



MINNESOTA WOMEN & FAMILIES NETWORK

Welcome to the first edition in Volume 2 of the Women and Families Network Newsletter!

HIV *Disclosure*

NEWS from the Network

The core group of the **Women and Families Network** is seeking HIV-positive women who are interested in joining the Network and taking leadership roles. This group meets on first Thursday of each month at 12 pm. For more information, please call Dori (612) 373-9175, or Sarah (651) 602-7570.

“Soul of a Woman” – Empowering Support Group for HIV-Positive Women

Where: African American AIDS Task Force
Sabathani Community Center
310 East 38th Street, Suite 304
Minneapolis, MN 55409

When: Every 2nd & 4th Wednesday of each month,
at 5 - 7pm

Contact: Sarah Armwood-Moses at (612) 825-1215,
smoses_aaatf@qwest.net

“Unleashing the Power of Wellness Within” A six-session wellness workshop

Where: Powderhorn/Phillips Cultural Wellness Center
1527 East Lake Street
Minneapolis, MN 55407

When: Every other Saturday starting June 5, 10 am

Contact: Dori Makundi (612) 373-9175 for more info.

About the Women and Families Network

The Women and Families Network is a voluntary collaborative committed to work for comprehensive, quality care for women, youth and families affected by HIV.

- Become a member of the network and join one of our committees.
- Sign up to receive quarterly newsletter filled with news, articles, and resources for both service providers and people affected by HIV.

Check out our Web site at
<http://www.wfnetwork.org>

Contact Sarah (651) 602-7570 or Dori (612) 373-9175 for additional information

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The mission of the **Women and Families Network** is to address the needs of women and families affected by HIV through collaboration, advocacy, training and resource sharing.

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The Women and Families Network Newsletter is distributed as a free community service. To subscribe please contact: Sarah Senseman at (651) 602-7570 or ssenseman@westsidechs.org

HIV Disclosure

“Being open about HIV is essential to combating society’s intolerance and misunderstanding. Those with the courage to speak out should be commended. But true courage is never doctrinaire. Each person should be allowed to decide if and when it is safe to disclose his or her HIV status. We must not scorn those who choose to remain silent in order to keep food on their tables and a roof over their heads. Sometimes, silence equals life.” - J. Hayford *Test Positive Aware Network (TPAN)*.

A person diagnosed with HIV is faced with a difficult decision: whether or not to tell anyone and whom to tell. For parents, this challenge may be more profound as they struggle to decide how and when to tell their children - some of whom may also be HIV-positive. Parents report that this decision is as emotionally charged as learning of the diagnosis itself.

Many issues impact a person’s decision. Disclosing may lead to a greater acceptance of HIV status, increased emotional support, reduced stress of keeping secrets and increased intimacy within relationships with partners, family and friends. However, disclosing may lead to rejection and loss of relationships with family, friends, community members, employers or co-workers; or pressures to become a public role model. In addition, parents may hesitate to disclose to protect their children from community stigma, and to avoid placing the weight of the diagnosis on their children and robbing them of their childhood and innocence.

This newsletter focuses the many facets of disclosure, and its impacts on the lives of women and families living with HIV. This issue features stories from women and families with HIV and their thoughts and experiences with disclosure. This is not a “how to disclose manual” – but rather a collection of materials, stories and resources to give ideas and get the discussion flowing. Clearly, there is no “best” disclosure communication plan - each person and family must explore the issues involved thoroughly and decide what is the right plan for them.

Sandra’s story

Sandra is a single mother living with HIV. Her children, one boy and one girl, are very close in age and are now in their early teens. Sandra opted to disclose her HIV status to her kids about six years ago. She felt that it was time for her to start talking to her kids about her HIV because she was starting to have “bad days” and it was difficult for her to explain these away on a regular basis. Sandra said that she had originally thought about not telling her kids that she was HIV-positive but didn’t feel like she could “pull it off”. She found it tiring enough to manage her symptoms and side-effects without having to juggle half-truths and dodge questions about her health. Sandra believes that it was helpful for her children that she was still relatively healthy when they first learned about her HIV. She later went through a very difficult period where she was hospitalized and feels it would have been more frightening for her children to hear about the HIV for the first time then.

Due to their age when she chose to disclose, Sandra started out by telling the children only very general information. One thing she did do from the start was to use the name HIV when she talked about her illness. To help keep the process of treatment and doctors visits from being a mystery to her

Disclosing Your HIV Status to Providers

By Karin Sabey and Kathy Kuempel

Whether or not to disclose your HIV status to a service provider is a question that many people living with the disease will encounter. Who needs to know, when, and most importantly, why, are all questions to be considered in such situations. Of course, each individual should do what feels most comfortable for him or her. Having said that, here are some things to consider when you are deciding whether or not to disclose.

First, let it be known that you are never obligated to disclose your HIV status to a health care provider. Universal precautions used in hospitals and clinics are implemented to help prevent the spread of HIV from a patient to a service provider or vice versa. However, there are many situations where it would benefit both you and the provider to disclose your status.

When you enter the emergency room or urgent care for treatment of an acute illness, disclosing your HIV status is definitely a wise idea. If the emergency room or urgent care team is aware of your HIV status from the start they will be better able to determine what is causing your pain or illness. This may save all involved a considerable amount of time and you, the patient, unnecessary tests and related costs.

For women visiting their gynecologist, it is also beneficial to tell providers that you are HIV-positive. An abnormal Pap test may be treated differently due to the increased risk of cervical cancer in women living with HIV. As well, vaginal infections may be harder to treat and may require a longer course of medication in HIV-positive women than in

negative women. If your gynecologist was not aware of your HIV status they may not prescribe the appropriate amount of medication and your symptoms may not go away or may come back sooner.

As well as having an HIV specialist, people living with HIV often have a primary care provider that they see for routine medical care. Again, disclosing your HIV status to your primary care provider will assist them in determining appropriate treatment for common health problems. Some health concerns such as hypertension, diabetes, and high cholesterol can be related to HIV medication. In addition, the knowledge that you are taking HIV meds will help your primary care provider avoid dangerous medication interactions.

When it comes time to visit the dentist, it would be helpful for an HIV-positive patient to notify the dentist about their HIV. A dentist or hygienist can be particularly helpful in recognizing HIV-related oral problems such as thrush, Kaposi Sarcoma lesions and other gum problems. This will translate into better oral health for you.

Mental health professionals such as your therapist, psychiatrist, or counselor are not always thought of as a health care provider and thus, is a provider that many patients neglect to disclose their HIV status to. HIV may not be the primary reason that you are in therapy but it generally has an impact on overall mental health in the same way that any chronic illness would. HIV often comes into play in decision-making, emotional status, and relationships.



As well, it is often intricately tied into a person's concept of self. Disclosing all issues relevant to your mental health will make for a more therapeutic and successful therapy experience.

Finally, anyone who prescribes medication for you or who would recommend any herbal therapies should be aware of any medications you already take, particularly if you are taking HIV medicines. Serious, harmful drug reactions are possible if providers are not fully aware of all the medications you are taking. Also, some herbal supplements should not be taken by those who have HIV or who are on specific HIV treatments.

So, while it is not mandatory for someone living with HIV to disclose their status to health care providers, there are advantages to doing so. Your HIV is an important component of your overall health and your providers will best be able to serve you if they have an accurate and complete health history for you. Keep in mind that disclosing your HIV status benefits both you and your provider and should never affect how you are treated by anyone in your clinic. You have the right to change providers if you feel that you are being discriminated against, in any way, or asked questions that you feel are inappropriate or irrelevant to your care. ❁

Disclosure: Being Out as an HIV-positive Teen

By Irie L. Session



Young people between the ages of 13-24 are the fastest growing group of individuals newly diagnosed with HIV in the U.S. Half of all new HIV infections occur among people under 25. In fact, every hour, two Americans under age 25 are infected with HIV.

Telling someone you're HIV-positive can be difficult at any age, but imagine being a teenager and thinking about how to tell your family, friends and boyfriend or girlfriend. One of the hardest decisions facing an adolescent with HIV is whether to keep the virus a secret.

Discovering an HIV Diagnosis

After an HIV diagnosis, many youth keep their status a secret from peers, family members and sexual partners. It's not uncommon for newly diagnosed adolescents

to try and make the news "go away" by ignoring it. Unfortunately, attempting to ignore their HIV status often leaves them feeling lonely and depressed. During this time it is important for youth who are HIV-positive to remember they are not alone! There are many other people their age who are going through the same thing.

Adolescent Development

Adolescents feel invincible and immortal, yet they struggle with developing a sense of their own identity and often worry about being normal. Being physically attractive, dating and developing close friendships are also important concerns.

Adolescents experience the world through their interaction with others. As a result, they fear rejection from family members and friends and are concerned about being labeled by peers or potential partners. Many face their HIV diagnosis with fear, denial and avoidance.

Adolescents and Medication

Since adolescents have the notion of being invincible, ("It will never happen to me"), many fail to take their medications. They want to establish a sense of themselves as "normal" and "not sick" and not be different from their peers. They don't want daily reminders of their illness. However, taking their medication can help many young people live a more normal and healthy life.

Getting sick often or having a lot of doctors visits may send a red flag to the peers of HIV-positive teens that something about them is different. By taking their medication, HIV-positive teens may not get as sick or have as many doctors visits. However, they may not want others to see them taking their pills.

To avoid this stigma, many youth take their medication either in the morning before school or at night. Youth can also be creative in the way they transport their medications to school or other outings. There are pieces of jewelry such as watches and lockets that can double as pillboxes.

Deciding to Disclose

Thinking ahead about reasons for telling, or not telling is one of the best ways to prepare for disclosure. Medical staff and family members of adolescents should support disclosure as a process and encourage appropriate timing, organization of support systems and using the right words. They can also support the youth by being open with them about the challenges and advantages of disclosure.

Here are a few questions those who support adolescents in the disclosure process can help them ask and answer:

- Why do you want to tell them?
- Why do you feel they need to know?

- Will they understand the importance of keeping it to themselves?
- What are the advantages of telling them?
- What are the disadvantages of telling them?
- How realistic are your expectations?
- Are you likely to regret having told them?
- In the future, are you likely to regret not having told them sooner?

If an adolescent is not ready to disclose their HIV status to someone they know personally, they can anonymously call a hotline or HIV service agency. There are also support groups strictly for adolescents. They're a great place to get information, vent intense emotions and make new friends. ❁

Irie L. Session is the Adolescent Services Coordinator for Bryan's House, a non-profit agency serving children, youth and families impacted by HIV/AIDS.

*Reprinted courtesy of
www.PositiveWords.com*

Robert's story

My name is Robert, I am 15 years old, and I am HIV-positive. I was born with HIV because my mom had it. My dad was HIV-positive too, he got sick when I was two years old, after that we all got tested; my mom was positive, my older sister was negative, but I tested positive. My dad died in 1995 when I was seven years old. I live with my mom now in Minneapolis. When my parents found out that I was HIV-positive, I started medicine right away.

I have known about my status since I was very young. I had many questions when I was little; when I was four years old I asked my mom why I was taking medicine? Why I had to go to the doctor so much? My older sister didn't. My mom told me that there was a "bug" that lived in my blood, and that the medication was keeping the bug small, and keeping me healthy. She later explained that this "bug" was HIV.

I am glad that this hasn't been kept a secret from me. When I started school we told the school nurse and my teacher, but no one else needed to know. It wasn't hard for me to keep our secret, I knew to do things like put on my own Band-Aid if I got hurt.

When I was in 3rd grade I told one of my friends about my HIV. He didn't care. He stayed my friend, I still see him sometimes. But, there was another friend whose grandma found out and told him not to eat over at my house anymore, or to drink out of our glasses. It didn't seem to be such a big deal to him though, he snuck over sometimes anyway. I explained to him how you could get HIV and how it was and wasn't spread, and that he couldn't get it from me.

My advice to parents is to tell their kids. If they don't, how are their kids going to trust them? My mom has always been straight with me, and that played a big part in the trust we have between us.

I am an average teenager now; school is ok, but I'd rather be playing basketball. I am going to an alternative high school and am in 10th grade. All the teachers and counselors know about my HIV and they are cool about it. If I have to miss school because of feeling sick or going to appointments they understand, or even when I have had to leave school to stay with relatives for a while because my mom was sick and in the hospital. I don't have to make up stories. This makes things easier for me, and my family. My viral load is undetectable and my T-cell count is 164. I feel good. I don't always do a good job of taking my medicine, they make me feel tired and sick sometimes. I know they are important but it is hard.

Tamara's story

Tamara* is a mother who has decided to wait to share her status with her children. She has disclosed her status with her husband, her parents and siblings. HIV also plays a key role in her professional life as she is very active working in the HIV community addressing the needs and treatment issues that people living with HIV face; she conveys the voice of accountability, reasoning and change.

Tamara shared that there was never a moment when HIV didn't play a role in the life of her children. From the time when she learned that she and her husband were expecting their first child, she also learned that she was HIV-positive. That was during the time when doctors knew very little about mother to child transmission so they recommended that she terminate her pregnancy. But she continued her pregnancy and gave birth to one of the most beautiful little bundles of joys that she had ever seen. Her baby was perfect in every way.

Timing is everything as Tamara wonders when will be the right time to share her story and status. Knowing that people are and can be very cruel, as a mother she sees her role as the protector of her children from those kinds of people and their ignorance. Tamara has decided to wait until there is a meaningful teaching moment, when her children are mature enough to understand all of the ins and outs of HIV. She doesn't want them to carry the weight of her status or to fear for her life, two issues that can rob

story continued on facing page ➡

Disclosure of an HIV diagnosis to a child: Psychosocial considerations

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- National Cancer Institute, National Institutes of Health



The decision to disclose a diagnosis of HIV to a child is very difficult and often a tremendous emotional burden. Most parents do eventually disclose the diagnosis to their child, though most benefit from help in knowing the best way to communicate this information.

Timing of the disclosure is of great importance. Careful thought should be given to the child's age, emotional development and cognitive abilities, the timing and location of disclosure, the words used, and how questions concerning transmission and future caregivers will be answered. Information must be supplied in a developmentally appropriate manner. Anticipating the child's responses along with careful planning and back-up supports will increase the chances of a more positive outcome. Once

a diagnosis is disclosed, it cannot be taken back. Parents should be made aware of all supports that are available to the child and the family. It is also important to remember that a parent's decision to discuss his/her HIV diagnosis [or a child's] may lead to other important disclosures, many of which may be long-kept family secrets, including biological parents' true identity, other family members with HIV/AIDS, and facts concerning disease transmission.

Disclosure of a diagnosis to a child seems to take place best in a supportive atmosphere of cooperation between health care professionals and parents. Accurate, simple, developmentally appropriate, yet complete explanations about the virus and medical procedures should be provided, so that the child does not perceive the

required treatment as punishment. The child needs to be reassured that he or she did not directly cause the illness. Parents should be prepared to answer a barrage of questions ranging from the simple and innocent to the accusing, angry and emotionally upsetting. Parents may find it helpful to discuss disclosure with another parent who has already been through the disclosure process successfully. Role-playing can help in trouble shooting certain questions or planning answers to more difficult issues that may arise.

While parents have cited many understandable reasons for holding off on informing their child[ren] about the HIV diagnosis, it is well known that a child's capacity to trust develops from the relationship the child has with his or her parents. Delays in disclosure and the fabrications that often accompany delayed disclosure can disturb trust. Children sense when something is out of the ordinary and silence and secrecy can deprive them from the opportunity to explore their emotions or fears and ask relevant questions. When children are not included in this process, they may feel confused, alone, forgotten, or abandoned.

When a family decides to disclose a diagnosis, they may require assistance in relating the information to their child[ren] in a style which takes into account the child[ren]'s age, emotional development, and cognitive abilities. It is essential that all intervention related to disclosure are planned from a developmental understanding of children's needs. The following guidelines can help health care professionals guide the family during the disclosure process.

Disclosure process

Step 1 - Preparation

- Have a meeting with the parent/ caregivers involved in the decision making process.
- The meeting should be held with the staff member that the family trusts the most if available, and if available, a disclosure specialist.
- Address disclosure of diagnosis and ascertain whether the family has a plan in mind.
- RESPECT the intensity of feelings about this issue.
- Talk about the pros and cons of disclosure and get feedback on the child's anticipated response.
- If the family is ready, guide them in the best ways to disclose the diagnosis (step two).
- If the family is NOT ready, encourage them to begin using words that they can build on later (immune problems, virus, infection, etc).
- Encourage the family to begin talking to the child about viruses in general, what they are, how they are spread, that people with viruses are no different than anyone else. If this information is new to the child, share books about viruses for young children (see resources list at end of this section).
- Explore the child's level of knowledge and his/her readiness (emotional stability and maturity).
- Strengthen the family through education and support so that they can reveal the diagnosis themselves.
- Schedule a follow up meeting. Let the family know that you will meet them on a regular basis

to help guide them through the disclosure process as well as afterwards to make sure additional help is not needed.

- RESPECT the family's timing – DO NOT RUSH the disclosure process, but strongly encourage the family NOT to lie to the child if he or she asks about whether they are HIV-positive.
- Remind the family to avoid disclosure during a medical crisis, during a fight or in anger.

Step 2 - Actual Disclosure

- In advance, have the family think through and/or write out how they want the conversation to go.

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Tamara's story continued...

their innocence and hinder their ability to excel in their educational environment. She also wants them to be able to judge the character of other people regarding their ability understand HIV with sensitivity. Tamara says her biggest fear about not telling her children is "that they would learn about her status from others" or that they might use her status as a weapon against her during their teenage years.

So, as the day for Tamara to disclose her status is quickly approaching, she is drawing from her past experience to gear up to empower her children with the strength, wisdom and the mother's wit that they will need to win life.

Life is all about timing and choices!

**Name changed for privacy protection.*

HIV/AIDS Disclosure and Childcare Providers

a commentary by Linda Atlas

As a member of the women and family network I was given the assignment to research the policy that govern childcare providers when it comes to HIV/AIDS disclosure issues. I contacted a couple providers from both center base programs and family childcare programs to get their view on disclosure. It became very apparent that when it came to policy many were interpreting reporting requirements (see box

Childcare Providers Illness Reporting Requirements

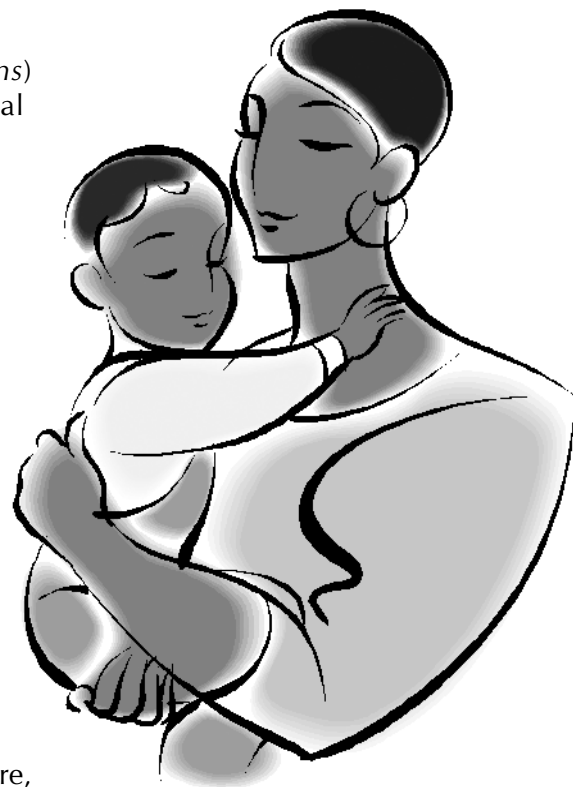
According to the National Resource center for health and safety in child care, the child care facility in Minnesota must give the following notices about illness or condition of a child:

- A. The license holder must ensure that a parent is notified immediately when the parent's child becomes sick at the center.
- B. The license holder must require a parent to inform the center within 24 hours, exclusive of weekends and holidays, when a child is diagnosed by a child's source of medical or dental care as having a contagious reportable disease specified in part 4605.7040, or lice, scabies, impetigo, ringworm, or chicken pox.
- C. The license holder must post or give a notice to the parents of exposed children the same day a parent notifies the center of a child's illness or condition listed in item B.
- D. The license holder must ensure that the health authority is notified of any suspected case of reportable disease as specified in part 4605.7040 within 24 hours of receiving the parent's report.

below for list of regulations) based on their own personal understanding.

The first provider informed me that it was not mandatory for the parents to disclose their child's status but she [personally] would like to know if she did indeed have an HIV-positive child receiving care from the facility. During my conversation with the second provider it was clear that the facility had interpreted HIV as a communicable disease that required reporting to the Minnesota Departments of Health and Human Services Childcare licensing Division. Furthermore, the provider thought that parents of other children in the facility would have to be notified if there was a positive child receiving care at the facility. Somehow, they had interpreted the policy as equating communicability of HIV to Measles, Mumps, Chicken Pox, Lice and Pink eye, just to name a few.

The second provider is not alone in misunderstanding the law. HIV is an infectious disease, but it is not transmitted in the same ways as the above-mentioned communicable diseases. The reporting requirements of communicable diseases are different from HIV. To be clear, childcare providers are not required to report to any state agency nor to the parents of other children in their facility. A parent does not have to disclose to the childcare provider that their child has HIV. The only time a provider can disclose this information is if



there is a direct health threat in which there has been a significant exposure to the bodily fluids that transmit HIV, and the laws regarding this are very specific.

Childcare providers are required to use universal precautions, wear gloves when changing diapers, and clean the changing table between each diaper change. If there is an accident, gloves and bleach are also required when cleaning up bodily fluids vomit, saliva and blood. Following these guidelines, there is no reason for a provider to worry about HIV infection being transmitted from one child to another. What is clear is that when people hear the phrases "HIV" coupled with "child care facility" a knee-jerk reaction causes them to forget that HIV is transmittable only through blood, semen, vagina secretion and breast milk – fluids typically not present in day to day activities at a child care facility.

Lack of valid, accurate information regarding HIV and transmission, and fear-laced stigmatizing and discriminatory attitudes continue to exist 20 years into the epidemic. As a network that advocates on behalf of women and families, one of our goals is to move providers who become aware of a person's HIV status from thinking "who shall I tell", but take the extra minute to ask "why would this person need to know". ❁

Sandra's story continued...

children, Sandra took them along to her clinic visits, when possible, and did not hide the fact that she was taking medication. As well, the kids were always permitted to adjust to any information at their own pace and she answered their questions in an honest, but age appropriate way. Now that her children are older, she talks to them more about transmission and about how they can protect themselves.

While Sandra chose to disclose her HIV status to her kids, she follows their lead when it comes to disclosing to their friends and neighbors. Sandra feels that her children are less able than she to deal with the prejudice and stigma that HIV/AIDS carries and she respects the impact of their peers. Both children have many friends who often spend time at the family's home. They have opted not to tell these friends about Sandra's HIV.

When asked if she has any regrets about telling her kids about her HIV, Sandra says "absolutely not!" Her biggest regret is that her children have to learn about HIV by in such a personal way. She is also saddened that her health doesn't allow her to do more activities with her kids. However, despite their challenges and with a little help from their support system, Sandra's family is enduring. She says that they have all learned how to live with HIV together as a family and that she wouldn't have it any other way.

Anita's story

Anita is a wife, mother, grandmother, daughter and a sister just to name a few of the hats that she wears. Anita learned of her HIV status about ten years ago after she had a long hospital stay due to a major bout with pneumonia. Anita received a call from Carol Fitzgerald [disease investigator from the Minnesota Department of Health] stating that she had some very important information to share with Anita. Anita booted her husband and children out of the house and invited Carol over to tell her of this important information. Carol arrived; they took a seat and she began the process of informing Anita of her HIV status. Anita was stunned by the information that she heard – not only did she have HIV, but it had developed into AIDS. Tears and thoughts of disbelief flowed from her eyes and through her mind. She had thoughts of "how can something like this happen to me" because had never entered her mind that she might be at risk for HIV.

Within a week of learning of her status Anita decided to disclose to her husband being that they love one another and they together would be able to work it out. Her husband, who is a man of lots of love, just kept pouring on the love and support. Later that week they met with their children to inform them of their mother's health status. Anita said it was unbelievable how informed and supportive their children were. One of their daughters began to talk about the things that she had learned in school regarding HIV such as transmission and risk factors. Anita believes that this was a real blessing that her daughter was so informed. They all cried together, they hugged each other and they laughed together – there was so much love, comfort and support as they faced that most unbelievable moment in time.

Anita has also disclosed her HIV status with her parents, sibling and her grandchildren. All of her family members are very supportive. Her grandchildren don't really understand the ins and outs of HIV but they know that their grandmom is sick. There is more to her story when it comes to disclosure to other people. Her extended family also knows about her HIV status and they look at her as if she was something from another planet.

Anita and her husband stand at the side of other HIV-positive parents who need to tell their children. Anita has a goal of becoming more involved as an educator in order to teach others about HIV and possibly producing an educational video.

Disclosure can produce mixed feelings!

Disclosure Dos and Don'ts:

Tips to help you prepare to disclose your HIV status to your kids

Reprinted courtesy of www.PositiveWords.com

DO forget the myth of the "right time." This information will hurt and worry your children; it's unavoidable. There's no magic "right time" to tell them. People who wait for this sometimes die without ever disclosing – leaving behind angry, hurt, confused kids.

DO recognize wrong times, however. If a child is in transition (changing schools, leaving home or dealing with a life tragedy) and you're not critically ill, you can wait a few months for things to smooth out.

DO provide information about HIV written for children or teens. Sources: local ASOs (AIDS service organizations), pharmaceutical companies and the Centers for Disease Control (CDC) –also see resource list at the end of this newsletter.

DO consider age. Generally, telling small children that you have an "illness" is specific enough. Teens are usually advanced enough to hear about HIV. For children between the ages of 7 and 12, it usually depends on the child. Some people choose to leave their medications out and wait for a child to ask when he or she is ready.

DO think about confidentiality. But remember, a child will need to tell someone. Forbidding it won't work.

DO be prepared for teens to act out. (It's often easier for them to show anger than fear).

DO be honest! Deal with your shame, guilt, and discomfort about talking to the kids about "things like that." Tell the truth about sex, drugs and family secrets such as homosexuality, infidelity, addiction, rape, and abuse. Talk about death. You want your kids to be honest with you, right? Here's where you show it's a two-way street.

DO give your kids plenty of time to adjust.

DON'T be afraid of tears – yours or theirs.

DON'T hesitate to ask a friend or HIV professional to help you break the news.

DON'T say AIDS at first; say HIV. Many children and teens think AIDS = Instant Death.

DON'T buy it if teens pretend to "know it all."

DON'T bring this up once and drop it. Provide more advanced information as your child gets older.

And finally...

DO realize that disclosure often brings families closer together than ever before!

Best of luck to you and your family.

Dr. Sandra Trisdale is a faculty member of the Arizona AIDS Education and Training Center. She is a specialist in HIV and mental health issues.



Clinical Trials in Minnesota

THE FOLLOWING IS A LISTING OF RESEARCH STUDIES AVAILABLE AT THE MINNESOTA AIDS CLINICAL TRIALS UNIT

We encourage more women to participate in research studies carried out by the ACTU in Minnesota. Women are an important part of our work as we try to find new information about how HIV and its treatments impact them differently than men. This is extremely important as rates of HIV in women continue to increase but most of the research and medication studies have been done with men. Given the fact that our bodies are very different, we need this information to ensure that women are being given the most effective information and treatment possible.

Current Studies Open at the Minnesota AIDS Clinical Trials Unit

Metabolic Disorders/Lipodystrophy Protocols

Study 1 – A5163 The Improving Bone Density Study: Evaluation of the effect of alendronate (Fosamax), calcium and vitamin D supplements on HIV-related decreased bone mineral density (osteopenia/osteoporosis). This medication is used safely in people who do not have HIV and we will be looking to see if it is safe and effective for those on HIV medications. Participants must not have a history of Hepatitis C infection.

Treatment Experienced

Study 1 – A5165 DAPD Salvage Study: A Phase I/II study testing the new nucleoside antiretroviral medication DADP for its safety and effectiveness. The drug mycophenolate will also be studied to see if it can increase the antiviral action of DADP. This study is for people who have taken many different HIV medications before and are not responding well to their current treatment. Payment will be made for each study visit.

Study 2 – A5146 Therapeutic Drug Monitoring Study: A new method of dosing HIV medications will be tested in this study. Therapeutic Drug Monitoring works to individualize the dosing of antiretroviral medications and along with resistance testing, should result in getting the best medication response possible for the participants. This study is for people who have taken many antiretroviral's before, including protease inhibitors, and may not be doing well on their current medications. Participants will receive a stipend while on this study.

Naïve Protocols/Beginning HIV Treatment

Study 1 – A5138 The Cyclosporin with Initial HIV Treatment Study: This study is for people who will be taking HIV medications for the first time. Cyclosporine will be added to an antiretroviral regimen to see if it will bring about a larger increase in CD4+ cells than taking HIV medications alone.

Other Protocol Opportunities

Study 1 – A5030 CMV Valgancyclovir Study: People who have CD4+ cell count less than 100, HIV viral load greater than 400 and have been exposed to CMV at sometime in their life (most of us have) will be followed every eight weeks to see if CMV virus is growing in the bloodstream. If it is, they will be randomized to Valgancyclovir or a placebo to see if the medication prevents people from becoming sick with CMV (it can cause blindness, or problems in the stomach and bowels, etc.) Participants will be paid \$20 for each study visit.

Study 2 – A5084 The Pregnancy Study: An observational study of pregnant women to measure the safety and complications of using antiretroviral therapy during pregnancy. To enroll, women must be HIV-positive and between 20-34 weeks pregnant. They also must be taking an HIV medication regimen that includes a protease inhibitor. This study is being done at the Hennepin County Medical Center HIV clinic.

Transportation assistance (bus, parking and cab fare) is available to all study participants. In addition, the MNACTU will provide a \$50 stipend for each study visit for people living outside of the 7-county metropolitan area (Hennepin, Ramsey, Carver, Scott, Dakota, Anoka and Washington) to help offset their travel costs.

For a more details about participating in clinical trials and a listing of research studies that are currently available at the Minnesota AIDS Clinical Trials Unit, please contact a study nurse at: Phone: (612) 625-1462 Fax: (612) 625-1923, email: minnactu@umn.edu or visit our website at <http://www.lamp.med.umn.edu/actu>.

continued from page 6.

Disclosure of an HIV diagnosis to a child

Encourage the family to begin with “Do you remember...” so that the child is given information they are aware of before introducing other facts. Build up with information about the child’s life, medications, and procedures that may explain questions they may have had.

- Encourage the family to also be prepared for questions the child may ask such as “How long have you known this?; Who else has the virus?; Will [you] I die?; Can I ever have children? Who can I tell?; Why did this happen to me and not my brother/sister? Will [you] I always have to take medicines?; Who else knows?” and perhaps other questions related to family members they have known well who have died.
- Have the family choose an environment where they and the child are most comfortable.
- Only those people that the child is most comfortable with should be there. Avoid large group disclosure.
- The health care provider can offer to facilitate this meeting, but if all possible, work should be done in advance so that the parents can share this information on their own.
- The diagnosis should be shared quickly keeping medical facts (immunology, viral factors) to a minimum.
- Try and have the family describe HIV as a chronic illness and to provide hope.
- Silence as well as questions needs to be accepted and allowed for.
- The child needs to hear that nothing has changed except for them having a name to put the illness.
- The child also needs to hear that their family will be by their side, they will not be alone, and nothing they did caused this to happen.
- After the disclosure, the child needs to be embraced, if he/she is comfortable with that.
- Offer the child the opportunity to meet with other children their age [who are HIV-positive or whose parents are HIV-positive].
- If the diagnosis is to be kept secret, it is important that the child be given the names of people they CAN talk to regarding questions they have about the virus or about their feelings in general. For example, instead of saying, “Don’t tell anyone”, a more helpful response is “You can talk to _____ about all of this. If there are other people you want to talk to, please come to me/us first so we can decide together about the best time to tell them.”
- Give the child a journal or diary for them to write private notes to themselves about their thoughts and feelings. Each page can begin with “Dear HIV” or “HIV, Today I want you to know...”
- If appropriate, share books about children living with HIV.
- Schedule a follow up meeting.
- disclosure and again every 2-4 weeks for the first 6 months to assess impact of disclosure, answer questions, and to help foster support between the child and the family.
- Ask the child to tell you what they learned about the virus.
- Writing and art techniques may be useful. Bibliotherapy might also be more useful at this time.
- Assess for changes in emotional well being and provide the family with a list of symptoms that could indicate that more intensive intervention is needed.
- Support parents in having disclosed the diagnosis if they are interested, refer them to a parents support group.
- Ask them if they would be interested in helping other parents considering disclosure with their child.
- Remind parents that disclosure is not a one-time event. How one understands the HIV diagnosis the day it is disclosed will be very different from how they understand it the first time that they are hospitalized for an HIV-related illness (or they hear about a person dying from the disease). Ongoing discussion of the disease and its impact on the child will be needed.
- Ask the parents about what other support they feel would be helpful to them and/or their child.
- Now that the child is aware of the diagnosis, provide information about specialty camp programs.

Step 3 - Post Disclosure

- Provide individual and family follow up two weeks after

RESOURCES

Warning features warranting referral to a mental health specialist

- A significant drop in grades
- Persistent anxiety about infection, parents' health, or own death
- Sleep disturbances
- Reluctance to go to school
- Loss of enjoyment and interest in previously enjoyable activities
- Loss of interest in appearance
- Irritability, grouchiness, and excessive moodiness that is new
- Harsh self-criticism, feelings of inadequacy, worthlessness and powerlessness to go on living in the face of the disease
- Withdrawal from peers
- Regressive behaviors (bed wetting)
- Destructive outbursts or other behaviors problems that are new in onset
- Separation anxiety affecting ability to function in day to day activities
- Changes in appetite/overeating or weight loss
- Self-destructive behavior, drug and alcohol abuse, sexual promiscuity, self-mutilation
- Suicidal ideation
- Depression

Dr Wiener, child psychologist and HIV specialist, works as a psychosocial research specialist at the National Cancer Institute – a branch of the National Institutes of Health. Contact her at 301-496-3062 or wienerl@mail.nih.gov. 🌸

Below is a short list of materials published on HIV/AIDS that can assist parents in the disclosure process. Please contact Dori Makundi 612-373-9175 for assistance locating resources listed.

BOOKS

Alex, The Kid with AIDS – by Linda Girard. Albert Whitman and Company: Morton Grove, IL, 1991

Be A Friend: Children Who Live With HIV Speak – by Lori Wiener, Aprille Best and Philip Pizzo. Albert Whitman and Company: Morton Grove, IL 1994

Bye-Bye Secrets: A Book About Children Living With HIV or AIDS in their Family – by the Group of Five. The Teresa Group: Toronto, Canada 2002

Children and the AIDS Virus – by Rosemarie Hauscherr. Clarion Books., New York, NY 1989

Come Sit By Me – by Margaret Merrifield. Women's Press: Toronto Canada, 1991

David Has AIDS – by Doris Sanford. Multnomah Press, Portland, Oregon, 1991

Does AIDS Hurt: Educating Young Children About AIDS – by Marcia Quakenbush and Sylvia Villarreal. Network Publications, a division of EYR Associate, Santa Cruz, CA

How Can I Tell You? Secrecy and Disclosure With Children When a Family Member Has AIDS – by Mary Tasker. Association for the Care of Children's Health, Bethesda, MD, 1992 [No longer in print, but is available at libraries and some agencies]

How Do I Tell My Kids? A Disclosure Booklet About HIV/AIDS in the Family. – by the Teresa Group. Teresa Group: Toronto, Canada, 1999

Jimmy and his Family – by Mary Tasker. Association for the Care of Children's Health. Maryland: Bethesda, 1992

Jimmy and the Eggs Virus – by Mary Tasker. Association for the Care of Children's Health. Maryland: Bethesda 1988

My Parents have HIV/AIDS: Some advice from an Eight-Year Old – by Stephanie & Kathy Gerus.

You Can Call Me Willy – by Joan C. Vernioero. Magination. Press, New York, NY, 1995

Watch Out, He's Got AIDS – by Mikey Handis. Water Row Press: Sudbury, MA 1998

WEB SITES

National Pediatric and Family HIV Resource Center
www.pedhiv aids.org

Provides a wealth of information for children and families living with HIV. Links to treatment information, tips on disclosure, and a place for people to submit questions and share resources.

Parent Soup
www.parentsoup.com

Offers helpful information for talking to kids at various ages about sexuality, including masturbation, dating, oral sex, pregnancy and HIV/STDs.

Talking With Kids About Tough Issues
www.talkingwithkids.org

This site provides guidelines for talking with kids about issues such as drugs and alcohol, sex, HIV and violence.

The Teresa Group Child and Family AID
www.teresagroup.ca
www.kidstalkaids.org

List of resources for families living with HIV. The 'kidstalk' site offers a place where kids, youth, parents & professionals living with and affected by HIV/AIDS talk with each other.

Young People and HIV/AIDS
www.thebody.com/whatis/children.html

Resources for teenagers, parents and teachers, including information on prevention issues among teenagers, telling children about HIV and talking to kids about tough issues.

Disclosure fact sheets

Information from the MN AIDS Project, Legal Department

HIV status is confidential information. There are very few settings where you are required to disclose you (or your child's) HIV status, and often you may be able to disclose that you (or your child) has a disability without explaining that the disability is due to HIV. Below are answers to some frequently asked questions related to HIV and disclosure in several settings. Due to space limitations, we have only printed information pertaining to landlords, schools, employers and insurance companies. In addition to these settings, we have information fact sheets on disclosure in health care settings, child-care facilities and substance abuse treatment centers. To access this additional information, please contact MAP AIDSLINE at 612 373 2437, or log onto <http://www.mnaidsproject.org/living/systems/index.htm>

As you read this, keep in mind that this document provides general information only. This is NOT legal advice and should not be used as a complete answer to an individual legal problem. If you need legal advice for a specific situation, contact an attorney. A resource list is included at the end of this section.

1. Can a _____ ask about my (my child's) HIV status?

a. Landlord: There are many laws regulating landlords and tenants including the Minnesota Human Rights Act, the federal Fair Housing Act, and the Americans with Disabilities Act, which make this area of the law very complex. Generally speaking, a landlord or the landlord's employees may not ask you about your HIV status because it would be discriminatory against a person with a disability. However, there are some legal exemptions for landlords who rent rooms in their home and for rental units that contain four or less units where the owner lives in one of the units. Also, if you are applying to rent housing that is set-aside for persons with a certain type of disability, you must show proof that you have a disability that.

b. My child's school: Schools are open to the public and as a general rule are not permitted to inquire about you or your child's HIV status.

c. Employers: Prior to extending a job offer, an employer may not ask about any existing disability including your HIV status. After a job has been offered, employers may require a medical exam as an extension of a job offer, if all employees are required to have a medical examination and the medical examination relates to essential job related activities

d. Insurance Companies: Insurers are permitted to collect medical information including your HIV status, in order to make appropriate decisions about coverage.

2. If _____ ask me about my (my child's) status, do I have to tell them?

a. Landlord: Not unless you are applying to rent housing that is set aside for persons with a specific HIV-related disability.

b. My child's school: Generally, you are only required to disclose you or your child's HIV status when there is a direct health threat. A direct health threat means a substantial risk of serious harm to the health and safety of another person that cannot be eliminated with a reasonable accommodation. Reasonable accommodation means making existing facilities and services accessible to persons with disabilities without creating an undue hardship on the facility. Employers: Generally an employee does not have to reveal their status. When a person with a disability requests a reasonable accommodation, documentation verifying the qualifying disability must be provide, and you may be able to verify a disability without disclosing HIV status.

c. Insurance Companies: You are required to give your insurance company any information they ask for if it is information they need to decide if your insurance policy must pay the bills that have been sent to them. If you provide false information, you could be criminally liable for insurance fraud and have your insurance benefits denied.

3. If _____ doesn't ask me about my (my child's) status, do I have to tell them?

a. Landlord: Unless you are seeking housing designated for certain disabilities, disclosure is not required. Often, proof of a qualifying disability can be provided without disclosure of HIV status.

b. My child's school: Generally a person is not required to disclose their status, unless a direct health threat exists (see section 2b) – Another reason you may want to disclose your child's status to the school is if the school nurse needs to treat or administer medication to your child.

c. Employers: No, you are not obligated to disclose your HIV status.

d. Insurance companies: Any time you are looking for insurance coverage you are required to tell the insurance company about any pre-existing medical conditions you have that could affect whether you are eligible to be covered by them. Your HIV positive status is a pre-existing condition.

4. Are there situations where _____ is allowed to disclose my (my child's) status to someone else?

a. Landlord: As mentioned before, landlord and tenant law is very complex. Public housing providers and housing providers who receive government funds often have legal requirements that are different from private owners of rental housing. You may wish to talk with an attorney or a legal service agency for more specific and detailed information. If you disclose your HIV status to your landlord and do not want others to know, tell your landlord that you would like this information to stay private to avoid any misunderstanding.

b. My child's school: Disclosure is only permitted when there is a direct health threat (see section 2b).

c. Employers: An employer must keep a person's status confidential with limited exceptions. A supervisor can be informed of an accommodation once it has been requested, but not the underlying medical reason. Also, first aid personnel may be notified of any conditions that may require emergency treatment.

d. Insurance companies: Medical information may be disclosed to prevent fraud, to health care institutions or professionals, to regulatory authorities, as required by law, warrant or subpoena and research studies.

5. What can I do if I find out my _____ disclosed my (my child's) status when they should not have?

a. Landlord: Because of the complexity of the laws involved, you will have to talk to an attorney or a legal service agency to find out what legal rights you have based on your particular housing situation. Your legal rights and the actions you may take may vary depending on the circumstances of the disclosure, whether your housing is publicly or privately owned.

b. My child's school: In general, HIV status is confidential information. If your child's school discloses that information, they could be sued for civil penalties and have criminal charges filed against them.

c. Employers: If your employer discloses your HIV status when they were not required or allowed, they could face penalties under the Minnesota Human Rights Act, the Americans with Disabilities Act and other laws. You should contact a legal service agency or attorney to discuss your options. Americans with Disabilities Act (ADA) you may be able to collect similar and even additional compensation.

d. Insurance Companies: You can file a complaint with the state insurance commission, the department of commerce, or other appropriate government agencies. You may also have some rights under the Data Practices Act. To determine what options you have, you will need to talk to a legal professional

6. What if _____ tells me they need to disclose my (my child's) HIV status to protect the health and safety of others?

a. Landlords: The health and safety of others is not threatened unless there is a significant exposure to the bodily fluids that can transmit the HIV virus. Under the law, this is sometimes called the direct health threat. If you are told that there is a "duty to warn", you should know that in Minnesota law, the duty to warn is very specific. There must be a serious threat of bodily harm or death and a clearly identified victim, plus only specific professionals are obligated to make the warning. Landlords do not have a duty to warn because they would not have access to specific information.

b. My child's school: same as for landlords

c. Employers: same as for landlords.

d. Insurance companies: same as for landlords (see above).

7. When would it help me to tell _____ about my (my child's) HIV status?

a. Landlords: If you are applying to rent housing that is set-aside for persons with a specific disability or an HIV-related disability, you may need to disclose your status. In addition, if you are requesting reasonable accommodation, you may need to disclose your status. Depending on your relationship with your landlord, you may find it helpful to disclose if you are having health problems that are affecting your ability to pay your rent or otherwise affecting your living situation.

b. My child's school: Disclosing you or your child's HIV status is a very personal decision. Disclosing to your child's school may help the school respond better to your child's needs, by properly administering medications, excusing frequent absences, such as for doctors appointments, and making other necessary accommodations. In deciding whether or not to disclose, you should take into account your relationship with the school, how comfortable you are discussing HIV with your child and with others outside of your family, and the possibility of unwanted disclosure. You should also consider with whom in the school you would like to discuss your or your child's HIV status. The school nurse is a good starting point and may be the only person you'd like to know. Other possibilities include your child's teachers, the principal or assistant principal. You should not feel pressure to disclose, "to protect" the other children, as all schools are required by OSHA to use universal precautions to protect the health and safety of employees and students.

c. Employers: Disclosing your HIV status is a very personal decision. Depending on your employer you may want to tell human resources or your supervisor about your HIV right away in order to make sure they know about your rights and their obligations. However, in most cases, the best time to tell your employer about your HIV is when it begins to affect your work.

d. Insurance companies: Because disclosing your HIV status is required to receive insurance coverage, it is unlikely that you would need to disclose your status for any other purpose.

Additional Resources

Minnesota AIDS Project Legal Services 612-373-9176
800-248-2437

Discrimination (employment, housing, accommodation)

Minnesota Department of Human Rights 651-296-5663
Minneapolis Civil Rights Department 612-673-3012
St. Paul Human Rights Department 651-226-8966

Employment Discrimination Only

Equal Employment Opportunity Commission 612-335-4040

Housing Discrimination Only

Housing Discrimination Law Project
(Hennepin County) 612-827-3774
Housing Equality Law Project (Ramsey County) 651-222-5863