

Paul Castro

When the doctor gave me my diagnosis of AIDS, I saw my whole world collapse before my eyes. At that time, most everyone automatically thought you were about to die. One of my best friends asked me where I wanted to be buried, Houston (my birthplace) or San Francisco. That was one of many questions that kept coming up in my head during the first weeks after diagnosis.

I was fortunate to have friends who did see an optimistic approach to my AIDS diagnosis. They encouraged me and gave me the type of positive support that I desperately needed. From that time on, I made a promise to myself to make the most of the situation I was facing.

While I felt that I could allow myself to be depressed and cry at times, I maintained as bright and positive as possible with my peers. I found that not everything is so dismal that you cannot bring yourself back on top.

My medical as well as psycho-social experiences have had good and bad points. The Interferon treatments I was receiving cleared my Kaposi's but the side effects were many times intolerable. I developed stronger ties with former friends and developed new friends (among them being my parents), but was rejected by others.

I learned to take the good along with the bad. I always made the most of the good times and downplayed the bad times. I personally would rather spend my time laughing with friends than crying over my problems. I found that contributing my time and energy through public education served a twofold purpose. It was therapeutically helpful to me in adjusting to my diagnosis by talking to others about coping with this medical phenomenon. In addition, it was impressed upon me that my efforts were calming the fears of many and making society more understanding of people with AIDS.

The most important thing, though is that it gave me a purpose in life and a good feeling that I was helping others. I strongly encourage getting involved in the fight against AIDS. While everything is not great about AIDS, it can be a rewarding experience if you can learn to look at the positive side.

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Distributed by: IMPACT AIDS, Inc.
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COPING WITH

AIDS

What is AIDS?

AIDS stands for:

- Acquired** — not born with
- Immune** — body's defense system
- Deficiency** — not working properly
- Syndrome** — a group of signs and symptoms

AIDS is caused by a virus called HIV. If the virus gets into the bloodstream, it attacks certain parts of the body's immune system. Some illnesses that the body normally would fight off become problems.

How Does Someone Get Infected with the AIDS Virus?

There are five ways that a person can get infected:

- Having sex with someone who is infected with the AIDS virus (through blood, semen, vaginal secretions, urine, or feces).
- Sharing intravenous (I.V.) needles with someone who is infected with the AIDS virus (because small amounts of blood are also shared).
- Receiving blood transfusions or blood products from someone infected with the AIDS virus. (Since 1985, when the blood banks adopted screening guidelines for the AIDS virus, this has not been a problem, but people who have already received blood still have a slight risk because AIDS can take 5 years or longer to develop.
- Using sperm from an infected donor for artificial insemination.
- As a baby, being born to a woman infected with the AIDS virus.

What is ARC?

ARC stands for AIDS Related Complex. It describes a variety of conditions resulting from infection with the

AIDS virus. These conditions are different and usually less severe than the specific diseases present with AIDS. At the present time, ARC has no "official" definition. Simply stated, ARC is usually a less severe reaction to the AIDS virus, and is a sexually transmitted disease that can also be spread by sharing needles. This makes ARC a very broad catch-all category that includes people with a wide range of diseases.

Many symptoms of ARC are the same as AIDS.

- Unexplained, persistent fatigue.
- Unexplained fever, shaking chills, or drenching night sweats lasting longer than several weeks.
- Unexplained weight loss greater than 10 pounds.
- Swollen glands (enlarged lymph nodes usually in the neck, arm pits, or groin) which are otherwise unexplained and last more than 2 weeks.
- Persistent white spots or unusual blemishes in the mouth.
- Persistent diarrhea.
- Unusual bruising or bleeding.

Remember, these symptoms are common in other illnesses as well. In AIDS or ARC, however, they tend to be longer lasting or more severe. Any disease symptoms should be evaluated by a qualified doctor.

Coping with AIDS

With such an emotional topic as AIDS, the fear of being diagnosed can be overwhelming. The first visit to a clinic or doctor's office for an AIDS related problem may be frightening and disorienting. Some things to remember:

1. Not everyone examined is diagnosed as having AIDS.
2. Some suspected AIDS is ARC (AIDS Related Conditions).
3. If you do have AIDS, good resources are available.
4. AIDS is not a death warrant. Many people are living with AIDS.
5. You are among friends. You can expect and ask for support.

Testing and Waiting for Results

Many tests are necessary to confirm or exclude a diagnosis of AIDS. Some tests will be familiar to you. Feel free to ask about tests, why they are needed and how to interpret the results. A realistic waiting period for test results is 10 to 15 days. During this waiting period many people experience anxiety and stress. Seeking support from others is important.

Diagnosis

Your reaction to a positive diagnosis will involve both your body and your emotions. It is important for you to be aware of how you react and not let the reaction become your biggest problem.

You may have known or guessed that you have been sick for a while. For some people a firm diagnosis is like a great weight of uncertainty being lifted. For others, the realization can be a crushing blow bringing the future into question.

Many people after diagnosis experience anger, anxiety, fear, embarrassment, helplessness, hurt, guilt, sweating, numbness, crying and weakness. These are all common reactions and are nothing to be ashamed of.

Some will retreat into themselves while others fall apart or even deny their diagnosis. No one expects you to take AIDS in stride, or to be unaffected. Lean on others for the support you need at this time. Your friends and relatives cannot help you if they do not know what your needs are.

At this initial stage, talking or confiding in someone might do more to help you than any medical or psychological advice you can get.

Overload

During the first weeks after diagnosis, you will be asked a lot of questions and may undergo testing by a variety of people. These tests and questions may be important for many reasons. Often, though, it feels like people are prying into your life and leaving you naked to the world. Voicing your frustrations is okay. If you are someone's 20th patient of the day, they may not give you the strokes you need. Patience and sensitivity is needed on everyone's part. It is important for you and the staff to work together. Everyone has the same goal in mind: Your Health!

The Healing Team

The healing team includes you, your doctor, nurses and other people with AIDS, social service workers, and organizations. AIDS is a very new and confusing disease. The doctors don't have all the answers. Your doctor and others will need your input and feedback as much as you need their advice and care. Progress in conquering AIDS is a team effort.

Importance of a Support System

The burden of dealing with a chronic health problem should be shared with others, not carried alone. Your friends and associates want to help, but they will take your lead and suggestions of how they can help. Often they are afraid of overstepping some unstated bounds. You can make it easier for yourself by giving them permission to support you and help you when you need it.

Support can come from many places:

- **Lover/Spouse.** If you are in an intimate relationship, your partner may have many of the same emotional needs that you do right now. Don't be afraid to lean on each other. Consider help from outside so that problems don't overwhelm your relationship.
- **Roommates.** It is important to discuss all aspects of your disease: emotional needs, physical needs and limitations, fear of contagion, etc. Understanding each other's needs and fears can help maintain a good relationship and avoid a breakdown in communications.
- **Family/Relatives.** How and when you tell your family that you've been diagnosed with AIDS will depend on your existing relationship with them. It is okay not to tell them right away – you be the judge. Knowing how someone else has told their parents may be helpful in making your decision. When you do tell them they may have less of an idea than anyone else what you need. Information referrals and other resources are available to answer their questions.
- **Extended Family.** These are the people that you've depended on most to help you get through life's problems: now is no different. Let them know how they can help you and encourage them to find out more about AIDS. Tell them it is okay to treat you the way they always have. Allow them the opportunity to nurture you and express their love and affections in positive ways.
- **Support Groups.** Interacting with others in support groups can provide a perspective, help ease fear and uncertainty and make you feel less alone with your disease. They can provide an environment where you can learn from the experiences of others in your situation and get a type of support that you can't receive from your friends and family. Many organizations also offer one-on-one counselling. See the Resource Guide for a complete listing.
- **Other People with AIDS (PWAs).** Many People with AIDS find great support and comfort in developing a

personal friendship with other PWAs. This gives them the opportunity to share and examine similar experiences, feelings and problems. Having the same diagnosis seems to develop a common bond and a level of understanding that is unique.

Sex

A diagnosis of AIDS does not mean that your sex life has ended. Some people out of fear or mis-information have become celibate, thinking that this is their only option. You **can** have sex with AIDS. It will require making some changes which may be difficult. Talk to your doctor or other medical personnel about guidelines and risks. Talk to other PWA's about how they have satisfied their sexual needs. You still have many creative ways in expressing your sexuality.

Attitude

Many doctors and psychologists feel that your attitude about your own health can be a factor in healing. If you are convinced that you will do well and overcome your present medical problems, then this may strengthen your own healing process. Pessimism about yourself works to your disadvantage in healing, just as in other parts of your life.

In the weeks following your diagnosis, AIDS will consume a large part of your thoughts and activities. This will hopefully taper off after a while but you can take part in slowing it down. With any serious illness, it is often easy to let the disease become your life. Continuing your previous routine with your friends, work, hobbies, pastimes, social interactions and other activities is important to your health and well being.

Words of Advice

Bobby Reynolds

Receiving a diagnosis of AIDS is scary. Learning to cope with that diagnosis is a slow and painful process. Numbness, shock and disbelief are very common reactions. Your mind will put up barriers to protect itself from the pain, anxiety and fear that you are being faced with. It will only allow these feelings to seep through to your consciousness a little at a time. During that period of numbness and shock, which seems to last 2-8 weeks, it's important to realize that you are not losing your mind, even though that is what it feels like.

I have been living with AIDS since I discovered the first KS lesion on my right ankle in March of 1982. I ignored it, convincing myself it was only a fleabite. Finally I was ready to deal with getting a biopsy. It was positive. On June 7, 1982, my life turned upside down. I thought I'd be dead in three months. I have since learned that a diagnosis of AIDS is not an automatic death sentence. There is a life to live after AIDS. A life that for me has become more meaningful and fulfilling than ever before. Given a choice I would definitely choose to be well, but as long as I have AIDS, I'll strive to do the best I can in living my life.

Learning to meet the challenges of AIDS, defining and facing my fears, reaching out to others with compassion and love have given me a greater sense of myself. Coping with needles and hospitals, tests, diarrhea, rashes, insomnia, and the question, "What next?", has often stretched me to my limits. Facing the failing health and the death of many friends has caused me much grief. But through it all I have never lost hope.

My advice to you is to be gentle with yourself. Learn to acknowledge and accept your limits and don't beat yourself up with feelings of guilt. Obtain as much information as you need in making decisions. Make a list of the questions you want to ask the doctor. Consider getting an appointment book to help organize your time. Speak out and stand up for your rights. Don't be afraid to reach out; we need all the support we can get. Finally, I'd like to encourage you to seek your own way, be true to yourself in finding a path through this journey of life that will lead where you choose to go.

I wish you a safe journey.

Dan Turner

A diagnosis of AIDS may come as a surprise rather than a shock. You may have thought your sexual habits were moderate compared with others. You may have never taken drugs. You may wonder why out of thousands of gay men across the country you had the bad luck to get AIDS. You may search many days and even weeks for answers why fate picked you to contend with a mysterious disease. You may experience these and many other feelings that I experienced when I was diagnosed with Kaposi's Sarcoma over two years ago.

When I was face to face with reality and finally accepted it, I learned to take life one day at a time. If I had a medical test Monday, I did not concern myself with the one I had on Tuesday, and Thursday, and Friday. I thought only moment by moment, and I tried to enjoy

those moments for what they were worth. I began to really appreciate the things we take for granted, the sky, the trees, the sounds of nature. I began to regard friends and family in a different way. I became less upset about getting stuck on the transit system. I really enjoyed the basic things like eating, like sleeping, like saying hello.

I left some of my trust in the hands of competent doctors I felt had my best interest at heart. I listened carefully to the choices I had for traditional and experimental treatment. I put some of my faith into science. I also left some of my trust and faith in myself and drew on the spiritual resources that were offered to me, as well as some I was familiar with. I decided to find ways to stimulate my immune system, since doctors could only offer me encouragement and not remedies. I inquired about alternative therapies and began acupuncture on a weekly basis. I also tried aura massage, visualization, and herbal tea. I recently began to practice transcendental meditation again after a hiatus of several years. I began to exercise at the gym, cautiously at first, and then with increasing enthusiasm – not too much, but enough to feel good and build confidence.

I quit my job and started doing the things that I like to do. If you like your job, there may be no reason to quit it. I wanted to spend my time writing, playing the piano, resting, and working in the garden. I decided to have as much fun as possible. I took a few short trips to visit friends in other cities. Eventually, I got involved with the AIDS Foundation – first through a concern to call attention to the growing problem, and then as a support to the gay community. I decided to give myself permission to be helped and cared for, and I decided to return the favor when I could.

I wrote a theater piece which was performed called "Pearls of Wisdom." In it, an older woman, who has lived a long life of 88 years says, "Life can be cruel, but you should never let it be cruel on purpose. It can be quite cruel enough on its own." She also states that "magic is what life is all about," and reflects on the highs and lows of her existence. Doubtless, you will become familiar with soul-searching, and perhaps get to know yourself a lot better.

Whether you stay around as long as that character, or check out of the hotel a little early, hold on to the good moments, for there are many that you will discover. Know that any suffering that you go through, whether physical or mental, will not be forgotten, but regarded as a contribution to your community of living gay men. Courage on any level releases its own good energy. Be proud to be challenged. It is a great experience.