

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 September 1, 2002. Let us know if you are interested in writing an article.

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Millions of us are looking for some connection to spirit so real, so unmistakably authentic, that it will release our capacity to make an enormous shift in how we treat each other and the world.
- Christina Baldwin

Sick and Tired of Being Sick and Tired (HIV-Related Fatigue)

David J. Sterken MN, CNS, CPNP

The changing face of HIV/AIDS has caused a shift in the paradigm of care-related issues. Many HIV/AIDS clinicians have mastered "terminal care" and the "technological techniques" of antiretroviral dosing, laboratory values, phenotyping, and genotyping, but do they recognize how this now chronic disease impacts quality of life?

Fatigue is a frequent complaint of HIV-positive patients. Many clinicians fail to understand the difference between "being tired" and "fatigued" and automatically associate fatigue with the physical need for sleep. Yet "fatigue" is multidimensional symptom involving physical, mental, emotional, and spiritual energy.

During the course of reviewing literature on fatigue I came across a very interesting definition of fatigue – an emotional state

associated with extreme or extended exposure to psychic pressure (Mosby's Medical and Nursing Dictionary). This very definition would seem to suggest that fatigue is the result of nonphysical (psychic) forces, and is a total body response. Imagine if you will the billions of new HIV cells that are made in your body every day. Next think about what happens when you take your medications – instant battle on a cellular level. I think it is safe to say that for those of us with HIV our body is in a constant state of alert on a cellular level. Add to this physical labor, emotional stress (conscious or unconscious), and spiritual challenge and you have an old fashioned recipe for fatigue.

The HIV journey demands that we strive to live consciously every day. Conscious living is simply being aware of how food, interaction with other people, job stress, exercise, daily meditation impact your "psychic" ability to express itself in physical reality.

Hints For Staying Healthy

David J. Sterken MN, CNS, CPNP

Since HIV-related fatigue is a multidimensional symptom beginning at the cellular level, our plan for combating fatigue must recognize the wholeness of our being. Fatigue is not just a "physical" or "emotional" problem. It is symptom of disequilibrium, or physical/nonphysical imbalance in the body. Restoring

balance to the physical and nonphysical body is vital to combating fatigue.

To restore balance you must look at yourself as a whole rather than the sum of your parts. Realize that experience comes to us in the realm of physical and nonphysical (emotions, thoughts, spiritual experience) reality.

Hints for Staying Healthy,
Continued from page 1

To love the folks in front of us asks us to look for the good in other people, even if we don't think it's there.
-Christina Baldwin

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;
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• **PHYSICAL**

- **Sleep** – Our body needs to go through the natural regenerative process. Most people need at least 8 hours. A body that is constantly trying to fight off the invasion of new HIV cells, needs time to regenerate the “spirit” of the person.
- **Diet** – In the world of fast food, eating healthy is a conscious choice.
 - **Caffeine and chocolate** – Stimulating a body that is always is already on “constant alert” increases your risk for fatigue
 - **Ice cold drinks** – Your body uses “energy” to warm these liquids
- **Empty calories** – Energy is used for digestion. This does not mean that you cannot treat yourself to desert etc., just do not make these types of foods the foundation of your diet
- **Exercise** – Maintains lean muscle mass, promotes cardiovascular health, oxygen to the tissues, and has been demonstrated to promote positive self worth.
- **Medications** – Everyone has there own unique cellular chemistry. Work with your physician to determine the right combination for you. If your body constantly has to deal with the side effects of medication (nausea, vomiting, diarrhea), it is expending energy and promoting fatigue.

• **MENTAL/EMOTIONAL**

- **Forgive** – Lack of forgiveness affects your physical and non-physical being. The “energy” of

holding onto the past and its hurts depletes your body of the energy it needs to deal with the HIV conflict. Forgiveness means that you not only forgive others, but yourself as well. Self-abuse utilizes vital energy that could be put to much better use elsewhere.

- **Choose how you respond to circumstances** – Remember that most circumstances come to use in a “neutral” form, how we respond is based on what we attach to the circumstance or event. The past does not own you, learn from it and move on.
- **Depression** – Fatigue is frequently linked with depression. Trying to deal with depression on your own will quickly zap your body of energy. You should not be ashamed to admit that you are depressed, for the challenges of living with this disease are at times overwhelming. Talk to your doctor or nurse case manager about treatment alternatives.

• **SPIRITUAL**

- **Quiet time alone** – Allow your inner spirit opportunity to talk to you. Each of use needs to spend time with ourselves each day otherwise we risk imbalance. Allow your spirit to show you how to reach your goals and overcome obstacles. It is in the quiet moments that we can hear the “still small voice” speaking to us and providing us direction.
- **Busy → Deaf to inner voice → Disequilibrium → Illness → Energy Used**

Life is all about choices. Conserve your physical and nonphysical energy and you will be at much less risk for fatigue.

Courage is only an accumulation of small steps.
-George Konrad

Self-care is never a selfish act -- it is simply good stewardship of the only gift I have, the gift I was put on earth to offer others. Anytime we can listen to true self, and give it the care it requires, we do so not only for ourselves, but for the many others whose lives we touch.

- Parker Palmer

ASK A NURSE

Richard S. Ferri Ph.D., ANP, ACRN, FAAN

“I have been suffering from fatigue for the past 6 months. I get at least 8 hours of sleep every night yet it takes every ounce of energy I have to get out of bed. I have been missing a lot of work lately because I just do not have the energy to take care of patients. I don't think my diet is too bad, what should I do?”

If you believe that you are suffering from fatigue you should call your healthcare provider so a proper work-up can be completed. An evaluation for fatigue may include studies/questions related to:

- **Mental-health:** A strong association has been found between depression and fatigue, so your doctor may question you about your overall mood.
- **Testosterone levels:** Fatigue has been

associated with low testosterone level in HIV+ males.

- **Thyroid:** Hypothyroidism has fatigue as a cardinal symptom
- **Anemia:** Anemia often results from HIB-induced ineffective hematopoiesis, opportunistic infections, infiltrative disease of the bone marrow, nutritional deficiencies, hemolysis, antiretroviral therapy, and other drug therapy.
- **Liver function:** Fatigue is a common manifestation of hepatic disorders; thus abnormal liver function, whether caused by hepatitis or some other entity could be linked to fatigue.
- **Cortisol levels:** Studies indicate differences in cortisol levels between HIV+ and HIV- men.
- **Sleep pattern:** Loss of sleep due to pain, nausea, diarrhea, urinary frequency
- **Substance abuse:** Street drugs containing amphetamines result in disturbed sleep patterns

“PSYCHIC” FATIGUE

David J. Sterken MN, CNS, CPNP

As positive nurses we must never forget the “psychic” impact of HIV on our energy level. You might eat a balanced diet, exercise on a regular basis, and get eight hours a sleep per night and yet still suffer from fatigue. I would propose that most HIV-related fatigue is not related to a physical cause but psychic (nonphysical) phenomena. Let me give you some examples of what I believe causes psychic fatigue.

- **Fear of rejection** – “People will treat me different if they know I am HIV+.”
- **Powerlessness** – “I don't have any choice.”
- **Fear of relapse** – “How long will my treatment keep my HIV under control?”
- **Lack of physical and emotional love**
- **Failure to recognize limits and ask for help** – Superman/Superwoman complex
- **Feel undeserving of anything good**
- **Inability to forgive self/others**
- **Inability to set boundaries**
- **Viewing yourself as a “sinner”**
- **Ignoring your inner voice**
- **“Blaming” the past**
- **Stress**

Don't be fooled into believing that all fatigue has a physical cause, look within and trust your own “psychic” ability.

Fatigue: Fighting to Remain “Normal”

Carla Parker RN

After the unbelievable shock had subsided following my HIV diagnosis, I began to face the realization that quality of life changes would have the most immediate impact on my life and family. Since antiretroviral therapy was started immediately, it did not take long before I began experiencing the gamut of side effects often attributed to these medications. I felt lucky that within a few months time that the nausea and lack of appetite disappeared. My emotional stability returned about six months post diagnosis and the mental fog seemed to lift at that time. I desperately hoped that physically I would soon start feeling like my old self, but fatigue had become my greatest enemy.

I had made a conscious decision that my daily life needed to remain as “normal” as possible for the sake of my mental health as well as that of my family. My husband and children were struggling to cope with the overwhelming changes brought into our life, and I felt that I needed to maintain an image of “well being” for their sake. Financially I needed to continue working, and work enabled me to shift my focus from my own health problems to those of my critically ill patients. Working 12-hour shifts drained me of all the energy I possessed and left me feeling completely exhausted. Returning home, after a full day of work, and picking up the role of wife and mother became nearly impossible, and while I fully intended for my life to remain status quo, it was becoming painfully obvious that I was no longer in control of my own life.

Each visit to the to the physician brought good news – my T cells were gradually increasing and my viral load was on its way down. The only physical complaint I could offer at each visit was the same – FATIGUE. Blood work failed to show that I

was anemic. My physician’s next choice of diagnosis was depression. While I did not believe that I was depressed I was so desperate to feel better that I agreed to start antidepressants. For six months I remained on the antidepressants, experiencing every possible side effect known to antidepressants, yet my fatigue remained unchanged. My life it seemed was spiraling downward and I felt helpless!

After two years of treatment my T cells were over 700 and my viral load was undetectable. I should have been on top of the world, but I was so fatigued that I sometimes struggled to walk and breath. I painfully struggled through simple activities like sitting through my son’s baseball games and shopping. I lost all desire to socialize with friends. It now became crystal clear to me why so many HIV+ patients stop taking their antiretroviral therapy, for it seemed that my treatment was reeking havoc in my life.

A “light” appeared at the end of my darkened tunnel during my next clinic visit. After reemphasizing my fatigue issues with my physician, I was informed of a study testing the effects of a new drug on patients having a good response to medications, but suffering “negative” side effects from antiretroviral therapy. While I was very afraid to make changes in my “effective” antiretroviral regime, I was desperate to have my life back again. I agreed to become part of the study group, and gradually over the next four weeks I began to feel more alive than I had been in two years. Two months later I felt like myself again. I looked forward to spending time with my family and friends, and it was no longer agony to work a 12-hour shift. I could not believe that a simple change in medication could have given me back my life. I was also thrilled to learn after 6 months that my T cells had risen to over 900.

While I would love to say that I am a bundle of energy, my husband reminds me that I am not as young as I used to be. I have been able to return to a normal lifestyle and HIV is no longer the primary focus of my life. I am ever thankful for the opportunity to prove that HIV can be treated as a chronic disease. I am hopeful with the advent of new and more effective treatments that more HIV+ patients will be as fortunate as I have been in returning to a life filled with hope and promise.

The only way we can find the pathway to satisfaction is by lessening our obsessive grip on doing and focusing more on being.

- Ingrid Bacci

DENIAL: Challenged and Transformed by Love The Personal Account of an HIV+ Nurse

Dennis RN

It is my goal in writing this not to impress but to inspire others. Every person who is HIV-positive has a story to tell and the potential to motivate. This is part of my effort. As I take you on the journey through my experience I ask each of you to think about those who are no longer here to tell their story.

In 1985 I was a young man in the Navy stationed in San Diego. I remember hearing about a disease that had hit the gay community. I recently “came out” of the closet but did not think about HIV very much. At that time there was little effort in promoting safer sex practices. After my tour in the service was over I decided to stay in San Diego rather than return back home. I was 20 years old and had been regularly testing negative. I met a gentleman that I became fond of rather quickly. After a couple of weeks of getting to know each other we decided to become intimate. Shortly thereafter he made me aware of the fact that he had potentially been exposed to HIV before we met and was waiting on the results from his test. In addition, he told me that he was in a relationship. Feeling rather down and out I decided that San Diego was not the place for me and packed up and went back to my home state of Texas. Remembering what I was told I decided to get tested. After a couple of months my test came back positive. “My life is over,” I thought to myself. I then dropped the idea of college and a prosperous life. I bought a sports car and started down a road of destruction. I declined seeking professional and medical help. “What is the point?” I remember thinking. I decided to not tell anyone because it was not something that I could handle.

You can overcome, you can succeed, you can be healed—if you believe in your divinity, bless it, act as if it were the real and true of you and keep on in the effort to “open out a way whence the imprisoned splendor may escape.”

- Eric Butterworth

To be here is to step out of the center of the world, and to simply join in.

- Christina Baldwin

As time went on I remember hearing about others that had passed away from AIDS and the horrible experiences they suffered through. It was not uncommon to see the obituaries in the local gay publications full of people who had recently died, and sometimes I knew of them. I began to go into a state of denial although I was not experiencing these horrible things that were common among the HIV-infected. I even doubted the accuracy of my positive diagnosis. I continued on with my life having denial as my coping mechanism.

By this time it was 1989 and I met a guy that I truly adored. Almost immediately we became a couple. I found out he was also positive. Soon after this I decided to start learning as much as I could about HIV and AIDS. As far as therapy, there was practically nothing available except for AZT so my learning efforts were directed toward the pathophysiology of the immune system and the effect the virus had on it. There were the many so-called treatments that turned out to be non-therapeutic. I remember the hype about drinking aloe vera juice, hydrogen peroxide, and something about enemas with cucumber juice. There were a lot of supposed promising treatments that did nothing at all.

A couple of years went by before my partner started to get sick. It was now 1991 and still there was nothing as far as effective treatments go. He got one opportunistic infection after another. It was horrible! To see someone go through what he did was very heartbreaking. I felt at times that I was experiencing a nightmare. He was stricken with meningitis, CMV retinitis, Kaposi sarcoma, PCP and so on. The attempts to treat the infections were almost as bad as the infections themselves. It was a roller coaster ride that I hope to never see anyone else go through. His battle ended with his death in 1994 at the age of 24. I cried and cried until there were no more tears to be made. At the same time, I felt relief that his courageous struggle was over.

After a few months had passed I decided to dedicate my life, however long that was to be, to becoming a part of the fight against HIV and AIDS. My first thought was to become a virologist and find a cure. After thinking realistically, I

Denial,
Continued from page 3

decided that becoming a nurse with the focus on HIV care would be the best and most rewarding avenue I could pursue. I started taking my prerequisites in 1995 just nine months after the death of my partner.

I started the BSN program in January of 1999. During my first semester I started to lose weight, became unable to concentrate, and started having night sweats. Denial was still a part of my coping. I thought nursing school was the culprit. I gathered my thoughts and called the local HIV community service organization. They came to my home and set me up to see a nurse practitioner. I was indigent at the time so I had to jump through the barrage of hoops to get on ADAP and other assistance programs. The news from my nurse practitioner was not good. I had a CD4 cell count of 59 and a viral load of 270,000. The first thing I asked her was, "Should I leave school and go back home?" She replied, "Do you want to finish school?" The answer was plain and simple. YES!! I wanted to beat this thing for as long as I could. My life's work was just beginning. I started taking medication (I wish they would have been available a few years earlier for my partner). Almost immediately I started to feel better and little by little my numbers improved. I didn't have opportunistic infections but was worried that I would come

down with something. I decided to continue to learn as much as I could by reading and attending HIV conferences. I also decided to volunteer my spare time at the local HIV organization that had helped me so much. I created an adherence program to help educate clients of the organization. I also taught a basic HIV/AIDS course to the public as well as nurses. Slowly but surely I became healthier and my numbers got better.

I graduated with honors in 2000. My next goal was to become employed in HIV care and start the process of becoming a nurse practitioner (I was inspired so much by mine). I currently work as an HIV research coordinator and am in graduate school pursuing my ARNP. I will graduate next year.

I am one of those people that feel HIV has enhanced my life. I have been positive for almost 16 years now and am in the best health of my life in all aspects (although I am still single). If it weren't for HIV I may not have the direction I needed to pursue my career, I would not have had the opportunity to meet the great people that I work with and have as patients, and I would not have met my nurse practitioner who I believe to be an inspiration to everyone who knows her.

To those of you who work in HIV care I say, "Thank you." Your efforts are truly appreciated.

Share Your Story.....

Antiretroviral therapy is not the magic bullet. Living with HIV is about healthy lifestyle changes, choice, and quality of life. Many of us have unique stories to tell which I believe may prove motivational and inspirational to fellow sojourners. This newsletter has been an outlet for some to tell their "stories" with very little editorial changes, yet I would like to explore the possibility of compiling and publishing multiple stories. I envision this project as a unique collection of stories (and maybe photos) of people sharing the unique journey of being an HIV+ nurse.

If you would like to be a part of this project please feel free to contact me at davidjaysterken@aol.com

Recommended Readings

from the desk of
David J. Sterken MN, CNS, CPNP

The Path of Transformation: How Healing Ourselves Can Change the World (Shakti Gawain)

The Power of Karma (Mary T. Browne)

Seven Whispers: Listening to the Voice of Spirit (Christina Baldwin)

So every day, here is my choice: to escalate the mantra of anxiety, or to take a few deep breaths and say firmly to myself: this seems like as good a time as any to maintain peace of mind!
-Christina Baldwin

Conference T-Shirts Available!

It's not too late! Short sleeve, 100% cotton T, navy blue with Conference logo on the left.
Item #1500 Was \$12.00, now only \$8.00

ANAC Logo Denim Shirt

So many of you requested these beautiful shirts at Conference, we were able to make special arrangements to order them in limited number. Long sleeve light denim, 100% cotton with ANAC logo in white above the left breast pocket. Allow 8 weeks for delivery.
Item #1600 S-XL \$35.00, XXL \$38.00

ANAC Sweatshirt

Jerzee long-sleeve sweatshirt with ANAC logo on the front. 80% cotton, 20% polyester.
Item #200 \$20.00

ANAC Polo Shirt

Red embroidered logo on left pocket area of shirt. 100% cotton-mesh knit. Comes in S, M, L, XL, and XXL.
Item #900 SALE! Was \$25.00, now only \$20.00

Bear of Hope

This bear named "Hope" was created by the Jerry Elsner Company to help children and families affected by HIV/AIDS.
Item #1000 \$20.00

Ribbon Cookie Cutter

This stainless steel cookie cutter was specially designed for ANAC. Perfect for cutting cookies, gelatin desserts, mini-sandwiches, et cetera!
Item #1100 \$3.00

ANAC Notecards

Blank notecards with the ANAC logo and a red ribbon on the front. 10 per box. Envelopes included. (No shipping charge.)
Item #600 \$10.00

ANAC Mug

White ceramic mug with ANAC logo and red ribbon.
Item #800 \$5.00

ANAC Travel Cup

White with ANAC logo, this 16 oz. insulated tumbler with handle is right or left hand adaptable with just a twist of the lid.
Item # 1200 \$10.00

ANAC Pill Fob with Keyring

Waterproof, impact-resistant pill fob holds numerous oversized pills, vitamins, or other small items.
Item #1400 \$3.00

ANAC Logo Denim Hat

Light blue denim hat with ANAC logo in red; bill is slightly longer. Attractive alone or when worn with the ANAC denim shirt!
Item #1700 \$18.00

ANAC Logo Letter Opener

Letter opener with a magnet on the back so that ANAC contact information is always available.
Item #1800 \$2.00

ANAC "Mouse Dot"

Comfort in the palm of your hand! Apply this ANAC logo "Mouse Dot" to the base of your mouse and feel the difference it makes. Makes for great, inexpensive door prizes.
Item # 1900 \$1.00

ANAC Logo Pen

Never be without ANAC's toll-free number. White pen with red logo and blue ink, medium point twist action pen. Terrific marketing tool or door prize.
Item #2000 \$1.00

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Payment Information: Check/Money Order enclosed for \$ _____

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Item #	Description	Size	Price	Quantity	Total Price

Merchandise	Total Price	Priority Mail	Merchandise	Total Price	Priority Mail
Up to \$30.01	\$30.00	= \$5.00	\$150.01 to \$200.00	\$200.00	= \$15.00
\$30.01 to \$60.01	\$60.00	= \$7.00	\$200.01 to \$500.00	\$500.00	= \$17.00
\$60.01 to \$90.01	\$90.00	= \$9.00	\$500.01 to \$1000.00	\$1000.00	= \$19.00
\$90.01 to \$120.01	\$120.00	= \$11.00	Call for orders over \$1000.00		
\$120.01 to	\$150.00	= \$13.00			

Merchandise Total Price _____
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