One of the most frequent concerns new patients have when they come to our Ryan White Clinic is how to talk to their children about their HIV diagnosis. Disclosure is a difficult issue that patients have to face.

For some parents there is a belief that the child should never be told. Patients may try to keep children from even hearing the terms “HIV” or “AIDS”. As with any family secret, the problem with this approach is that the children will find out sooner or later. Some parents want to tell their children because they don’t want them hearing it from someone else, because the kids have already been asking questions or because it simply takes so much energy to keep the secret.

I believe it is helpful for children to be given information about what is going on in their lives, but it also is important that as a parent, you do not disclose your HIV status until you are ready.

The information you provide can range from minimally revealing to overly detailed. Either way, plan for reactions and questions. The range of reactions from your children can vary from a stunned silence to an all-night discussion, so be prepared. If the parent is calm and poised with the disclosure, the children will have minimal reactions. However, if the parent is highly stressed, the chances are greater that the children might become emotionally overwhelmed. If you cannot maintain a sense of calm, perhaps you should wait until you are ready.

If you want to tell your children about your HIV/AIDS but have yet to do it, you have started the disclosure process just by thinking about it. Disclosure is not an event but a slow, on-going discussion process with your loved ones. It is important to have a plan before you begin the disclosure process. In order to be prepared for disclosure, here are a few ideas to consider:

- Practice your speech. Be as brief as possible. Be prepared to answer questions.
- You may need several backup people for support. The CAMC Ryan White Program’s health care professionals are trained to help in this matter, so please ask if you need some help. Helping your children understand is important, but that does not mean you are the only one involved. Consider family, clergy, counselors and friends as backup.
- The WV State AIDS Program and the CAMC Ryan White Program have a lot of materials such as coloring books, storybooks and information pamphlets that can help you when you are talking to your children about HIV.
- Many children, some as old as 16, think that when parents get sick, it is because of something they said or thought. Children need to be taught that their illnesses or a parent’s illness is not their fault and that having an illness is not a punishment. You can say, “Sometimes I get angry when you don’t do your chores, but it is not your fault when you or I get sick.”

- How much to disclose depends on the child’s age. A 5-year old, for example, needs very simple information, such as “Sometimes I have to go to the hospital for a checkup.”
- With older children, ask indirect questions to determine if now is the right time to open this discussion. “I haven’t been feeling well lately. Have you noticed?” or “Have you wondered what is going on?” Your child’s answer will guide you about what to say next.
Should I tell
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Joining a group such as the Charleston AIDS Network's Something Positive Support Group can be helpful. You can ask other parents what has worked for them. Keep in mind that every child is different and no one can tell you exactly how your child will react.

As children get older you can start giving more information, and don’t be surprised when unexpected questions leave you feeling unprepared. Don’t be uncomfortable saying, “I don’t know but I’ll find out. I’ll get back to you later and we can continue this discussion.”

Remember that disclosure is different in every family, and maybe for each child within the same family. There is no set “rule” regarding age. Some information can be given to children of any age, and the trick is adapting it to each child’s level of understanding. Two children of the same age can be at different levels in terms of their readiness to talk about HIV/AIDS.

“Finally, try to think of disclosure as a gift from you to your child. As difficult as it is to think about talking to your children about HIV/AIDS, as you begin giving even the simplest explanations, you will be giving your children important tools to help them understand and cope with the unpredictable events in their lives,” says Marianne Hardart of NYU Medical Center.

Augustine, a medical social worker, is a member of the CAMC Ryan White Program’s Care Team.

The benefits of exercise – you can do it
By Laura Wilhelm, PhD

We’ve all heard that exercise helps a person feel better. This idea might sound good, but it is hard for many people to get started on an exercise program. Understanding the benefits of exercise might increase your chances of trying it.

The benefits of exercise have been proven repeatedly. Numerous research studies have shown that exercise can improve depression, anxiety, stress management, sleep, physical self-concept and physical health. Mechanisms through which exercise is helpful include the following: increased blood flow to the brain, biochemical changes such as the release of endorphins that elevate mood, distraction from worries, development of a sense of mastery in a physical activity and, of course, improved physical endurance, strength and appearance.

When beginning an exercise program, keep in mind that your discomfort level might increase during the first few minutes of your workout. However, as you continue to exercise, the distress will subside. By the end of the exercise, expect to feel better than before you started (even if you are more tired). Over time, regular exercise usually gives people more energy, not less!

We hope you will consider giving more physical activity a try. You don’t have to “feel like it” to start moving more. This is a situation in which taking action is often the first step, regardless of how much you may want to – or don’t want to. Motivation to continue and do more exercise often comes after the first walk.

Wilhelm, a psychologist, is a member of the CAMC Ryan White Program’s Care Team.

To get started with an exercise routine, here are some tips:

1. Let your doctor know that you are beginning to exercise. See if he or she has recommendations for specific activities for you, or limitations to consider.
2. Choose an activity you will enjoy. Some options include walking, jogging, aerobics classes, strength training, dance, yoga, tennis, softball, basketball, and volleyball.
3. Consider doing your exercise choice with a friend or a group. You will enjoy the activity more – and will be more likely to do it regularly. Many people like to listen to their favorite music while they exercise.
4. Begin the activity slowly and proceed carefully. Try not to get impatient and do too much at once. Remind yourself that it is better to increase your exercise intensity and duration at a gradual pace, rather than at a rushed one. Pay attention to your body’s reactions.
5. Try to do some form of exercise at least four to five times each week. Realize that as you continue to exercise regularly, the activity will become more of a positive habit, and less of a chore or a burden. Exercise is an area where it is important to keep in mind: Practice makes permanent.
6. Give yourself credit for your exercise efforts. How about keeping an exercise log to chart your improvements? It can be particularly helpful to monitor mood levels before and after a workout so that you can see how exercise improves your feelings.
Did you just learn that you’re HIV-positive?

It can be very scary to learn that your AIDS blood test came back positive, but it’s not a death sentence. The test means that you are infected with the human immunodeficiency virus (HIV), the virus that causes AIDS. Even though there is no cure for HIV disease, there are many new treatments that help keep the disease under control.

When you first find out that you have HIV, you’ll need to adjust to this change in your life. Family members or friends might be able to help you, or you could talk with a counselor or social worker. Take your time and don’t feel that you have to tell everyone about your HIV status right away. Then start taking the next steps:

Learn more about HIV

HIV is a virus that can multiply rapidly in your body. Without treatment, HIV can make your immune system very weak. If this happens, you might get an opportunistic infection (OI). Common germs cause these diseases. People with healthy immune systems can be exposed to these germs and not get sick. The same germs can cause serious illnesses in people with weak immune systems.

The first medication for HIV was approved in 1987. Now there are many different drugs that can be used to slow down the HIV virus. Most people with HIV disease can now expect to live healthy lives for many years.

You will probably have a lot of questions about HIV disease. There are many good sources of information, including:

- Your HIV case manager or physician
- Your local public health department
- The resources listed at the bottom of this article

Be careful about the information you’re getting - check it out with your doctor or other sources to make sure it’s accurate.

Monitor your immune system

In addition to your regular medical exams, there are two special blood tests used to help keep track of HIV disease.

They are the viral load test and the T-cell test.

The viral load test helps show how strong the virus is in your body. It measures the amount of HIV in your blood. Lower levels are better. This test is used to help decide when it’s time to start using HIV medications, to see if the drugs are working and to know when to change medications.

The T-cell test helps show how strong your immune system is. It counts how many infection-fighting white blood cells you have. These cells are also called CD4+, T-4 or T-helper cells. The more you have, the better. If your T-cell count gets too low, you might develop an OI. This test is used to help decide when it’s time to start using HIV drugs or medicines to prevent OIs.

Your doctor will probably want to do these tests every three months. If your viral load stays low and your T-cell count stays high, you might choose to delay treatment.

Decide how you want to deal with HIV

HIV may not be the only health issue you are dealing with. The better your health is overall, the better you can deal with HIV. Be sure to get regular medical and dental checkups, and get treatment for conditions like diabetes, hepatitis, high blood pressure or high cholesterol. If you can avoid smoking, drinking too much alcohol, recreational drug use and sexually transmitted diseases, you will probably find your HIV easier to control.

Although there are many different medications that can help slow down the HIV virus, no one knows exactly when or how best to use them. You will need to get information and work with your doctor to decide what kind of treatments fit best with your beliefs, desires and life style. You might choose to be very aggressive, and use HIV medications very early in your disease. You might be more conservative and decide to wait until you reach specific viral load or T-cell levels. It’s up to you.

Remember, you are in charge of your own health care. You will decide which doctor to work with, and whom else you want to consult about your treatments. You will decide which treatments you want to use and when you want to use them. Take your time and learn about your options.

Toll-free resources:

- CAMC Ryan White Program: 1-877-565-4423
- WV AIDS/STD hotline: 1-800-642-8244
- National AIDS hotline: 1-800-342-2437

Reprinted courtesy of www.PositiveWords.com

Take the test!

The decision to be tested for HIV is the first step in taking responsibility for yourself and the health of others with whom you may be intimately involved.

HIV testing locations

Many testing sites offer free testing, but some charge a fee. Some locations require an appointment; others accept walk-ins. Call ahead to be sure!

On the Internet you can find a list of test sites in your area by entering your zip code. Go to www.hivtest.org.

By phone, you may call:

- WV AIDS/STD Hotline: 1-800-642-8244
- CAMC Ryan White Program care coordinator in Charleston: 388-9337 or toll-free: 1-877-565-4423
- National HIV/AIDS Hotline: 1-800-342-2437
- Your local county health department
Women and HIV

By Barbara Joseph

It’s a fact. Women have become the “new face of AIDS.” Today, the Atlanta-based Center for Disease Control (CDC) reports that over 40,000 new HIV infections occur in the U.S. each year and nearly 30 percent are women. In 2004, more than 11,000 women in the USA learned they were HIV-positive…women in New York, in Texas, and yes, even in West Virginia! Heterosexual contact was the source of more than 70 percent of these new infections.

Many of these women are victims of stereotypes and misinformation, believing that HIV/AIDS is a “gay disease.” Others, according to author JL King (On the Down Low), become "martyrs to the disease rather than insist on safe sex (condoms) with their partners.” The CDC agrees, stating that some women may not insist on condom use because they fear that their partners will physically abuse them or leave them.

Condom negotiation
The following discussion about “condom negotiation” is reprinted from the American Social Health Association’s web site, www.ashastd.org:

It's about respect – and responsibility – for yourself and your partner. Before deciding to have sex it pays to think about protecting yourself from sexually transmitted infections (STIs), including HIV/AIDS.

Not having sex is the best way to keep from getting an STI, but if you choose to be sexually active, using condoms correctly and consistently is a key way to reduce risks. Don’t be shy to talk with your partner about safer sex and condoms: For both of you, this is one of the most important conversations you can have. It’s also one of the smartest!

The following statistics reinforce the importance of safe sex for women:

■ AIDS is now the third leading cause of death among American women age 25 to 44.

■ In the U.S., about one in ten women diagnosed with AIDS is age 50 or older.

■ Among teenagers 13 to 19, girls account for over half of new HIV infections.

■ In the United States, more people are infected with HIV through heterosexual sex than through IV drug use. Of those, two out of three are women.

■ AIDS is the number one killer of African American women age 25 to 34.

■ The proportion of AIDS cases among women has more than quadrupled – from 7 percent in 1985 to nearly 30 percent today.

Symptoms
Symptoms that could serve as warning signals of HIV infection may go ignored because many women do not perceive themselves at risk.

It is possible for a person infected with HIV to show no signs of infection. For women, the most common symptoms of exposure to the HIV virus are frequent or severe vaginal infections, abnormal PAP smears, or pelvic infections (PID) that are difficult to treat.

Within a few weeks of having been infected, many people have flu-like symptoms. However, in some cases, symptoms do not show for many years. As the infection progresses, some symptoms can include 1) swollen lymph glands in the neck, underarm, or groin area, 2) recurrent fever including “night sweats,” 3) rapid weight loss for no apparent reason, 4) constant tiredness, 5) diarrhea and decreased appetite, 6) white spots or unusual blemishes in the mouth.

Get tested
If you or someone you know is at risk, HIV tests are available at local health departments and many other locations. Call the West Virginia STD/AIDS Hotline at 1-800-642-8244 for testing locations in your area. Early diagnosis of HIV infection allows women to take full advantage of HIV-specific health care, including new drug treatments that can forestall the development of AIDS-related symptoms and prolong life in HIV-infected women as well as men. Early diagnosis also allows women to make informed reproductive choices.

Joseph is the outreach coordinator for the CAMC Ryan White Program.