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of Nursing

Premiere issue!

+NURSE is a newsletter for HIV-positive nurses by HIV-positive nurses. Published quarterly, it will seek to deal with issues unique to the HIV-positive nurse.

This is the **first issue**, and your comments and suggestions for topics are welcome. Please send them to +NURSE, c/o Association of Nurses in AIDS Care, 11250 Roger Bacon Drive, Suite 8, Reston, VA 20190-5202, or to aidsnurses@aol.com.

The Inception . . .

What is ANAC? Founded in 1987 to address the specific needs of nurses working with HIV/AIDS, the Association of Nurses in AIDS Care has rapidly become a leader in response to HIV disease and AIDS. The leadership of ANAC recognizes that HIV/AIDS has personally affected many of its members, and within its collective membership are nurses living with HIV.

Recognizing the unique struggles often experienced by the HIV-positive nurse, the national organization granted HIV-positive nurses a voice by establishing the HIV-Positive Nursing Committee. Over the past several years, the evolving committee has grown and sought to establish a supportive network for HIV-positive nurses within the membership of ANAC.

One of the main goals of the HIV Positive Nursing Committee is to reach out to all HIV positive nurses, regardless of practice setting or organizational affiliation.

For several years, this outreach program seemed confined to those who joined our yearly committee meeting at the national conference. Our focus, however, has broadened both nationally and internationally, stemming from an event that occurred in October 1999.

The *American Journal of Nursing* (AJN) published a letter, "Aiding Nurses with AIDS" from the committee. None could have imagined the impact of three short paragraphs. Letters and phone calls from HIV positive nurses across the nation poured into

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Testing Positive—A Nurse's Story

By David J. Sterken, MN, PNP

The Twilight Zone

Most of us vividly remember the day that we were diagnosed with HIV. Structure disappeared and chaos ruled supreme. Emotions such as fear and anxiety dominated our thoughts and we walked around feeling numb, our actions seemed robotic. Self-worth changes, leaving us feel like "damaged goods." Future is overshadowed by feelings of death, illness, and unpredictability. This time of great turmoil has been referred to by some as "The Twilight Zone" (R. Dennis Shelby, Ph.D., *People With HIV and Those Who Help Them*).

My journey with HIV began four-and one-half years ago, a time when I was working in the hospital as a nurse practitioner. For several weeks following my diagnosis, I walked around in what I describe as "a cloud"—numb and dazed, performing out of mere duty since every ounce of my emotional strength was being used to deal with the anxiety and fear of having HIV.

It is amazing how in the course of seconds your life totally changes. He, who once seemed to have life by the tail, was now broken and vulnerable. I think the thing I hated

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most was that I felt like I had lost all control in my life. It would be only a matter of time before my insurance company was aware of my diagnosis. What if my employer found out? Would I lose my job?

Even as I relive those days, my body feels the intensity of the emotion and is overwhelmed by the hopelessness that existed in my life. The journey has not been easy. I am not even certain it is correct to say that it gets easier.

I believe that what occurs in each of our lives is a transformation. We learn to “convert the challenges of HIV into a fuller appreciation of life” (*A Crisis of Meaning*—Steven Schwartzberg).

No matter how much we would like the physical, emotional, mental, and spiritual pain associated with HIV to go away, we can either choose to ignore it, and deal with the consequences, or deal with it. R. Dennis Shelby, Ph.D., has written a book entitled *People With HIV and Those Who Help Them* in which he highlights the properties of “The Twilight Zone.”

For the benefit of those of you who have been diagnosed for a few days/weeks/months, I hope reviewing the properties of “The Twilight Zone” will help to loosen fear’s paralyzing grip as you seek to rediscover and recreate meaning in your life.

A Great Fear

Fear is perhaps one of the most dominant individual emotions after the diagnosis of HIV/AIDS. The focus of this fear is on becoming ill and dying and the terrifying journey leading up to the “death sentence.” Shelby points out that “while testing positive is often initially perceived as a death sentence, it is a sentence without a definite day of execution” (p. 41).

Feelings such as helplessness and loss of control further add to the erosive effects of fear. Insurance, job, and health care often become basic concerns for the individual who is positive. Many also fear the disruption of important relationships. Realize that fear exists at some level in the everyday experi-

ence of the person with HIV.

Alone in the Storm

The sense of isolation felt by the individual with HIV often exists on a personal and social level. The possibility of a relationship seems unattainable due to the social stigma associated with HIV/AIDS.

At a time when a human contact might provide some emotional release, often the person with HIV feels like an outcast: untouchable and cut off from established friendships. The social stigma associated with HIV/AIDS often deprives the individual of social support unlike others with an “acceptable” terminal illness (i.e., cancer or multiple sclerosis). The anxiety related to telling friends and family about one’s seropositive status further adds to the isolation and aloneness of being HIV positive.

Damaged Goods

Some have described HIV/AIDS as the leprosy of the 20th century. Initially, it is not uncommon for the individual with HIV to feel damaged, flawed, or infectious. Such feelings have a profound effect on self-esteem and often leave the individual emotionally raw and vulnerable. HIV colors everything in day-to-day existence.

Loss of Future

Chaos reigns and a sense of future is lost. When one’s sense of future is challenged, the mind may assume that illness and death are imminent. Dreams and long term plans may lose their appeal.

Spinning Wheels

After testing positive, intense disorganization may occur since it seems that all control in life has been lost. Self-destructive behaviors may emerge in an attempt to manage the anxiety associated with being HIV positive.

Sexual Dialogues

“Tremendous blame may now accompany sexuality” (Shelby, p. 50). Most often, the individual blames him or herself for not acting responsibly in the face of public

+ NURSE

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
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knowledge about transmission of HIV. Many are highly fearful of infecting someone else and feel cut off sexually. Still others choose not to have sex, rather than risk rejection due to seropositive status.

Revelation

Whom to tell about your HIV and how to tell them is a complicated issue. How this is done is unique for each individual. Some choose to be very open about their status, while others are more reluctant.

Feeling vulnerable and apprehensive during these encounters is not uncommon, for often you are faced not only with your own anxiety but also with the anxiety of the recipient of the information. Realize that these encounters are often emotionally, mentally, and physically draining.

Helpers

I refer to these people as “angels.” They are the “people who calm, reassure, and assist you in your efforts to stabilize, to find your way in a world that feels so dramatically different and frightening” (Shelby, p. 54).

Initially, helpers tend to be physicians, case managers, therapists, and other HIV-positive individuals. As you are able to work through the intensity of your feelings, reorganize, and regain some control, your matrix of helpers will expand.

Spoilers

“Spoilers are people who, by their interactions or statements in general, are experienced as rejecting and unempathic” (Shelby, p. 57). For several months following your diagnosis, your greatest fear will be rejection due to your HIV status.

Spoilers are those you encounter who cause you further disorganization and damaged self-esteem. Spoilers can be those with whom you have no relationship (i.e., someone you overhear making a comment about people with HIV/AIDS) or those with whom the relationship is long and established. The sense of rejection, hurt, and betrayal runs much deeper when the spoiler and HIV-positive person have an established relationship.

“The Twilight Zone” is a temporary period for those of us with HIV, but the speed with which one works through the various issues differs from person to person. The journey is in no way easy, and you may find yourself taking two steps forward and then three steps back. You will find yourself rebuilding the foundation of your life brick by brick in an attempt to rediscover meaning and purpose.

Remember “helpers” may significantly impact the period of rediscovery. Building a matrix of support serves to provide salve for the wounded and a shoulder to lean on when crippled emotionally.

*Friends are
angels
who lift us
to our feet
when our wings
have trouble
remembering
how to fly.*

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the ANAC office. The committee decided it was time to do more, and that is how this first issue of **+NURSE** came into existence.

According to R. Dennis Shelby, Ph.D., author of *People With HIV Infection and Those Who Help Them*, “The challenges of living with HIV are many: to find ways to modulate the states of often intense and overwhelming feeling; to find people who understand the impact of being positive and offer the reassurance of a sense of belonging; to feel one is engaged with one’s life, and—what is most fundamental—to keep

finding meaning in life even though it may seem that all meaning has been whittled or blasted away.

“While living with HIV is a fine motto to live by, it is not always easy to do. Living with HIV is challenging. It is not always tragic; many triumphs are to be found. But there will be many valleys when despair is dominant, death feels imminent, and confusion reigns . . . the challenge is to find ways of working with people in such a way that they are helped to continue to find meaning in life.”

Ask the **+NURSE!**

Dear **+NURSE**,

I am an ICU nurse and I have just tested HIV positive and my head is spinning, to say the least! Am I obligated to report my HIV status to my employer or state licensing board?

—Mike in Missouri

Dear Mike,

Great question—and a complicated answer. First, be assured you are not alone. There are many nurses who are HIV positive in clinical practice. There is very little chance of nurse-to-patient disease transmission when standard procedures are followed (and why wouldn't any nurse not follow them?).

Reporting status to employers is an institutional issue. You may want to review any policy and procedure manual at your institution. However, remember that all people living with HIV are protected by the Americans With Disability Act. Also, if your institution has a policy about nurses reporting their HIV status, **+NURSE** would like to know (send us a copy).

You may want to consult with your local AIDS organization (ASO) before you say anything to anybody. Frequently, ASOs will have some free legal advice to offer. Better to be prepared then face it alone.

There are 62 different Boards of Nursing (BONs) that regulate professional and practical/vocational nursing in the United States and its territories. **+NURSE** has surveyed all of them, and the requirements range from silence on the issue to rather draconian measures. Therefore, which states you hold active nursing licenses in will shape the HIV/AIDS

reporting issue.

Many boards hold the position that all nurses are expected to adhere to “universal precautions” and any nurse not doing so (regardless of their HIV status) can be held accountable—pretty standard stuff. Others require HIV-positive nurses to report their status if they do “invasive procedures.” This, of course, is open to interpretation. However, what nurse does *not* perform “invasive procedures?” Some states require an “expert review panel” to judge if the nurse is competent to practice if living with HIV disease.

As you can see, the rules and regulations vary greatly, and we would highly recommend that you contact your local board of nursing to investigate any updates, etc. All the boards can be located on the Web at www.ncsbn.org/files/boards.asp.

Listed on the following pages are all the state BONs that require HIV reporting to various degrees. This list is as up-to-date as possible but should not be construed as the final word on each board. If a board is not listed, that means it responded to the survey by saying that it had no specific policy or regulation.

Ask the **+NURSE! is a regular feature where you can send us questions about anything from practice to personal issues. Our expert panel of nurses will answer. All questions are welcomed.**

Reporting Your HIV Status to the State Boards of Nursing

Recently the HIV-Positive Nursing Committee of ANAC conducted a survey of each state's Board of Nursing to find out which states require mandatory reporting. The results of the survey are as follows.

Board of Nursing	Brief Reporting Summary	Contact
Alabama Board of Nursing	"...require infected health care workers to submit to review by an expert panel; to authorize the State Health Office to issue restrictions on practice of the infected health car worker..."	Alabama Board of Nursing RSA Plaza 770 Washington Ave., Ste. 250 Montgomery, AL 36130-3900 Phone: 334-242-4060 Fax: 334-242-4360 Contact person: N. Genell Lee, MSN, JD, RN, executive officer Web site: www.abn.state.al.us/
Idaho Board of Nursing	No "official reporting requirements." However, there are "Guidelines on HIV/HBV Infected Health Care Workers" that states that all HCWs should adhere to universal precautions. Also, an "expert panel [will] be convened by the Department [of Health and Welfare] to determine if practice limitations are warranted."	Idaho Board of Nursing 280 N. 8th St., Ste. 210 P.O. Box 83720 Boise, ID 83720 Phone: 208-334-3110 Fax: 208-334-3262 Contact person: Sandra Evans, MA, Ed; RN, executive director Web site: www.state.id.us/ibn/ibnhome.htm
Iowa Board of Nursing	No "required reporting." However, a license may be revoked or suspended for "continued practice while knowingly having an infectious or contagious disease which could be harmful to the patient's welfare."	Iowa Board of Nursing River Point Business Park 400 S.W. 8th St., Ste. B Des Moines, IA 50309-4685 Phone: 515-281-3255 Fax: 515-281-4825 Contact person: Lorinda Inman, MSN, RN, executive director Web site: www.state.ia.us/government/nursing/
Kansas State Board of Nursing	No "required reporting." However, "[The] Risk Management Act could require reporting under certain circumstances. Failure to report could result in licensing discipline and/or criminal prosecution."	Kansas State Board of Nursing Landon State Office Building 900 S.W. Jackson, Ste. 551-S Topeka, KS 66612 Phone: 785-296-4929 Fax: 785-296-3929 Contact person: Mary Blubaugh, MSN, RN, executive administrator Web site: www.ink.org/public/ksbn/

Board of Nursing	Brief Reporting Summary	Contact
Kentucky Board of Nursing	Practice guidelines established. "Nurses who perform expose-prone invasive procedures and who know their status to be HIV seropositive or HBV seropositive in the absence of hepatitis B vaccination may seek counsel from the Board."	Kentucky Board of Nursing 312 Whittington Pkwy., Ste. 300 Louisville, KY 40222 Phone: 502-329-7000 Fax: 502-329-7011 Contact person: Sharon Weisenbeck, MS, RN, executive director Web site: www.kbn.state.ky.us/
Louisiana State Board of Nursing <i>This Board governs only RNs and APs.</i>	RNs must report their HIV and/or HBV status to the Board within 90 days. All reports are confidential. The board may "deny, revoke, suspend, probate, limit, reprimand, or restrict to practice as an RN or an APN, impose fines, assess costs, or otherwise discipline an individual."	Louisiana State Board of Nursing 3510 N. Causeway Blvd., Ste. 501 Metairie, LA 70003 Phone: 504-838-5332 Fax: 504-838-5349 Contact person: Barbara Morvant, MN, RN, executive director Web site: www.lsn.state.la.us/
Louisiana State Board of PracticalNurse Examiners <i>This Board governs practical nursing.</i>	LPNs may engage in exposure-prone procedures if they inform the Board in writing. "The nurse may be reviewed by the board." "Alternatively, if the nurse has not been reviewed by the board and approved for practice to include invasive and exposure-prone procedures... the nurse must affirmatively advise the patient or the patient's lawful representative that he or she has tested HIV or HBV positive."	Louisiana State Board of Practical Nurse Examiners 3421 N. Causeway Blvd., Ste. 203 Metairie, LA 70002 Phone: 504-838-5791 Fax: 504-838-5279 Contact person: Claire Glaviano, BSN, MN, RN, associate director
Mississippi Board of Nursing	No "required reporting." The board may "convene an expert review panel as necessary to consider performance of exposure-prone procedures by a nurse who is infected with HIV or HBV..."	Mississippi Board of Nursing 1935 Lakeland Dr., Ste. B Jackson, MS 39216 Phone: 601-987-4188 Fax: 601-364-2352 Contact person: Marcia Rachel, Ph.D., RN, executive director
Missouri State Board of Nursing	No "required reporting." However, "All licensed nurses and nursing students with HIV or HBV who perform invasive procedures are encouraged by the Missouri State Board of Nursing to voluntarily participate in the Department of Health's evaluation process."	Missouri State Board of Nursing 3605 Missouri Blvd. P.O. Box 656 Jefferson City, MO 65102-0656 Phone: 573-751-0681 Fax: 573-751-0075 Contact person: Calvina Thomas, Ph.D., RN, executive director Web site: www.ecodev.state.mo.us/pr/nursing/

Board of Nursing	Brief Reporting Summary	Contact
Nebraska Health and Human Services System	No "required reporting." Infected healthcare workers who provide direct patient care are required to seek the advice of an expert review panel that will determine if the person can continue to practice.	Nebraska Health and Human Services System Department of Regulation and Licensure, Nursing Section 301 Centennial Mall, S. P.O. Box 94986 Lincoln, NE 68509-4986 Phone: 402-471-4376 Fax: 402-471-3577 Contact person: Charlene Kelly, Ph.D., RN, executive director Web site: www.hhs.state.ne.us/crl/nns.htm
North Carolina Board of Nursing	Nurses who perform or assist in invasive procedures shall notify the State Health Director.	North Carolina Board of Nursing 3724 National Dr., Ste. 201 Raleigh, NC 27612 Phone: 919-782-3211 Fax: 919-781-9461 Contact person: Polly Johnson, MSN, RN, executive director Web site: www.ncbon.com/
South Carolina State Board of Nursing	Not reporting HIV status is considered "misconduct." Expert review panel to determine practice of HIV-positive nurses.	South Carolina State Board of Nursing 110 Centerview Dr., Ste. 202 Columbia, SC 29210 Phone: 803-896-4550 Fax: 803-896-4525 Contact person: Debbie Herman, MS, RN, executive officer Web site: www.llr.state.sc.us/bon.htm
Texas Board of Nurse Examiners	Expert review panel to determine practice of HIV-positive nurses.	Texas Board of Nurse Examiners 333 Guadalupe St., Ste. 3-460 Austin, TX 78701 Phone: 512-305-7400 Fax: 512-305-7401 Contact person: Katherine Thomas, MN, RN, executive director Web site: www.bne.state.tx.us/
Texas Board of Vocational Nurse Examiners	Potential discipline if the LPN "knowingly performs an exposure-prone procedure while suffering from an infectious and communicable disease..."	Texas Board of Vocational Nurse Examiners William P. Hobby Building, Tower 3 333 Guadalupe Street, Ste. 3-400 Austin, TX 78701 Phone: 512-305-8100 Fax: 512-305-8101 Contact person: Mary Strange, RN, executive director Web site: http://link.tsl.state.tx.us/tx/bvne/



Visit **www.anacnet.org**
to register online and for
the latest program updates,
or call **800-260-6780**
for information.

Fax: **703-435-4390**
aidsnurses@aol.com

Mark your calendar

for the

ANAC
ASSOCIATION OF
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13th Annual Conference

to be held

November 2-5, 2000

at the

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www.CaribeHilton.com

info@CaribeHilton.com

in **San Juan, Puerto Rico**

