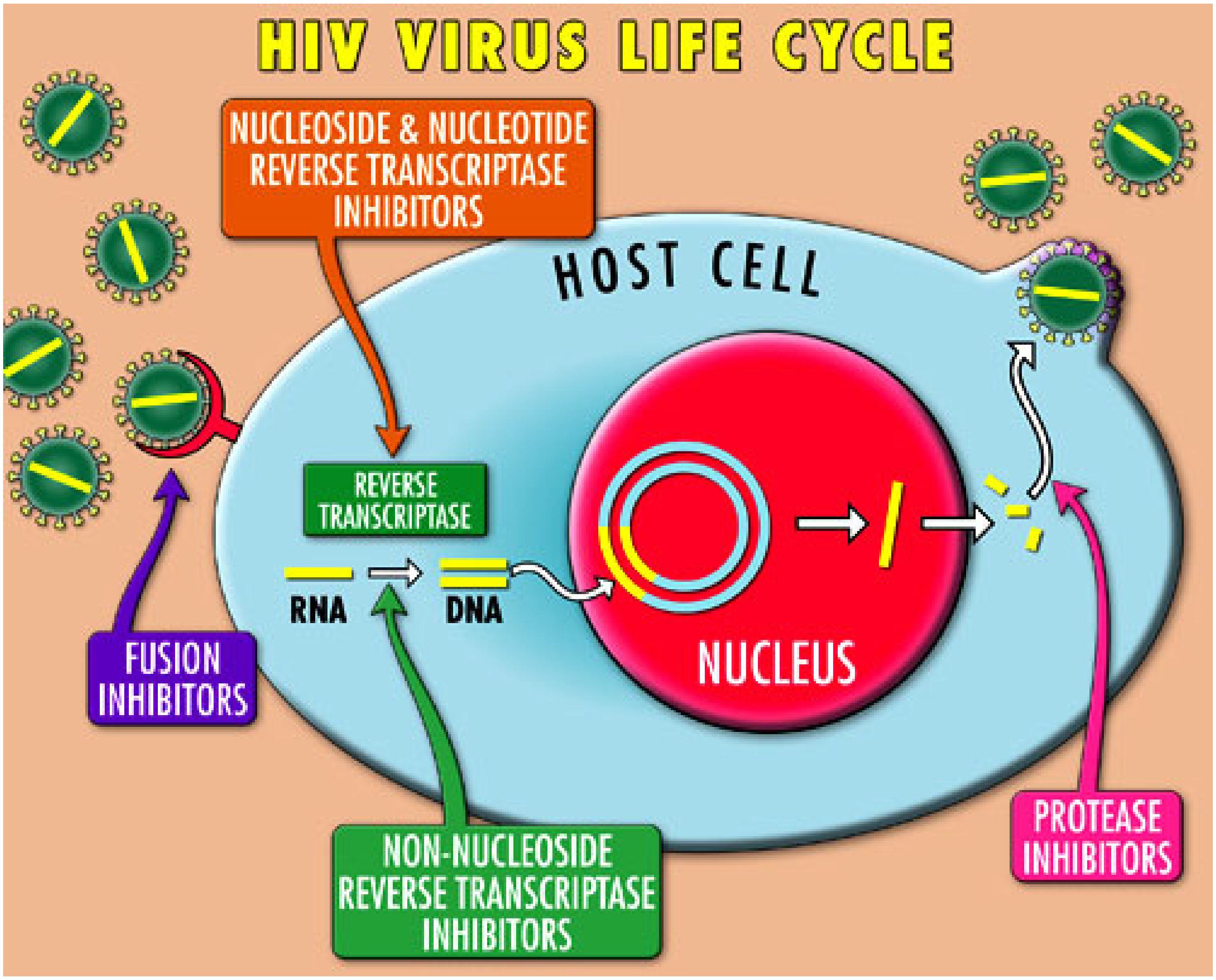
Lifestyle Habits That Contribute to Optimal Health

- Eat a balanced diet with plenty of fruits, vegetables, and whole grains
- Get some exercise every day
- Sleep at least eight hours every night
- Avoid smoking and second-hand smoke
- Reduce alcohol intake

HIV Life Cycle



The HIV lifecycle are the steps that HIV takes to enter and infect cells in our body.

In order for viruses to reproduce, they must infect a cell. Viruses are not technically alive: they are sort of like a brain with no body. In order to make new viruses, they must hi-jack a cell, and use it to make new viruses. Just as your body is constantly making new skin cells, or new blood cells, each cell often makes new proteins in order to stay alive and to reproduce itself. Viruses hide their own DNA in the DNA of the cell, and then, when the cell tries to make new proteins, it accidentally makes new viruses as well. HIV mostly infects cells in the immune system.

Each step of the life cycle is also a site where HIV medications work to slow down the infection.

10 Things You Can Do to ADHERE to Your Medication Schedule

By Frank Pizzoli

1. **Watch clocks and calendars.** Clocks and calendars rule in managing adherence. Buy a cheap plug-in clock with numbers so bright you'll see them for miles. Set the alarm if that helps. Calendars help track when prescriptions need refills. Buy calendars with whatever kind of pictures keep you looking at each month.
2. **Buy a wristwatch** that allows you to set at least three alarm times in 24-hours. Adherence is achieved when you keep to your pill-taking schedule of every 6 or 12 hours, depending on your regimen.
3. **Free pill trays** are often available from your AIDS service organizations. Grab two trays. Keep one filled with a week's worth of meds. It's time consuming to count out each dose, each time, on time, more than once daily. In the second pill tray keep a day's worth of pills in your car or at work, just in case you forget.
4. **Put medicines in sight** such as on the kitchen counter or where you throw your keys once inside or next to the TV remote. If you can "see" your meds routinely, there's a better chance you remember to take them on time, every time.
5. **If you have food requirements** be sure to chart out exactly what and when you can and cannot eat. Generally, high-fat foods don't go well with HIV meds, although some meds will advise you to eat fatty foods to help you absorb the drug.
6. **Agree with a friend to accept calls** reminding you to take your medicines. Make a telephone-tree of all your friends on HIV meds. Commit to calling around the circle to insure adherence.
7. **Take your morning and/or night dose when you brush your teeth.** Maybe there's another daily routine that could be easily combined with taking meds, like immediately before or after you exercise.
8. **Reward yourself.** If you make it through a week or month without missing a dose, reward yourself. If you miss a dose, be gentle. Adherence is a lifelong commitment.
9. **The best defense against side effects** involves knowing what they are and how they affect you. For example, keep a log for a week or longer. Write down all your side effects, when they occur, for how long. Note any links to mealtime or certain foods. Then avoid the foods and situations that lead to your discomfort.
10. **Always coordinate your care with a health care provider.** Don't be afraid to ask questions and seek guidance. If your doctor or case manager is annoyed by questions, find another one.

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wise words

hiv/aids treatment
information & advocacy
by and for women

When to use anti-HIV therapy:

the decision is yours to make!

Making a decision about when to start anti-HIV therapy and what drugs to take can be a challenge. There's no one right answer about when to start or what therapies to use, but there are answers that are right for you. As you embark on this decision, think about your needs, as well as the medical facts, and how starting therapy—or even waiting—fits into your life. Take time to look at both the risks and the benefits of starting therapy as well as waiting to start.

There are many tools that can help you in making an informed decision about treatment. The Federal Guidelines for the use of anti-HIV therapy is one of these tools. The Federal Guidelines are just what they say, a guide. They provide information, recommendations and suggestions on when to start treatment. They also outline the risks and benefits of treatment, what drugs to start with and options for changing therapy. The Guidelines are not a "one size fits all" solution, but rather a tool to assist you in making decisions.

On page 2 is a summary of the Federal Guidelines. Keep in mind that they are periodically reviewed and revised. You can also access the most current guidelines at *www.hivatis.org*.

In the following pages you'll find discussion points to consider if you're thinking about using anti-HIV therapy for the first time, to help you decide—for yourself—if starting therapy is right for you. You'll also find information on ways you can promote your own health. These are things you might consider exploring now, whether or not you decide to use therapy. Learning about anti-HIV therapy, the risks and benefits of starting now or waiting, and further developing for yourself your own decision-making process is central to making an informed decision.

Remember, this is your decision—take your time to make it.

WHAT'S INSIDE WISE

Greetings Wise Women!!

My name is Shalini Eddens and I recently joined Project Inform as the new Program Manager for Project Wise. Project Wise was truly blessed to have the leadership of Angela Garcia. Earlier this year, Angela went on to continue her education. Her contributions to Project Wise and *Wise Words* will be remembered and appreciated. We wish her the very best.

I am optimistic and excited about the future of Project Wise. More importantly, I'm grateful to each of you for being such an important part of *Wise Words.* I invite your questions, comments or anything that keeps *Wise Words* your newsletter! Contact us at wisewords@projectinform.org. or 415-558-8669 x205.

This issue is for women who are considering therapy, specifically those with a chronic established infection vs. acute infection. A chronic infection means you were exposed to the virus over a year ago. An acute infection means within the last year.

These timelines are not written in stone—varying factors can influence an infection being acute or chronic. If you're unsure about the time of your infection, talk with your doctor.

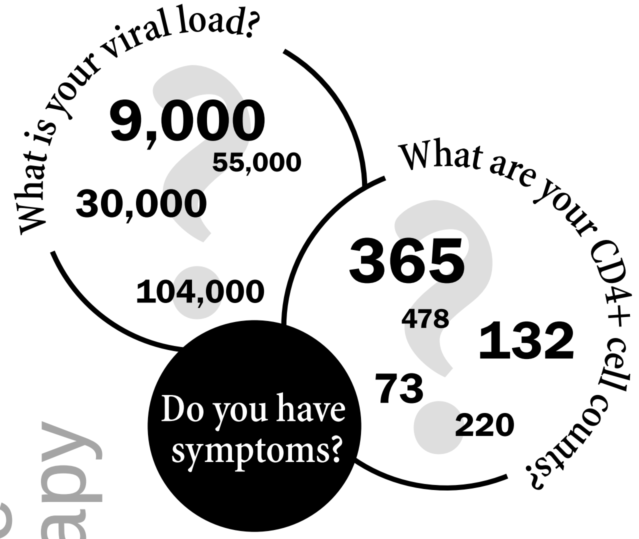
I hope you can make this issue of *Wise Words* more personal to your life. *Remember, the best decision is an informed decision—one that you made for **YOU!*** Peace

Shalini Eddens

Shalini Eddens
Program Manager, Project Wise

Wise Words
is a program of
PROJECT
inform

federal guidelines for the use of anti-HIV therapy



- **Advanced stage disease (severe symptoms of AIDS, with any CD4+ or viral load level.**
  All people with severe symptoms of AIDS are encouraged to be treated with anti-HIV therapy. In this case, therapy is shown to prolong life and improves symptoms. When starting therapy to prevent or treat serious infections (called *opportunistic infections*) at the same time as starting anti-HIV therapy, special care should be taken to avoid drug interactions. A person experiencing an opportunistic infection is generally encouraged to continue anti-HIV therapy.

- **No symptoms of HIV disease, with CD4+ cell counts below 200 and any viral load.**
  Anti-HIV therapy should be offered after considering the issues for making treatment decisions.

- **No symptoms of HIV disease, with CD4+ cell counts between 200-350 and any viral load.**
  Anti-HIV therapy should generally be offered, though controversy exists. Some experts believe it is often safe to wait until the CD4+ cell count falls to 200. Others believe this offers too little room to accommodate individual differences in how HIV disease progresses. In this case, they feel it's safer to start therapy at CD4+ cell counts of 350.

- **No symptoms of HIV disease, with CD4+ cell counts above 350 and viral load above 30,000 copies by bDNA or 55,000 by RT-PCR.**
  There are two unproven theories about treating early HIV infection in people without symptoms: aggressively vs. conservatively. For people who meet this definition, there are no data to suggest which approach results in longer survival. Very early, aggressive treatment might lead to longer life and greater preservation of the natural immune response against HIV. Or, it might lead to using up the limited supply of therapies too early in the course of disease. As well, it risks early exposure to possible long-term side effects from therapies. As a result, many experts would delay starting therapy and continue to monitor CD4+ cell counts and viral load until certain levels are reached. On the other hand, the risk of disease progression over the next three years is somewhat high (over 30%) in people who meet this definition. As a result, other experts prefer to start treatment without further delay, believing that preventing damage by the virus may be preferable to trying to repair what breaks later on.

- **No symptoms of HIV disease, with CD4+ cell counts above 350 and viral load below 30,000 copies (bDNA) or 55,000 (RT-PCR).**
  Many experts would delay therapy and continue to monitor CD4+ cell counts and viral load. The risk of disease progression over the next three years in this group is low (below 15%).

- **Acute HIV Infection (very early, typically within days to weeks after initial infection)**
  If infection is suspected, test for HIV using sensitive methods. (Note: technologies that measure viral load are not approved for diagnosing HIV infection and are discouraged for this use.) Experts agree that if treatment is offered this early, it should only be done in the context of a study. People interested in exploring very early treatment should be made aware of all its potential risks. The true long-term effect of early treatment is unknown because current studies are not yet complete. The hope, though, is that it might lead to a less aggressive course of disease. Whether or not this is the "right" approach remains unknown.

The following are the wise words of two women who have considered anti-HIV therapy at one point or another. They share the processes they went through in making their decisions, what helped and the challenges they faced.

WORDS OF EXPERIENCE FROM POSITIVE WOMEN

sarah

Sarah has gone back and forth about starting therapy. Her CD4+ cell count is just below 350 and her viral load fluctuates between 30,000 to 40,000 copies. Her provider recommended she begin therapy. She decided not to start anti-HIV therapy. Instead, she uses traditional Chinese medicine, herbs, acupuncture, eats well and only organic fruits and vegetables. She is healthy and feels great!

Q: What types of things did you think about when considering therapy?

A: As I was going through the motions of investigating, while my heart told me not to take it (anti-HIV therapy) my doctor and other people told me to start taking them. A lingering feeling of the gamble if I take it or if I wait is always at the back of my mind. It's a constant struggle.

Q: What kinds of resources did you use to help you think through the decision?

A: I spoke to friends and Project Inform. I read a lot and used the internet or got information from places like TheBody.com, Kaiser Family Health Foundation, Centers for Disease Control, National Institute of Health, and BETA (San Francisco AIDS Foundation's treatment publication).

Q: What type of advice would you give to a woman considering therapy?

A: The decision that they make is theirs; other people shouldn't tell you what to do. Understand the medications and what they do. Flush out all your concerns, expectations and fears. You need a lot of education!

diane

diane was diagnosed with HIV in 1988 when only one drug was available—AZT (zidovudine, Retrovir). Her doctor tried everything he could think of to stall the progression of the virus and put her on a 30-day cycle of AZT at 1,200mg/day. That's 3 pills every four hours all day. This is twice the currently recommended dose of AZT, but was still used by many doctors in 1988, especially in people who didn't have AIDS. Diane recalls her experience: "It was a very negative introduction to meds for me and it really scared me."

In 1992, Diane's CD4+ cell count dropped to 500. After three times of her labs showed CD4+ cell counts below 500, her doctor suggested therapy.

"I asked him if I take meds until my T cells (CD4+ cells) go above 500, can I stop? He said no, that I would be taking meds for the rest of my life. It felt like the beginning of the end. I felt like I was being punished. I had not disclosed my status and didn't know how to deal with that. I knew there were a lot of side effects.

"At some point, I began to realize that the pills were not my enemy. I was supporting my body, they (the pills) are like this superpower. At the same time, they were also harming my body. They reminded me that I was sick! So I had to make friends with my pills. The more I learned about what the meds were doing, the more I could understand it. I started to embrace them."

Q: What advice would you give to women considering therapy?

A: Ask every question you possibly can, as many times as you can, until you completely understand it. Understand that the drugs are not perfect. They are a tool in your toolkit along with the healthy eating and taking care of yourself. They are a component in a whole picture. Find a buddy who is also on meds. It is possible to live your dreams with HIV, and taking meds can be part of the success!

Q: How did you deal with side effects?

A: Side effects are as unique as the individual. They don't happen 100% of the time, they happen 10-20% of the time (and not in everyone). Talk out your fears about side effects. Take a few days off if you can at the start to get used to the drugs. Have someone around—you may feel sick. Talk to other folks, and talk with them about your fears. Never put a handful of pills in your mouth ... one at a time between bites of food (*only for drugs taken with food*). Drink water with a splash of juice to ease the nausea that may come with the taste of the pills.

Q: Do you have any other advice?

A: Find a buddy to cheer you on! Numbers (like CD4+ cell counts and viral loads) are guides. Even if you are far from taking therapy, it's okay to start researching and asking questions now so you're not overwhelmed when you come closer to making that decision.

Walking your way through making a decision

When considering therapy, there are many issues to keep in mind. Though research has not defined an absolute standard time to start anti-HIV therapy, some criteria can assist you in making a decision tailored to your needs. This road map highlights these criteria and may help you in this process. It may be a good idea to bring this with you to your doctor's appointment for discussion. Remember, take your time and don't feel pressure to make the decision today.

1

Your readiness and belief in therapy

Before you start any kind of medical treatment make sure that you're ready. Take time to reflect and contemplate how taking therapy is going to impact your life. Ask yourself questions like: Do I feel ready? What kind of expectations do I have? Do I have a support system or someone I can talk to about therapy? Am I scared? If so, of what am I afraid of? Explore your own beliefs and fears about therapy. Ground yourself in knowledge rather than fears. Talking to other people about their treatment decisions can be extremely beneficial, but remember ... what works for one person does not always work for another.

2

Viral Load

What is your viral load? __________

Has your viral load *trend* ...

☐ gone up more than 3-fold (ie., an increase from 10,000 to 30,000) or
☐ gone down over your last few tests?

30,000 or below (generally considered low)

Therapy is generally not recommended, but if you're experiencing symptoms or have very low CD4+ cell counts, considering therapy might still be warranted.

30,000-50,000

Federal guidelines suggest considering therapy if your CD4+ count is also below 350. However, if your CD4+ cell count is high (above 350), it's reasonable to wait.

Viral load readings, especially in the first 3–5 years after infection with HIV, may be different in women and men. While viral load readings of 30,000–50,000 is generally considered moderate/low in men, this might be high for a woman and signal a more pressing need for intervention.

100,000 or above (considered high)

Increased risk of disease progression. Federal Guidelines strongly suggest and encourage anti-HIV therapy.

For more information, read Project Inform's *Blood Work: A Useful Tool for Monitoring HIV; Wise Words #3;* and *Vaginal Candidiasis.*

3

CD4+ Cell Counts

What is your current CD4+ Cell Count? ___________

Over your last few tests, has your CD4+ cell count *trend* ...
☐ gone up or ☐ gone down?

Is your CD4+ count generally declining or is mostly stable, with just modest movement (100 points or less) up and down? A stable CD4+ count, as long as it's above 200, has less risk of progression than one that's steadily declining.

CD4+ cell count above 500 (normal range 500–1,500+)

Maintain good healthy habits (nutrition, exercise, monitor disease progression and labs).

Therapy is generally not recommended. If your viral load is high and/or you're experiencing symptoms, therapy might still be warranted. However, if the CD4+ count is declining rapidly and consistently, and the viral load is high, some doctors might recommend treatment or more frequent monitoring.

CD4+ cell count 200-500

If you are in this range, you may want to consider therapy, especially if you have developed symptoms associated with immune dysfunction. Examples include shingles (zoster), and recurrent and aggressive yeast infections. When no symptoms are present, most doctors would consider delaying treatment at least until the CD4+ count consistently falls below 350.

Guidelines suggest considering therapy when CD4+ cell count is consistently at or below 350

If your CD4+ cell counts are above 200, and you experience recurrent fungal infections (thrush, etc.), preventive therapy for pneumocystis carinii pneumonia (PCP) is recommended.

CD4+ cell count 200 and below

There is an increased risk for developing serious and life-threatening infections (*opportunistic infections*) and therefore the Federal Guidelines highly recommend anti-HIV therapy.

If you choose not to use antivirals at this point, talk with your provider about preventive therapies against common infections, like mycobacterium avium complex (MAC), cytomegalovirus (CMV) and toxoplasmosis. Monitor your lab values, weight, minor symptoms and overall sense of well-being.

If your CD4+ cell count and/or viral load levels change drastically from one test to another, discuss this with your provider. Large sudden changes are often the result of lab errors or other health factors (like a flu shot or stress).

For more information, read Project Inform's
Blood Work: A Useful Tool for Monitoring HIV.

If you come to the decision that you want to start therapy, here are 4 other points to consider before starting and as you develop your strategy.

4

The goal of HIV treatment

Take time to understand how therapy works. Get informed so you have solid foundation in understanding the goal of treatment. Learn about all of your possible treatment op-tions. It's important to understand the risks and benefits of both *starting* and of *waiting*. If you start therapy now, what are the possible side effects and how will you monitor to make sure therapy is working for you? If you wait to start, or decide not to start at all, what is your risk of HIV disease progression?

Take time to talk with your doctor about his/her opinions and experiences with treatment and other people who you trust and have an understanding of therapy.

For more information, read Project Inform's *Anti-HIV Therapy Strategies*.

5

What about side effects?

There are many side effects from anti-HIV therapy. It's important that you are aware of them and learn how they can be monitored and managed. Not everyone on therapy experiences side effects (only 10–20% of people have serious ones). It's not uncommon for people to have some short-term side effects like nausea and headaches during the first 4-6 weeks of therapy. After this adjustment period, often short-term side effects diminish. Therapies can have long-term side effects too, including body changes (called *lipodystrophy*) and changes in lab results like cholesterol.

For more info, read Project Inform's *Drug Side Effects: Lipodystrophy Syndrome(s)*; and *Mitochondrial Toxicity and Lactic Acidosis*.

6

Adherence

Adherence is crucial to treatment being effective. Adherence means taking medications exactly as prescribed by your provider. If anti-HIV medications are not taken according to instructions, the risk of developing drug-resistant HIV increases. Drug-resistant HIV may not respond to the anti-HIV drugs and, as a result, treatment options become limited. Numerous factors can influence adherence: the responsibility of children, your housing status, busy and demanding work, potential side effects from anti-HIV drugs, being in a domestic violence situation and many others.

Take a moment to reflect upon the various factors that can make taking your medications correctly challenging. Discuss this with your provider as you develop a treatment strategy. In addition, use those sources of support which will motivate you to stay adherent.

For more information, read Project Inform's *Adherence: Keeping Up With Your Meds* and *Drug Dosing Schedule*.

7

Co-infection

Have you been diagnosed with Hepatitis C (HCV)? ☐ Yes ☐ No

Some anti-HIV therapies, especially protease inhibitors and non-nucleoside reverse transcriptase inhibitors, can increase liver enzymes and/or cause hepatitis. Liver enzyme levels should be carefully monitored soon after starting anti-HIV therapy.

Are you taking treatment for HCV?
☐ Yes ☐ No

A 1–2 month gap is suggested between starting HIV and HCV treatment.

Treating HIV or HCV first will depend on the stage of liver disease and your CD4+ cell count and/or (HIV) viral load.

For more information, read Project Inform's *Hepatitis C*.

8

Drug Interactions

Are you currently on any other therapy (contraceptives, methadone, anti-depressants, etc.)? ☐ Yes ☐ No

There are known drug interactions between a variety of drugs, and even herb-drug interactions. These can worsen side effects and/or cause one or both therapies to be less effective. For example, some protease inhibitors can decrease the level of ethinyl-estradiol (chemical in oral contraceptives), making them less effective.

If you decide to take therapy, take all the medications, vitamins, supplements and/or alternative therapies that you're taking to your next doctor's appointment. Whenever you add or change a therapy or supplement, be sure to talk with all your health practitioners (and pharmacist) to make sure these products may be taken together safely.

For more information, read Project Inform's *Drug Interactions*.

9

Opportunistic Infections

Have you had any opportunistic in-fections (OIs)? like MAC, PCP or CMV?

☐ **Yes.** If you have an active OI, talk to your physician about treating that OI before you start anti-HIV therapy.

☐ **No.** If you have had a major OI, aggressive anti-HIV therapy is almost always recommended after treating the OI.

four ways to access meds


ADAP


PAPs


experimental


clinical study

Most people in the United States get their medications through insurance—either public insurance like Medicaid or Medicare, or private insurance. A comprehensive insurance plan that pays for doctor's visits, hospital and home care, prescriptions and other services is the best way to get quality HIV care. But what do you do if you don't have and can't get complete coverage?

If you can't afford or obtain private insurance, you may have other options. In addition to Medicaid and Medicare, states and even some localities may have services to help you obtain insurance or access care. Some programs, however, don't cover prescription drugs. For example, Medicare (the national insurance program for the elderly and some disabled persons) doesn't cover prescriptions. A description of some of the main drug assistance programs follows.

If you have questions about these programs or need information about how to qualify and participate, call Project Inform's Hotline at 1-800-822-7422. The Hotline will help you explore your options and link you to local resources. For more information on Medicaid and AIDS Drug Assistance Programs, visit *www.aidsinfonyc.org/network/access*.

1

AIDS DRUG ASSISTANCE PROGRAM

The AIDS Drug Assistance Program (ADAP) is a federal and state program that provides HIV-related medications to uninsured and underinsured people who can't otherwise afford them. All 50 states, the District of Columbia, Puerto Rico, Guam and the Virgin Islands have ADAPs. Benefits and eligibility vary from state to state. Due to inadequate funding, some ADAPs may experience shortages that limit services in the upcoming year. You can sign up at offices in various locations.

2

PATIENT ASSISTANCE PROGRAMS

Patient Assistance Programs (PAPs) are run by drug companies. They provide prescription drugs to people without means of getting the drug. The eligibility criteria are not public but do include income limits. PAPs can be more difficult to use because each company has a separate program with its own application process. You have to reapply fairly often. Usually, your doctor or medical advocate has to fill out paperwork. Some companies also charge a small co-payment each time you get your drugs. You can sign up by contacting the company that makes the drug you need.

3

EXPERIMENTAL DRUGS

EXPERIMENTAL DRUGS: Sometimes you may need or want an experimental drug not yet approved by the Food and Drug Administration. Because less is known about experimental drugs, it's important to consult closely with your doctor before making decisions. There are two ways you can get these drugs. EXPANDED ACCESS PROGRAMS are run by drug companies. They allow people who meet certain medical criteria to get experimental drugs. You sign up through your doctor's office. COMPASSIONATE USE typically does not have pre-set criteria. Working with your doctor, you can apply to get the drug, and the company then decides on a case-by-case basis.

4

CLINICAL STUDIES

Clinical studies may be run by drug companies or academic institutions. They are research studies and not meant to provide ongoing treatment or care. However, there may be good reasons to consider enrolling. Work closely with your doctor and make sure you read and understand the study's *informed consent* form. Informed consent is a document that details the study, known risks of the experimental drug and your rights as a research subject. It can be technical and confusing. Be sure your questions are answered before you sign and enter the study.

it's never too early to take charge of your health

developing a comprehensive health plan is something that's better done sooner rather than later. This means a plan that addresses health as it concerns your whole being. It includes the health of your body (biological health), mind (psychological health), spirit (spiritual health), and community (social health).

Each area is connected to one another. So, improving health in one has benefits in other areas too. Studies show that people facing life-threatening illnesses who address health holistically live longer and have a better quality of life. Some people think holistic means excluding things, like medicines. Instead, it is an inclusive approach that uses medicines as needed, but also addresses other needs.

The key to creating a solid long-term plan is to make gradual improvements, ones that you can sustain and fit into your lifestyle. There's no one right way to do this—no perfect recipe. In fact, tailoring a plan that you feel good about and matches your beliefs about health and well-being is central to success.

the mind

It's easy to see how improving the body might have a positive impact on your psychological health as well. Reducing stress not only strengthens the immune system, but it also clears the head! Many people with HIV experience depression, especially people who are co-infected with HIV and hepatitis B or C. A disproportionate number of people live with both HIV and mental illness. Some mental illnesses may be caused, sustained or worsened by HIV. Seeing a therapist, especially one with HIV experience, can help you manage the unique challenges of living with HIV. Seeking support groups with professional facilitation is another option. Resolving tensions or resentments, dealing with your fears, addressing depression and diagnosing and managing mental illness all help to improve your psychological health. This includes finding space and time to reflect on your life and your mental and emotional health.

the body

Project Inform provides many resources about biological health and HIV. This includes information on anti-HIV therapy and preventing and treating serious infections. It also includes information on nutrition, stress reduction and strategies for understanding your test results and monitoring your health regularly. Building a strong foundation of biological health will strengthen your body, reduce side effects of therapies and increase the likelihood that you will benefit from therapies. Also, if you choose not to use therapies, strengthening your body will help it fight disease and remain healthy.

get enough sleep

Eight hours a night is recommended. This isn't possible for everyone, especially women with young children and infants. But if you only sleep five hours a night, then five hours and fifteen minutes is an improvement!

reduce stress

Chemicals released in the body when you are stressed out weaken your immune system. A recent study suggests that stress decreases the benefit of anti-HIV therapy. Taking time for yourself, meditating, talking with friends about what's going on in your life and seeking support are all ways to promote health and reduce stress.

eat well

HIV hangs out in lymph tissue. 80% of the lymph tissue in the body is in the gut, where food and nutrients are absorbed into the body. Eating three balanced meals daily is a good way to improve nutrition. Taking vitamins is probably not necessary if you're eating well, and it's likely true that the best way to get vitamins is from food. Still, adding a multi-vitamin to your daily diet is not harmful and could be helpful! Improve your diet gradually, in ways you can sustain and fit into your life. Sudden and dramatic changes in diet can cause stomach upset and other problems.

exercise

Blood and other fluids move more effectively through the body when our hearts beat faster and when muscles move. Keeping things moving helps your cells get to where they need to be, moves oxygen throughout your body and helps keep you healthy. Aerobic exercise—like walking, running, swimming and biking—is particularly good for keeping things moving. Again, gradual improvements are key to success. If you never go to a gym, then committing to stretching a few minutes each day is one way to start. You could also simply take a walk around the block and then extend your walking distance over time.

continues on page 8 ...

it's never too early continued

the community

Social networks are critical to promoting health and well-being. These include friends, family and the people in the various communities you identify with. Improving social health might mean changing the relationships you have, like ending relationships that are harmful. It might mean nurturing and strengthening existing or new relationships. Social health is about cultivating a network of people around you who support you in exploring and achieving your potential. They help you in difficult times and speak with you openly and honestly. Social health is also about giving back to the community. This might include volunteer work, becoming involved in civic activities or starting a buddy network of people who help each other.

the spirit

A number of studies suggest that people facing life-threatening diseases who have a strong spiritual foundation live longer and have a better quality of life. Whether that foundation rests in Judaism, Christianity, Buddhism, Islam, native spiritual beliefs or religions of nature may be less important than nurturing a spiritual well-being that supports your beliefs in a personally meaningful and life-affirming way. There are many spiritual paths to explore. For one person this may be Catholicism; for another it may be Wicken. For someone else it may be a personal spiritual path of expression not associated with an organized religion.

These are just a few places to start thinking about in building a holistic foundation of health. You might find it useful to keep a diary. You could record things like your lab work, menstrual cycles and changes, how you're feeling and any symptoms or health conditions you're experiencing. You could also outline what you're doing to promote your health in various areas.

Project Inform is mostly a resource for biological health, as it relates to treating HIV and its related conditions. Biological health is only one aspect of overall health, however, and information about therapies and ways to treat HIV is not the entire picture of biological health. It also includes general healthcare, routine physicals and age-appropriate screening (like mammograms to detect breast cancer, bone density screening for osteoporosis, etc.), addressing substance use and addiction to name a few.

Resources for exploring and promoting psychological, spiritual and social health are available in your local community. How you address health in these areas will likely be as unique as you are. There's no one holistic health plan that's best for everyone. The first step to defining what's best for you requires you to define health for yourself.

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DEALING WITH DRUG SIDE EFFECTS

■

suggestions for coping with the side effects from taking medications

A PUBLICATION FROM
PROJECT inform
Information,
Inspiration and
Advocacy for People
Living With HIV/AIDS

JANUARY 2004

Dealing with drug side effects can be a challenge for anyone. Every anti-HIV drug has its own possible side effects. This is also true of drugs that prevent and treat infections. These effects can vary from one person to the next. Some people experience few or no side effects at all, while some have ones that are mild and manageable. For others, they may be quite severe. This publication provides a discussion on coping with side effects and tips for managing them. On pages 4–6, charts provide information about the side effects seen in studies and the percentage of people who had them.

The key to coping with your side effects

The key to coping with side effects is knowing what to watch out for and having a plan in place to respond if problems occur. If a drug you are taking or are planning to take has a side effect that may be life-threatening, it's important to know what early symptoms of that effect are and to monitor for them. It is also 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.

Before starting any therapy, talk to your doctor about the risk of side effects from various drugs. This information usually comes from studies conducted on the drug. Ask how often side effects were reported.

Are women different?

Women may experience a different type or frequency in side effects compared to men, including therapies not related to HIV. Why this is so is not well understood. It may be due to differences in the way a woman's body breaks down or stores drugs. Generally speaking, women have smaller body weight/sizes than men. It may be that, for their weight, some women take too high a dose of drug. This could also be an issue for men with small frames. Women's hormones may also affect drugs. Or it may be due to other unknown differences. Still, current information about side effects remains useful in guiding the ways women manage them.

What to look for, what to do?

Many people experience an adjustment period when starting a new therapy. This period usually lasts about four to six weeks as your body adapts to the new drug. During this time, you may experience headache, nausea, muscle pain in your arms and occasional dizziness. These kinds of side effects typically lessen or disappear as your body adjusts.

Learn to recognize, monitor and manage side effects should they arise. Often, simple solutions exist to lessen many side effects. In other cases, a particular side effect may be an important signal that requires immediate medical attention.

Once you notice any unusual reactions after starting or changing a drug, report the side effects to your doctor. If possible, talk to others who have used the same drug. They may be able to offer solutions.

Caring for your whole self

Some conditions believed to be side effects may actually be due to anxiety, depression or stress. Caring for your *whole* self—including your emotions, thoughts and general health, as well as specific anti-HIV strategies—can help minimize negative feelings and their effects.

There are some things you can do that may make the adjustment period easier. If possible, take some time off work or lighten your schedule to allow yourself to adjust to the change. If things get hard, see if someone can help out around the house or with children or other obligations.

Take time to re-prioritize *your* health needs, and make sure you get plenty of sleep and rest. Eat well and keep foods on hand that help combat common side effects like nausea and diarrhea (see pages 3 & 8). Try to get a little exercise during the day—even if just taking a walk.

Most importantly, reach out for support—be it your family, friends or support group. If you can, let them know what's going on. Sometimes just talking helps, but they may also have ideas to help ease side effects that your doctor might not mention.

A word about switching

Sometimes people facing serious side effects will ***switch*** drugs simply to improve their quality of life, even though the drugs were controlling HIV well. This is one way to deal with the side effects linked to that drug.

Switching a drug solely because of side effects may also save that drug as a future treatment option. In fact, side effects that you have with a drug at one time *may not* occur again if or when you try that drug again.

However, it is dangerous to simply ***stop*** taking one drug in your regimen, reduce its dose without talking to your doctor or pharmacist, or decide only to take it periodically. This can do more harm than good as it leads to drug resistance, making that drug—and perhaps others—less useful for you now or in the future.

Getting a handle on side effects

Side effects often occur after starting a new anti-HIV drug but lessen or disappear after a few weeks. Other times they persist as long as that drug or combination is used.

Many symptoms related to drug side effects are also conditions that people face when they have other health conditions. This may include infections, hormonal imbalances, pregnancy, depression or HIV itself.

Whenever you have symptoms, it's important to talk to your doctor to diagnose the cause. But regardless of how severe or persistent the side effects are, you can try some things to manage them. The tips on the following pages are for *medication* side effects.

Fatigue

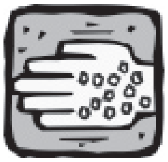
It's not unusual to feel tired, especially when life is hectic. A sense of tiredness that doesn't go away with rest is a problem. If ignored, fatigue can worsen.

Symptoms of fatigue can be physical—like it's difficult to getting out of bed or walk up stairs. They can also be psychological—like having a hard time concentrating. Fatigue is also a symptom of another drug side effect—anemia.

Getting a handle on fatigue begins with acknowledging it. If you're feeling fatigued, ask yourself: how long have you been tired? Are there activities that are difficult today that weren't a problem a few months ago? Are you having trouble concentrating? Are you having trouble sleeping or sleeping more than normal? The more information you can give your doctor about your physical, psychological and daily habits, the more likely the two of you will be able to decide the proper treatment for your fatigue.

TIPS FOR FATIGUE

- Try going to sleep at night and waking in the morning at the same time every day. Changes in your sleep schedule can actually make you feel tired.
- Try to get a little exercise. Exercise eases stress and makes you feel stronger and alive.
- Keep easy-to-prepare foods on hand for times you're too tired to cook.



Rash

Rash seems to occur slightly more often among women taking certain anti-HIV drugs than men, though it does occur in men as well. Nevirapine (Viramune) and nelfinavir (Viracept) appear to be the main culprits, but more research on rash among women taking other anti-HIV drugs is needed. Of note is the fact that it is not just that rash seems to occur more often in women, but women appear more prone to *severe* rash. It's important to check your skin for discoloration and changes in its surface, especially after starting a new medicine.

TIPS FOR RASH

- Keep medications like Benadryl on hand in case you develop a rash. It will soothe and comfort the skin.
- Try using unscented, non-soap cleansers or oatmeal soaps.
- Avoid extra hot showers or baths. They irritate the skin.
- Protect your rash from sun exposure as the ultraviolet (UV) rays of the sun may exacerbate a rash.

Peripheral Neuropathy

Peripheral neuropathy is caused by damage to nerves. When these nerves are damaged, it can cause a sensation of burning, stinging, stiffness, tickling or numbness in the feet, toes or hands. These sensations can be mild or severe enough to prevent someone from being able to walk. Peripheral neuropathy can be caused by HIV itself or as a side effect of certain anti-HIV drugs or drugs to treat opportunistic infections.

Treatment of peripheral neuropathy usually involves stopping or decreasing the offending drug. This usually results in clearing up the symptoms. However, there is no drug that can reverse nerve damage. *Talk to your doctor if you have signs of peripheral neuropathy.* If neuropathy is severe, it's a good idea to consult a doctor that specializes in pain management.

TIPS FOR PERIPHERAL NEUROPATHY

- Wear loose-fitting shoes, roomy cotton socks, and padded slippers around the house. Good air circulation around the feet helps.
- Keep feet uncovered in bed. Bedding that presses down on your toes can add to the problem.
- Walk around, but not too much. Walking helps blood circulate in the feet (a good thing), but too much walking or standing can make the problem worse.
- Soak feet in ice water to reduce foot pain.
- Massage your feet. This reduces foot pain temporarily.
- Try ibuprofen to reduce pain and swelling.
- Use L-acetyl carnitine (available at health food stores or through prescription) to prevent the peripheral neuropathy related to ddI, d4T and / or hydroxyurea.

Diarrhea

Aside from being annoying, the biggest concern is that diarrhea can cause dehydration. So the first course of action is to replenish lost liquids by drinking plenty of fluids, like Gatorade, ginger ale, chicken or beef broth, herb tea or just plain water. Chronic diarrhea may lead to weight loss. Foods that provide nutrients, calories, and absorb liquid (like the BRAT diet—bananas, rice, applesauce and toast) are good ways to deal with diarrhea.

Anti-diarrhea medications like Lomotil, Kaopectate, Imodium, or Pepto-Bismol can help, as can bulking laxatives like Metamucil. Nutritional supplements, such as L-Glutamine, Provir or Shaman Botanicals-Normal Stool Formula (SB-NSF) may also help, but can be expensive.

TIPS FOR DIARRHEA

- Eat foods high in *soluble fiber,* which slows diarrhea by absorbing liquid. In addition to the BRAT diet, these foods include oatmeal, cream of wheat, grits and soft bread (not whole grain).
- Try psyllium husk fiber bars (another source of *soluble fiber*). A recent study showed that two bars eaten one hour before bedtime with a large glass of water can really help diarrhea. They can be found at health food stores.
- Avoid foods high in *insoluble fiber*, like the skins of vegetables and fruits. These foods can make diarrhea worse.
- Try to avoid milk products and greasy, high-fiber or very sweet foods. They tend to aggravate diarrhea.
- Try calcium supplements (500mg twice a day).

Side effects chart of drugs used to treat HIV

This chart may not adequately reflect the percentages of side effects seen in women due to the limited number of women in many studies of these drugs.

HOW TO USE IT

The left hand column (vertical) lists all the side effects reported for the combined list of drugs. The top row (horizontal) lists drugs most commonly used in HIV disease. The columns underneath each drug heading lists the rough percentage of people reporting each side effect for each drug.

	Protease Inhibitors								
DRUG SIDE EFFECTS	Amprenavir	Atazanavir	Fosamprenavir	Indinavir	Lopinavir + ritonavir	Nelfinavir	Ritonavir	Saquinavir (hgc)	Saquinavir (sgc)
Abdominal pain		⊙		⊙	◇	◇	◇	◇	⊙
Altered taste	◇			◇			⊙	◇	◇
Anorexia (reduced appetite)		◇		◇		◇	⊙	◇	◇
Arthralgia (joint pain)						◇		◇	◇
Chills							◇	◇	◇
Constipation		◇					◇	◇	◇
Depression	◇	⊙				◇	◇	◇	
Diarrhea	⊙	⊙	⊙	◇	■	■	■	◇	■
Dizziness		◇		◇		◇	◇	◇	◇
Fatigue		◇		◇			◇	◇	⊙
Fevers		◇		◇		◇	◇	◇	◇
Headache		⊙		⊙	◇	◇	⊙	◇	⊙
Insomnia (sleep problems)		◇			◇	◇	◇	◇	⊙
Malaise		◇		◇			◇	◇	◇
Menstrual Irregularities							◇		◇
Myalgia (muscle pain)		◇				◇	◇	◇	◇
Nausea	■	⊙	⊙	⊙	⊙	⊙	■	◇	■
Nephrolithiasis (kidney stones)				⊙ | ■c					
Neurological Symptoms		◇				◇	◇	◇	◇
Neuropathy (pain / tingling in arms / legs / hands / feet)							◇	◇	◇
Pancreatitis (inflammation of pancreas)		◇‡		◇‡		◇‡	◇‡	◇‡	◇‡
Paresthesia (numbness, prickling, tingling)	■			◇			⊙	◇	◇
Rash	■‡	⊙‡	⊙‡	◇‡		◇‡	◇	◇‡	◇
Seizures						◇			
Vomiting	⊙	⊙	◇	⊙	◇	◇	⊙	◇	◇

DRUG SIDE EFFECTS ON LAB VALUES	Amprenavir	Atazanavir	Fosamprenavir	Indinavir	Lopinavir + ritonavir	Nelfinavir	Ritonavir	Saquinavir (hgc)	Saquinavir (sgc)
Anemia (low red blood / hemoglobin count)						◇	◇	◇	◇
Leukopenia (low white blood cell count)						◇	◇		
Neutropenia (low neutrophil count)		◇		◇	◇	◇		◇	◇
Thrombocytopenia (low platelet count)					◇c	◇	◇	◇	◇
Elevated Alkaline Phosphatase (liver)						◇			
Elevated Amylase (pancreas)		◇		◇	◇	◇			
Elevated Bilirubin (liver)		■		⊙	◇c	◇		◇	◇
Elevated Cholesterol	◇	◇		◇	⊙	◇	■	◇	◇
Elevated Creatinine (kidney)						◇			
Elevated Glucose (blood sugar)	⊙		◇	◇	◇	◇	◇	◇	◇
Elevated Liver Functions	◇	◇	⊙		⊙	◇	⊙	◇	◇
Elevated Triglycerides (cholesterol)	⊙			◇	⊙	◇	■	◇	◇

EXPLANATION OF BULLETS

■	Reported in >15% of people in clinical studies.
⊙	Reported in 5–15% of people in clinical studies.
◇	Reported in <5% of people in clinical studies.
blank space	Side effect has not been reported.
c	Side effect reported only in children, or more commonly in children.
‡	Potentially fatal side effect.

NNRTIs			NRTIs										E.I.
Delavirdine	Efavirenz	Nevirapine	3TC	Abacavir	AZT	AZT+3TC (Combivir)	AZT+3TC+ABV (Trizivir)	ddC	ddI & ddI EC	d4T	Emtricitabine (FTC)	Tenofovir	Enfuvirtide (T-20)
◇	◇	◇	⊙		⊙	⊙		◇	◇	◇	⊙	◇	⊙
◇	◇				◇			◇					◇
◇			⊙	⊙	⊙	⊙	⊙	◇	◇	◇			◇
◇	◇	◇						◇			◇		
◇			⊙			⊙		◇	◇	◇			
◇					◇			◇					
◇	◇		⊙		◇	⊙		◇			⊙	⊙	⊙
◇	⊙	◇	■	⊙	◇	■	⊙	◇	■	■	■	⊙	
◇	⊙		⊙		◇	⊙		◇				◇	
◇	⊙	◇	■			■	■	◇					
◇	◇	◇	⊙			⊙		◇	◇	◇		◇	◇
⊙	⊙	◇	■	◇	⊙	■	■	◇		■	■	⊙	
◇	⊙		⊙	⊙		⊙	⊙	◇		◇	⊙	◇	
◇	◇		■	◇	⊙	■	■	◇					
◇	◇	◇	⊙			⊙		◇	◇	◇	◇		⊙
⊙	⊙	⊙	⊙	⊙	■	⊙	■	◇		■	■	◇	
◇	■				◇	◇	◇	◇					
◇	◇		⊙			⊙	◇	■	■	■	◇	◇	
◇‡	◇‡		◇‡	◇‡	◇‡	◇‡	◇‡	◇‡	⊙‡	◇‡		◇‡	
		◇	◇		◇	◇	◇				⊙	◇	
■‡	■‡	■‡	⊙‡	⊙‡	◇	⊙‡	⊙‡	◇‡	⊙‡	■‡	■‡	◇‡	◇‡
					◇	◇	◇	◇					
◇	⊙	◇	⊙	⊙	⊙	⊙	■	◇		■	⊙	◇	

NNRTIs			NRTIs										E.I.
Delavirdine	Efavirenz	Nevirapine	3TC	Abacavir	AZT	AZT+3TC (Combivir)	AZT+3TC+ABV (Trizivir)	ddC	ddI & ddI EC	d4T	Emtricitabine (FTC)	Tenofovir	Enfuvirtide (T-20)
			◇	◇	■	◇	◇	⊙	◇	◇			◇
					◇			⊙	◇	◇			
◇		◇	⊙	⊙	⊙	⊙	⊙	⊙			⊙	◇	◇
◇			◇	◇	◇[c]	◇	◇	◇	◇	◇			◇
◇													
◇			◇	◇		◇	◇	◇	⊙	⊙	◇	⊙	⊙
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	◇												
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◇	◇	⊙	◇	◇	◇	◇	◇	⊙	⊙	⊙	◇	◇	◇
◇	◇			■			■	◇			⊙		⊙

Other Side Effect Warnings

ALL anti-HIV drugs

Changes in body fat distribution, called *lipodystrophy*, has been associated both with HIV infection and anti-HIV therapy. A warning about lipodystrophy is now included in the label information for all anti-HIV drugs.

ALL nucleoside analogs (NRTIs)

A build-up of lactic acid in the body (*lactic acidosis*) and severe liver enlargement (*hepatomegaly*) with fatty liver (*steatosis*), including fatal cases, have been reported with using NRTIs alone or in combination. Fatal lactic acidosis has been reported in pregnant women who took d4T (stavudine, Zerit) and ddI (didanosine, Videx) with other anti-HIV drugs. The combination of d4T and ddI should be used with caution during pregnancy.

AZT

AZT (zidovudine, Retrovir) has been associated with low neutrophil counts (*neutropenia*) and severe reductions in red blood cells (*anemia*), particularly in patients with advanced HIV disease. Prolonged use of AZT has been associated with muscle weakness (*myopathy*).

Abacavir

Fatal hypersensitivity reactions have occurred in up to 8.5% of people taking abacavir (Ziagen). People with fever, skin rash, fatigue, nausea, vomiting, diarrhea, abdominal pain, and/or respiratory symptoms are advised to call their doctor *immediately* and stop using abacavir if directed, as soon as a hypersensitivity reaction is suspected. Once abacavir treatment is stopped, it should be permanently discontinued as a more severe reaction may recur within hours if it is restarted and may include life-threatening symptoms and death.

d4T/ddI

Fatal and non-fatal inflammation in the pancreas (*pancreatitis*) has occurred with the combination of d4T and ddI. Neither d4T nor ddI should be used in people with suspected or confirmed pancreatitis.

Enfuvirtide

Nearly 100% of people using enfuvirtide (T-20, Fuzeon) will have injection site reactions including redness, inflammation, pain and hardening of the skin.

Side effects chart of drugs used to treat common OIs

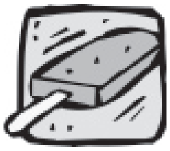
This chart may not adequately reflect the percentages of side effects seen in women due to the limited number of women in many studies of these drugs.

	MAC / MAI			PCP			CMV			FUN-GAL
DRUG SIDE EFFECTS	Azithromycin	Clarithromycin	Rifabutin	Bactrim / Septra	Dapsone	Aero. Pentamidine	Cidofovir	Ganciclovir (IV)	Foscarnet	Fluconazole
Abdominal pain	◇	◇	◇	◇					⊙	◇
Altered taste		⊙	◇			◇			◇	
Anorexia (reduced appetite)			◇	⊙			■	⊙	⊙	
Arthralgia (joint pain)				◇					◇	
Chills							■	⊙		
Constipation									◇	
Depression									⊙	
Diarrhea	⊙	⊙	◇				■	■	■	◇
Dizziness						◇			⊙	
Fatigue									⊙	
Fevers			◇			◇	⊙	■	■	
Headache	◇	◇	◇	◇	◇		■		■	◇
Insomnia (sleep problems)			◇						◇	
Malaise										
Menstrual Irregularities										
Myalgia (muscle pain)			◇	◇					◇	
Nausea	◇	◇	⊙	⊙	◇	⊙	■		■	◇
Nephrolithiasis (kidney stones)										
Neurological Symptoms										
Neuropathy (pain / tingling in arms / legs / hands / feet)								⊙	⊙	
Pancreatitis (inflammation of pancreas)									◇‡	
Paresthesia (numbness, prickling, tingling)									⊙	
Rash	◇‡	◇c‡	⊙‡	⊙‡	⊙‡	◇‡	■‡			◇‡
Seizures									⊙	
Vomiting	⊙c	⊙c	◇	⊙	◇		■	⊙	■	◇

DRUG EFFECTS ON LAB VALUES	Azithromycin	Clarithromycin	Rifabutin	Bactrim / Septra	Dapsone	Aero. Pentamidine	Cidofovir	Ganciclovir (IV)	Foscarnet	Fluconazole
Anemia (low red blood / hemoglobin count)	◇		⊙	◇	◇	◇	■	■	■	
Leukopenia (low white blood cell count)	◇		■	◇	◇	⊙		■	⊙	◇
Neutropenia (low neutrophil count)	◇		■	◇			■			◇
Thrombocytopenia (low platelet count)	◇		⊙			◇		⊙		◇
Elevated Alkaline Phosphatase (liver)			◇						◇	
Elevated Amylase (pancreas)										
Elevated Bilirubin (liver)	◇			◇						
Elevated Cholesterol										
Elevated Creatinine (kidney)	◇					◇	■		⊙	
Elevated Glucose (blood sugar)	◇									
Elevated Liver Functions	◇		⊙			⊙				
Elevated Triglycerides (cholesterol)										

EXPLANATION OF BULLETS

■	Reported in >15% of people in clinical studies.	blank space	Side effect has not been reported.
⊙	Reported in 5–15% of people in clinical studies.	c	Side effect reported only in children, or more commonly in children.
◇	Reported in <5% of people in clinical studies.	‡	Potentially fatal side effect.



Dry Mouth

Dry mouth can result from taking certain medicines. It is an uncomfortable condition, making chewing, swallowing and talking difficult. Dry mouth can affect your sense of taste and can promote mouth problems, like tooth decay and oral yeast infections (*thrush*). Treating dry mouth can be as simple as drinking plenty of liquids during or between meals. Avoid sugary or sticky foods or caffeinated drinks as they can make your mouth even drier. Chewing sugarless gum can stimulate saliva. If these things don't work, your doctor can prescribe a synthetic saliva or other medicine, like pilocarpine.

TIPS FOR DRY MOUTH

- Rinse your mouth throughout the day with salted warm water.
- Try *slippery elm* or *licorice tea* (available in health food stores)—they lubricate the mouth and taste great!
- Suck on sugarless candies, lozenges or crushed ice to cool the mouth and give it moisture.
- Ask your doctor to prescribe products or mouth rinses to treat dry mouth.

Headache

The most common cause of headache is tension, something most people have at some point! Different kinds of medicines can also cause them. Headaches are mostly just a pain and can be eased by over-the-counter medicines like aspirin, acetaminophen, ibuprofen, or naproxen sodium. They can also be helped, and prevented, by reducing stress.

TIPS FOR HEADACHE

- For on-the-spot headache relief: try resting in a quiet, dark room with your eyes closed; place cold washcloths over your eyes; massage the base of your skull with your thumbs and massage both temples gently; take hot baths.
- To prevent headaches from recurring: try to anticipate when pain will strike. Avoid or limit foods known to trigger headaches, especially caffeine (from coffee, tea, soft drinks or some medications), chocolate, red wine, citrus fruit (if more than 1/2 cup a day), food additives (like monosodium glutamate, or MSG), nuts, onions, hard cheese and vinegar.

Hair Loss

Most people experience hair loss as they get older. This is normal and affects some people more than others, especially if baldness runs in the family. Hair loss can be disturbing nonetheless and can damage one's self-confidence.

Sudden or abnormal hair loss can result from taking certain drugs (like some used to treat HIV, cancer, circulatory disorders, ulcers or arthritis).

TIPS FOR HAIR LOSS

- To protect your hair from further damage and loss: avoid or decrease damaging hair care practices or use them infrequently. These include dyeing, perming, straightening, braiding, corn-rowing, using hair dryers, etc.
- Don't be fooled by fraudulent claims for products that promise to cure baldness. They do not exist! The only remedy that comes close is the medication Rogaine, available over-the-counter. It has shown promising results for some (but not many) cases of baldness.
- Stress can make hair loss worse, so taking steps to reduce stress and anxiety often help.

Anemia

Anemia is low red blood cells. Those are the cells that deliver oxygen to different parts of your body. When your body is short on oxygen, you feel fatigued. Long-term or severe anemia can cause damage to your body. Most people with HIV have anemia at some point. HIV can cause it. So do many drugs used to treat HIV, like AZT (Retrovir). For women, problems with periods can also be a cause or symptom of anemia.

To check for anemia, have blood work done at least every three months, even if you're not using anti-HIV drugs. A change in diet or nutritional supplements can lower the risk of developing anemia. Using medication to correct moderate anemia (Procrit, Epogen) can also help. In some cases, stopping or changing the drugs that are causing anemia may be necessary. Treating severe anemia requires a blood transfusion.

TIPS FOR ANEMIA

- Know your red blood cell (hemoglobin) count! Get it checked regularly.
- Fish, meat, and poultry are high in iron and vitamin B-12, both of which may lower risk of anemia.
- Spinach, asparagus, dark leafy greens, and lima beans are high in folic acid, another nutrient that may lower risk of anemia.

Nausea and Vomiting

Feelings of nausea and the urge to vomit vary greatly among people. The two symptoms often occur together. Certain medications used to treat HIV or related conditions can cause nausea. (See the Drug Side Effects Chart on pages 4–6 to identify drugs that may commonly cause nausea.)

Persistent vomiting can lead to serious medical problems, like dehydration, chemical imbalances and even tearing of the esophagus (throat). Call your doctor if you vomit repeatedly throughout the day or if nausea or vomiting is persistent and/or interferes with your ability to take your medication.

TIPS FOR NAUSEA AND VOMITING

- The BRAT Diet (Bananas, Rice, Applesauce, and Toast) helps with nausea and diarrhea.
- Leave dry crackers by your bed. Before getting out of bed in the morning, eat a few and sit in bed for a few minutes. This can help reduce nausea.
- Try some peppermint, chamomile or ginger tea—they can calm the stomach.
- Sip cold carbonated drinks like ginger-ale, 7-Up or Sprite. They can help avoid nausea.
- Avoid hot, spicy, strong-smelling and greasy foods.
- If vomiting occurs, replenish fluids with broth, carbonated beverages, juice, Jell-O or popsicles.
- Talk to your doctor about the benefits / risks of anti-nausea medications (such as Compazine, Marinol, Ativan, Tigan, Zofran and Phenergan).

Weight Loss

Weight loss can be a serious problem in HIV disease. It can result from some of the side effects discussed in this section—like vomiting, nausea, dry mouth, anemia or fatigue.

Unfortunately, even though the signs of weight loss can be obvious, it is not always seen as a problem. In fact, many positive women who lose weight due to HIV-related problems are praised and told they “look good”.

If you’re losing weight and it’s not because you altered your diet or exercise patterns for that purpose, it’s ***never*** a good thing. Talking to a doctor to identify its cause is critical to treating unwanted weight loss.

TIPS FOR WEIGHT LOSS

- Monitor your weight. If you are losing weight, work with your doctor to determine the cause. Is it stress-related? Is it accompanying nausea or vomiting? Has it occurred after starting a new medicine? What other things are going on?
- Try high protein shake mixes, like Med-Rx or Metabol. Look for products high in protein and low in sugar. These are available at most health food and vitamin stores.
- Ask about discounts at health food and vitamin stores. They sometimes provide people with life-threatening diseases special savings on nutritional products.

Period Problems

Period problems are common in all women, but particularly in women with weakened immune systems. These problems include irregular, heavier, lighter and/or painful periods or the end of menstrual bleeding altogether. Problems with periods can be a side effect of some medications. Most recently, excessive menstrual bleeding has been seen when using ritonavir (Norvir).

More research is needed to determine which anti-HIV drugs have an effect on menstruation. Meanwhile, it’s a good idea to track your periods, noting changes if they occur, particularly around the time of beginning a new anti-HIV drug.

TIPS FOR PERIOD PROBLEMS

- Consider what else is happening in your life. Have you lost weight? Are you stressed out? These factors might give you clues as to why you’re having period problems. Addressing them might help in more ways than one!
- For menstrual cramps, hold a hot water bottle or a heating pad over your lower stomach or back. Or take a hot bath. This reduces stress, too!
- Do mild exercise, like walking or stretching. Exercise may increase blood flow and decrease period pain.
- Oral contraceptives (the Pill) are sometimes used to regulate abnormal periods. Some anti-HIV drugs interact with the Pill. A list of drug interactions can be found in Project Inform’s publication, GYN Conditions in Women Living with HIV / AIDS.

Meditation on Taking Medicine Within

(To be read slowly to a friend or silently to oneself)

Sitting comfortably in a chair or lying easily in bed, pick up the medicine container and just feel it there in your hand. Feel its shape, its denseness, its texture, its quality of coldness or warmth. Let your hand make contact, feel the sensations generated there. Let the fingers open the container with awareness. Notice any strain or urgency and soften all about it. Feel the medications, the pills, as they drop onto the palm of your hand. Take a moment to look at the pills.

Take a moment to notice if the pill is regarded wholeheartedly as a medium of healing, or if there is a modicum of shame or failure that accompanies it. Focusing on the healing quality with the medication, look on the medicine as a healing potential to enter fully into the area of discomfort, its power to bring equanimity and balance. See the pills there in your hand. Feel their slight weight against the sensitive nerve endings in your palm.

Listen to the medicine. Does it have something to say? What is it tone of voice? Is there any sense of helplessness in your relationship to the medicine? Just notice it. Meet with mercy and awareness any resistance we may have previously ingested along with our treatments. Look on these medications with loving kindness and gratitude. Thank the pills for whatever healing they may have to offer and place them gently in your mouth.

Feel your tongue, feel the liquid taken to swallow it entering across your lips. Feel the tongue moving the pills into position to be swallowed. Feel the swallowing. Let the pills be drawn past the heart into the awaiting stomach. Feel the medication settling into your stomach, radiating like a soft golden light. Feel the medication conveyed into the place of need.

With loving kindness, direct its healing quality to the area of greatest need. Feel the area absorb the healing. Let it in.

Receive the medication as a blessing. Find an image that opens you to the healing in your medication. See it as a gift from a great teacher, as a sacred communion between the outer and inner worlds, as a smile of unbearable compassion.

Let it in. Absorb it.

Allow the loving kindness to combine with the treatment and direct it into the area that calls for healing. Allow the medication to be drawn in, mercy and awareness binding to each molecule sent wholeheartedly into the cause of suffering.

Feel the medication dissolving the resistance of a lifetime, dispelling the tension and difficulty around illness.

Feel it enter directly. Feel it melting the injury and illness.

Let the medication heal you and make you whole again.

~Stephen Levine

Day 4:
HIV/AIDS – Part 2

1 Safer Sex & Harm Reduction

2 Disclosure

3 Reading & Understanding Our Labs

4 HIV Case Studies

5 Lotus Jeopardy

6 Closing & Homework

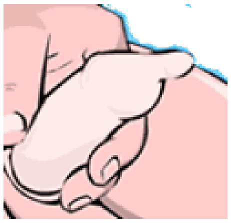
SKILL BUILDER:
How to Use a Condom

1. Use a condom every time you have a sexual interaction. Make sure the condom has not been stored in a warm place (in a car, pocket, etc). Heat can damage the condom.
2. Check the expiration date on the back of the condom.
3. Handle the condom carefully, making sure not to damage it with your teeth, fingernail or other sharp object.
4. Place the condom on a "hard" penis before it touches anywhere near your vaginal area. If the man is uncircumcised, roll down the foreskin before you put the condom on.
5. Do not pull the condom tightly against the tip of the penis.
6. For a condom without a reservoir tip, leave a small empty space-about a half-inch-at the end of the condom to hold semen. Some condoms come equipped with a reservoir (nipple) tip that will hold semen.
7. Unroll the condom all the way to the bottom of the penis. Add lubricant on the top of the condom, if needed.
8. If the condom breaks during intercourse, withdraw the penis immediately and put on a new condom and use more lubricant.
9. After the guy ejaculates/cums, carefully withdraw the penis while it is still hard.
10. Hold on to the rim of the condom as the penis is withdrawn from the vagina to prevent the condom from slipping off.
11. Remove the condom carefully from the penis, making sure that semen does not leak out.
12. Wrap the used condom in a tissue and discard it in the garbage. Do not flush it down the toilet, as condoms may cause problems in the sewers. Wash your hands thoroughly with soap and water.

1-2

3-4

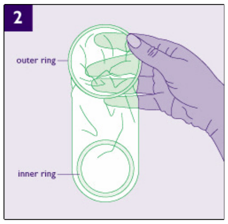
5-7



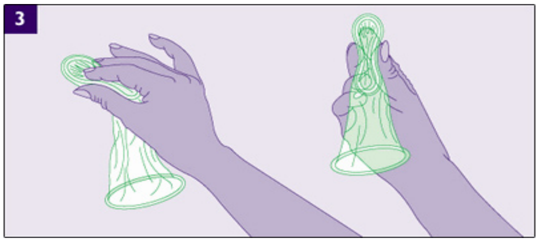
8-12

SKILL BUILDER:
How to Use a Female Condom

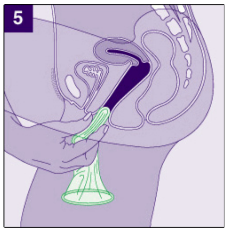
1. Open the package carefully; tear at the notch on the top right of the package. Do not use scissors or a knife to open.



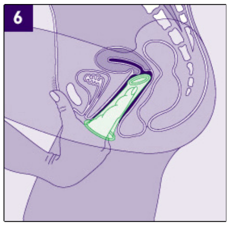
2. The outer ring covers the area around the opening of the vagina. The inner ring is used for insertion and to help hold the sheath in place during intercourse.



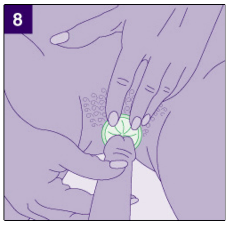
3. While holding the sheath at the closed end, grasp the flexible inner ring and squeeze it with the thumb and second or middle finger so it becomes long and narrow.
4. Choose a position that is comfortable for insertion – squat, raise one leg, sit or lie down.



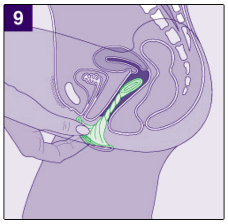
5. Gently insert the inner ring into the vagina. Feel the inner ring go up and move into place.



6. Place, the index finger on the inside of the condom, and push the inner ring up as far as it will go. Be sure the sheath is not twisted. The outer ring should remain on the outside of the vagina.
7. The female condom is now in place and ready for use with your partner.



8. When you are ready, gently guide your partner’s penis into the sheath’s opening with your hand to make sure that it enters properly – be sure that the penis is not entering on the side, between the sheath and the vaginal wall.



9. To remove the condom, twist the outer ring and gently pull the condom out.
10. Wrap the condom in the package or in tissue, and throw it in the garbage. Do not put it into the toilet.

SKILL BUILDER:
How to Use a Dental Dam or Other Latex Barriers

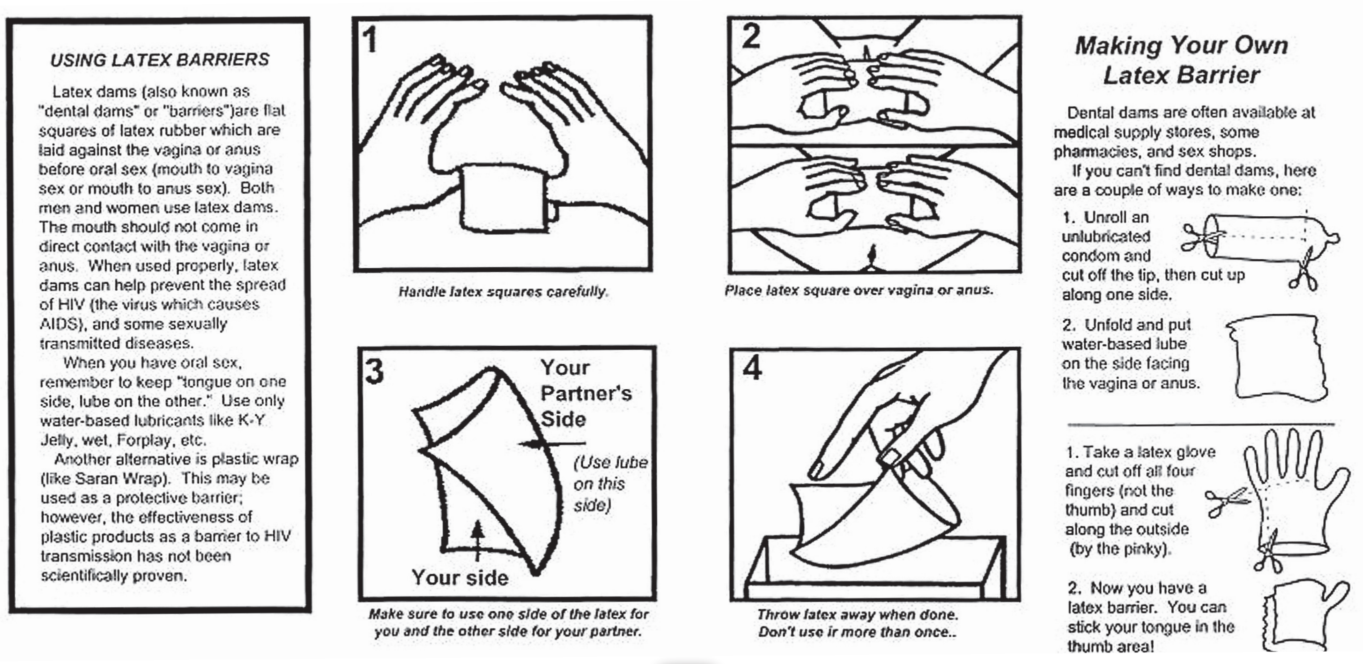
Dental dams or Glyde dams are squares of latex. They can usually be obtained at family planning clinics, women's clinics, or AIDS organizations. During sex, dams can be used over the outside of the vagina or anus while it is being orally or manually stimulated.

The following suggestions may help you with your dental dam:

1. Before you try using a dam with a partner, experiment with it yourself. Try stretching it, tasting it, and rubbing it against your skin.
2. You may want to wash the dam before using it to improve its flavor. Use a mild soap, and rinse it well.
3. For increased sensitivity, consider using a water-based lubricant to the side of the dam that will be put against the genitals.
4. Because the dam may slip during use, keep track of which side is which. Consider keeping several dams nearby in case one slips off and you lose track of which side is which. Partners can take turns using it.
5. Although you can wash dams thoroughly and reuse them once or twice, it is safer to discard them and use a fresh one each time.

Other options other than dental dams:

1. Plastic wrap. This has not been scientifically tested, but it may provide similar protection to that of the dental dam. Do not expose it to heat or hot water. Do not reuse it. Non-microwaveable plastic wrap is recommended.
2. A condom or a latex glove may be cut in half and used like a dental dam.
3. Finger cots (condoms for fingers) and latex gloves can be used if someone has open sores or cuts on their fingers. They will also provide extra protection against genital warts and other STD's.



USING LATEX BARRIERS

Latex dams (also known as "dental dams" or "barriers")are flat squares of latex rubber which are laid against the vagina or anus before oral sex (mouth to vagina sex or mouth to anus sex). Both men and women use latex dams. The mouth should not come in direct contact with the vagina or anus. When used properly, latex dams can help prevent the spread of HIV (the virus which causes AIDS), and some sexually transmitted diseases.

When you have oral sex, remember to keep "tongue on one side, lube on the other." Use only water-based lubricants like K-Y Jelly, wet, Forplay, etc.

Another alternative is plastic wrap (like Saran Wrap). This may be used as a protective barrier; however, the effectiveness of plastic products as a barrier to HIV transmission has not been scientifically proven.

Handle latex squares carefully.

Place latex square over vagina or anus.

Make sure to use one side of the latex for you and the other side for your partner.

Throw latex away when done. Don't use ir more than once..

Making Your Own Latex Barrier

Dental dams are often available at medical supply stores, some pharmacies, and sex shops.

If you can't find dental dams, here are a couple of ways to make one:

1. Unroll an unlubricated condom and cut off the tip, then cut up along one side.
2. Unfold and put water-based lube on the side facing the vagina or anus.

1. Take a latex glove and cut off all four fingers (not the thumb) and cut along the outside (by the pinky).
2. Now you have a latex barrier. You can stick your tongue in the thumb area!

10 Things You Can Do to Practice Harm Reduction If You Use Drugs

By Paul Cherashore - *Harm Reduction Coalition in New York City*

1. **Drink lots of water** since it's cheap, eliminates toxins, relieves stress on kidneys and liver, good for your skin and promotes regularity. To be safe, drink bottled water or tap water that has been boiled first.
2. **Prevent overdosing** by not mixing drugs (especially depressants and opiates), and by being aware of changes in drug tolerance. Most ODs happen either because people mix drugs with similar effects, or undergo a change in tolerance but don't make the necessary dosage adjustment.
3. **Keep physically active.** Moderate exercise stimulates your immune system, can reduce the chances of stroke and heart disease, and is good for your mental health too!
4. **Support your recovery.** While relapse is now acknowledged to be part of the recovery process, you can still treat it like the rain: let it come another day. Check the Yellow Pages or Directory Assistance for Narcotics Anonymous (NA) and/or Alcoholics Anonymous (AA).
5. **If you're still using, moderate your use** since it's easier to do this before it gets out of control than after. You may want to check out the substance use management groups.
6. Take the following steps to **reduce personal and public health risks,** if you inject drugs:
    - Never reuse or share syringes, water, or drug preparation equipment.
    - Use only syringes obtained from a reliable source (e.g., pharmacies).
    - Use a new, sterile syringe to prepare and inject drugs.†
    - If possible, use sterile water to prepare drugs; otherwise, use clean water from a reliable source (such as fresh tap water).
    - Use a new or disinfected container (cooker) and a new filter (cotton) to prepare drugs.
    - Clean the injection site with a new alcohol swab before injection.
    - Safely dispose of syringes after one use.
7. **Catch those minor health problems early.** Seek out programs and institutions that provide preventive care and that can tackle problems before they become too serious.
8. **Try ear acupuncture** which can help those who are thinking about cutting down or stopping, or who are just stressed out.
9. **Take care of your mental health.** Seek out psychotherapy or other types of mental health care for help with any issues you may be struggling with.
10. **Be informed about hepatitis C.** Up to 90% of HIV-positive people who got infected by drug use also have the hepatitis C virus (HCV). Contact local groups that address hepatitis or search for information on the Internet. It is also important to get screened for HCV and screened and vaccinated for the hepatitis A and B viruses (no vaccination currently exists for HCV).

SEX AND PREVENTION CONCERNS FOR POSITIVE PEOPLE

A PUBLICATION FROM
PROJECT inform
Information, Inspiration and Advocacy for People Living With HIV/AIDS

SEPTEMBER 2002

Safer sex and prevention messages are often targeted solely to HIV-negative people. Yet, preventing HIV and other infections remains an important issue for people living with HIV as well. Whether your partner is HIV-positive, HIV-negative, female, male or transgendered, there are many reasons to be concerned about safer sex and prevention. This publication explores some of the most common sexual transmission concerns for people living with HIV.

WHAT'S INSIDE

what are the risks of passing HIV to my HIV-negative partner?

A concern of many people living with HIV is passing HIV to their uninfected partner(s). While much evidence suggests that men transmit HIV more easily than women, women can still pass HIV to uninfected partners—both male and female. This is because HIV is present in blood (including menstrual blood), vaginal secretions and in cells in the vaginal and anal walls. In fact, high levels of HIV can be found in these areas even if there's a low amount of HIV in your blood.

For women, HIV levels in vaginal fluids greatly increase when you have gynecological (GYN) conditions, like yeast infections or inflammation. Several studies in test tubes show that some sexually transmitted infections (STIs), like chlamydia, increase HIV reproduction. Vaginal inflammation, a common symptom of these infections, causes tiny scrapes and cuts on the delicate skin of the vaginal area that can then harbor HIV. HIV levels can also temporarily increase after treating some of these conditions.

Likewise, men with active STIs, especially active herpes lesions, etc., are more likely to both acquire and transmit HIV. Less is known about whether HIV levels are actually higher in blood and semen during an active STIs in men, but certainly any infection that causes a lesion, like herpes, provides a portal for HIV to pass through and makes transmission more likely. Studies do show that even when a man has undetectable levels of HIV in his blood, there are sometimes detectable HIV levels in semen and pre-cum fluid. HIV transmission from men with undetectable HIV levels in their blood has been documented several times.

In short, if you're not practicing safer sex, there's no way to know when you're more or less likely to pass HIV to your partner(s). Exposure to vaginal or anal secretions, semen or other blood with high levels of HIV increases your risk of transmission. The risk further increases when one's partner has an infection or inflammation. It's also possible to have active infections or GYN conditions without having symptoms or knowing it. (For general guidelines on safer sex practices, see page 8.)

> (IN SHORT, IF YOU'RE NOT PRACTICING SAFER SEX, THERE'S NO WAY TO KNOW WHEN YOU'RE MORE OR LESS LIKELY TO PASS HIV TO YOUR PARTNER(S).)

Finally, a number of known cases have shown multi-drug resistant HIV being passed from people living with HIV to their partners. What this means is that the newly infected partners have a form of the virus difficult to treat with anti-HIV drugs, leaving them with limited options to treat their infections.

what kinds of infections can I protect myself from getting?

Prevention isn't just about protecting someone else from getting HIV; it's also about protecting yourself from other harmful infections. You can do something about many common and serious infections. The risks of unsafe sex are numerous because many STIs can cause serious harm in people living with HIV.

Cytomegalovirus (CMV) is such a condition. While most adults are infected with CMV, it doesn't cause disease in healthy, HIV-negative people. Therefore, most people carry the virus but don't have active CMV disease. However, once CMV becomes an active infection, it's the leading cause of blindness and among the major causes of death in people with AIDS. Ways to prevent CMV infection include practicing safer sex.

CMV prevention is probably much more relevant to women than to men, particularly adult gay men. The rate of CMV infection among women is generally lower (40% among women living with HIV) than what's seen among adult gay men (80–90% of whom are already infected with CMV, regardless of HIV status). The bottom line is that if you're not infected with CMV, safer sex remains a potent tool in helping to prevent CMV disease.

Like CMV, human papilloma virus (HPV) is another STI. HPV is the virus that causes genital warts in some people. These warts may or may not be visible by external examination, yet might be present in the anus or cervix. As one of the major causes of anal and cervical cancer, HPV is common and difficult to treat among people living with HIV. Some types of HPV are more likely to develop into cancer than other types.

Both men and women are at risk for anal cancer associated with HPV. Some studies suggest that a woman living with HIV is more at risk of developing anal cancer as opposed to cervical cancer associated with HPV infection. Unlike other conditions associated with HIV disease, the rate of anal and cervical cancer associated with HPV infection does not appear to be dramatically declining with increased use of anti-HIV therapy. Unfortunately, condom and other barrier protections may not protect you from HPV infection and transmission, but they might decrease the risk of transmission.

Hepatitis, cryptosporidiosis, parasites and other infections can also be passed during sexual activity. Every condition described above can be deadly in anyone living with HIV, especially with a weakened immune system. (For more information on how to prevent these infections, see pages 4–5.)

It's important for people living with HIV to protect themselves from these unwanted and possibly dangerous infections. Lab tests can detect these infections, but your medical coverage may not pay for them. You can ask your doctor about possibly getting these tests. Then, use the results to build a prevention plan that helps protect you from getting new infections.

☎

For more treatment information, call Project Inform's toll-free National HIV/AIDS Treatment Information Hotline at 1-800-822-7422.

You can prevent getting

Bartonella (*Cat Scratch Fever*)

A bacterial infection that can cause fevers, headaches and a marked reduction in red blood cells (i.e. anemia).

Put on the flea collar!

- Avoid adopting kittens or cats under one year old.
- Avoid cat scratches or allowing cats to lick open cuts or wounds. Promptly wash all cat scratches or wounds.
- Use flea control for cats.

Campylobacter

A bacterial infection that can cause diarrhea, abdominal pain and vomiting.

When Fluffy has the runs, run!

- Avoid contact with animals that have diarrhea.
- In general, get someone else to handle potty duties for pets.

Coccidioidomycosis (*Valley Fever*)

A fungal infection that causes fevers, difficulty in breathing and night sweats.

On your next archeological dig, bring Endust!

- Although there are areas of the country such as the deserts of the Southwest where it may be impossible to avoid exposure to this pest, you can still reduce the risk of exposure by avoiding excavation sites and dust storms.

Cryptococcosis

A fungal infection that primarily infects the brain resulting in headaches, fevers and altered mental behavior.

Don’t feed the birds!

- Avoid areas that may be heavily contaminated with the pest that causes the infection (called *Cryptococcus*), including areas with a lot of pigeon droppings. Avoid handling birds, even those kept as pets.

Cryptosporidiosis

A parasite that can cause diarrhea.

Put down the baby, and move away from the goat!

- Wash hands after fecal contact (like after changing a baby’s diaper) and after gardening or other contact with soil.
- Avoid contact with young farm animals or animals with diarrhea (including pet stores and animal shelters).
- Wash hands after handling pets and avoid contact with pet feces.
- Boil water for at least one minute. If possible, install a water filter system that can filter out *Cryptosporidium*.
- Avoid swimming in water that may be contaminated by *Cryptosporidium*. Some lakes, rivers, swimming pools and salt water beaches may be contaminated with human or animal waste that contains *Cryptosporidium*.

For more information on preventing infection with crypto, call Project Inform’s Hotline.

Cytomegalovirus (CMV)

A virus that infects the entire body. (Left untreated, CMV can cause diarrhea, blindness, inflammation of the brain, etc.)

Safer sex is hot sex (and it’s not just about HIV infection)!

- Wash hands after fecal contact.
- Follow safer sex practices.
- If blood transfusions are required, only CMV antibody negative or leukocyte-reduced blood products should be used.

Hepatitis A, B and C Virus (HAV, HBV and HCV)

Viral infections that can cause liver damage, failure and sometimes cancer.

- Talk to your doctor about the appropriateness of vaccination (for HAV and HBV).
- Follow safer sex practices.
- Learn about particular risks for HAV and traveling in areas where threat for exposure is great and vaccination prior to travel highly recommended.

common infections at home!

Herpes

A viral infection that can cause ulcer lesions around the mouth, genitals and rectum.

- Follow safer sex practices.

Histoplasmosis

A fungal infection that can cause fevers, reduction in red blood cells and difficulty in breathing.

Put down the mop and move away from the chicken coop!

- Although it may be impossible to avoid exposure to this organism in areas of the country like the Midwest river valleys, people can still reduce their risk by not cleaning chicken coops, disturbing soil under bird roosting sites or exploring caves.

Human Papilloma Virus

A viral infection that can cause warts, which can become cancerous.

- Follow safer sex practices. Condoms cannot wholly prevent HPV transmission.

Listeriosis

A bacterial infection that can cause meningitis, an inflammation in the brain.

- Avoid eating any non-pasteurized dairy products, such as soft cheeses like Brie and goat cheese.
- Heat ready-to-eat foods like hot dogs and ensure that they're steaming hot before eating them.

Microsporidiosis

A parasite that can cause diarrhea.

- Wash hands frequently and follow other good personal hygiene measures.

Salmonella

A bacterial infection that can cause food poisoning and diarrhea.

- Avoid Caesar salads or anything that may contain raw eggs.
- Avoid eating under-cooked eggs and poultry.
- Avoid contact with animals that have diarrhea.
- Avoid contact with reptiles like snakes, lizards, iguanas and turtles.

Toxoplasmosis

A parasite that mostly infects the brain resulting in confusion and delusional behavior.

These recommendations only apply to people who are NOT antibody positive to *Toxoplasma.*

- Avoid eating raw or under-cooked meats. (Cook to an internal temperature of 150°F or 65.5°C.)
- Wash hands after contact with raw meat and after gardening or other contact with soil.
- Wash fruits and vegetables in filtered water or in a .05% bleach solution before eating raw.
- Wash hands after changing a cat's litter box or preferably have an HIV-negative person change it.
- Cats should be kept indoors and be fed canned or dried commercial cat food and not raw or undercooked meats.

Tuberculosis

Primarily infects the lungs and can cause cough, weight loss and fatigue.

- If possible, avoid working or volunteering in facilities considered high risk for tuberculosis, such as healthcare and correctional facilities and homeless shelters.

Varicella-Zoster

A viral infection commonly known as chicken pox and shingles.

- People who have NOT had chicken pox or shingles should avoid direct contact with people with active chicken pox or shingles.

we're both positive. what are our concerns?

For people whose partner(s) also live with HIV, prevention messages and reasons to practice safer sex sometimes become unclear. A common question is: "If I'm positive and my partner is positive, then why do we have to practice safer sex?" Simply put, safer sex remains important among positive partners. This is because in addition to preventing new infections as discussed above, other factors place positive sex partners at risk.

One of these factors is re-infection with HIV. While the issue of re-infection remains unclear, some new evidence shows that it can and does happen. If you're on therapy that HIV has become resistant to, it's possible for you to transmit the drug-resistant strain to your partner, possibly crippling the benefits of those therapies for your partner. On the other hand, if your partner is on anti-HIV therapy, you could become infected with his or her drug-resistant strain(s) and have decreased benefits from therapy. (For more information on drug-resistant virus, see page 7.)

Finally, it's important to remember that your partner's viral load (amount of HIV in blood) may not relate to the level of virus in semen or vaginal or anal fluids. Therefore, while HIV levels in blood may be undetectable by a lab test, they still may be present in high levels elsewhere. (Note: Standard viral load tests do not measure HIV in semen or vaginal or anal fluids. Also, in studies, even when viral load tests of semen came back undetectable, HIV-infected cells could still be found in the semen. These cells are believed important for passing HIV from person to person.)

When both partners live with HIV, consider these points when discussing safer sex:

- Infections like CMV, HPV, herpes, hepatitis (B and C) among others, remain major concerns. All these are potentially deadly infections in people living with HIV, but they can be prevented, to some degree, through practicing safer sex.
- Re-infection with drug-resistant or more aggressive strains of HIV remains a theoretical possibility. It must be considered when negotiating safer sex between positive partners.

the reality of safer sex

You put yourself at risk for infections through unprotected sex with a partner—activities that expose you to your partner's blood, blood products, urine, feces, semen or vaginal or anal fluids. In some cases these infections may never harm your partner, but they might be life-threatening to you should your immune system weaken as a result of HIV.

If your partner(s) is also living with HIV, neither of you is immune to new infections. Be aware of both the real and theoretical risks as you discuss and negotiate safer sex. Every sexual behavior or activity carries some level of infection risk. It's generally believed that some activities are less risky than others, but *low risk* obviously doesn't mean *no risk*.

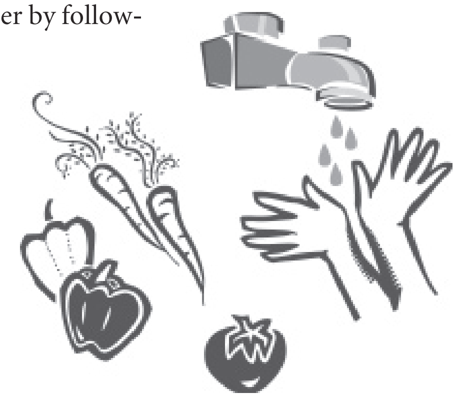
Negotiating safer sex and using risk reduction to prevent passing or getting HIV or other infections is not easy. Safer sex requires the involvement of willing partners. This is especially difficult for women because safe and low-cost woman-initiated methods of HIV prevention do not currently exist. For people in situations where domestic violence occurs, this willing involvement can be almost impossible. In this case, seeking family violence prevention services is probably the safest and smartest plan of action.

preventing your risk of infections

People living with HIV must consider taking precautions to avoid exposing themselves to common infections, which are possibly deadly in people with a weakened immune system. Although safer sex is usually thought of in regards to preventing HIV infection, exposure to many major infections and STIs can be reduced if safer sex is followed. Avoiding oral-anal contact can greatly reduce the risk of getting parasites that can cause diarrhea and other symptoms. (Examples of parasites include tape worms, scabies and more common among people with HIV are *Toxoplasma* and *Cryptosporidium*.)

Safer sex is not the only way to prevent exposure to infections, however. There are a number of things you can do to decrease your risk of potentially harmful infections.

In general, people with HIV should not eat raw or undercooked meats, poultry or seafood. Avoid unpasteurized dairy products, which may contain parasites, bacteria or viruses that in turn can cause severe illness. For example, eating raw shellfish can result in hepatitis A infection. Risks can be reduced further by following guidelines for "safer" food preparation.



transmission of multi-drug resistant HIV

There is increasing concern over the transmission of drug-resistant virus and multi-drug resistant HIV. People infected with multi-drug resistant HIV are unlikely to optimally benefit from most, if not all, of the available anti-HIV therapies. While many known cases of AZT-resistant HIV transmission have occurred in the past, transmission of multi-drug resistant virus is being seen increasingly. These observations underscore the importance of including safer sex in your life, even when you and your partner(s) are both living with HIV.

HIV and STDs: woman-to-woman

Woman-to-woman sexual activity has generally been associated with a lower risk of passing HIV, although a number of cases have been reported. The risk of passing HIV and other STIs between women has not been thoroughly studied. But the few studies to date note that many women who have sex with women engage in a number of high-risk behaviors that may increase their risks of both getting and passing HIV and other STIs (including the types of HPV associated with cervical and anal cancer). So in the meantime, it's best to play safe and refrain from making easy assumptions about HIV and STI transmission during woman-to-woman sex.

Safer sex guidelines

In addition to protecting from HIV infection and transmission, practicing safer sex also reduces the risk of passing or contracting other diseases, like chlamydia, gonorrhea, herpes and hepatitis. These can be especially troublesome in people with weakened immune systems. A few tips on how to protect yourself and your partner during sex are found below.

One word: Plastics!

Use latex condoms and plenty of water-based lubricant (K-Y Jelly, Astroglide, Probe) for vaginal and anal sex. If you're sensitive (*allergic*) to latex, try polyurethane condoms (Avanti). The female condom (Reality) is also made of polyurethane. However, polyurethane condoms may have higher breakage problem than latex.

Protect the environment and your condoms!

Don't use oil-containing lubricants like Crisco, Vaseline, baby oil, lotion or whipped cream as they can destroy latex. (Note: Oil-based lubes can be safely used with polyurethane condoms.) Good water-based lubricants last longer and often feel better anyway.

Read the label!

Many people avoid products with the spermicide, Nonoxynol-9. Some studies now show it can cause irritation that may promote STIs, including HIV.

Wrap it to go!

For oral sex with a man, it's safest to use a condom. For oral sex with a woman or oral-anal sex (rimming), it's safest to use a dental dam (latex square), plastic food wrap, or a condom or latex glove cut to make a flat sheet.

Try a breath mint instead!

Avoid brushing or flossing your teeth up to two hours before or after oral sex to minimize small cuts. Be aware of bleeding gums, cuts or sores on or in the mouth.

Let your fingers do the walking!

Use latex gloves for hand jobs (sex with your hands) or fisting. Try powder-free latex or polyurethane gloves for folks who are sensitive to latex.

Good clean fun!

If you share sex toys (like dildos or vibrators), put on a fresh condom for each user and/or when going to or from the anus and vagina. Clean toys with bleach, alcohol or soap and water between uses.

On the wild side!

Avoid contact with blood, semen and vaginal and anal fluids. Sex toys like whips or knives can break the skin and should not be used on another person until they're disinfected with bleach or cleaning solution.

www.projectinform.org

ⓘ Go online around the clock and get connected to treatment information in the privacy of your own home!

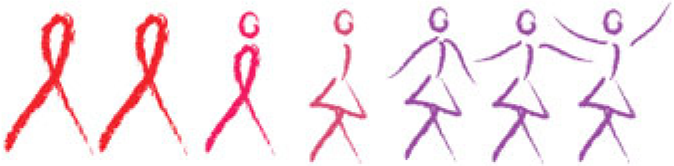
Telling

1. A good experience that I had with telling someone else that I living with HIV…

2. A not-so-good experience that I had with telling someone else that I living with HIV…

3. One thing I do well when deciding who to tell is…

4. One thing I will change about disclosing my HIV status in the future is…



HIV & Disclosure

Preparing for Disclosure

"Disclosure" means telling someone that you are HIV+. Who to tell about your HIV status and how to tell them can be a very complex and personal decision.

There is no one best way to tell someone, just as there is no sure way to gauge their reaction to your news. But it will help to ask yourself a few questions before disclosing:

1. Who do I want to tell and why do I want them to know?
2. How much am I ready to share or are they ready to hear?
3. How will disclosing my HIV status affect me and how will it affect the people around me?
4. Think about the people you rely on for support, like family, friends, or coworkers.
5. Figure out your relationship with each of these people and the advantages and disadvantages of telling them.
6. Determine any issues the person might have that will affect how much he or she can support you. For example, does the person have any health problems of her own? Can you trust her?
7. Look at the person's attitude and knowledge about HIV. Do they have fears or preconceived ideas about HIV?
8. Think about why you'd want to disclose to this person. What kind of support can this person provide?
9. For each person, decide if the person should be told now, later, or to wait and see.

Deciding who to tell may take a short time or a long time.

There is no right way to do this.

It is a very personal decision that only you can make.

Julianne Serovich, PhD, Professor, Marriage and Family Therapy

Who Needs to Know You are HIV +

You do not have to tell everyone that you are HIV+. You should tell people that you may have exposed to HIV so that they can be tested and seek medical attention if required. These people could be sexual contacts or people with whom you have shared needles. If you do not want to tell them yourself, The Department of Health can inform your contacts without even using your name.

In about 27 states, the law requires that you disclose your HIV status before knowingly exposing or transmitting HIV to someone else. Penalties vary from state to state.

You need to tell your doctors and other healthcare providers to ensure you receive appropriate care. Your doctor also needs to know how you were infected to determine if are at risk for other diseases, such as hepatitis C for injection drug users and other sexually transmitted diseases for women infected through sex.

Who Does Not Need to Know

You do not have to tell your employer that you are HIV+. If you do tell, remember that, as long as you are performing your job, your employer cannot legally discriminate against you. People with disabilities, including HIV, are protected from job discrimination under the Americans with Disabilities Act (ADA).

Who You May Want to Tell

Women often choose to disclose their status to close friends and family. For many, telling those closest to them provides them with both emotional and practical support.

Some people decide to become more public and use their stories to advocate for others with government or media. Others may disclose for educational purposes to neighbors, community and religious groups, schools, other HIV+ people, or healthcare providers. Many women find a sense of purpose and increased self-esteem by telling their story.

You may want to consider how much of your story you are ready to tell. Many people will ask you how you became infected. If you decide not to share that information, have a reply ready such as, “does it really matter?” or simply state that you are not ready to talk about that.

Disclosing to Loved Ones

Disclosing to Children

For moms considering telling their children, it is important to ask yourself why you want to tell them:

- Will they be angry if you keep a secret?
- Do they suspect something?
- Are you sick?

Children can react to the news of HIV in the family in many different ways. Older kids may be upset that you kept a secret from them. Younger children may just want to go back to their toys. Partial truths can be helpful when telling children. You may decide only to tell them as much as you consider appropriate for their age.

Do not forget that kids need support too. If you can, give them the name of another adult they can talk to, perhaps an aunt or grandparent. Several books are available that deal with the issue of disclosure to children. (Find books at Let's Talk.)

Disclosure and Relationships

Women who are dating find it difficult to know when to disclose. Should you tell on the first date or only if the relationship is getting serious? While there is no correct answer, the longer you wait, the more difficult it becomes.

Be aware that women are at risk for violence when disclosing their HIV status, especially pregnant women. If you are worried that your partner may become violent, think about having the discussion with a neutral third party present: a therapist, an HIV advocate, or a health professional.

In close relationships, studies show that living with a secret, such as HIV, can be more emotionally harmful than the rejection that could result from disclosure. Many women who have kept a secret for a long time feel a sense of relief after telling. Community based organizations and AIDS clinics can offer resources to guide women through the disclosure process.

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understanding your lab results

acria

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Everyone needs lab tests.

If you are living with HIV, lab tests are one of the most important ways you and your healthcare provider can monitor your health. They can help you:

- Decide when to start drugs to treat HIV and other infections;
- Determine whether or not the drugs are working;
- Determine if the drugs are causing certain side effects;
- Watch for other infections and problems associated with HIV infection.

Lab tests come in many different forms. Some require blood samples, while others require urine or stool (feces) samples. Each sample can then be used to conduct a wide range of lab tests, depending on your healthcare provider's orders. A Pap smear, which scrapes cells from the wall of the cervix (and sometimes the anus), is another type of important laboratory test.

This brochure has been produced by the AIDS Community Research Initiative of America (ACRIA) to help you better understand the different types of lab tests commonly recommended by healthcare providers. With this information, we hope that you will be able to talk with your healthcare provider about your lab results in order to better understand your health. Perhaps you'll start keeping copies of your lab reports to monitor your health. Or maybe this brochure will simply help you understand why your doctor, nurse, or laboratory specialist needs to take so many tubes of blood!

Blood Tests

Blood tests are among the most comprehensive – and complex – laboratory tests used to monitor the health of people living with HIV. Very often, healthcare providers will ask for blood to be taken every three to six months, or sometimes more frequently, depending on the patient's health or if he or she is enrolled in a clinical trial.

Blood samples are typically used to perform five different types of tests:

Hematology tests: Used to measure the number and amount of "formed elements" in the blood. Formed elements include red blood cells, white blood cells, and platelets.

Blood chemistry tests: Used to measure chemicals in the blood, such as those produced by the liver, as well as nutritional elements such as vitamins, proteins, fats, and sugar.

Microbiology tests: Used to find certain disease-causing microorganisms in the blood. These can include bacteria, fungi, and parasites.

Serology tests: Used to find antibodies produced by the immune system in response to specific disease-causing microorganisms. The HIV and hepatitis C virus (HCV) antibody tests are examples of serology tests.

HIV-specific tests: Viral load, a measurement of the amount of HIV in a milliliter of blood, is an example of an HIV-specific blood test.

Before going into a more detailed overview of the various blood tests, it's important to understand how the tests are reported. The report sent to your healthcare provider by the laboratory lists the results of your blood tests. It contains a lot of information but is fairly simple to understand. Listed on your lab report are the names of the tests performed, the results of the tests, and the normal **reference ranges** . Your results are typically reported either as an absolute number per specified unit or as a percentage. These results can then be compared with the reference ranges, which reflect average results found in a healthy population.

It's important to understand, however, that a test result outside a given reference range doesn't necessarily mean that you are sick or having a problem. For starters, different labs use different reference ranges. Blood test results can mean many different things and are often analyzed by healthcare providers in the context of other important factors, such as symptoms (fever, pain, or diarrhea, for instance) and the results of a physical examination. Moreover, certain blood test results can vary greatly depending on the time of day blood is taken, whether or not you've eaten before having blood drawn, if you've recently received an immunization, or if you're experiencing another illness – for example, the flu or a herpes outbreak – at the time blood is taken. Also, there is always the chance that the lab result is an error. If you have questions about any of your blood tests, be sure to speak with your healthcare provider.

Hematology Tests

The most commonly used hematology tests to monitor HIV infection are the complete blood count (CBC) and lymphocyte subsets. As the name CBC implies, this test measures the number of red blood cells, white blood cells and platelets. The most commonly followed lymphocyte subsets include CD4 and CD8 cell counts and percentages.

The Complete Blood Count (CBC)

Many of the blood cell counts discussed below – including the red blood cells, white blood cells, platelets, differentials, the CD4 cell count, and the CD8 cell count – are listed on lab reports as the number of cells per cubic millimeter (mm^3 or cu.mm) of blood. Sometimes, lab reports list the number of cells per microliter (mL) of blood. A microliter is a thousandth of a milliliter and is the same as a cubic millimeter.

Red Blood Cell count (RBC): Red blood cells, also called erythrocytes, are responsible for delivering oxygen throughout the body. There are between 3.6 to 6.1 million red blood cells in a single cubic millimeter of blood. Anemia, a condition generally defined as a decreased number of red blood cells, can be caused by certain anti-HIV drugs or be a sign of an underlying illness. Women of child-bearing age may also experience anemia as a result of blood loss from their menstrual periods. One of the most common physical symptoms of anemia is fatigue.

Hematocrit and Hemoglobin: Hematocrit measures the percentage of blood volume that is occupied by RBCs. Generally speaking, red blood cells should make up 40% to 52% of the total blood volume in men and 35% to 46% in women. Hemoglobin is a protein normally found within the RBCs that carries oxygen throughout the body. Normal hemoglobin levels range from 12 to 16 grams per deciliter of blood (g/dL). Healthcare providers usually keep track of the hematocrit and hemoglobin rather than the RBC count itself.

Red blood cell indices: This category includes the mean corpuscular hemoglobin (MCH), the mean corpuscular hemoglobin concentration (MCHC), the mean corpuscular volume (MCV), and the red cell distribution width (RDW). These indices are used to help define anemias.

Platelets: Platelets, also called thrombocytes, are elements in the blood that are necessary for blood to clot. A normal platelet count is between 150,000 to 440,000 per cubic millimeter of blood. Some people with HIV have low platelet counts – called thrombocytopenia – which can be caused by some drugs, as well as by HIV itself.

White Blood Cell count (WBC): White blood cells, also called leukocytes, defend the body against infection. They form in the bone marrow and consist of several different types and sub-types. On average, a healthy adult has between 4,000 and 11,000 white cells per cubic millimeter or microliter of blood. A high WBC count often means that an infection is present in the body, while a low number can mean that a specific disease or drug has impaired the bone marrow's ability to produce new cells. Most people with HIV have WBC counts at the low normal end of the range.

Differential white blood cell count: The differential is a count of the number or percentage of WBCs made up by each major type of WBC. **Neutrophils** (also called polymorphonuclear leukocytes, PMNs, or poly's for short) are WBCs that fight most bacterial infections. The neutrophil count may be lowered by certain medications used by people with HIV, such as Retrovir (AZT) and Cytovene (ganciclovir). If the neutrophil count becomes too low, there is an increased risk of bacterial infections. **Lymphocytes** are the key WBCs involved in immune responses (see CD4 count below) and are often lowered by HIV infection. **Monocytes** play important roles in fighting certain types of infections by maturing into **macrophages** that can ingest bacteria and cellular debris. **Eosinophils** are involved in fighting certain parasitic infections and are sometimes elevated due to allergic reactions. The function of **basophils** is not well understood.

Lymphocyte Subsets

CD4 Count (helper T-cell count): Counting the number of helper T-cells – technically called CD4+ lymphocytes – is perhaps the most important tool used to assess the overall health of the immune system in people with HIV. Helper T-cells, as the name implies, are responsible for signaling other immune system cells to fight an infection in the body. The normal CD4 count is somewhere between 500 and 1500 cells per cubic millimeter.

Without anti-HIV treatment, the average HIV-infected person undergoes a decrease in helper T-cell count of about 50 to 100 cells per cubic millimeter each year. Opportunistic infections such as *Pneumocystis* pneumonia (PCP) typically occur once the helper T-cell count falls below 200. Other infections typically occur when the count is less than 50 to 100. For this reason, medications to prophylax (prevent) certain infections are started once the helper T-cell count falls to certain levels, such as below 200 for PCP prophylaxis. The helper T-cell count also plays a major role in deciding when to start anti-HIV treatment. Currently, the U.S. Department of Health and Human Services (DHHS) recommends anti-HIV drug treatment for all HIV-positive people with helper T-cell counts below 200 and encourages treatment for all HIV-positive people with helper T-cell counts below 350.

CD4 Percentage: In a healthy adult, helper T-cells account for between 32% and 68% of the total number of lymphocytes (which includes B-cells and other types of T-cells). The CD4 percentage is sometimes a more reliable measurement than the CD4 count because it tends to vary less between measurements. For example, one person's CD4 count may vary between 160 and 240 over a period of several months while their CD4 percentage remains constant at, say, 15%. The reason for this is that the CD4 count isn’t actually a direct count of CD4 cells, but rather a calculation based on the results of three other tests (the CD4 percentage, the lymphocyte percentage, and the WBC count), each of which can vary slightly each time it’s measured. Occasionally the CD4 count may be relatively high while the CD4 percentage is low (less than 21%). In this situation, many healthcare providers would consider the immune system to be significantly impaired based on the CD4 percentage.

CD8 count, CD8 percentage, T-cell ratio: CD8 cells, also called suppressor T-cells, play a role in fighting viral infections such as HIV. A healthy adult usually has between 150 and 1,000 CD8 cells per cubic millimeter. In contrast to CD4 cells, people with HIV often have elevated numbers of CD8 cells, the significance of which is not well understood. Lab reports may also list the T-cell ratio, which is the number of CD4 cells divided by the number of CD8 cells. Since the CD4 count is usually lower and the CD8 count higher than normal, the ratio is usually low in people with HIV. A normal T-cell ratio is usually between 0.9 and 6.0. The expected response to effective combination anti-HIV treatment is an increase in CD4 count, a decrease in CD8 count, and an increase in the T-cell ratio.

Blood Chemistry Tests

As with the CBC, healthcare providers will often order blood chemistry tests on a regular basis to monitor your health. The blood chemistry test – also known as the chem screen – measures some of the most important chemicals produced and needed by your body to function properly. While abnormal chem screen test results don't usually mean that HIV disease is progressing, they can sometimes mean that another disease is present in the body or that a specific drug is causing side effects.

A chem screen can involve dozens of different tests, but usually measures between 6 to 24 chemicals. Some of the most important chemical levels in people living with HIV are discussed here:

Liver Enzyme Tests: **ALT** (**SGPT**) and **AST** (**SGOT**) are two important enzymes produced by the liver. The levels of these enzymes in the blood can vary considerably; the normal range of ALT is between 5 and 60 IU/L (international units per liter) and the normal range of AST is between 5 and 43 IU/L. Liver disease (such as viral hepatitis or liver tumors) and excessive alcohol consumption can cause these enzymes levels to increase.

Other liver tests to watch for include **alkaline phosphatase**, **gamma GT (GGT or GGTP)**, **LDH**, **albumin**, and **bilirubin**. It is important that anyone taking antivirals and other medication – especially those broken down by the liver (the protease inhibitors, for example) – watch their liver function tests carefully. The protease inhibitors Crixivan (indinavir) and Reyataz (atazanavir) may cause elevations in bilirubin, which can result in jaundice (yellowing of the skin and whites of the eyes), but is usually harmless if levels don't become too high.

Kidney Tests: **Blood urea nitrogen** (**BUN**) and **creatinine**, both of which always appear on a chem screen report, are important blood values associated with kidney health. Normal BUN levels should be between 8 and 23 milligrams per deciliter of blood (mg/dL); normal creatinine levels should be between 0.7 and 1.3 mg/dL. These tests are very important to watch by people taking drugs that may affect the kidneys, such as Foscavir (foscarnet) and Vistide (cidofovir) for CMV and Viread (tenofovir) for HIV. Other important tests which can be affected by kidney function include **phosphate** and **bicarbonate** (**carbon dioxide**).

Pancreatic Tests: **Amylase**, an enzyme produced by the pancreas to aid in the digestion of carbohydrates is, when elevated, a strong indicator of pancreatic disease (pancreatitis). Pancreatitis, if not properly dealt with, can cause serious illness and even death. Drugs such as Videx/Videx EC (ddI) can cause pancreatitis, which is often reversible once the offending drug is stopped. Amylase is also found in saliva, and elevated blood levels of amylase are sometimes due to leakage from the salivary glands. Further tests can be done to distinguish between these two sources of amylase.

Electrolytes: **Sodium**, **potassium**, and **chloride** are electrolytes. Electrolytes play a crucial role in the operation of cells and the electrical activity of the heart. Sodium levels should be between 136 and 144 milliequivalents per liter of blood (mEq/L); potassium should be between 3.6 and 5.1 mEq/L; and chloride should be between 99 and 108 mEq/L. Very often, a person with HIV who is experiencing severe diarrhea or vomiting will have abnormal electrolyte levels. Medical care is often necessary for someone with electrolyte imbalances.

Nutritional Values: Food products, no matter what they are, take the form of glucose (sugars), proteins, or fats once inside the bloodstream. A balance of each is necessary to fulfill the body's energy needs and to keep all cells, tissues, and organs functioning properly.

Albumin is one of the major types of **protein** made by the liver and its level in the blood reflects both dietary intake of protein and the liver's ability to make proteins. Albumin levels, which are normally between 4 and 5 gm/dL, may be low in persons who are sick. Total protein levels, which are normally between 6.6 and 8.3 gm/dL, are often elevated in people with HIV because of abnormally increased production of antibodies.

Normal **glucose** levels should be between 65 and 125 milligrams per deciliter (mg/dL) of blood. For the most accurate results, it's best to check glucose levels before eating the first meal of the day (known as the fasting glucose level). Sometimes, a healthcare provider may order a post-prandial glucose test: the amount of glucose in the bloodstream two hours after eating a full meal containing sugar. Abnormally high glucose levels, especially fasting glucose levels, is usually a sign of diabetes. Medications like Glucophage (metformin), the "glitazones" Avandia (rosiglitazone) and Actos (pioglitazone), and insulin can be prescribed, along with dietary changes, to help control abnormally high glucose levels.

Normal **triglycerides** should be between 50 and 200 mg/dL. Like glucose levels, it's best to measure triglyceride levels first thing in the morning, before the first meal of the day. High triglyceride levels are associated with pancreatitis and, quite possibly, heart disease. Pancreatitis becomes a concern when the level of triglycerides is in the thousands. It's not clear if a moderately elevated triglyceride level – triglycerides in the mid to high hundreds – is associated with any immediate health risks. Fibric acid derivatives (fibrates), including TriCor (fenofibrate) and Lopid (gemfibrozil), can be prescribed for elevated triglyceride levels. TriCor is less likely to interact with anti-HIV medications than Lopid.

Cholesterol is another type of fat that is commonly measured in the blood. The three most important cholesterol tests to look for on a lab report are the amounts of total cholesterol, LDL cholesterol, and HDL cholesterol. **Total cholesterol** is the total amount of cholesterol in the bloodstream and includes both LDL and HDL cholesterol. The desirable total cholesterol level is anything below 200 milligrams per deciliter (mg/dL) of blood. The **LDL cholesterol** level is the amount of "bad" cholesterol in the bloodstream. The optimal LDL cholesterol level is below 100 mg/dL (the lower the better). LDL cholesterol levels above 160 mg/dL are considered high and increase the risk of cardiovascular disease. The **HDL cholesterol** level reflects the amount of "good" cholesterol in the bloodstream. A normal HDL cholesterol level is between 40 and 59 mg/dL. An HDL cholesterol level below 40 mg/dL can increase the risk of cardiovascular disease, as there isn't enough good cholesterol to help get rid of artery clogging caused by LDL cholesterol. Maintaining higher-than-normal HDL cholesterol levels – meaning an HDL cholesterol level above 60 mg/dL – may help reduce the risk of cardiovascular disease.

Microbiological Tests

Healthcare providers often recommend microbiological tests when an HIV-positive patient has symptoms of a specific infection. For example, a healthcare provider might order a *Mycobacterium avium* microbiology test for a patient experiencing unexplained fever, weight loss, and anemia. To test for this bacteria, the lab will try to grow out, or "culture," *Mycobacterium avium* complex (MAC) in a chemical mixture that contains the patient's blood, other body fluids, or tissue. If the test is positive, the healthcare provider will know to start treating the patient for MAC.

Some microbiological tests require body fluids other than blood. For example, a patient who has symptoms of pneumonia or tuberculosis may need to produce sputum (phlegm) so that microbiological tests can be conducted. Patients who are thought to have an infection in their brain may need to have microbiological tests of their spinal fluid, which requires a procedure called a lumbar puncture or spinal tap. Stool (feces) is used for various microbiological tests as well and is discussed on page 14.

Serologic Tests

Unlike microbiological tests, which look for the presence of a disease-causing microorganism, serologic tests most often look for specific antibodies produced by the immune system. Also unlike microbiology tests, serology tests are extremely useful to determine if someone has been exposed to an infection before they show signs of disease or to indicate if an infection or disease was present some time in the past.

The HIV tests, known as the ELISA and Western blot assays, are both serologic tests. Neither test looks for the presence of HIV, but rather the antibodies produced by the immune system to fight HIV. Antibody testing has remained one of the cheapest, most reliable methods of diagnosing HIV. HIV antibody testing also allows patients to find out their status many years before they get sick, thus allowing them to start medications to treat HIV and prevent opportunistic infections early. A number of HIV-antibody tests are available to healthcare providers and patients, including standard tests requiring blood samples to be sent to laboratories, tests that can be performed on oral samples, tests that can determine the presence of HIV antibodies in 15 to 30 minutes, and home-collection kits with the results available by phone.

The following is a list of additional serologic tests recommended by healthcare providers for their HIV-positive patients:

Toxoplasma Serology: Toxoplasmosis is a serious infection of the brain. Between 15 to 40 percent of people living with HIV have antibodies to *Toxoplasma gondii*, the protozoan responsible for causing toxoplasmosis. If a patient with HIV is positive for Toxoplasma antibodies and has a T-cell count less than 100, he or she will need to take Bactrim or Septra (TMP/SMX) to prevent the infection from causing disease. TMP/SMX is also the antibiotic used to prevent *Pneumocystis* pneumonia (PCP) when the T-cell count is less than 200.

Syphilis Serology: Syphilis (*Treponema pallidum*) is a potentially fatal bacterial infection usually spread through unsafe sexual activity (vaginal, oral, or anal sex without a condom). If detected early and treated, syphilis can be successfully controlled. If left unchecked, it becomes much more difficult to treat and can result in serious disease of the brain and death. It's generally recommended that sexually active adults and teenagers be tested for syphilis antibodies every year.

Serology testing can be used to diagnose syphilis and to determine if the infection has responded to therapy. However, syphilis testing isn't always accurate. It's estimated that between 6 to 10 percent of people with HIV will test falsely positive; a much smaller percentage will test falsely negative. No one is sure why this happens, but it may have something to do with abnormalities in the immune system or the presence of yet another infection.

Hepatitis B and Hepatitis C Serology: Hepatitis B virus (HBV) and Hepatitis C virus (HCV) can both cause liver problems in HIV-positive and -negative people. Even though many people with HIV are also infected with HBV, only a small percentage will actually develop symptoms from the infection. HBV isn't usually fatal, but can cause liver problems in a small percentage of those infected. HCV, on the other hand, can cause serious liver disease in some patients infected with the virus.

Tests for HBV and HCV are both available, but their interpretation can be complicated. People who have hepatitis B surface antigen (HBsAg) present in the blood are either carriers of HBV or have active infection with the virus. People who have recovered from HBV (that is, have cleared the virus from their bodies) and those who have had the HBV vaccine will have hepatitis B surface antibody (HBsAb) present in the blood. In other words, in the case of HBV, having the antibody present means that the person is immune to HBV infection, either from having had it in the past or from having had the vaccine. HIV-positive patients who test HBsAg-positive require additional testing to determine the status of the infection. HIV-positive patients who test HBsAg-negative and HBsAb-negative should talk to their healthcare provider about getting vaccinated against hepatitis B.

The presence of antibodies to HCV in the blood means that a person has HCV infection unless proven otherwise. Tests that are similar to viral load tests for HIV can be done for HCV to establish the presence of the hepatitis C virus. So with HCV, having the antibody usually means that a person is infected with the virus rather than immune to it, like in the case of HBV. There is no vaccine for HCV at this time, and the infection is best avoided by not sharing needles or other drug paraphernalia and by practicing safer sex.

HIV-Specific Tests

Viral Load: Viral load tests – measurements of the amount of HIV per milliliter of blood (copies/mL) – are important tests for HIV-positive people. When used in combination with CD4 count results, viral load is useful in determining when to begin therapy and, more importantly, to determine how well therapy is working.

Don't look for this important test in your basic lab report; viral load tests are ordered separately by your healthcare provider and are sometimes conducted at different laboratories than those that perform CBCs. A viral load report will specify which test was used. Typically, labs use either Amplicor polymerase chain reaction (**PCR**) assays or Quantiplex branched DNA (**bDNA**) assays. Because these tests measure the amount of virus differently, it's recommended that the same test and, ideally, the same laboratory be used each time to get consistent results.

There is no "normal" range of HIV, since the virus isn't normally present in the body. The reference range on a viral load lab report usually lists the lowest amount of virus that the particular assay can detect. For example, the most commonly used version of Amplicor PCR can't accurately detect less than 50 copies of the virus in a millimeter of blood. If HIV can be detected, the results of the lab report will include the number of HIV copies found (10,000 copies/mL, for example). If HIV can't be detected, the virus is said to be "undetectable." This, however, doesn't mean that HIV is no longer present in the body or that the virus can no longer be transmitted to somebody else; less than 5% of HIV in the body is found in the blood. It's also important to keep in mind that PCR and bDNA can't detect very small amounts of HIV that may be present in the blood.

In terms of deciding when and how to treat HIV based on these results, the goal is simple: to keep the level of HIV as low as possible. If viral load doesn't become undetectable, or becomes detectable again after a period of being undetectable, this is usually a sign that treatment isn't working effectively and that it might be necessary to change the drug regimen being used.

Drug Resistance Tests: While viral load tests can help patients and healthcare providers determine whether or not a treatment is effective, drug resistance tests may help determine why a treatment or combination of treatments may not be working. Drug resistance tests may also be useful in choosing treatments.

There are two types of drug resistance tests: genotype and phenotype. **Genotype** tests are really nothing more than careful inspections of the HIV in someone's blood. If HIV doesn't appear to be responding to a drug or combination of drugs, the virus' genetic material (RNA) is examined to look for small changes, called "mutations," in its structure. While some mutations are harmless, others may cause HIV to become less sensitive to a drug designed to stop it from reproducing. Over time, this HIV accumulates additional mutations which prevent it from responding to the drug altogether. Genotype tests look for the key mutations associated with resistance to a particular drug. By finding out which mutations are present, it may be possible for patients and their healthcare providers to figure out which treatments they should start with and, if necessary, which treatments they should switch to.

Unlike genotype testing, **phenotype** testing directly measures the sensitivity of a patient's HIV to particular antiviral drugs. These tests measure the concentration of a drug required to inhibit viral reproduction in the test tube by a defined amount, such as 50% or 95%. This is called IC50 or IC95. IC stands for inhibitory concentration. In other words, a laboratory conducting a phenotype test is trying to determine the amount of drug needed to stop HIV from reproducing. If it only takes a standard amount of the drug to halt viral reproduction – a concentration equal to those used by HIV-positive people – HIV is not resistant to the drug. If higher amounts of the drug are needed to stop HIV from reproducing, HIV is considered to be less sensitive to the drug being tested (the higher the concentration needed, the less sensitive the virus is to the drug being tested). The concentration of drug necessary to inhibit virus replication is expressed in units called nanomoles (nM). For example, if the IC50 of drug-sensitive virus is 100nM and that of the test virus is 400nM, the test virus is considered to be fourfold resistant to the drug being tested. In other words, HIV in the patient is four times less sensitive to the drug. For some drugs, this would be a high-level of resistance. For other drugs, it might mean a low-level of resistance. Phenotype testing is more expensive and takes longer to perform than genotype testing.

In recent years, a lot more information about drug resistance tests has been generated by clinical trials, which means that many healthcare providers are now familiar with how to use them and how to interpret their results. Several studies have demonstrated that using genotype or phenotype testing can help keep viral load undetectable longer than simply reviewing a person's treatment history or switching a regimen based on "common knowledge" about each drug's resistance profile. What's more, drug resistance tests can help figure out which drug in a regimen is no longer working. In other words, it may be possible to switch only one drug instead of all three or four being used in a particular combination.

Therapeutic Drug Monitoring (TDM): At the present time, the doses of medications used to treat HIV are the same for all adults in most cases. For some people, however, it might be necessary to increase or decrease the doses of these drugs. For example, someone experiencing side effects might be able to take a lower dose without compromising the effectiveness of the drug. Similarly, some people, even though they are taking the standard dose, may not have enough of a drug in their bloodstream to keep HIV undetectable, which can lead to drug resistance. This is why researchers are now experimenting with blood tests to check the levels of anti-HIV drugs in the bloodstream, which is better known as therapeutic drug monitoring (TDM).

Drug levels in the bloodstream can vary from person to person for many reasons. Some people metabolize (break down) medications faster, while others metabolize them slower (genetics can play a role here). Someone with a low body weight may have high levels of a drug and someone with a high body weight may have low levels of a drug. Anti-HIV drugs can interact with food, nutritional supplements, and other drugs, which can either increase or decrease the amount of the anti-HIV drugs in the bloodstream. Anti-HIV drug levels can also increase or decrease in HIV-positive women who are pregnant, given hormonal changes and changes in body weight and size. Also, certain diseases that affect the kidneys and liver, such as hepatitis, can have an impact on anti-HIV drug levels in the bloodstream. For all of these – and other – situations, experts are interested in learning more about the usefulness of TDM for people with HIV.

TDM can be used to check levels of protease inhibitors (PIs) and non-nucleoside reverse transcriptase inhibitors (NNRTIs) in the bloodstream. TDM, in its current form, isn't able to check levels of nucleoside reverse transcriptase inhibitors (NRTIs) in the bloodstream. What matters most with NRTIs is the amount of drug inside cells, not the bloodstream, and most TDM tests don't have the ability to measure cellular levels of these drugs.

Because there are a number of lingering questions regarding how best to use TDM, these tests aren't routinely used or available in the United States (TDM is used regularly in many parts of Europe). As of April 2004, four laboratories in the U.S. are providing commercial TDM services – in Buffalo, New York (The University of Buffalo [716/645-3635 ext. 245]); in Cocoa Beach, Florida (TDM Laboratories [312/784 2880]); in Van Nuys, California (POMG Laboratories [818/994-9714]); and in Washington, DC (Children's National Medical Center [202/884-2096]. TDM testing for anti-HIV drugs is expensive and isn't covered by private or public health insurance plans (including AIDS Drug Assistance Programs).

Urine Tests

Urine tests, usually known as urinalysis or urine culture, are most commonly used by healthcare providers to monitor kidney function and to test for infections in the urinary tract.

Various drugs – including cidofovir, pentamidine, foscarnet, and amphotericin B – can cause serious kidney damage. As a result, it's extremely important for patients on these and other potentially toxic drugs to have their blood and urine tested regularly. While looking for changes in a patient's blood levels of BUN and creatinine (discussed on page 6), it will also be important to keep an eye out for **proteinuria** (protein in the urine) and **glycosuria** (glucose in the urine). If significant levels of either develop while someone is taking a drug known to cause kidney problems, the dose of the drug may need to be reduced or stopped altogether. Glycosuria may also be a sign of diabetes.

The presence of red or white blood cells in the urine is usually abnormal and may indicate disease processes such as bladder infection or kidney stones. Blood in the urine isn't usually a cause for alarm for women who are having their periods since blood can sometimes get into the urine specimen during collection. To make sure that urine does not contain blood, it might be necessary for a woman to repeat a urinalysis after her period is over.

Stool Tests

Call it what you will, stool (feces) is an important body substance examined by healthcare providers to check for the presence of disease-causing microorganisms, particularly parasites and bacteria. For the most part, labs use microbiology tests – similar to microbiological blood tests – to determine if disease-causing microorganisms are present.

For an HIV-positive patient with diarrhea, a stool test is often the first step. Labs routinely check for common bacterial and protozoal infections. Very often, these prove to be the cause of the diarrhea and most can be treated relatively easily. If the results of the stool test come back negative, the healthcare provider may need to specifically order stool tests to look for isosporiasis, microsporidiosis, and cryptosporidiosis, three relatively uncommon infections that can cause serious diarrhea in patients with substantially compromised immune systems.

Pap Smears

HIV-positive women may be at an increased risk of developing cervical disease, including cancer. Pap smears are more than 90 percent accurate in determining if cells around or in the cervix are normal or abnormal. HIV-positive women should have a Pap smear every 6 or 12 months. A Pap smear requires a doctor or other trained medical professional to lightly scrape the cervix and its surrounding area with a small spatula. The scraping is applied to a glass slide and sent to a pathology laboratory for examination under the microscope.

Another method of examining the cervix uses a colposcope. A colposcope is a microscope that can examine the cervix carefully for abnormal cell growth and tumors in their very early stages. Both Pap smears and colposcopy examinations can be performed at a healthcare provider's office or clinic.

Some healthcare providers also recommend anal Pap smears and/or anal colposcope to look for abnormal cell growth, including warts and pre-cancerous lesions (dysplasia), inside the anus. Men who have sex with men and women with a history of cervical dysplasia – particularly if they are HIV-positive – are at a higher risk of anal dysplasia caused by human papillomavirus (HPV).

We hope that this booklet has been helpful and will allow you to better understand why laboratory tests are such an important part of your healthcare. However, keep in mind that interpreting laboratory tests can often be a complicated task. Work closely with your provider to interpret test results and to understand just how they could affect your course of treatment. Always feel free to consult your healthcare provider if you have questions about your laboratory report.

Sample Laboratory Report

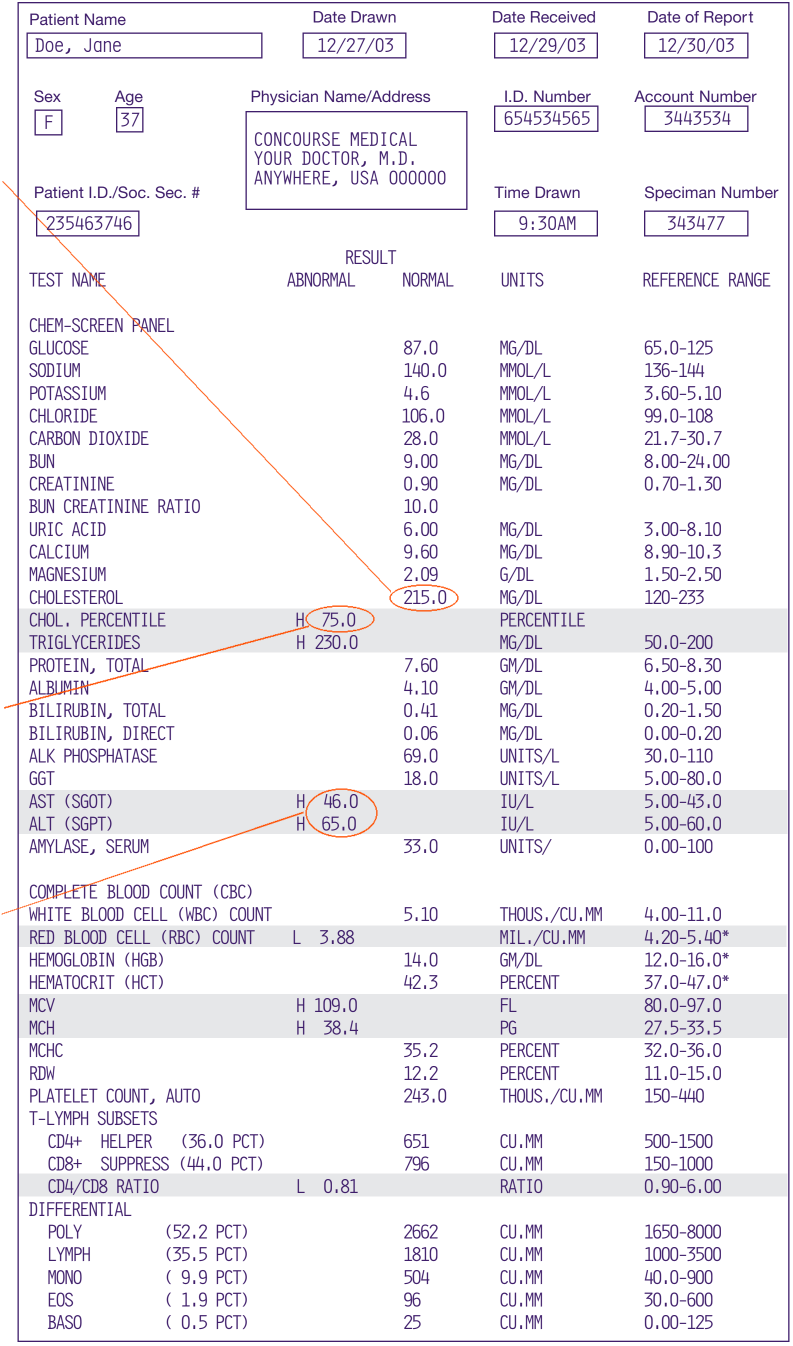
This example of a lab report may or may not look like the one from your healthcare provider's office or clinic. Different labs report results differently, and tests such as chemistry panels may include slightly different groups of tests. However, the general concepts illustrated here should still apply. Consult your healthcare provider if you have questions about your specific lab results.

Ms. Doe's cholesterol is at the upper end of the reference range and is not reported as "abnormal" or "high". Ideally, the cholesterol level should be less than 200 to reduce the risk of heart disease. So Ms. Doe's healthcare provider might suggest further testing (such as a fasting lipid profile to determine the values of certain types of cholesterol), prescribe cholesterol-lowering drugs, and counsel Ms. Doe on how to change her diet. This example shows how a lab value in the "normal" range may sometimes prompt further evaluation.

Ms. Doe's cholesterol value is greater than 75% of women in the same age range. A cholesterol between the 75th and 90th percentiles indicates a moderate risk and greater than 90th percentile a high risk of developing coronary artery disease.

An "H" means the result is higher than the reference range, and an "L" means it is lower. A high or low value is not necessarily a cause for alarm. 5% of healthy people will have values outside of the reference range. Here, Ms. Doe's liver enzymes are minimally elevated. Her healthcare provider might review her medications for drugs that can cause this, order further blood tests, or simply follow the enzyme levels over time.

Clinical Laboratory Report



Patient Name: Doe, Jane
Date Drawn: 12/27/03
Date Received: 12/29/03
Date of Report: 12/30/03

Sex: F
Age: 37

Physician Name/Address:
CONCOURSE MEDICAL
YOUR DOCTOR, M.D.
ANYWHERE, USA 000000

I.D. Number: 654534565
Account Number: 3443534

Patient I.D./Soc. Sec. #: 235463746
Time Drawn: 9:30AM
Speciman Number: 343477

TEST NAME	RESULT		UNITS	REFERENCE RANGE
	ABNORMAL	NORMAL		
CHEM-SCREEN PANEL				
GLUCOSE		87.0	MG/DL	65.0-125
SODIUM		140.0	MMOL/L	136-144
POTASSIUM		4.6	MMOL/L	3.60-5.10
CHLORIDE		106.0	MMOL/L	99.0-108
CARBON DIOXIDE		28.0	MMOL/L	21.7-30.7
BUN		9.00	MG/DL	8.00-24.00
CREATININE		0.90	MG/DL	0.70-1.30
BUN CREATININE RATIO		10.0		
URIC ACID		6.00	MG/DL	3.00-8.10
CALCIUM		9.60	MG/DL	8.90-10.3
MAGNESIUM		2.09	G/DL	1.50-2.50
CHOLESTEROL		215.0	MG/DL	120-233
CHOL. PERCENTILE	H 75.0		PERCENTILE	
TRIGLYCERIDES	H 230.0		MG/DL	50.0-200
PROTEIN, TOTAL		7.60	GM/DL	6.50-8.30
ALBUMIN		4.10	GM/DL	4.00-5.00
BILIRUBIN, TOTAL		0.41	MG/DL	0.20-1.50
BILIRUBIN, DIRECT		0.06	MG/DL	0.00-0.20
ALK PHOSPHATASE		69.0	UNITS/L	30.0-110
GGT		18.0	UNITS/L	5.00-80.0
AST (SGOT)	H 46.0		IU/L	5.00-43.0
ALT (SGPT)	H 65.0		IU/L	5.00-60.0
AMYLASE, SERUM		33.0	UNITS/	0.00-100
COMPLETE BLOOD COUNT (CBC)				
WHITE BLOOD CELL (WBC) COUNT		5.10	THOUS./CU.MM	4.00-11.0
RED BLOOD CELL (RBC) COUNT	L 3.88		MIL./CU.MM	4.20-5.40*
HEMOGLOBIN (HGB)		14.0	GM/DL	12.0-16.0*
HEMATOCRIT (HCT)		42.3	PERCENT	37.0-47.0*
MCV	H 109.0		FL	80.0-97.0
MCH	H 38.4		PG	27.5-33.5
MCHC		35.2	PERCENT	32.0-36.0
RDW		12.2	PERCENT	11.0-15.0
PLATELET COUNT, AUTO		243.0	THOUS./CU.MM	150-440
T-LYMPH SUBSETS				
CD4+ HELPER (36.0 PCT)		651	CU.MM	500-1500
CD8+ SUPPRESS (44.0 PCT)		796	CU.MM	150-1000
CD4/CD8 RATIO	L 0.81		RATIO	0.90-6.00
DIFFERENTIAL				
POLY (52.2 PCT)		2662	CU.MM	1650-8000
LYMPH (35.5 PCT)		1810	CU.MM	1000-3500
MONO (9.9 PCT)		504	CU.MM	40.0-900
EOS (1.9 PCT)		96	CU.MM	30.0-600
BASO (0.5 PCT)		25	CU.MM	0.00-125

*These reference ranges are for females.
The ranges for men are: RBC=4.7—6.10, HGB=14.0—8.0, HCT=42.0—52.0

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ACRIA is an independent, non-profit community-based AIDS research and education organization committed to improving the length and quality of life for people living with HIV/AIDS through medical research and treatment education.

ACRIA conducts a free Treatment Education Program to offer people living with HIV/AIDS the tools and information to make informed treatment decisions. Education program services include: workshops conducted on site at community-based groups throughout the New York City area in English and Spanish; technical assistance trainings for staff of AIDS service organizations; individual treatment counseling, and publications, including our quarterly treatment newsletter, *ACRIA Update*, and brochures in English and Spanish on specific treatment-related topics. ACRIA's National Treatment Education Technical Assistance Program offers ongoing support to help non-medical service providers and community members in various parts of the country acquire the skills and information needed to provide HIV treatment education in their communities.

To learn more about ACRIA's research studies or the Treatment Education Program, please call 212-924-3934. Information about ACRIA's programs and copies of *ACRIA Update* are also available on our web site: www.acria.org.

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BLOOD WORK:
A USEFUL TOOL FOR MONITORING HIV

A PUBLICATION FROM
PROJECT inform
Information, Inspiration and Advocacy for People Living With HIV/AIDS

MAY 2007

Lab tests, or blood work, can give important clues about your overall health and HIV disease. Many of these tests should be done shortly after learning that you're HIV-positive. This will establish a "baseline" measure of your immune health and show how active HIV is. Knowing this information will help you watch for changes in your health over time as well as check the impact of any treatments that you take. Factors such as age, gender, stress, medicines, active infections and others can all affect these test results. Lab results should be considered with these factors in mind.

Understanding your test results may seem difficult at first. However, they can help you take charge of your health and understand why your doctor prescribes certain tests and medicines. With practice over time, it becomes easier to understand these results.

Nearly all lab reports make it simpler to understand test results by including a "normal" range, or high and low values. The results that fall outside normal ranges are likely the most important ones. Those that are above or below normal are often highlighted on your lab report by being bolded, printed in a different color or printed in a different column.

It is your right to have and keep copies of all of your medical records. You can then keep track of your results to look for overall trends. Ask for and keep copies of your lab reports, and make a chart or table of them to note trends or changes. For examples of these charts, read Project Inform's publication, *Personal Tracking Charts*, available at 1-800-822-7422 or *www.projectinform.org*.

WHAT'S INSIDE

Although this publication may seem long and involved, it gives a thorough background to the types of tests that you may need to take over time. There are 5 key points to keep in mind when reading this material:

1

"Normal" test values can differ. For example, lower cholesterol values may be considered normal in an HIV-positive person not on anti-HIV therapy. Be sure to discuss these differences with your doctor. Test results outside the lab's "normal" range may not be cause for alarm.

2

No single test result provides all the answers. Most results need to be considered along with other reports and within the context of your overall health.

3

Different labs can get different results from the same blood sample because they use different methods or equipment. If for some reason you cannot use the same lab, you may need to establish a new baseline at the new lab. In the case of viral load tests, try to have the same type of test (bDNA, PCR, etc.) done each time. If your doctor sends you to the same place to give blood for testing, it's likely the same labs and types of tests are being used. If you move or if you change doctors or health plans, it's a good idea to check and see if your lab has changed as well. If you ever see dramatic changes in your lab results, you might ask your doctor if the lab or type of test have changed.

4

Several things can impact your test results. For example, they can vary due to the time of day your blood is drawn. If possible, try to schedule blood draws at the same time of day every time. If you're sick or have an infection, like a cold or flu, these can also affect your test results. You may want to wait to have lab work done or repeat the tests after you've become well again. Getting a flu shot or other vaccination can also alter lab results, as it stimulates the immune system and can increase how active HIV becomes. HIV levels usually return to "baseline" within a month after a vaccination.

5

A dramatic change in results may be due to testing errors. As for CD4+ cell counts and HIV levels, it's wise to have the test run again and to not make therapy decisions from any one test result.

Complete blood count (CBC)

The CBC is the most common blood test that doctors order. It checks levels of white blood cells, red blood cells and platelets. Generally, even people without symptoms of HIV disease should have a CBC test done at least every 6–12 months. People whose blood work trends are changing may want to have their CBCs done every three months, or more often. People with symptoms of HIV disease should have a CBC every 3–6 months.

CBC testing is done more often in people with symptoms of low red blood cells (*anemia*), low white blood cells (*leukopenia*) and low platelets (*thrombocytopenia*). In each case, if a change occurs that worries you or your doctor, the tests should be done again a few weeks later. Of the tests explained in this publication, the most important ones are the red blood cell, white blood cell and platelet counts.

Platelet count

Platelets are a part of the blood that helps it to clot. They travel to the site of an injury where they "stick" and help develop a clot or scab to stop the bleeding. A normal count is 150,000–440,000. A low count (*thrombocytopenia*) can be caused by HIV infection or by some drugs.

Although a platelet count below 150,000 is considered low, most people are not at risk of uncontrolled bleeding with counts of 50,000 or even lower. However, because platelets are necessary for blood clotting, the chance of major bleeding rises as the platelet count drops. If your platelet count is very low (in the 10,000 range) and/or you have symptoms related to thrombocytopenia, your doctor may want to change your treatment, or may teach you special ways to prevent bleeding.

What do CD4+ cell counts mean?

Above 500 CD4+ cells

- **No unusual conditions likely. Emphasize good health habits and health care maintenance, including vaccines and nutrition.**

200–500 CD4+ cells

- **Increased risk for shingles (zoster), thrush (candida), skin infections, bacterial sinus and lung infections, and TB.**
- **Life-threatening OIs (such as PCP, MAC and CMV) are rare.**
- **Anti-HIV therapy is generally recommended when CD4+ cell counts are in the 200 to 350 range.**

50–200 CD4+ cells

- **Increased risk for PCP and other life-threatening OIs.**
- **Preventive treatment for PCP is indicated.**
- **If counts are below 100, consider preventive treatment for MAC, CMV and invasive fungal infections.**

Below 50 CD4+ cells

- **Increased risk for OIs, including MAC and CMV.**
- **Continue preventive medications.**

Red blood cells: the oxygen carriers

Red Blood Cell (RBC) Count

RBCs are produced in your bone marrow, and they carry oxygen and carbon dioxide through your body. The RBC count is the number of red blood cells found in a small amount of blood called a cubic milliliter, or mL. Normal levels for men range from 4.5–6.1 million/mL, and for women 4.0–5.3 million/mL. It's not uncommon for people with HIV to have RBC values below normal.

Slightly lower values should not be cause for alarm. However, greatly lower numbers can be a sign of anemia. Symptoms include fatigue, shortness of breath, pale skin color and menstrual problems. Anemia can be caused by some medicines and/or illness. Low RBC counts occur with lower hemoglobin and hematocrit levels. Anemia may be treated with iron supplements, erythropoietin (Epogen) or in severe instances, a blood transfusion.

Hemoglobin

Hemoglobin is a RBC protein that carries oxygen through the body. Normal levels in women are 12–16 grams per deciliter (g/dl) and in men 14–18g/dl. It's not uncommon for people with HIV to have lower than normal hemoglobin levels. This is usually due to fewer RBCs produced by the bone marrow because of HIV or some anti-HIV drugs that suppress the marrow.

Hematocrit

The hematocrit is another way to measure RBCs. It is the percentage of blood cells in your body that are red blood cells. Normal values range in men from 40–54% and in women 37–47%. Hematocrit values indicate the thickness of the blood as well as its ability to carry oxygen. A low hematocrit also indicates anemia.

Mean Corpuscular Volume (MCV)

The MCV measures the average size of red blood cells. The average MCV ranges from 80–100 femtoliters (fL). A low MCV shows that cells are smaller than normal. This may be due to an iron deficiency or chronic disease. MCV is generally higher than normal in people taking Retrovir (zidovudine, AZT) or in people with vitamin B12 and folic acid deficiencies.

Mean Corpuscular Hemoglobin (MCH) and Mean Corpuscular Hemoglobin Concentration (MCHC)

These measure the amount and volume of hemoglobin in an average cell. These are less important but help to detect various anemias and leukemias.

White blood cells: infection fighters

White Blood Cell (WBC) Count

WBCs, or leukocytes, help prevent and fight infections. A normal count ranges from 4,000–11,000/mm3 in a healthy adult. A high count may mean that your body is fighting an infection. Low counts may result from taking certain drugs (AZT or ganciclovir), minor viral infections, stress or more serious opportunistic infections such as tuberculosis, histoplasmosis or other infection. Low counts also indicate a greater risk to infection. White Cell Differential: This is a breakdown of the different types of white blood cells as percentages of the total WBC count. The three main groups of WBCs are: 1. lymphocytes, 2. granulocytes and 3. monocytes.

Lymphocytes

Lymphocytes are WBCs that produce antibodies and keep the immune system working. They make up 10–45% of your WBCs. There are two main types: B cells and T cells, and they fight infection in different ways. CD4+ cells—a type of T cell—are cells that HIV uses to infect and/or destroy. You may have heard the term “CD4+ count” or “T cell count.” This refers to a kind of T cell that controls the activity of other immune cells. (See the section “Lymphocyte Subsets” on page 8 for more information.)

Monocytes

These circulate in the blood for about 24 hours. From there they move into tissues and mature into macrophages, which then eat up infection and foreign bodies. (Macrophage means “big eater”.)

Granulocytes (polymorphonuclear cells or PMNs)

These are the most common types of WBCs, making up 55–80% of your total WBC count. PMNs help fight bacterial infections. Specific PMNs include:

- **NEUTROPHILS**
  The most common PMN. They fight infection and play a key role in destroying bacteria and other foreign matters in the body. Some drugs used to treat HIV or HIV-related conditions can decrease neutrophil counts.
- **EOSINOPHILS**
  These PMNs are involved in fighting parasitic infections and allergic reactions. Their numbers will rise during an allergic reaction or asthma attack.
- **BASOPHILS**
  These are very important for releasing histamine. This is the substance that makes you feel congested and miserable during a cold or allergies. However, they help your body heal by making the blood vessels “leakier” so that cells can travel faster to the areas of infection.

Chemistry screen (CHEM-25 OR SMA-25)

A chemistry panel (chem panel, chem screen) tests the levels of 25 chemicals in the blood. It can help determine if your body is working properly. (Other types test 12, 14 or 20 chemicals and are called SMA12, SMA14 and SMA20.) A chem screen should be done once a year in people not taking medications and more often in people who are. Some of the important values follow.

Sodium (Na)

The normal range is 135–145 mEq/liter.

Sodium is a part of table salt and is important for keeping the balance of fluid in your body, nervous system and muscle tissue (including the heart). Too much of it can be a symptom of being dehydrated while too little can be caused by excessive IV fluids or may indicate kidney problems. Eating salty foods will not affect your sodium level as long as you're drinking fluids.

Potassium (K)

The normal range is 3.5–5 mEq/liter.

Potassium is mostly found inside your cells and helps to regulate nerve impulses and heart muscle. A high level may indicate kidney failure and severe injuries. A low level can occur after severe vomiting, diarrhea, long periods without food and in people on high doses of pills to reduce water retention (*diuretics*). Potassium is found in most foods. People who eat a fairly balanced diet will have no problem getting enough of it.

Chloride and Magnesium (Cl and Mg)

The normal range of chloride is 100–106 mEq/liter.
The normal range of magnesium is 1.5–2.0 mEq/liter.

Chloride and Magnesium are two important elements in your blood. Chloride is important for controlling your body's balance of fluid. Magnesium is involved in muscle contractions and processing protein.

Glucose

Normal levels are 75–125mg/dl.

Glucose is sugar, and glucose values are used to check for diabetes. Some drugs may alter glucose levels, such as Pentam (IV pentamidine) or drugs that affect the pancreas. Insulin resistance is one cause of high blood glucose. Insulin resistance occurs when insulin (the hormone that moves sugar into cells) is less effective than usual in your body. This may occur with long-term use of anti-HIV drugs, from HIV itself or from both HIV and the drugs. It is treatable with medications.

Cholesterol and triglycerides

Normal cholesterol levels are 150–250mg/dl. Triglycerides can range from 47–175mg/dl.

Cholesterol and triglyceridesare fatty substances in the body. Their levels help measure the risk for conditions such as heart disease and wasting. Triglycerides often decrease in people with HIV, possibly due to malnutrition or wasting in advanced stages of disease. High cholesterol and triglycerides may occur among people living with HIV for many years. They can also be a side effect of anti-HIV drugs.

Liver Function Tests (LFTs)

LFTs include a number of lab results that help the health of the liver. These include ALT (SGPT), AST (SGOT), LDH, alkaline phosphatase and total bilirubin. Elevated liver enzymes are caused by some medications. It can also be caused by liver disease such as hepatitis B or C, injuries and tumors. Abnormal LFTs are common in 60–70% of people with HIV, but liver failure is unusual. High alkaline phosphatase levels along with normal bilirubin levels can show serious disease and are often seen in people with MAC (Mycobacterium Avium Complex), CMV (cytomegalovirus), histoplasmosis, drug side effects or KS (Kaposi's Sarcoma). Bilirubin, a product of dead red blood cells, is removed through the liver. High bilirubin levels can be a sign of hepatitis (perhaps with a yellow skin color), bile duct obstruction and other liver problems. Some HIV drugs—specifically Reyataz (atazanavir) and Crixivan (indinavir)—can cause high bilirubin levels. However, this may not be a sign of liver problems. If a pregnant woman has high bilirubin, this can harm the unborn child.

Amylase

Normal levels are 25–125 milliunits/mL.

Amylase is secreted by the saliva glands as well as in the pancreas. Elevated levels may be an early sign of inflammation of the pancreas, or pancreatitis. This is a serious side effect of some common medications used to treat HIV and its conditions.

Kidney Function Tests

Two indicators are used to assess kidney function—creatinine and BUN (blood urea nitrogen). High levels of both indicate kidney disease or being dehydrated. High uric acid levels can be a sign of kidney deficiency but may also indicate other conditions like lymphoma or inflammation. Kidney problems in people with HIV can by caused by HIV itself (HIV Associated Nephrotoxicity, HIVAN) and/or may result from drug side effects.

Proteins

Albumin and globulin are the two main types of protein in the blood. High albumin levels indicate dehydration and low levels can signify malnutrition, liver failure or kidney disease. Globulin levels are less important.

Lymphocyte subsets and viral load: specific tests for people with HIV

Lymphocytes are a type of white blood cell. Routine counts provide information about the state of your immune health. Three types of lymphocytes are routinely tested: B cells, T cells (CD4+ and CD8+ cells) and NK cells (natural killer cells). B cells are involved in the production of antibodies. They also deal with infections that are outside cells. CD8+ cells deal with infections that are inside cells. CD4+ cells "help" B cells and CD8+ cells do their jobs.

CD4+ and CD8+ cell counts

CD4+ cells help control the activity of other cells. HIV infects CD4+ cells and makes more copies of itself. Over time, HIV causes a decline in the number of these cells. So getting routine CD4+ cell counts done is the main way to keep track of your immune health.

In HIV-negative people, normal CD4+ cell counts are 500–1,500/mm3 of blood. Normal CD8+ cell counts are 300–800/mm3. In general, people have 2-to-1 ratios of CD4+ to CD8+ cells. So for every two CD4+ cells, an HIV-negative person has one CD8+ cell in their blood. However, in most people living with HIV who are not on anti-HIV therapy, it's common for the normal CD4+/CD8+ ratio to be reversed.

It's also helpful to look at the percentages of CD4+ and CD8+ cells in a blood sample. The CD4+ percentage is the percentage of CD4+ cells in the total lymphocyte count. The normal range is 28–58%. Another helpful measure is the CD4+/CD8+ ratio.

CD4+ cell counts are also the best guide for when to start preventive therapy for opportunistic infections, or OIs. CD4+ cell counts may vary due to many factors, such as the time of day, an active infection, stress or lab variations. Therefore, it's important to look at your CD4+ cell count trends over time and not be alarmed by any one test result. CD4+ cell counts also are used to make decisions on when to start or change therapy.

Viral load tests

Viral load tests measure the amount of HIV in about a teaspoon of blood. They are important for monitoring HIV disease and how well therapy is working. When HIV levels decrease or stay low and stable over time, it's a sign that potent anti-HIV therapy is working. When the levels increase, it's often a sign that a regimen has stopped working.

At first, two tests should be taken about 2–4 weeks apart to establish a baseline level. After that, viral load tests should be done every 3–4 months. People should generally avoid having viral load tests done during an active infection (like a cold), after a vaccination (like flu) or during flare-ups of infections (like a cold sore). These can all cause HIV levels to briefly increase. They usually return to normal within a few weeks after a vaccination or the end of the infection.

A viral load test should also be done 3–4 weeks after starting or changing therapies. To get accurate results and trends over time, it's wise to get the same brand of test done each time at the same lab. The trend of viral loads over time is the most important and not an individual result.

Low, stable and decreasing viral load is considered a good thing. High or increasing levels call for attention as it may point to the failure of a regimen. Viral load below 10,000 copies is generally considered "low." Viral load above 100,000 copies is generally considered "high."

Women may have a "naturally" lower viral load than men, especially in early HIV infection. Therefore, women should be aware that a viral load above 30,000 or even 60,000 might indicate a "high" viral load for them.

People with "undetectable" viral load should remember that it does not mean that their HIV is gone. HIV may actually be there, but just in too small of a quantity to detect.

Resistance tests

HIV can change itself so that anti-HIV drugs do not work as well. This is called drug resistance, and it's one of the most common reasons why therapy fails. There are two different types of resistance tests. Genotypic tests look for changes in the genes of HIV that are linked to drug resistance. Phenotypic tests assess which drugs can stop HIV growing in a lab setting. Several different labs offer these tests.

People who use resistance test results to help make treatment decisions face a better and more sustained reduction in HIV levels than those who make decisions based on their treatment history and viral load results. To accurately test drug resistance, people should have a viral load over 1,000 copies. Otherwise, the results may not be accurate or the test cannot be done.

A replication capacity test measures whether HIV can reproduce and how fast. This is sometimes called viral fitness. The test is usually done along with a resistance test. It is thought to be most useful for people with fewer treatment options who are trying to put the best possible regimen together.

Another test that looks at HIV is called a tropism assay. It looks at which of two common proteins—called CCR5 (R5) and CXCR4 (X4)—HIV uses to enter CD4+ cells. This test will be used for people wanting to block R5 with anti-HIV drugs, like maraviroc. Four results are possible: uses R5 only (*R5 tropic*), uses X4 only (*X4 tropic*), can use either (*dual tropic*), or some combination of the first three (*mixed tropic*).

Other tests that may be done

The following tests are considered routine in people living with HIV, but do not need to be done as often as CD4+ cell counts and viral load tests.

PPD Skin Test and Chest X-ray

A PPD tests the skin to detect an earlier exposure to tuberculosis (TB). If you've been exposed, the PPD causes a bump to appear within several days at the site of the test. A positive or inconclusive PPD is followed up by a chest x-ray and sputum culture to determine active TB disease.

Pap Smear

Women should have a cervical Pap smear done at least once every three years. Women living with HIV should talk about when and how often they should get a Pap test done with their doctors, as they may recommend more regular tests based upon your health and risk factors. If the results are abnormal, follow up with other types of tests may be needed. To take a Pap test, your healthcare provider uses a "Pap stick" or cotton swab to take one or more samples of cells from the cervix and cervical canal. You may feel a slight scraping sensation. The process may be uncomfortable but usually not painful. It may hurt if there is inflammation and sensitivity in the area. For more information about HIV and GYN exams, read Project Inform's publications, *Gynecological Conditions and HIV Disease* and *Positive? How Are You Feeling?*

Anal Pap

This test can be done in the anus to look for damage caused by HPV (human papillomavirus). High rates of anal HPV occur in HIV-positive men and women, including those who do not report having anal intercourse. For this reason it's important that all HIV-positive people have an anal Pap. If the results are abnormal, more tests may be needed.

Hepatitis Serology

As stated before, liver function tests can show hepatitis infection. Other tests can be done to find antibodies to hepatitis B (HBV) and C (HCV)—diseases that affect the liver. These tests should be done after first learning your HIV status, if you have not been tested before. Learn about how to protect yourself from getting HBV and HCV if you have not been exposed to them. There is a vaccine to prevent HBV infection. For more on hepatitis and other liver problems, read Project Inform's publications, *Towards a Healthy Liver*, *Hepatitis and Liver Problems*, and *Hepatitis C*.

Toxoplasmosis Serology

This test may be done to detect antibodies to the toxoplasmosis (toxo) organism. Toxo can cause problems in the brain and central nervous system. A positive test result may help to decide on preventive therapy. The test is usually done when people first find out their HIV status. That way, if they're negative for toxo, they can take precautions to prevent contact with it. For more information, read the publication, *Toxoplasmosis*, available from Project Inform.

www.projectinform.org

Go online around the clock and get connected to treatment information in the privacy of your own home!

Table of common tests and ranges

Each lab typically provides “normal” ranges of values along with the test results. Some labs may differ in the exact ranges of the normal values. Remember to ask your doctor for a copy of your lab report for your own personal records, so that you can track trends of your lab results.

LAB TEST	RANGE OF NORMAL VALUE	UNIT OF MEASUREMENT
Red Blood Cells (RBCs)		
RBC Count	Female: 4.0–5.3. Male: 4.5–6.1.	million cells per cubic millimeter (million/mm^3)
Hemoglobin (HB or HGB)	Female: 12–16. Male: 14–18.	grams per deciliter (g/dL)
Hematocrit (HCT)	Female: 37–47. Male: 42–52.	%
White Blood Cells (WBCs)		
WBC Count	4.3–10.8	thousand cells per cubic millimeter (thousand/mm^3)
Percentage of White Blood Cells		
Basophil %	0–3	%
Eosinophil %	0–7	%
Lymphocyte %	12–50	%
Monocyte %	0–12	%
Neutrophil %	40–73	%
Lymphocyte Subsets		
Total T Lymphocytes (CD3)	990–1,910	cells/mm^3
Total CD4 T-cells	590–1,120	cells/mm^3
Total CD8 T-cells	330–790	cells/mm^3
T-lymphocyte percentage (CD3 %)	61–85	%
CD4 T-cell percentage (CD4 %)	28–58	%
CD8 T-cell percentage (CD8 %)	19–48	%
Platelet Count	**140,000–440,000**	**cells/mm^3**
Liver Function Tests		
ALT (SGPT, Alanine aminotransferase)	0–45	units/liter (u/L)
AST (SGOT, Aspartate aminotransferase)	0–41	u/L
Lactic Dehydrogenase (LDH)	50–115	u/L
Phosphatase (alkaline)	36–125	u/L
Bilirubin (total)	0.1–1.2	mg/dL
Kidney Function Tests		
BUN (Blood Urea Nitrogen)	7–28	mg/dL
Creatinine	0.6–1.5	mg/dL
Uric Acid	3–7	mg/dL
Red Blood Cell Indices		
Mean Corpuscular Hemoglobin (MCH)	27–33	picogram per red blood cell
MCH Concentration (MCHC)	32–36	%
Mean Corpuscular Volume (MCV)	79–100	femtoliters (fL)
Amylase	53–160*	units/liter (u/L)
Calcium (urine)	Female: <250. Male: <300.	mg/day
Cholesterol	120–220	mg/dL
Creatine Phospokinase (CK or CPK)	Female: 10–79. Male: 17–148.	u/L
Glucose	70–125	mg/dL
Magnesium	0.6–1.0	mmol/L
Potassium	3.5–5.3	mmol/L
Sodium	135–146	mmol/L
Protein	6.0–8.3	g/dL
Total Albumin	3.2–5.5	g/dL
Globulin	1.5–3.8	g/dL
Triglycerides	35–160	mg/dL
Urea Nitrogen (see BUN)	7–28	mg/dL

* In our review of lab reports, the normal range for amylase, in particular, varied widely.
As with all these values, it’s important to examine your report to find the normal ranges for your lab.

Interpreting your viral load numbers

Copies HIV RNA	Log Value
100,000,000	8
60,000,000	7.75
30,000,000	7.5
20,000,000	7.25
10,000,000	7
6,000,000	6.75
3,000,000	6.5
2,000,000	6.25
1,000,000	6
600,000	5.75
300,000	5.5
200,000	5.25
100,000	5
60,000	4.75
30,000	4.5
20,000	4.25
10,000	4

Copies HIV RNA	Log Value
6,000	3.75
3,000	3.5
2,000	3.25
1,000	3
600	2.75
300	2.5
200	2.25
100	2
60	1.75
30	1.5
20	1.25
10	1
6	0.75
3	0.5
2	0.25
1	~0

Some other guidelines to help you better understand logs.

If your viral load value decreases by:	Your change is:
1/2 (original divided by 2)	0.3 log
1/3 (original divided by 3)	0.5 log
1/4 (original divided by 4)	0.6 log
1/5 (original divided by 5)	0.7 log
1/10 (original divided by 10)	1.0 log
1/100 (original divided by 100)	2.0 log

If your viral load value increases by:	Your change is:
2 (original times 2)	0.3 log
3 (original times 3)	0.5 log
4 (original times 4)	0.6 log
5 (original times 5)	0.7 log
10 (original times 10)	1.0 log
100 (original times 100)	2.0 log

If you have other questions on logs, please call Project Inform's toll-free National HIV/AIDS Treatment Hotline at 1-800-822-7422.

Yes, I want to help Project Inform remain at the forefront of HIV treatment information!

☐ Enclosed is my Pledge Partner pledge: $_____ per month for _____ months.
($40 or more per month for a year entitles you to Partners In Hope membership)

☐ Enclosed is my donation: ☐ $35 ☐ $50 ☐ $100 ☐ $250 ☐ Other $______

☐ Enclosed is my Partners in Hope donation: ☐ $500 ☐ $1,000 ☐ $2,500 ☐ Other $______

☐ In Honor of / In Memory of: (circle one) ______________________________________

ADDRESS

Mr. / Ms. / Mrs.

Address ☐ This is a new address.

City State Zip

Email Fax

PAYMENT

Circle One: CHECK VISA MasterCard AMERICAN EXPRESS

Credit Card # Exp. Date

Print Name Shown on Card Phone Number

Signature

FACT

Day 4 HIV Case Study: Edie

Edie's CD4+ cells have been dropping and her viral load has been increasing. Her doctor let her know that she would have to start HIV medications. Edie was feeling apprehensive and nervous about the side effects, but she was willing to get started. Her doctor prescribed Atripla that she would take once a day at bedtime. After a week of being on medication, Edie had side effects like strange dreams, felling dizzy, depressed, and emotional.

She shared her medication experience at support group. She was upset and was crying, saying she would not keep taking these meds with these side effects. Participants talked with her, telling her that the side effects would last possibly one to two weeks more, but to hang in there.

Her CD4+ cells are now in the 450's and her viral load is less than 95. She was elated to share her results with the support group after her visit with her doctor.

Questions:

1. What medications are in Atripla?
2. Which medication in Atripla may cause some of the symptoms that Edie is experiencing?
3. What class of medications is Atripla in?
4. There is one thing that makes Atripla different from all the other HIV medications. What is that?
5. What can you say of do to encourage or affirm Edie's decision to start medications?
6. What are two suggestions that you can give to Edie to deal with the side effects?

Day 4 HIV Case Study: Ivy

Ivy, a 39 year-old Caucasian woman who recently returned from Africa is 3 ½ months pregnant. She also has an 8-year-old son. She was diagnosed with HIV in February 2006. Ivy has no income, is living with friends, and has debt from when she left the United States. Ivy says she practiced safe sex and tested regularly; however, she had one incident where the condom broke.

Ivy's CD4+ is 1130 and she has an undetectable viral load. She feels there is no need for her to take medicine because her doctor cannot tell her if there will be any long lasting side effects to her unborn child. Ultimately, Ivy decides not to take meds during her pregnancy or AZT at the time of delivery.

Ivy's baby tested negative at birth. However, Ivy hasn't contacted you (her peer advocate) for seven months, so you don't know how or where Ivy is.

Questions

1. What steps can you (the peer advocate) take to find Ivy?
2. What can you tell Ivy about HIV medications and pregnancy?
3. Which HIV medication(s) should Ivy avoid?
4. At what age can doctors confirm a baby's HIV status?
5. What kinds of concerns may come up for you as the peer advocate? How can you deal with them?

Day 4 HIV Case Study: Linda

Linda has a triple diagnosis: HIV+, paranoid schizophrenia, and alcoholism. Linda was referred to you by her social worker. Linda has given you permission to accompany her to doctor visits and visits to her payee at a mental health clinic. Linda is not taking any medications for either HIV or her mental diagnosis. She refused to take them. Her social worker, doctor, and you have all notice her psychosis as she speaks and rambles.

She lives in a group home, and has a male friend who lives there also. She drinks a couple of half-pints of hard liquor every day.

With her mental health problem in mind, if he does not have sex with her she will accuse him of raping her (not sure what you mean by this??)

You go to visit Linda at her home one day. When you get there, she shows you her lab results. Her CD4+ count is 130 and her viral load is 500,000.

Questions

1. What are three things you can say to Linda when she shows you her lab results?
2. How can you support Linda?
3. What kind of support or resources can you get for yourself?
4. What HIV meds should Linda avoid and why?

Day 4 HIV Case Study: Maria

Maria is a 49-year-old Puerto Rican woman who was diagnosed HIV+ in 1999. She was later diagnosed with Hodgkin's Lymphoma, and is currently in remission. Over the past six to eight months she has been suffering from vomiting, intense and sometimes debilitating headaches, and diarrhea that keeps her home-bound from time to time. Maria's doctor has looked at everything that could be causing these symptoms, from environmental and physical to psychosocial. She is currently taking Sustiva and Combivir daily. Her T-cells continue to be between 700 and 800 and her viral load is undetectable.

Maria is concerned that her doctor cannot figure out why she is getting the headaches and diarrhea. She has recently become a part of the Consumer Group, but her headaches sometimes stop her from attending the meetings and being involved in her community as much as she wants to. Maria is very frustrated and has expressed interest in switching doctors. She is afraid that she might be dying. Maria has lost 1 brother and 2 sisters from HIV.

Questions

1. What are the 3 suggestions that you can give Maria to deal with her symptoms?
2. What are 3 things you can do to support Maria with her concern about her doctor? (List three options.)
3. What can you tell Maria about her fears of death?
4. What class of medications are Sustiva and Combivir?
5. Combivir is a combination of which two medications?
6. List at least two side effects associated with Sustiva and Combivir.

Day 5
Bringing It All Together

1 Setting Up Your First Client Meeting

2 Challenging Case Scenarios

3 Am I Ready to be a Peer?

4 Evaluation

5 Closing Ceremony & Celebration

Meeting with a Client

First Visit with a New Client:

1. ☐ Introduce yourself and the agency you work with.
2. ☐ Explain peer education and who you are.
3. ☐ Explain confidentiality.
4. ☐ Get verbal/written consent from client to begin helping her as a peer.
5. ☐ Ask open-ended questions about the client's needs and listen.
    - ☐ Seek information from client regarding her situation.
    - ☐ Seek information on client's health behaviors (ex. Is she taking mediations, has a doctor, safer sex, drug use, etc)
    - ☐ What are barriers present in client's life?
    - ☐ What are resources available in client's life?
    - ☐ What are client's immediate needs? What can peer do for the client?
6. ☐ Provide emotional support and find a way to connect.
7. ☐ Fill out necessary paperwork.
8. ☐ Set priorities or goals for next meeting.
9. ☐ Set up next meeting time (crucial!).

Tasks for Peer Before Next Visit with Your Client:

1. ☐ Search for appropriate referrals for client's needs.
2. ☐ Communicate with referral source and coordinate services if necessary.
3. ☐ Follow-up with the client regarding referral.

At the Next Meeting with Your Client:

1. ☐ Check-in with client regarding referrals and last meeting.
2. ☐ Follow through with support and addressing needs.

Things to Remember:

Recognize own need for support from supervisors, co-workers and others.
Recognize your need for self-care and personal reflection.
You may not follow these steps in this order but make sure to cover ALL the steps.

Sample Peer Contact Form

Client Code: ________ Peer Code: ________ Date of Contact: ___ /___/___

Description of the contact *Please check the appropriate item*

Who initiated contact?
- ☐ Client
- ☐ Peer
- ☐ Other individual

Life Stressors Addressed:
- ☐ None
- ☐ Health
- ☐ Anxious/depressed/lonely
- ☐ Benefits/Insurance
- ☐ Problems with partner/kids
- ☐ Money
- ☐ Housing
- ☐ Family's Health
- ☐ Death of family/friend
- ☐ Legal problems
- ☐ Any accident
- ☐ Isolation
- ☐ Immigration issues
- ☐ Other (Explain)

____

____

____

Where?
- ☐ Unsuccessful contact
- ☐ Phone contact
- ☐ ID clinic
- ☐ Street
- ☐ Hospital wards
- ☐ Drug program
- ☐ Client's home
- ☐ Other location

Type of contact:
- ☐ Face to face
- ☐ Phone
- ☐ Mail
- ☐ Left message only
- ☐ Phone, but no answer
- ☐ Other

Who was contacted?
- ☐ Client
- ☐ Family/Friends
- ☐ Case Worker
- ☐ Medical
- ☐ Other
- ☐ Not applicable

Referrals made:
- ☐ None
- ☐ Case Manager
- ☐ Health Educator
- ☐ Medical Provider
- ☐ Support group
- ☐ Mental Health
- ☐ Supplies (food, baby, etc.)
- ☐ Other ______________

Incentive Provided:
- ☐ Yes
- ☐ No

Did you talk about adherence?
- ☐ Yes
- ☐ No

Did the client say she/he is adherent?
- ☐ Yes
- ☐ No

Did you discuss T-cells or viral load?
- ☐ Yes
- ☐ No

Did the client mention missed days or med holidays?
- ☐ Yes
- ☐ No

If the client has missed meds, about how many days?

________days

Notes and next steps:

Next Visit: ____/____/____

Sample Confidentiality Agreement

As a client of ____________ and a participant in the ___________ Peer Advocate Program, you can expect to receive peer support that is professional, respectful, and trustworthy.

Professional peer support means that you can expect your Peer Advocate to maintain a confidential relationship with you. She will not share information about you with anyone outside of WORLD without your consent. There is, however, an exception to this rule. Confidentiality may be waived if your safety or the safety of someone close to you is in question. If questions of safety arise, she will contact either your FCN case manager or another professional for assistance. In most cases, the peer advocate will let you know if she plans to speak with your case manager.

Respectful peer support means that you can expect your Peer Advocate to honor your privacy. You may choose to share many personal topics with your Peer Advocate; however, you need only to share personal information if and when you feel comfortable. At times, she may offer advice or suggestions, but she will keep in mind that you know what is best for you.

Trustworthy peer support means that you can expect your Peer Advocate to follow through with the support that she offers to you. She will be on time and listen to you during your time together. Time spent together may include peer counseling, accompaniment to doctor visits, visits to your home, phone check-ins, and other activities as decided upon by you and your Peer Advocate.

<u>As a client of our organization, you are encouraged to speak with your Peer Advocate if you have questions, concerns or complaints about the program</u>.

By signing below, you and your Peer Advocate are agreeing to the above guidelines. You also are indicating your understanding of the standards inherent in the peer advocate/client relationship:

Client:

Print Name ______________________________

Signature _______________________________ Date __________

Peer Advocate:

Print Name ______________________________

Signature _______________________________ Date __________

Peer Role:

You are a peer advocate. A woman who has been diagnosed with HIV for several years is referred to you by a social worker. The social worker told you that the client is doing okay, but she is new to the area and feeling isolated.

Client Role:

you are stable on medication. You just moved to the area and you told your new social worker that you are lonely. She referred you to what she called a "peer advocate." You are unsure what a peer advocate is, but you are open to anything.

Challenging Situation Case Scenarios

Scenario 1

You have a long term client who did not show up for a couple of meetings. When you went to her house at 1pm in the afternoon, she was just getting out of bed. She tells you that she lost her job and that she and her baby's father broke up about a month ago. She starts crying and confides that she is having a lot of trouble "getting through the day". She tells you she is completely exhausted, is sleeping and crying a lot, and drinking almost every day. She thought about calling you earlier to let you know what was happening, but "couldn't get it together" and then "felt like it was too late". She also tells you that she was not remembering her medication and knew that skipping was not good, so she stopped.

Discussion Questions:

1. What are some pressing concerns for your client?
2. List at least three open-ended questions you might ask the client to gather information about her situation.
3. What thoughts, concerns, or feelings might come up for your clients?
4. What thoughts, concerns, or feeling might come up for you as a peer?
5. What support and/or information could you offer her?
6. What action steps might your client, you or both of you consider taking? List 3-5.

Challenging Situation Case Scenarios

Scenario 2

You have a client who went back to work after several years out of the workforce due to HIV/AIDS related illnesses. Your client was very excited to get the position. In your regular meeting with her she reports that she has been having increasing difficulties with her job. The position she has is in the hotel food service industry and one of the most important benefits of the job in her perspective is that she has medical and dental benefits for herself and her children. During one of the hotel's largest event of the year a manager raised her voice at the staff because she was not satisfied with how fast they were working. Your client reports that she had to go to the hospital because she started having trouble breathing, became dizzy and her chest hurt. The doctor told her she had a panic attack. She has not disclosed her status at work and now has started having difficulty sleeping and concentrating because she thinks work might ask her questions about what happened and/or find out that she has HIV and "find a reason" to fire her.

Discussion Questions:

1. What are some pressing concerns for your client?
2. List at least three open-ended questions you might ask the client to gather information about her situation.
3. What thoughts, concerns, or feelings might come up for your clients?
4. What thoughts, concerns, or feeling might come up for you as a peer?
5. What support and/or information could you offer her?
6. What action steps might your client, you or both of you consider taking? List 3-5.

Challenging Situation Case Scenarios

Scenario 3

You have a client who has been having a difficult time for the past three months. She was in a serious car accident where one of the passengers, a niece, was killed and her sister severely injured. The first couple of weeks after the accident, she would show up to groups but not speak. A month after the accident she talked to her doctor about difficulty sleeping and feeling extremely sad. She was prescribed medication to help her sleep and anti-depressants. She stopped coming to the agency's support groups and missed a meeting with you. You called and when you spoke with her, she said that she was having difficulty coming to the agency because she couldn't get into a car without thinking about the accident and seeing it over and over in her head. She said she finished the medication the doctor gave her, but had not refilled the prescription. She had not refilled any prescription – including her HIV medications – this month. She was having trouble sleeping still as she had nightmares almost every night about the accident. She did not want to ask her family for help as her sister was having a very difficult time and she did not want to bother them.

Discussion Questions:

1. What are some pressing concerns for your client?
2. List at least three open-ended questions you might ask the client to gather information about her situation.
3. What thoughts, concerns, or feelings might come up for your clients?
4. What thoughts, concerns, or feeling might come up for you as a peer?
5. What support and/or information could you offer her?
6. What action steps might your client, you or both of you consider taking? List 3-5.

Challenging Situation Case Scenarios

Scenario 4

You have a client who you know has a bipolar diagnosis and takes mood stabilizing medication. She has a history of alcohol and substance abuse. Your experience with her mood disorder up until now has been depression related. While you know that she was hospitalized after a couple of incidents, you only had contact with her after she had stabilized on medications. Over the past two weeks, you have noticed that she had been calling you with increasing frequency. She has seemed upbeat, but you noticed that on the last two calls she has begun speaking more and more quickly. She called and left you a message that she needs to speak with you immediately. When you return her call she asks you if you can loan her some money for a couple of days. She knows the upcoming winning lottery numbers for California and New York and she is willing to share the winnings with you if you can loan her some money to buy tickets. She is laughing but when you tell her you are not allowed to loan her money, her voice changes and she becomes loud and agitated sounding. She says she is not asking you for money – only a loan, she is silent for a few seconds, you hear her begin to cry and then she hangs up. Your phone rings 10 minutes later and when you answer the phone it is her again.

Discussion Questions:

1. What are some pressing concerns for your client?
2. List at least three open-ended questions you might ask the client to gather information about her situation.
3. What thoughts, concerns, or feelings might come up for your clients?
4. What thoughts, concerns, or feeling might come up for you as a peer?
5. What support and/or information could you offer her?
6. What action steps might your client, you or both of you consider taking? List 3-5.

Sample Client File
(From WORLD)

WORLD
Women Organized to Respond to Life Threatening Disease

Cover Sheet for FCN Client File

Date file opened: ____ / ____ / ____ Date file closed: ____ / ____ / ____

Peer Advocate's Name ________________________________

Client ID: ___ ___ ___ ___ - ___ ___ ___ ___

Paperwork Time Line and Check Off

First or Second Meeting (phone or in person):

___ FCN Encounter Form (1st mtg)

___ WORLD Intake Form

___ Consent for Release

___ Referral/Follow Up (if needed)

Third or Fourth Meeting (in person):

___ Care Plan (Goal #1)

___ Referral/Follow Up (if needed)

Please list all FCN agencies/providers that are being utilized by this client:

____

____

____

____

Please list non-FCN community agencies being utilized by this client:

____

____

____

____

Peer Advocate Signature________________________________

FAMILY CARE NETWORK

WORLD Newly Enrolled Client Data Intake

Peer Advocate/Client Navigator Assigned to Client: ______________________________

☐ **Peer Advocacy** ☐ **LINCs** ☐ **Retreat**

Client Identifier **Date of Birth** **Zip Code of Residence**

___ ___ ___ ___SS# ___ ___ ___ ___ _____/_____/_____ ________________

First 2 letters first name, first 2 letters last name, last 4 digits SS#
(if no SS#, four digits for month and day of birth)

Month / Day / Year

Gender ☐ Female ☐ Male ☐ Transgender

Start Date of Service by WORLD: _____/_____/_____
Month / Day / Year

Is Client a Parent (w/child under 18)? ☐ Yes ☐ No

Enrolled at Which Primary Care Site?
☐ Children's Hospital Oakland ☐ EBAC ☐ Highland Hospital ☐ La Clinica de la Raza ☐ Other ________________

Consent Form Signed? ☐ Yes ☐ No If Yes, which agencies was consent granted? ☐ All agencies granted consent.
Only the following checked agencies granted consent:

☐ Children's Hospital Oakland
☐ East Bay AIDS Center
☐ East Bay Community Law Center
☐ East Bay Community Recovery Project
☐ Hawkins Center
☐ Highland Hospital
☐ La Clinica de la Raza
☐ Circle of Care
☐ W.O.R.L.D.

Other Enrolled Family Members (*First 2 letters of first name, first 2 letters of last name & last 4 digits SS#)*

1) ___ ___ ___ ___SS# ___ ___ ___ ___ 2) ___ ___ ___ ___SS# ___ ___ ___ ___

Ethnicity
☐ Black or African American
☐ Asian/Pacific Islander
☐ Latino/Hispanic
☐ Native Am, Alaskan/Aleutian/Eskimo
☐ Caucasian
☐ Other______________
☐ Unknown

HIV Exposure Category
☐ Heterosexual contact
☐ Injection drug use, gay/bisexual
☐ Hemophiliac
☐ Gay/bisexual male contact
☐ Injection drug use, heterosexual
☐ Receipt of blood transfusion
☐ Injection drug user
☐ Not identified
☐ Perinatal Transmission

Currently pregnant? ☐ Yes ☐ No

HIV Status: ☐ Unknown/not tested ☐ HIV negative ☐ HIV+, disease status known ☐ HIV+, disease status unknown

Primary Caregiver
☐ Self
☐ Spouse/partner
☐ Foster parent
☐ One or both parents (biologic, adoptive, or step)
☐ Other adult (sibling, other relative, friend)
☐ Grandparent (non foster parent)
☐ Professional caregiver
☐ Other ____________________

Housing
☐ Permanent housing (includes apts, houses, foster and boarding homes, long-term residences, as long as not time-limited)
☐ Non-permanent (homeless, transient/temporary housing)
☐ Institution (group homes, treatment programs, hospitals, nursing homes, hospice, correctional facilities)
☐ Other ______________________ ☐ Unknown

Services Provided
☐ Clinical Trials Education
Outings and Recreation
☐ Housing Support
☐ Peer Support
☐ Information and Referral
☐ Support Groups
☐ Logistical Support (transpo, babysitting)
☐ Other____________________________

Comments ____

FAMILY CARE NETWORK

CONSENT FORM

Introduction: The Family Care Network ("FCN") is a group of medical and social service providers to people with HIV. To best serve clients and patients, the FCN and its affiliated agencies and staff may need to share information about them. The information will be shared for the sole purpose of helping clients and patients with the matter(s) for which they have sought FCN assistance.

Authorization: I hereby authorize the below-initialed Family Care Network agencies to share information with each other about me, including, if any, the following: **1) my HIV test result information regarding my HIV condition, 2) my mental health care, 3) my substance use care, and 4) any other information as may be necessary to assist me.** *I understand that I may limit or refuse to authorize such information-sharing, but that this may prevent the FCN from best serving me.*

This authorization will remain in effect unless changed by me in writing. Photocopies or facsimiles of this authorization shall be as valid as the original.

Name ____________________ Date of Birth ____________________ Social Security Number ____________________

Signature ____________________ Today's Date ____________________

TO BE COMPLETED BY FCN CLIENT

Initial either:

Yes	**No**	**Family Care Network Agency**
________	________	Children's Hospital Oakland (medical)
________	________	East Bay AIDS Center (medical)
________	________	East Bay Community Law Center (legal)
________	________	East Bay Community Recovery Project (counseling & support groups)
________	________	14th Street Clinic (methadone maintenance)
________	________	Hawkins Center (legal)
________	________	Alameda Co. Medical Ctr. at Highland (medical)
________	________	PediatriCare (counseling & support groups)
________	________	W.O.R.L.D. (peer advocacy)
________	________	La Clinica De La Raza (medical)
________	________	Other (specify):____________________
________	________	Other (specify):____________________

W O R L D

Client Intake Form

Client's ID ___ ___ ___ ___ - ___ ___ ___ ___

Peer Advocate ______________________________

Date of Intake ______________________________

Referred by ______________________________
(Utilize FCN referral/follow up form)

Address ______________________________

____

Phone(s) ______________________________

____

How can I find you? ______________________________

____

If you are providing a contact name and phone number, does this person know you have HIV?

____

Do you want to receive WORLD's newsletter by mail? ____

Age __________ Ethnicity __________ M F

Family/living situation:

Peer Advocate's Signature ______________________________

MEDICAL INFORMATION:

Date of diagnosis:

When/how infected:

CD4+ / date *(see back for log)*:

Viral load / date *(see back for log)*:

Medical Provider:

Social Worker:

Medications *(see back for log)*:

Side effects:

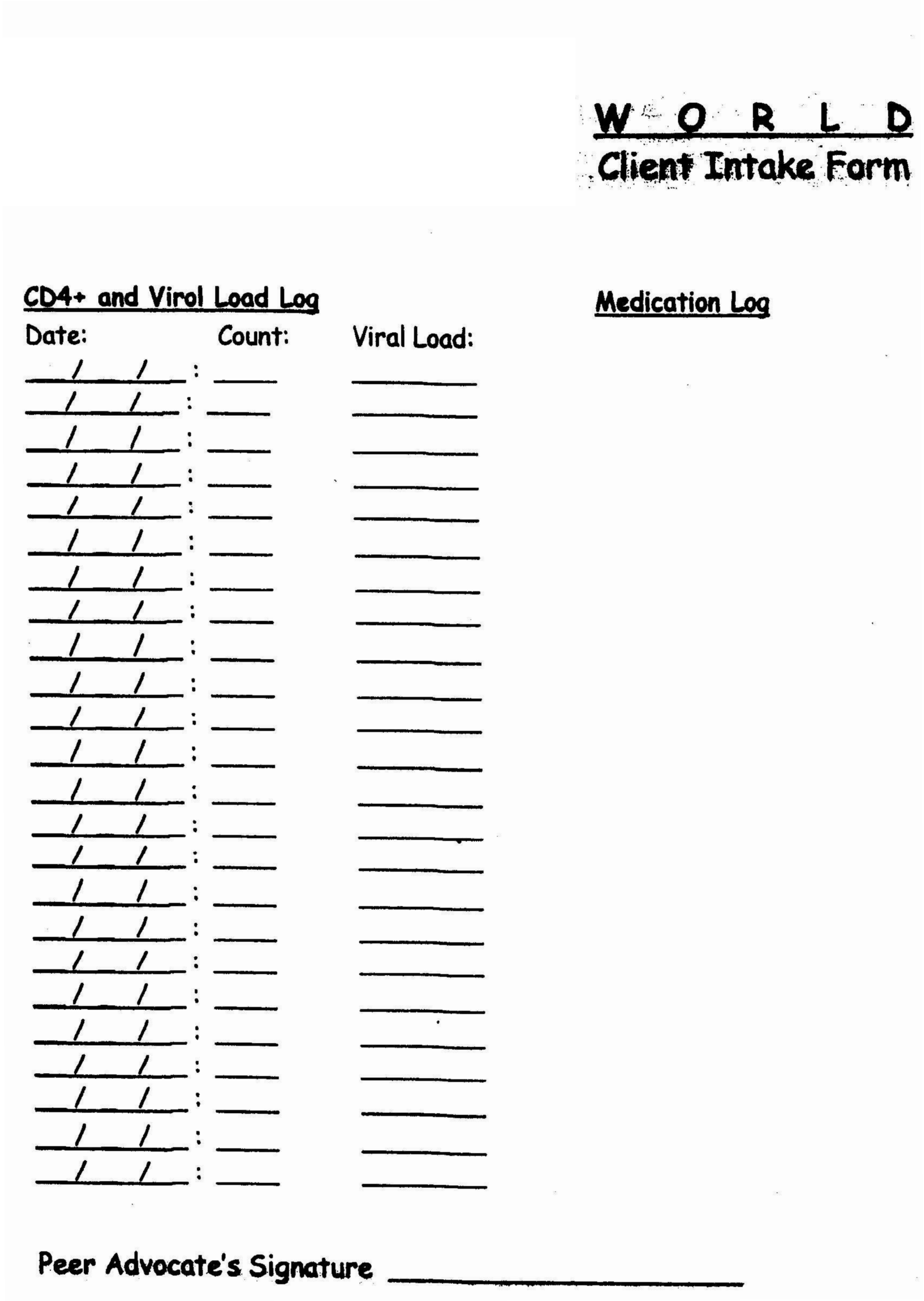
Adherence issues:

Dates to remember:

Care plan completed?

Termination of Services Date:

Reason for Termination of Services:



W O R L D

Client Intake Form

CD4+ and Virol Load Log

Date:	Count:	Viral Load:
___/___/___ :	______	__________
___/___/___ :	______	__________
___/___/___ :	______	__________
___/___/___ :	______	__________
___/___/___ :	______	__________
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___/___/___ :	______	__________
___/___/___ :	______	__________
___/___/___ :	______	__________

Medication Log

Peer Advocate's Signature ______________________

W O R L D

Peer Advocate Plan

Client's ID ___ ___ ___ ___ - ___ ___ ___ ___

Peer Advocate ______________________________

Case Manager/other ______________________________

Today's Date ______________ Target Date ______________

***Peer Advocates*: Please obtain the following information from the *Case Manager* or other referring party.**

Please check all areas of concern that apply:

__Recently Diagnosed
__Transportation
__Adherence
__Housing
__Legal/Immigration
__Mental Health
__Depression/Isolation
__Grief
__Alcohol Use
__Drug Use
__Domestic Violence
__Pregnancy
__Parenting
__Disclosure
__Relationships
__Other: ______________

I. What are the client's top three strengths?

1) ____

2) ____

3) ____

II. What is the treatment/health status of this client?

How can a peer advocate be of assistance in this area?

III. Please describe the client's relationships to her providers:

IV. Please describe the client's living situation and social support system:

Peer Advocate's Signature ______________________ Program Manager's Signature ______________________

W O R L D

Peer Advocate Plan

***Peer Advocates*: Please fill out the remainder of the plan either with the Case Manager or on your own and review with the Program Manager.**

ACTION PLAN:

I. Where will you meet with this client? Please circle all that apply:

WORLD Clinic Phone Other

If other, please explain:

II. How often will you meet/speak with client?

III. List your primary goal(s) with this client:

1) ______________________________

____

2) ______________________________

____

3) ______________________________

____

V. What types of practical support does the client need from a peer advocate?

V. What other types of support does the client need from a peer advocate? Please be specific.

VI. What other WORLD programs might be appropriate?

VII. How will the peer advocate and case manager coordinate care (i.e. weekly meetings/phone conversations)?

Peer Advocate's Signature ____________________ Program Manager's Signature ____________________

My Action Plan Worksheet

How confident do you feel about each of these?	Not at all confident	Slightly confident	Pretty confident	Very confident
Help a client decide to reduce their drug use				
Discuss how to have safer sex with a client				
Help a client understand how HIV medications can improve their health				
Help a client talk openly with his or her doctor.				
Go with a client to health care or social service appointment				
Provide emotional support to a client				
Talk with a client about a behavior change that impacts their health				
Help a client find or choose HIV services				
Help a client find or choose social or support services				
Help a client make choices about disclosing HIV status				
Help a client to take HIV medications correctly				
Set clear boundaries with clients				
Help a client understand what confidentiality means				
Other:				

Am I Ready To Be A Peer Advocate?

In the next 6 months, I plan to do the following 3 things (steps) to either improve on my work as a peer educator or to start working as a peer educator:

1. ____
2. ____
3. ____

To be a stronger peer, I want to work on …

I want to work on these issues because …

Some challenges I may face in working on this is…

I'll get support from or find resources to address these challenges from …

I'll reward myself by …

My 3 biggest strengths are…

15 Steps to Starting a Support Group

1. Keep your meeting at the same place and at the same time during the beginning weeks. Have your meeting even if no outside guests show up. Sometimes it will take a few weeks for you to start getting participants on a regular basis.
2. Create flyer about your group and post at clinics, other agencies, churches, supermarket, etc.
3. Make phone calls to interested participants.
4. Search for volunteers to lead your support group.
5. Make a welcome kit for new participants: include a confidentiality agreement, contact sheet, fact sheet about HIV, and an outline of the general format of group meetings.
6. Make a sign-in sheet, and have participants sign it at every meeting.
7. Create group agreements on the first day of group and post the agreements at every session.
8. Have different topics available for each group meeting.
9. Provide incentives if possible.
10. Conduct a needs assessment every six months.
11. Providing food is very important; if you don't have money for food, then do a pot-luck style, or see if there are near-by restaurants willing to donate.
12. Choose a point person for the support group - someone who doesn't mind sharing their contact information or screening new participants.
13. Create a crisis plan in case your participants have serious issues going on in their lives.
14. Make a list of possible outside speakers for group meetings
15. Give everyone a contact sheet with names and phone numbers of participants who do not mind sharing their information with group.

Tips:

- Observe time limits. Start on time and end on time so that members feel you are reliable. If they should have babysitters, they will be able to work with them easier.
- Be up front if no child care is available, let members know ahead of time if children are welcome and if not, don't make exceptions.
- Be prepared to have you or your co-leaders do most of the speaking at the first few meetings until your members begin to feel comfortable with each other.
- Free space can sometimes be found at the local school, churches, non-profit and social agencies or at member's homes.
- Place chairs in a circle and close enough that all members can hear.

Tips For Writing an Effective Resume

It isn’t important to follow the sample resume exactly. What is more important is that you **represent your strengths** effectively. Follow these quick tips to make sure that your potential employer understands why you are a great candidate for the job!

1. **List your most important experiences closest to the top of the resume.** For example, if you haven’t had a job or any education recently, put the “skills” section first. If you just took a continuing education or vocational class, list your education first.

2. **Don’t hold back!** Make sure you list any experience that you have had that will make you better at the job you hope to get. Your resume is NOT limited to past jobs or formal college degrees! Include volunteer positions, certifications, language abilities, and any other important skills, training, or work experience.

3. When listing your experiences, **use action words** to describe your responsibilities at jobs and volunteer positions. Think about the specifics of important tasks you performed. Don’t just describe your achievements by saying, “helped HIV positive women.” Instead, say “coordinated weekly support group of 15 women aimed at building a local support network of positive women” or “motivated 4 HIV positive clients, through weekly meetings, to seek support services and medical treatment.”

   The best way to write an experience section is to brainstorm a list of accomplishments—in detail—that you had in each job, and then select one or two that best illustrate your skill set to include on your resume.

4. **Tailor your resume to fit each job that you are applying to.** When you first sit down to write a resume, include every experience that you think might help you get ANY job. But when you actually apply, **look carefully at the job description** and include experiences and skills that fit the position. For example, if you are applying for a job as a peer advocate, your skill section should include skills like: “good listener, ability to work on a team, knowledge of local HIV support services, training experience, etc.” If you are applying to an office job, your skill set will be different, including instead, “computer skills, organizational skills, writing and editing ability, etc.”

   Think carefully about what skills you bring to the table, and list them thoroughly.

5. **Proofread your resume!** And then have someone else proofread it! Your resume is an example of your writing ability and your work ethic; if it looks messy, has misspellings or grammatical errors, employers get a bad first impression.

If you are interested in a full step-by-step guide for writing resumes and cover letters, get in touch with us at the Center for Health Training (510.835.3700 x115 or x119) and we will send one to you!

Sample Cover Letter

Your Name Here
Address: 555 Main Street, Apt 2
San Francisco, CA 94105
Phone: 415.555.8000
Email: firstname_lastname@yahoo.com

Today's Date

Name of Contact
Title
Name of Organization
Address
City, State, Zip

Dear Mr./Ms. [Last Name of Contact],

I am responding to your posting for a peer advocate (or job title you are applying for) in this Sunday's Chronicle with excitement, as I recently completed a peer advocacy training program and, as an HIV positive woman, am eager to help build a supportive community for HIV positive women in the area. I have included my resume for your consideration.

I think that you will find that my skills and interests match well with [name of organization here]. At W.O.R.L.D. (Women Organized to Respond to Life Threatening Disease), I have been using my status as a positive woman to mentor other recently diagnosed women. I have provided emotional support and education for women whose experience I understand personally, and have also gained experience and knowledge of local support services available for women with HIV. I am dedicated to helping women learn more about and accept their HIV positive status, and I look forward to having the opportunity to continue this work with your organization.

I am excited for the possibility of working with [name of organization here]! Please feel free to contact me at 415-555-8000 at your earliest convenience. Thank you so much for your consideration.

Sincerely,

Your Name Here

SAMPLE RESUME

Your Name
Address
City, State Zip Code
Phone Number
Email address

OBJECTIVE OR INTERESTS:

One to two lines about what are your interests in the field and what type of jobs you are looking for.

PAST EMPLOYMENT:

Title of Position
Year Started-Present or date ended, City, State

Description of Position: tasks you performed or job description.

EDUCATION:

College or Classes you have attended

Trainings relating to HIV and peer education (Lotus Training)

SKILLS:

For example: computer skills, group facilitation, public speaking etc.

VOLUNTEER ACTIVITIES:

Here you can list where you have volunteered: Planning Councils, advocacy, outreach, public speaking gigs, and board membership.

Additional Resources

Domestic Violence...What is It?

In an abusive relationship, the abuser may use a number of tactics other than physical violence in order to maintain power and control over his or her partner:

Emotional and Verbal Abuse: Survivors of domestic violence recount stories of put-downs, public humiliation, name-calling, mind games and manipulation by their partners. Many say that the emotional abuse they have suffered has left the deepest scars.

Isolation: It is common for an abuser to be extremely jealous, and insist that the victim not see her friends or family members. The resulting feeling of isolation may then be increased for the victim if she loses her job as a result of absenteeism or decreased productivity (which are often associated with people who are experiencing domestic violence).

Threats and Intimidation: Threats — including threats of violence, suicide, or of taking away the children — are a very common tactic employed by the batterer.

The existence of emotional and verbal abuse, attempts to isolate, and threats and intimidation within a relationship may be an indication that physical abuse is to follow. Even if they are not accompanied by physical abuse, the effect of these incidents must not be minimized. Many of the resources listed in this book have information available for people who are involved with an emotionally abusive intimate partner.

What Can You Say to a Victim?

- I'm afraid for your safety.
- I'm afraid for the safety of your children.
- It will only get worse.
- We're here for you when you are ready or when you are able to leave.
- You deserve better than this.
- Let's figure out a safety plan for you.

Adapted from: Sarah Buel, Esq., in "Courts and Communities: Confronting Violence in the Family," Conference Highlights, National Council of Juvenile and Family Court Judges, 1994.

Creating Safety Plan?

Every individual in an abusive relationship needs a safety plan. Shelters and crisis counselors have been urging safety plans for years, and police departments, victim services, hospitals, and courts have adopted this strategy. Safety plans should be individualized—for example, taking account of age, marital status, whether children are involved, geographic location, and resources available — but still contain common elements.
National Domestic Violence Hotline - 1-800-799-SAFE

When creating a safety plan:

- **Think about all possible escape routes.** Doors, first-floor windows, basement exits, elevators, stairwells. Rehearse if possible.
- **Choose a place to go.** To the home of a friend or relative who will offer unconditional support, or a motel or hotel, or a shelter - most importantly somewhere you will feel safe.
- **Pack a survival kit:**
  - ☐ identification
  - ☐ birth certificates for you and your children
  - ☐ social security cards
  - ☐ school and medical records
  - ☐ money, bankbooks, credit cards
  - ☐ keys--house/car/office
  - ☐ driver's license and registration
  - ☐ medications/copies of prescriptions
  - ☐ change of clothes
  - ☐ welfare identification
  - ☐ passport(s), green card(s), work permits
  - ☐ divorce papers
  - ☐ lease/rental agreements
  - ☐ pets
  - ☐ insurance papers
  - ☐ address book
  - ☐ pictures, jewelry, items of sentimental value
  - ☐ children's favorite toys, blankets, etc.
  - ☐ personal protection order
  - ☐ important phone numbers, hotline number
  - ☐ legal documents (separation agreements & protection orders)

Sometimes it is IMPOSSIBLE to take anything with you when you leave a violent situation. Your personal safety should always come FIRST!

Adapted from: "Preventing Domestic Violence" by Laura Crites in Prevention Communique, March 1992, Crime Prevention Division, Department of the Attorney General, Hawaii.

Adapted from Domestic Violence Awareness Handbook, U.S. Department of Agriculture Safety, Health and Employee Welfare Division, retrieved 4/7/06 from http://www.usda.gov/da/shmd/aware.htm.

Symptoms and Danger Signs of Depression and Suicide

Warning Signs of Suicide

- Talking about suicide.
- Statements about hopelessness, helplessness, or worthlessness.
- Preoccupation with death.
- Suddenly happier, calmer.
- Loss of interest in things one cares about.
- Visiting or calling people one cares about.
- Making arrangements; setting one's affairs in order.
- Giving things away.

A suicidal person urgently needs to see a doctor or psychiatrist.

Symptoms of Major Depression

Not all people with depression will show all symptoms or have them to the same degree. If a person has four or more symptoms, for more than two weeks, consult a medical doctor or psychiatrist. Remember that only a medical doctor can diagnose depression.

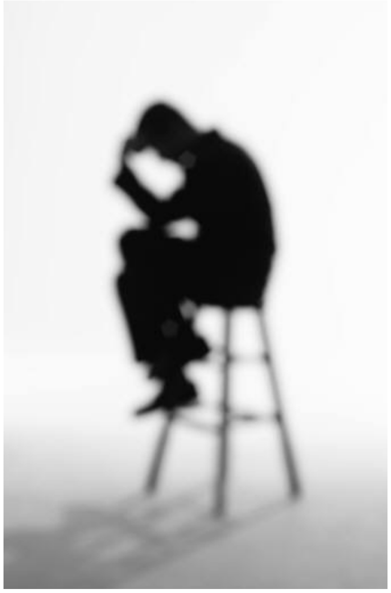
In Adults

- Persistent sad or "empty" mood.
- Feeling hopeless, helpless, worthless, pessimistic and/or guilty.
- Substance abuse.
- Fatigue or loss of interest in ordinary activities, including sex.
- Disturbances in eating and sleeping patterns.
- Irritability, increased crying, anxiety or panic attacks.
- Difficulty concentrating, remembering or making decisions.
- Thoughts of suicide; suicide plans or attempts.
- Persistent physical symptoms or pains that do not respond to treatment.

In the Elderly

- Unusual complaints of aches and pains (back, stomach, arms, legs, head, chest), fatigue, slowed movements and speech, loss of appetite, inability to sleep, weight increase or decrease, blurred vision, dizziness, heart racing, anxiety.
- Inability to concentrate, remember or think straight (sometimes mistaken for dementia). An overall sadness or apathy, withdrawal; inability to find pleasure in anything.
- Irritability, mood swings or constant complaining; nothing seems to make the person happy.
- Talk of worthlessness, not being needed anymore, excessive and unwarranted guilt.
- Frequent doctor visits without relief in symptoms; all tests come out negative.
- Alcoholism, which can mask an underlying depression.

Someone You Know is Suicidal



The Journal of the American Medical Association has reported that 95% of all suicides occur at the peak of a depressive episode. Education, recognition and treatment are the keys to suicide prevention.

Know What to Watch For

Symptoms of Depression Warning Signs of Suicide

Know What to Do

Stigma associated with depressive illnesses can prevent people from getting help. Your willingness to talk about depression and suicide with a friend, family member, or co-worker can be the first step in getting help and preventing suicide.

If you see the warning signs of suicide…

Begin a dialogue by asking questions. Suicidal thoughts are common with depressive illnesses and your willingness to talk about it in a nonjudgmental way can be the push a person needs to get help. Questions to ask:

"Do you ever feel so badly that you think of suicide?"
"Do you have a plan?"
"Do you know when you would do it (today, next week)?"
"Do you have access to what you would use?"

Asking these questions will allow you to determine if your friend is in immediate danger, and get help if needed. A suicidal person should see a doctor or psychiatrist immediately. Calling 911 or going to a hospital emergency room are valid options. Always take thoughts of or plans for suicide seriously.

Never keep a plan for suicide a secret. Don't worry about endangering a friendship if you truly feel a life is in danger. It's better to regret something you did, than something you didn't do to help a friend.

Don't try to minimize problems or shame a person into changing her mind. Your opinion of a person's situation is irrelevant. Trying to convince a person it's not that bad, or that she has everything to live for will only increase her feelings of guilt and hopelessness. Reassure her help is available, that depression is treatable, and that suicidal feelings are temporary.

If Not In Immediate Danger

If you feel the person isn't in immediate danger, acknowledge the pain as legitimate and offer to work together to get help. Make sure you follow through. This is one instance where you must be tenacious in your follow-up. Help find a doctor or a mental health professional, participate in making the first phone call, or go along to the first appointment. If you're in a position to help, don't assume that your persistence is unwanted or intrusive. Risking your feelings to help save a life is a risk worth taking.

This Advocates Brief have been developed by the Global Campaign for Microbicides in close collaboration with the other endorsing organisations listed here. While it articulates the current concerns and positions of these organisations, it is also a work in progress. We plan to re-issue this Advocates Brief in 2007, with revisions that reflect our collective perspectives on these issues.

POSITIVELY WOMEN
living with HIV ... changing lives

International Community of
Women Living with HIV and AIDS

GNP+
GLOBAL
NETWORK
OF PEOPLE
LIVING
WITH HIV/AIDS

National Association of
People with AIDS (US)
NAPWA

Global Campaig
FOR Microbicide

HIV Positive Women and Microbicides

Microbicides have the potential to benefit HIV positive women by enhancing their sexual lives and helping reduce their risk of infection with new or resistant strains of HIV and other sexually transmitted infections (STIs). The development of effective microbicides, which would be user-controlled, is important for women who cannot always negotiate condom use with their male sex partners or who do not wish to use condoms (for instance, those who want to conceive). Ensuring that promising microbicide candidates are safe, affordable, and responsive to the needs of HIV-positive women will require ongoing and targeted research. Here are some of the ways microbicides might enhance the lives of HIV-positive women.

Microbicides could benefit women living with HIV, their partners and families. Microbicides could help protect against HIV and possibly other sexually transmitted and vaginal infections that pose serious problems, especially when one's immune system is weakened. A broad-acting microbicide that is active against multiple STIs could help prevent some of these infections in HIV-positive women, and might even promote healthy vaginal conditions to ward off yeast infections or bacterial vaginosis.

Some of the candidate microbicides now in development may also eventually prove to be bi-directional – that is, capable of protecting women's sexual partners by disabling HIV in both semen and vaginal secretions.1 Such a product could give HIV-positive women a way to reduce their male partners' risk of infection even if he chooses not to use condoms. Microbicides are not expected to be as protective as condoms – but they will be far more protective than nothing when used by people who aren't using condoms.

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[1] First generation microbicide trials – those enrolling women now – are designed to evaluate whether microbicides reduce HIV transmission from HIV positive men to HIV negative women. Separate trials would be needed to establish whether a product that works in this direction would also work to protect the HIV negative male partners of women already living with HIV.

Some of the candidate microbicides under development will also be contraceptive, while others will not. Condoms prevent pregnancy, so the only way at present for an HIV positive woman to fully protect an HIV negative partner while also attempting to conceive is by using alternative insemination (depositing semen in the vagina with a device such as a syringe or a diaphragm, rather than during intercourse). There are other ways for a positive woman to reduce the risk while attempting to become pregnant – such as having unprotected sex only right after ovulation (thus reducing the number of times her partner is exposed). Taking anti-retroviral drugs may also potentially lower transmission risk by reducing the viral load in her vaginal fluids (although by how much is still unclear). But alternative insemination remains the only method currently available for introducing sperm into the vagina without any risk of transmission to a male partner.

A non-contraceptive, bi-directional microbicide would give HIV positive women who want to have children another option for safer pregnancy. Contraceptive microbicides, on the other hand, would give women another way to avoid an unwanted pregnancy. Microbicide researchers are also investigating the possibility of developing compounds that could be added to breast milk to make it safe for infant feeding.

Candidate microbicides must be proven safe for HIV positive women
Women living with HIV may have different needs for, and responses to, various microbicide products. We must understand these factors before microbicides become widely available, both because positive women will be using them, and because some women may not know their HIV status before using a microbicide. To date, only two of the three microbicides in large-scale efficacy trials have been through any testing to evaluate their safety for use by positive people. These preliminary safety trials must be followed by trials that generate long-term use data among women living with HIV so that researchers can adequately assess the long-term safety of such products if used by HIV positive women.

It must also be recognised that some types of microbicides (those that incorporate anti-retroviral drugs for vaginal application) may turn out not to be appropriate for use by HIV-positive women. It is possible that use of an ARV-based microbicide by an HIV positive woman could cause the development of drug resistant strains of the virus in her body, which might compromise her future treatment options. If testing proves that drug resistance is a problem (which is still an open issue), this particular type of microbicide might only be appropriate for HIV negative women.

With the exception of ARV-based microbicides, it is imperative that all candidate microbicides – even those intended to protect HIV negative women – be tested for safety among positive women and men before being allowed to advance to large-scale effectiveness trials.

Microbicide trials must protect the confidentiality and health of all participants.
Trials must take clear and specific measures to protect women's confidentiality and to

counteract any public perception that women excluded from clinical trials are presumably HIV positive. Since positive people are stigmatised in many places, such assumptions may be both inaccurate and harmful to women and their families.

All trials include eligibility criteria. The current microbicide effectiveness trials enrol HIV negative women (for reasons described below). But several factors other than HIV status may also result in trial exclusion, such as:

- other health problems a woman may have,
- a desire to become pregnant in the near future (since trial participants are asked to use condoms),
- inability or unwillingness to adhere to the trial regimen (which often includes coming in for frequent clinic visits) or
- the woman's own decision not to participate.

Researchers and trial promoters need to make it clear to the communities in which they are working that exclusion from the trial could occur for any of these reasons and that people should not assume that women who don't participate must be HIV positive.

Clinical trial sponsors/researchers must further ensure that women who seroconvert during a microbicide trial have access to comprehensive HIV care including anti-retroviral drugs (ARVs) when appropriate. Microbicide trials also have a special obligation to attend to the sexual and reproductive health needs of participants, including offering to provide safe, appropriate contraception for trial participants.

Each clinical trial site should explicitly define the health care services that it will provide to trial participants and negotiate with community stakeholders (including relevant community and/or civil society groups) to determine the package of prevention services that will be provided to participants. It must also specify how access to this care will be ensured and provided.

How can HIV-positive women participate in effectiveness trials for microbicides?
In addition to gathering data about how safe microbicides will be for use by women living with HIV, we also need to give high priority to the question of whether they will protect the partners of HIV positive women.

Three candidate microbicides are currently in the large-scale trials designed to answer the most basic question -- whether it is possible for a vaginal product to reduce the risk of HIV transmission. In these efficacy trials, HIV negative women are followed to see whether they become infected over the course of a trial. It is important to note that all trial participants receive the best known prevention package – which consists of intensive condom counseling, supplies of free, high quality condoms and regular screening, and treatment if needed for STIs. The women are encouraged to use condoms and are never deliberately exposed to HIV or asked to forego condom use during a trial. However, some women nonetheless become infected because they are unable, despite assistance and counseling, to insist on consistent condom use with their partners.

Since male to female transmission is much more likely to occur than female to male transmission, enrolling HIV negative women is the fastest way of determining “proof of concept” – i.e. showing whether the basic concept of a microbicide is feasible. These efficacy trials won’t show exactly how good the potential microbicide is at preventing male to female transmission – only whether the women who use it experience fewer sero-conversions than those who are provided with condoms and the inactive product (placebo).

If one of these trials demonstrates that the test product does help prevent male to female transmission, then it will be time to look at the opposite question – whether it can also prevent transmission from women to men. But a clinical trial to test this concept will look very different from these first trials. Instead of enrolling HIV negative women, these “next question” trials will have to enrol sero-discordant couples in which the woman is HIV positive and the man is negative. Their goal will be to see whether men become infected over the course of the trial.

Researchers can’t just enrol men to answer this question because it will be their female partners, the HIV positive women, who will be inserting the candidate products into their vaginas. These women will need to be well informed about all aspects of the trial before giving their consent to use the test product. It would be unfair to the women if researchers just gave test products to men and asked them to get their partners to use it. It is essential that the women, themselves, receive all the available information about the trial and the test product and give their informed consent before using it.

Since these two trial designs are very different from each other, it is not possible to answer both questions (whether the product protects both women and men) in the same trial. But this doesn’t mean that finding out whether HIV-positive women can use microbicides to protect their partners isn’t a high priority. It just means that the questions must be asked and answered in order. While waiting for the initial proof of concept to be established, the field can and should prepare itself to answer the second question by investing more money in gathering vital background data on vaginal immunology, ecology, viral shedding, the mechanisms by which HIV transmission from women to men occurs, etc.

What is the advocacy message?

HIV-positive women are some of the most vocal advocates for microbicides, as well as for expanded research on all aspects of HIV positive women’s reproductive health. Together, we can advocate forcefully for the development of user-controlled interventions, such as microbicides, that promote sexual and reproductive health and rights. Although we aim for the ideal of sexual relationships based on mutual respect and responsibility, we recognise that many women need methods that give them greater power to protect themselves and their male sexual partners.

Some areas in which our advocacy is urgently needed now include:

1. Making sure that all candidate microbicides are tested for safety among positive women and men before being allowed to advance to large-scale effectiveness trials.
2. Demanding that all microbicide trials are designed to fully protect participant confidentiality and privacy, that the sexual and reproductive health needs of all participants are met and that women who seroconvert during the trial have access to comprehensive HIV care including anti-retrovival drugs (ARVs) when necessary.
3. Insisting that the microbicide field invest and engage now in gathering essential information on vaginal immunology, ecology, viral shedding, the mechanisms by which HIV transmission from women to men occurs, etc.
4. Calling on the field to commit to trials to assess the potential for bi-directional protection of any non-ARV-based candidate microbicides after they show proof of concept.

Frequently Asked Questions About Microbicides

What is a microbicide?

A microbicide (mī-KRO′-bĭ-sīd) is a substance that can substantially reduce transmission of sexually transmitted infections (STIs) when applied either in the vagina or rectum. A microbicide could be produced in many forms, including gels, creams, suppositories, films, lubricants, or in the form of a sponge or a vaginal ring that slowly releases the active ingredient. The word "microbicides" refers to a range of different products that share one common characteristic: the ability to prevent the sexual transmission of HIV and other STI pathogens when applied topically.

Are microbicides currently available?

No. Scientists are currently testing many substances to see whether they help protect against HIV and/or other STIs, but no safe and effective microbicide is currently available to the public. However, scientists are seriously perusing over 30 product leads, including 10 that have proven safe and effective in animals and are now being tested in people. If one of these leads proves successful and with sufficient investment, a microbicide could be ready for distribution in a handful of countries by the end of 2010.

How would a microbicide work?

A microbicide could prevent HIV and STIs by:

1. killing or otherwise immobilising pathogens
2. blocking infection by creating a barrier between the pathogen and the cells of the vagina or rectum; or
3. preventing the infection from taking hold after it has entered the body

Ideally, a microbicide would combine these mechanisms for extra effectiveness.

Would a microbicide eliminate the need for condoms?

No. When used consistently and correctly, male or female condoms are likely to provide better protection against HIV and STIs than microbicides, so they will still be the preferred option. But for people who cannot or will not use condoms, and particularly for women whose partners refuse condoms, using microbicides can save lives and have a substantial impact on the spread of HIV. In fact, researchers developed a mathematical model that shows that if even a small proportion of women in lower income countries used a 60% efficacious microbicide in half the sexual encounters where condoms are not used, 2.5 million HIV infections could be averted over 3 years.

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For info contact: info@global-campaign.org
Updates available at: www.global-campaign.org/download.htm

What if a woman wants to get pregnant?
Some of the microbicides being investigated prevent pregnancy and some do not. It is important to have both non-contraceptive microbicides and "dual-action" microbicides that prevent pregnancy and infection, so that women and couples can protect their health and still have children. This is not possible with condoms.

Would a microbicide protect against all sexually transmitted infections?
Since STIs are caused by different pathogens (some viral, some bacterial), a microbicide that works against one STI pathogen would not necessarily protect against another. Many of the microbicides currently being tested work against HIV and at least one other STI. Eventually, a product that combines different microbicides and mechanisms of action may offer a protection from a wide range of sexually transmitted infections, including HIV.

Would microbicides be safe?
Any new product must go through rigorous safety testing before becoming available to consumers. Women's health activists and researchers are working closely together to ensure that the clinical testing of microbicides is thorough and ethical. Fortunately, many of the substances and mechanisms of action under investigation are already commonly used in over the counter products.

Would men benefit from microbicides as well?
There is every reason to believe that a woman's male partner would also be protected from infection if she used a vaginal microbicides that is bi-directional (one that disables HIV in vaginal secretions as well as semen). It may also be possible to develop microbicides that can be use rectally, but the safety and effectiveness of microbicides for rectal use must be established separately. Rectal safety studies of some potential microbicides are beginning.

Who is working on microbicide research and development?
Virtually all microbicide research to date has been conducted by non-profit and academic institutions or small biotech companies. Studies are funded by charitable foundations and government grants. These public funds also support basic science, social and behavioural research, and clinical trial infrastructure that contribute to microbicide research and development. Large pharmaceutical companies have not invested significantly in this field, primarily because microbicides are a classic "public health good" which would yield tremendous benefits to society but for which the profit incentive to private investment is low.

Why do we need microbicides if we will eventually have an HIV-vaccine?
No one strategy or technology will "solve" the AIDS pandemic. We must employ all existing prevention strategies – such as behaviour change, voluntary counselling and testing, STI diagnosis and treatment, broad access to male and female condoms, access to sterile syringes, and anti-retroviral interventions – as well as expand our repertoire of tools and technologies. Microbicides will likely be available and accessible sooner

than an HIV-vaccine. Even after a safe and effective vaccine is discovered, vaccines and microbicides will have different, complementary roles to play in an integrated, multi-faceted global HIV prevention strategy.

How much will microbicides cost, and will people be able to afford them?
It is essential that microbicides get into the hands of women and men who need it at a price they can afford. In the past, new health technologies have rarely become widely available in developing countries until more than a decade after their approval in Europe and the US, an unacceptable delay for this life-saving technology developed primarily with public funds. Advocates are working with researchers and policy makers now to emphasise the need to address issues of access and affordability up front, in order to be prepared to deliver a microbicide rapidly as soon as one is proven safe and effective.

How can you get involved?
Visit the Global Campaign for Microbicides website: www.global-campaign.org to sign a petition, sign up for our electronic newsletter, write to your parliamentarian, meet up with local advocacy groups in your region, and learn more about microbicides. We need your help to make a safe and effective microbicide available as soon as possible.

The Global Campaign for Microbicides is a broad based, international coalition of organisations working to accelerate access to new HIV prevention options. Visit our website: www.global-campaign.org or contact us:

Global Campaign Europe, 98 Rue du Trône (7th Floor) 1050 Brussels, Belgium
Email: ameijer@path.org
Tel: +32 2507 1229 Fax: +32 2507 1222

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Updates available at: www.global-campaign.org/download.htm

Resources and Information for Women Living with HIV/AIDS

REGIONAL WOMEN'S ORGANIZATIONS

CALIFORNIA

Christie's Place is a nonprofit social service organization providing HIV/AIDS education, support and advocacy to empower women, children, families and individuals whose lives have been impacted by HIV/AIDS to take charge of their health and well-being.
2440 Third Avenue
San Diego, CA 92101
619-702-4186
www.christiesplace.org

Esperanza Pallana Family Service Network Coordinator
995 Potrero Avenue
Box 0874, Building 80, Ward 87
San Francisco, CA 94110
415-476-4082, ext.121
www.php.ucsf.edu

UCSD Mother, Child, and Adolescent HIV Program Regents of University of California, San Diego
150 W. Washington Street, Suite 100
San Diego CA 92103
Contact: Mary Caffery RN MSN, Program Coordinator
619-543-8080, 619-298-2698 - fax

Women Alive publishes a quarterly newsletter and is active in policy and treatment issues affecting women living with HIV.
1566 Burnside Avenue
Los Angeles, CA 90019
1-800-554-4876

Women At Risk provides emotional and educational services to women living with HIV/AIDS and their families, as well as education outreach to the communities in the greater Los Angeles area.
5183 Overland Avenue, Suite B
Culver City, CA 90230
310-204-1046
connect@womenatrisk.org

WORLD (Women Organized to Respond to Life-threatening Diseases) provides support, information and education to women living with HIV, their families & loved ones promotes public awareness of the issues women living with HIV/AIDS face.
414 Thirteenth Street, 2nd Floor
Oakland, CA 94612
510-986-0340
www.womenhiv.org

GEORGIA

Aniz, Inc.
Zina Age, President & CEO
233 Mitchell Street, SW, Suite 200
Atlanta, Georgia 30303
866-521-2410
www.aniz.org

SisterLove is a reproductive and sexual health rights organization providing education, support and advocacy to women and their families affected by HIV/AIDS.
1285-A Ralph David Abernathy Blvd., SW
Atlanta, GA 30310
404-753-7733
www.sisterlove.org

NEW JERSEY

New Jersey Women and AIDS Network provides a range of support, educational, counseling and outreach activities to HIV positive women and women at risk.
103 Baynard St., 3rd Floor
New Brunswick, NJ 08901
732-846-4462
SisterConnect Warmline: 1-800-747-1108

NEW YORK

GMHC—The Women's Institute is a place that honors the whole woman, where women can come together to group and support each other. Programs include, child life program, nutritional support, lesbian AIDS project, and women in action supporting women in recovery.

119 West 24th Street
New York, NY 10011
212-367-1363 (Information Line)
www.gmhc.org/programs/womens_institute

Iris House provides a range of services and support for women and their families affected by HIV/AIDS.

2348 7th Avenue
New York, New York
646-548-0100

SMART University provides treatment education and support for all women living with HIV/AIDS in order to increase their self-confidence and self-esteem.

306-308 West 38th Street, 6th Floor
New York, NY
212-564-3282
212-560-6558 (infoline)
www.smartuniversity.org

SOUTH CAROLINA

HopeHealth, Inc.
Christine Gordon ACRN, BSN
Regional Director Lower Savannah & Edisto
151 Waterloo Street
Aiken, SC 29801
803-643-1977, 803-644-2743 - fax
www.hope-health.org

TEXAS

A Sister's Gift is a community/faith-based nonprofit organization providing services to HIV positive women in Dallas and surrounding counties.

1515 North Town East Blvd., #138-380
Mesquite, TX 75150
972-523-0815
www.sistersgift.org

Mujeres Unidas Contra el SIDA
Yolanda Rodriguez-Escobar
307 E. Evergreen Street
San Antonio, TX 78212
210-738-3393
www.mujeresunidascontraelsida.org

Women Rising Project
c/o AIDS Services of Austin
Sylvia Lopez, Program Director Women Rising Project
P.O. Box 4874
Austin, TX 78765
512- 458-2437
ww.asaustin.org

WASHINGTON

BABES Network is dedicated to building a community among women from all walks of life who are facing HIV/AIDS. They are a non-profit organization providing peer counseling, support groups, advocacy, trainings and educational forums, retreats and a newsletter. BABES Network-YWCA.

1118 Fifth Avenue
Seattle, WA 98101
1-888-292-1912
www.babesnetwork.org

WASHINGTON, DC

Women's Collective is a non-profit organization dedicated to meeting the needs of women with HIV/AIDS. It's services are peer-led, women focused and family oriented.

1436 U Street NW, Suite 200
Washington, DC 20009
202-483-7003
www.womenscollective.org

NATIONAL HOTLINES AND INFORMATION LINES

National Women's Health Information Center is a government-sponsored hotline provides information on women's health issues, including HIV and pregnancy.
1-800-994-WOMAN

Centers for Disease Control and Prevention National AIDS Hotline
1-800-342-AIDS

HIV/AIDS Treatment Information Service (HATIS) is a hotline that answers questions about HIV treatment and distributes the Federal Guidelines on HIV Treatment free of charge.
1-800-HIV-0440

AIDS Clinical Trial Information Service has information about pediatric and adult clinical trials and specific trails in your area, including studies of AIDS drugs in pregnancy.
1-800-TRIALS A

Project Inform's National HIV/AIDS Treatment Infoline
Mondays, Wednesdays, Thursdays 9am–4 pm PST; Tuesdays 9 am–7 pm.
1-800-822-7422

NATIONAL RESOURCES/ORGANIZATIONS

American Foundation for AIDS Research (amfAR) is a non-profit organization dedicated to HIV/AIDS research, prevention, and advocacy.
1-800-39-AMFAR

National Minority AIDS Council (NMAC) is dedicated to developing leadership within communities of color to address the challenges of HIV/AIDS.

1931 13th Street, NW
Washington, DC 20009
202-483-6622
www.nmac.org

Black AIDS Institute is a policy center dedicated to reducing HIV/AIDS health disparities by mobilizing Black institutions and individuals in efforts to confront the epidemic in their communities.

1833 West 8th Street, Suite 200
Los Angeles, CA 90057
213-353-3610
www.blackaids.org

For a comprehensive list of national and local organizations that have public policy and advocacy programs, go to www.projectinform.org/org/presources.html.

NEWSLETTERS AND WEBSITES

Positively Aware is a bi-monthly newsletter for people living with HIV published by Test Positive Aware Network in Chicago. Newsletter covers a wide range of health, legal, social and financial issues. They also publish HIV Drug Guide, with comprehensive information on all the approved HIV medications.
773-989-9400
www.tpan.org

POZ publishes a monthly newsletter and a variety of other resources and educational materials for people living with HIV both nationally and internationally.
www.poz.com

The Well Project provides health information for women living with HIV/AIDS.
www.wellproject.org

AIDSmeds.com provides easy to read, comprehensive HIV/AIDS information.
www.aidsmeds.org

National AIDS Treatment Advocacy Project (NATAP) strives to educate individuals about HIV and Hepatitis treatments and to advocate on the behalf of all people living with HIV/AIDS and HCV on a local, national, and international levels.
www.natap.org

AIDSMAP is a British based organization, providing reliable and accurate HIV information to people living with HIV and their providers.
www.aidsmap.org

AIDS Education Global Information System (AEGIS) provides information & resource portal with information for HIV-related treatment, research, services & access.
www.aegis.com

Treatment Issues is a monthly newsletter published by the Gay Men's Health Crisis (GMHC) covering a range of HIV treatment information, research, public policy and advocacy issues both nationally and internationally. For subscription contact:
GMHC Treatment Issues
The Tisch Building
119 West 24 Street
New York, NY 10011
ti@gmhc.org

The Body provides accessible information on line. Gather articles and information from numerous sources.
www.thebody.com

San Francisco AIDS Foundation—BETA (Bulletin of Experimental Treatments for AIDS) is a newsletter that covers developments in AIDS treatment research; available in English and Spanish.
P.O. Box 426182
San Francisco, CA 94142-6182
415-487-8060
beta@sfaf.org

New Mexico AIDS Infonet is an international English/Spanish online resource for information on HIV/AIDS.
www.aidsinfonet.org

International Community of Women Living with HIV/AIDS is the only international network for women, providing information, support and advocacy for women living with HIV. Website is in English and Spanish.
www.icw.org

Glossary

HIV Definitions

1. **Adherence** The extent to which a patient takes his/her medications according to the prescribed schedule (also called "compliance").
2. **AIDS** Acquired Immunodeficiency Syndrome
3. **Antibody** A chemical that is part of the immune systems. Antibodies recognize and help fight germs.
4. **Antiretrovirals (ART)** A class of drugs that slow down retroviruses like HIV.
5. **Asymptomatic** To have no symptoms.
6. **B Cell** A type of white blood cell that produces antibodies.
7. **Biopsy** Removal of a piece of tissue for examination under the microscope, for diagnostic purposes.
8. **Candidiasis** The medical term for a yeast infection. Can be treated with a cream or suppository.
9. **CDC** Center for Disease Control and Prevention
10. **CD4+ Cell** Also known as "T4" or "helper T cell," the CD4 cell is the primary target of HIV.
11. **Cervix** The opening to the uterus from the vagina. This is what dilates during labor.
12. **Chlamydia** A sexually-transmitted disease caused by *Chlamydia trachomatis*; easily treated with antibiotics.
13. **HAART (Highly-Active Anti-Retroviral Therapy)** A combination of three or more anti-HIV medications.
14. **Gonorrhea** A sexually transmitted infection caused by bacteria. Also known as "Clap". Can be treated with pills or an infection.
15. **HIV** Human Immunodeficiency Virus. Virus which infects humans by breaking down their immune system. There is not cure, but there are treatments.
16. **HPV** Human Papillomavirus. A sexually transmitted infection caused by a virus. There is no cure, but there are treatment.
17. **Immune System** The system in our bodies that protects us against infections and illness.
18. **Immunocompromised, Immunosuppressed** When the immune system does not work efficiently, so a person is more susceptible to illness.
19. **Lymph** This is the fluid runs through lymph nodes. Lymph contains lots of white blood cells. You can think of it as the transporter of your white blood cells.

20. **Lymphocyte** Another term for a type of white blood cell.
21. **Peripheral Neuropathy** A condition where the endings of the nerves are damaged. This can cause tingling, numbness and difficulty to walk or use your hands. It cannot be reversed.
22. **NNRTI (Non-Nucleoside Reverse-Transcriptase Inhibitor)** A class of drugs that inhibit an enzyme used by HIV called "reverse transcriptase."
23. **Opportunistic Infection (OI)** A germ (such as a virus or bacteria) that gets into the body and takes the "opportunity" to cause an illness.
24. **Resistance** This is a term used when a person's body is no longer accepting or reacting to some kind of medication.
25. **Side Effect** A symptom that is caused by taking a medication that can last for a few weeks to a longer time. Not everyone experiences side effects.
26. **STD** Any sexually-transmitted disease, like gonorrhea, syphilis, HIV, etc.
27. **Viral Load** The amount of virus in a given sample of body fluid (usually blood).

Key Definitions in Peer Advocacy

1. **Adherence** Taking medications or undergoing other treatment as prescribed, including frequency and food restrictions. Nearly-perfect adherence to anti-HIV regimens is typically required to avoid the development of drug resistance. Also called compliance.
2. **Advocates** People who actively support an idea or cause to benefit society, another person, or themselves. Advocacy is the act of being a supporter. I am an HIV Prevention advocate.
3. **Affirming** positive messages or providing positive support to someone. Examples: "I'm glad you asked that." "Good for you!"
4. **Anxiety** a disorder that causes its sufferers chronic and exaggerated worry and tension that seem to have no substantial cause. Persons with generalized anxiety disorder often worry excessively about health, money, family, or work, and continually anticipate disaster. It may be associated with physical symptoms such as rapid heart beat, feeling faint and trembling. It can be a normal reaction to stress or worry or it can sometimes be part of a bigger problem. I think this definition is too technical.)
5. **Closed-ended questions** Questions that invite a "yes" or "no" response. Usually begin with "do," "are," "will," etc. Useful if you want to find out one specific piece of information.
6. **Confidentiality** Keeping peoples' business to yourself. Not allowing information about someone else's HIV status, or anything else about their private life to slip out to someone they don't want to know.
7. **Countertransference** is defined as any thought, feeling, wish, hope or fear that might come up for a peer advocate that is directed towards the client. Sometimes the thoughts and feelings that arise for the peer relate to his/her past experiences. For example, a peer who was hurt in a domestic violence incident might become overly afraid that her client who is also in a domestic violence situation might get hurt in the same way, or to the same degree that she did. Other situations to think about are substance abuse, co-infection with Hepatitis, pregnant client, newly diagnosed client are all other examples. The peer also might have a tendency to be too "advice-giving" and less able to empathize and "meet the client where she is at".
8. **Cultural bias** Making assumptions or judging someone or something based on your own cultural beliefs.
9. **Depression** A mental state of depressed mood characterized by feelings of sadness, despair and discouragement. Depression ranges from normal feelings of the blues through dysthymia to major depression. It in many ways resembles the grief and mourning that follow bereavement, there are often feelings of low self esteem, guilt and self reproach, withdrawal from interpersonal contact and physical symptoms such as eating and sleep disturbances. (I think this definition is too technical.)

10. **Disclosure** telling something private about yourself, or having it told.
11. **Dual relationship** relationship in which there are two or more different kinds of relationships between the same two people. Each person in the relationship has more than one role with the other person. An example would be a peer advocate who has her own social worker, and the same social worker is also someone she works with in her job as a peer advocate. Peer advocates might find that they have dual relationships with either colleagues or clients.
12. **Epidemiology** the study of who is getting or is affected by a disease or condition.
13. **Ethical codes of conduct** are principles or rules that are used in a working situation
14. **Ethics** a set of morals or principles; what a person defines as right and wrong
15. **Fight or Flight response** which is the body's automatic response that prepares the body to "fight" or "flee" from a perceived attack, harm or threat. Usually includes fast heart beat, fast breathing, shakiness and anxiety.
16. **Guided Visualization** A technique used to relax your mind and body by helping you to create a peaceful image in your mind by having a calm, soothing voice giving you directions
17. **Illusion** a false perception; the mistaking of something for what is not.
18. **Intimate partner violence** Also called domestic violence, is violence between people in a family or between sexual partners.
19. **Meditation** is a technique in which the individual focuses on a word or phrase to get rid of other thoughts. It has been shown to lower blood pressure and reduce stress.
20. **Mood disorder** A condition where the prevailing emotional mood is distorted or inappropriate to the circumstances.
21. **Morals** the sense of right and wrong.
22. **Open-ended questions** are questions that can't be answered by "yes" or "no" or a number or date. Usually begin with "what," "where," "how," "when," "who," or "why." They are useful to get much more information from people and to participant's "own" information about what they're learning.
23. **Peer Education** Peer is a person who belongs to the same social group as another person or group. The social group may be based on age, sex, sexual orientation, occupation, socio-economic status, HIV status, or other factors. Education refers to the development of a person's knowledge, attitudes beliefs or behaviors as a result of the learning process. Peer Education is a principle that people who share a commonality or experience have something to offer each other which cannot be provided by professionals.

24. **Post-traumatic stress disorder (PTSD)** a debilitating condition that can occur after someone has gone through a trauma, for example, violent personal assaults such as domestic violence, rape or mugging, or natural or human-caused disasters, accidents, or military combat.
25. **Self affirmations** positive messages you give yourself
26. **Self-care** Taking care of yourself using stress reduction activities.
27. **Self-talk** Talking to yourself to reduce stress.
28. **Sexual health** The World Health Organization (WHO) defines sexual health as "an integration of the physical, emotional, intellectual, and social aspects of sexual being in ways that are enriching and that enhance personality, communication, and love." WHO is the United Nations specialized agency for health. WHO's objective, is promote health at all levels and throughout the world.
29. **Shame** Feeling embarrassment, regret, guilt or bad about something you have done or who you are because of society. Stigma is what society imposes on an individual that can make them feel shame. Shame is the emotion that results from stigma.
30. **Stigma** Use of negative labels to devalue a person. Mark of disgrace; Unfavorable attitudes, beliefs and policies directed toward people who have an illness or perceived to have an illness. Social disapproval or mark of shame.
31. **Stress** a physical, chemical, or emotional factor that causes bodily or mental tension and may be a factor in disease causation
32. **Substance abuse** substance use turns to abuse when a person continues to use a substance even if using that substance is putting the person at risk (health, financial, etc.)
33. **Transformation** A change in someone's perception, appearance, behavior, or character, usually for the better.
34. **Trauma** A dangerous or physically or mentally threatening event causing profound feelings of fear, anger, and devastation.
35. **Triggers** People, places, things, etc that set-us off. Triggers lead to negative attitudes which can lead to situations which lead to negative consequences.
36. **Warrior woman** a person using who they are to fight to make someone or something different. Opposite of victim.

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