

We as a committee would love to hear from you. Do you have ideas for articles? We would welcome anyone who would like to submit an article. Deadline for our next publication date is November 1, 2001. Let us know if you are interested in writing an article.

In this issue...

- **“Coming Out Positive”**
- **“EXPOSURE” -- Don't take it Lightly**
- **ASK A NURSE**

Examine the labels you apply to yourself. Every label is a boundary or limit you will not let yourself cross.

-Wayne Dyer

Can I Still Work As A Nurse?

(David J. Sterken MN CPNP)

What do I want to be when I grow up? As adolescents and young adults our minds seemed tortured by this question. Yet there always seems to be those who as a child set their sights on a particular career of choice and through a carefully guided decision making process make their dream a reality. I was not one of those “focused” souls.

Acting always intrigued me, yet I blush at the thought of “performing” in front of large groups of people. Nursing was a profession that never crossed my mind. Perhaps it was because I was deathly afraid of needles or fainted at the sight of blood. Me a nurse – yeh right! How is it that it was not until my senior year of college upon completing a Bachelor's

Degree in both Psychology and Sociology, and the gentle but persistent nudging of my Aunt June, who was an LPN, that I decided to become a nurse? Sure could have saved myself some time and money if the “light bulb” had gone on earlier. Yet in hindsight if I had started any earlier I would not have been ready.

Readiness — I believe occurs as a result of the twists and turns, bumps and bruises, falls and failures that occur in each of our lives. It is destiny's way of preparing us to fulfill our life purpose. I have pursued my nursing career with ferocity determined to make a difference. Yet my hopes and aspirations all came to a screeching halt in July of 1995 when I found out that I was HIV positive.

continued on page 2

Work Issues for the HIV + Nurse

(David J. Sterken MN CPNP)

HIV is fast becoming more of a chronic condition, than a terminal disease, thanks to many of the new treatment modalities. While there are still many unknowns in regard to long-term treatment outcomes we have considerably more information about drugs, side effects, and the effect of the virus itself on the body than researchers two decades ago. How does

this knowledge translate into work-related issues for the HIV+ nurse?

Fatigue

Fatigue is not something that should be dismissed as a fact of life for the HIV+ nurse. Granted your career choice may lend itself to feeling like “your get up and go has got up and went” but do not rule out other factors that could be attributing to your

continued on page 3

*Can I Still Work As A Nurse,
Continued from page 1*

Fatigue, emotional and physical, plagued my daily existence as I fought to keep up my duties as a pediatric nurse practitioner on a busy pediatric oncology floor. Nausea and diarrhea meant frequent trips to the bathroom and probably little absorption of my already decreased oral intake. Fear became the personification of job and insurance loss. Isolation, physical as well as emotional, I believed protected me from wagging tongues and labels like “promiscuous”. Suddenly, all that I had worked so hard to achieve seemed to be slipping through my fingers like sand through an hourglass.

Nursing was what was I born to do! The first two years were rough – I survived the medication side effects, found some “angels” along the way that loved me and supported me, and quit cold turkey a 2 year “closeted” cocaine addiction that I had developed to “help me cope” with the pain of my diagnosis. I began an “inner journey” of enlightenment finding reward internally as well as externally.

ASK A NURSE

Question: If I change jobs am I “required” to report my HIV status to my new employer?

Answer: I asked myself the same question when I moved from Atlanta to Michigan so let me share with you some of the information that I gleaned from the experience.

- Many states have legal aid for

The members of ANAC (Association of Nurses in AIDS Care) have been one of the external rewards that I cherish very close to my heart. At my first conference, some 5 years ago, I was stunned by how much the attendees enjoyed life. The conference halls were filled with laughter and the welcome gala found everyone dancing. You were welcomed with open arms into a “group”.

Some might argue that the nurses who work HIV/AIDS care are a “different lot”. I would agree, but only because I believe that these are nurses who have discovered what they were born to do. Tuned by tragedy, their melodious symphonies are a mixture of tears, sweat, determination, laughter, and a desire to unify all of mankind, without regard to race, sex, social status, religion, or sexual orientation.

What was I born to do – be a nurse! Nursing is one profession that allows expression of your “calling” in a multitude of ways. DO NOT let your HIV status steal your sense of fulfillment or your job satisfaction. The *HIV+ Nurses Committee* is here to support you.

people with HIV – prior to going for your physical ask a lawyer about the laws in your state.

- If you lie on your Human Resource paperwork you can be fired and you can be denied insurance.
- Human resource paperwork is confidential and the information that you share about your HIV status is not supposed to be accessible to just anyone.

continued on page 4

*“EXPOSURE” -- Don’t Take It Lightly,
Continued from page 6*

illness than a terminal disease. I was thrilled to find out that there was a very good possibility that I could live a “normal” life. Initial tests proved my T cell count to be very low so treatment was begun immediately. I must admit that the side effects, nausea and fatigue, from the medications were awful, but my drug cocktail proved successful. My T cells rebounded quickly and my viral load within a few months was soon undetectable.

I was encouraged by my physician to inform the hospital of my exposure. The very thought terrified me, yet I realized that if at some point my illness prevented me from working for long periods of time I would need my health insurance to cover not only physician services, but medications as well. My physician assured me that my job at the hospital would not be in jeopardy. Despite my fears I went forward with the information and felt very supported by the hospital administration.

Fear became a reality, however, when my workmen’s compensation claim was denied. Upon revealing my status to the hospital a workmen’s compensation investigation ensued, which probably proved to be one of the most humiliating experiences of my life. Investigators requested intimate details about my health as a child, every doctor I had ever seen, and my own sexual behaviors. I also had to endure the indignity of having a caseworker from the local Health Department show up on my doorstep seeking information about my personal life. Despite the investigators failed attempts to find evidence of any other risk factors my claim was denied without explanation.

Hurt, humiliated, and angry I decided that in order to protect my family I would have to bring a lawsuit against the hospital. I was amazed that a large healthcare corporation would risk exposure by treating an employee in this manner, but I decided win or lose I wanted to be sure that this would never happen to another nurse. The lawsuit entailed another 18 months of grueling questions, accusations, and depositions. Many times I felt I had made a grave mistake and wanted to back down, yet my anger proved to be the driving force that got me through the tough times.

As you might expect word of my circumstances and the lawsuit quickly spread

through the hospital grapevine. There were more than a few ugly remarks and insinuations but for the most part I felt supported by my co-workers. Through it all I managed to keep my chin up and forge ahead, and through example challenged by co-workers to face their fears and bias regarding those infected as well as affected by HIV. I preached regarding the seriousness of workplace exposures and was thrilled when people began taking “exposure” seriously by filing incident reports and talked more openly about HIV. I was gratified to be called on to counsel two nurses who had suffered needle stick injuries. I was beginning to feel that I was able to create some good from a bad situation.

Thought I am prohibited from giving details regarding my litigation, I will say that I was vindicated in my quest to be treated fairly by both my employer and workman’s compensation. As the litigation was resolved, I was informed that I would need to leave my position, in the hospital I had been employed, since I now was considered “high risk”. It seemed like it really did not matter that I had been an excellent employee for five years. I soon realized finding another position would prove to be challenging for now I would need to scrutinize medical benefits, quality of physicians, and insurance plans. I would be restricted to staff positions and would have to forfeit the lucrative pay of per diem assignments. I would never be able to allow my health insurance to lapse a single day for fear of being deemed uninsurable in the future.

My life has undergone some incredible changes in the past few years. As I begin by third year of medication my T-cells remain high and viral load undetectable. The fatigue has been nearly eradicated by a recent change in medication. The depression has gradually faded, and I look forward to each new day. It has been my good fortune to hear of the HIV+ Nurse’s Committee. Through the committee I was given a lifeline of support that I desperately needed. I have been blessed with good health and the ability to celebrate all the wonderful joys of my family. In addition, my experience with this disease has given me new insight into my patient’s lives, and provided me a level of compassion most of my peers could not understand. I have made my mission to make more nurses aware of the possible hazards of all exposures – not just needle sticks. Though I fully understand how fragile life is and how unpredictable, I now embrace the path I must take and try to live in the “moment” and enjoy the journey.

The difference between a successful person and others is not a lack of strength, not a lack of knowledge, but a lack of will.

- Vincent Thomas “Vince” Lombardi (1913 - 1970)

Contact us...

One of the main goals of the HIV-Positive Nursing Committee and ✦ Nurse is to reach out to all HIV-Positive nurses, regardless of practice setting or organizational affiliation. You do not have to be a member of ANAC or an AIDS nurse to benefit from ✦ Nurse.

You can contact us at ✦ Nurse, c/o Association of Nurses in AIDS Care, 80 S. Summit Street, 500 Courtyard Square, Akron Ohio 44308; **Phone:** 330-762-5739 or 800-260-6780; **Fax:** 330-762-5813; **E-Mail:** anac@anacnet.org; **Web site:** www.anacnet.org.

Co-editors

David J. Sterken, MN, PNP
Richard S. Ferri, PhD, ANP, ACRN, FAAN
Editorial Reviewers
Alton Burch, RN, ACRN
Cheryl Erichsen, LPN
Richard MacIntyre, PHD, RN
Robert Thompson, RN
CRNI

Fear

Some people believe incorrectly that a health care worker with HIV places patients at greater risk for getting HIV. Scientifically it has been proven that certain body fluids of an HIV-infected person can spread the virus: blood, semen, vaginal fluid, breast milk. Putting your patient's at risk would mean that you would either have to be having sex with them, sharing needles, directly expose them to your blood, or drinking breast milk. Yes, it is absurd – but you would be amazed at how many people in the medical profession react emotionally rather than from solid scientific evidence when faced with the news of an HIV positive colleague.

Insurance & Employment Issues

You cannot be denied insurance benefits because you are HIV positive. Nor can your HIV status be used by an employer to limit your employment or to change your job assignment. Bartlett and Finkbeiner (1996), in their book *The Guide to Living with HIV Infection*, commit an entire chapter to legal, financial, and medical decisions. In an earlier chapter however, when discussing work the author's state:

"The employee has considerable legal recourse as a result of the Rehabilitation Act of 1973, which became law in the United States in July 1992. This protects every citizen against unfair discrimination based on sex, race, or handicap. Under this law, HIV infection is a handicap, and those who have HIV infection are legally protected. The employer must provide the employee with continued employment in the same job as long as she or he is capable of performing this job." (p. 128)

Managing Medication Side Effects

There is nothing worse than trying to do patient care when you are experiencing side effects from your medications like nausea, vomiting, and diarrhea. If you must go into work my advice to you is not to put into your GI system things that will further aggravate your symptoms (i.e. caffeine, spicy or greasy foods, milk products, chocolate). Stick to that exciting "bland diet" – crackers, rice, bananas – and sip Sprite. Again if you are unable to do patient care because of how you feel "admit it". Talk to your supervisor and see if there are other options for you. Most employers choose to keep reliable and qualified employees and may willing to work with you.

ASK A NURSE,

Continued from page 2

- ❑ Remember some states require that you inform the Board of Nursing of your HIV status. This does not mean, however, that you need to inform your manager or anyone else for that matter, unless you are performing a "invasive" (a term which I am still not sure is defined very clearly) procedure.
- ❑ If your confidentiality has been breached get legal advice immediately.
- ❑ Conversations regarding your HIV status and your "ability to perform your job" should only take place if you have legal representation present or the conversation is audio taped.
- ❑ Employment policies should address the nurse's ability to perform essential functions of the job. Employment decisions should never be based solely on the HIV status of the nurse.

The ANA (American Nurses Association) Position Statement on Personnel Policies and HIV in the workplace states that "while employment and personnel policies frequently reflect societal attitudes on a number of issues, health care employers **MUST** base HIV policies on scientific facts

continued on page 5

Coming Out Positive

Richard S. Ferri PhD., ANP, ACRN, FAAN

Coming out as HIV positive in the work place is a very personal issue especially if you are a nurse, and more particularly an AIDS nurse. The issues surrounding "coming out" seem nearly endless.

On a practical level your decision to "come out" may be dictated by nurse practice act/laws in the state in which you practice. In the first edition of *+Nurse* and the *Journal of the Association of Nurses in AIDS Care* we have attempted to detail the states that have mandatory self-reporting laws. It is very advisable that as an HIV positive nurse you know what your individual state requirements are before you do anything.

The other issues involved include your health and how you want to practice nursing. The health issue may guide you since you may have to request some special considerations as specified in the American with Disabilities Act. Personally, I felt the need to be up front and disclose my status for many reasons, the most compelling for me was related to medication side effects. Mornings were especially difficult for me as there were days when I simply was not on top of my game, and I needed to take it easy until the waves of nausea passed. Even worse were my "foggy" mornings, when I woke up feeling "hung over" from my efavirenz, and felt out of sorts until mid-afternoon.

I also keep a stash of "emergency" medications in my desk – my antiretrovirals and medications for nausea and diarrhea. There are days when the virus rears its ugly head and knocks me down. Sometimes all I need to do is simply sit down and rest due to my overwhelming fatigue.

On a professional level I decided to be "out" regarding my HIV status because I am an AIDS practitioner working in an AIDS clinic. I did not want to hide my status. I wanted to be able to share with patients and staff alike the dual role of being an HIV positive and an AIDS

clinician. As I learned being "out" about my HIV status at work does have a downside. Sometimes the patients worry too much about you and want to know how you are doing. While this caring is certainly appreciated it can sometimes get in the way caregiver/patient relationship. I am there to care for them and not the other way around. It is sometimes difficult to discuss treatment regimes with patients who wish to focus on what is working for me, rather than what is best for their individual needs and lifestyle.

There are many other issues HIV positive clinicians need to consider such as work place violence, harassment, patient rejection. Always remember, however, that you need to look out for yourself! Discuss work place issues with a counselor, therapist or support group. Do not go at it alone and, plan for all possible reactions. Remember you can always contact a member of the HIV Positive Nurse Committee of ANAC for support. We are here for you!

ASK A NURSE,

Continued from page 4

rather than misinformation and/or in response to political/social pressures." It goes on to state that "policies **must explicitly forbid** retaliation for involvement in and/or the reporting of injuries or incidents associated with HIV exposure."

To be on the safe side, when applying for a new job, ask a Human Resource representative for a copy of their personnel policies. If they don't have a policy on HIV infected health care workers – BEWARE! If a policy does exist according to the ANA position paper the policy should:

- ❑ Address all aspects of HIV in the workplace;
- ❑ Reflect the most current scientific and epidemiological knowledge;
- ❑ Create a safe, supportive and healthful environment for workers, patients/clients, students, volunteers;
- ❑ Incorporate sound principles of supervision and management;
- ❑ Protect against social and economic discrimination.

Only those who dare to fail greatly can ever achieve greatly.

- Robert Fitzgerald Kennedy

Few people even scratch the surface, much less exhaust the contemplation of their own experience.

- Randolph Borne

“EXPOSURE” -- Don't Take It Lightly

Anonymous

Change – to some it is something to be feared, but all I could think about was my deep-seated desire to become a nurse. At forty-something I was changing careers and anticipating the Spring, when I would complete nursing school and take my dreaded board exam. The past 3 years had been a long and grueling combination of balancing family, class, clinical rotations, and working full time nights at a local hospital. My family was thrilled for me, not only for my accomplishment, but because they would finally have me back in the role of wife and mother. This would be the start of a new life for me and for my family, and I welcomed the change. Little did I realize just how dramatic a change I would experience.

Prior to entering nursing school I gave up my former career and took a job as a nursing assistant. Since I was a novice to the medical world I thought this position would afford me opportunity, experience, and confidence. I accepted a position on the Pulmonary Care Unit of our local hospital – a high census unit that housed high acuity patients and many with complicated infections. The unit proved to be very busy, and during my three years as a CNA it became quite commonplace to experience accidental exposure to some type of body fluid. The exposures happened so often that most were ignored or dismissed by the entire staff as part of the job. A mistake that would alter the course of my life forever!

One night, shortly before graduating from nursing school, while caring for and end stage AIDS patient I noted that my glove was torn allowing the patient's blood direct contact with my skin. The gloves were of rather poor quality and I do not know the length of time that had passed between the tear and my exposure. Immediately I removed the gloves and scrubbed my hands thoroughly. I was not terribly concerned by the exposure, after all it was to “seemingly” intact skin. Without batting an eye I donned a new pair of gloves and went back to caring for my patient. I left that night without

filling out an incident report, my mind preoccupied with preparing for graduation.

I survived graduation and nursing boards and accepted a RN position on the Pulmonary Care Unit where I had worked as a CNA during nursing school. It was wonderful working as a RN alongside the same nurses who had helped me out so much during my years as a student. During my orientation period I received a call from the local blood bank requesting that I donate blood. I was a regular donor and although I felt I was too busy to donate in the end I relented. It was this very act, often termed “the gift of life”, that saved my own life. Two weeks after donating blood I was notified that my donation was “not acceptable” because I was HIV+. Surely there must have been some mistake – here I was a middle-aged heterosexual female, married for 28 years to the same wonderful man, proud mother of 4 sons – it could not possibly be happening to me! To my knowledge I had no risk factors, except...gulp...my work. Could it be that what I had passed off as a “simple skin exposure” was to change the course of my life, and that of my family's, forever!

The news seemed like a dream and my mind seemed cloudy. Thoughts came flooding into my head so quickly that it was impossible to sort through them. How could this be happening to me? How was I going to tell my husband? Had I also infected him? Would our marriage be strong enough to survive? How was I going to tell my 10-year-old son that I might not be around to see him grow up? Would I lose my job as a nurse because of my diagnosis? Thoughts of suicide swirled around in my already confused brain. I was devastated and numb. I had no idea what I was going to do next. It took me five days to gather the courage to share the awful news with my husband. We cried long and hard together and then made plans for how we would spend the rest of our lives. Telling my children was an even harder task, but my fear of rejection was unfounded. The five wonderful men that I had in my life gave me the strength and support I needed to forge onward and upward.

Soon after my diagnosis I began seeing an Infectious Disease specialist that I knew from the hospital. I learned that HIV was being treated as much more of a chronic

Failure is only postponed success as long as courage coaches ambition. The habit of persistence is the habit of victory..

- Herbert Kaufman

Calling is the inner urge to give our gifts away. We heed that call when we offer our gifts in service to something we are passionate about in an environment that is consistent with our core values.

- Richard J. Leider & David A. Shapiro (Whistle While You Work)

Work Issues for the HIV + Nurse, Continued from page 1

fatigue. Some of these may include, but are not limited to:

- ❑ **Sleep patterns** – I am amazed at how many people in our society try and squeeze 27 hours into a 24 hour period. Our body was created with natural rhythms. Sleeping allows your body to go through the rejuvenation process that it will need to meet the challenges of the next day.
- ❑ **Drugs** – Sustiva is known to produce vivid “realistic” nightmares that do not allow the individual a restful night of sleep. Do not forget that caffeine is a drug and is contained in many over the counter medications only packaged under another name. AZT can result in anemia.
- ❑ **Anemia** – secondary to AZT, blood loss, the chronicity of an illness, inadequate dietary intake (JANAC – Journal of Association of Nurses in AIDS Care — will be publishing an article in this regard in the not too distant future – stay tuned!)
- ❑ **Inadequate nutrition** – secondary to nausea, vomiting, diarrhea

Risk of Infection

You do not want to unnecessarily expose yourself to pathogens that could be dangerous to your health. What can you do to protect yourself?

- ❑ Be meticulous in your observance of isolation technique
- ❑ Avoid contact with patients that have TB.
- ❑ Get a flu shot every year.
- ❑ If you are concerned about putting your health at risk when caring for a particular patient

request that your assignment be changed. Realize that in doing so questions may be raised and you may have to share your health status with your nurse manager, who is obligated to keep such information confidential.

- ❑ Eat a balanced diet. Nurses are notorious for skipping meals and then sacrificing nutritional content for something quick and easy – usually junk food. An individual's nutrition state has a direct influence on immune response. If you do not take care of yourself, how can you take care of other people? I would recommend eating small more frequent meals and consciously making time to sit down and eat. Some suggestions for nutritional snacks at work include fruit, raw vegetables with dip, cheese and crackers, and yogurt. Be sure to drink lots of water.
- ❑ Get plenty of sleep. Sleep allows your body to totally slow down and get ready for the challenges of a new day. Deny yourself sleep and you disrupt your body's attempt to maintain equilibrium and decrease your body's natural method of defense against disease. Not everyone needs a full 8 hours of sleep, listen to your body – when it tells you to rest take it seriously. Emotions also tend to run high when we have not had enough sleep.
- ❑ Exercise! Studies have shown that exercise can have a direct impact on immune responsiveness but is dependent on factors such as intensity, duration, mode of exercise, body temperature, and hydration status. Exercise is also known to improve mood status, reduce psychological stress, and increase coping behavior.