

Creed — You Are Not Alone

There are nearly a million of us in the United States. Don't isolate yourselves.

By Jim Lewis and Michael Slocum

Maybe you have tested HIV-positive very recently; maybe you've known it for some time, but this is the first time you've reached out for information or support. You need to know that you are not alone. There are an estimated 1 million HIV-positive people in the United States.

Testing positive for HIV does not mean that you have AIDS, but HIV is probably the greatest threat to your life you have ever faced. This virus may remain inactive in your body for a long time, but it may not. If you are healthy now, you may still go on to develop some sort of health problems related to HIV. You may develop AIDS. There remain many uncertainties surrounding HIV, and though there is currently no "cure" for HIV infection, there are treatments. You need to learn what information is available and make informed choices about your health.

Many HIV-positive people now live fulfilling and happy lives. Many are healthy and show no symptoms of disease. Many choose to take treatments and drugs that promise to lengthen their lives. So, as serious as this is, there is hope. You do not have to look at testing HIV-positive as if you've been given a death sentence.

It's a good thing you found this out. As upsetting as testing positive may have been for you, you are better off knowing, so you can learn about HIV and decide what you want to do about it. The fact that you cared enough about yourself to get the HIV test and the fact that you are reading this magazine show that you are concerned about your health. So give yourself some credit. You have taken important first steps to take care of yourself, and you should be glad about it.

Years ago, those who tested HIV-positive had few places to turn for support. These people felt like they were hanging in limbo. Fortunately, much has changed. We know more about HIV now and many organizations have formed around the world to offer support and information to people living with this virus. Many have already faced the questions inherent in living with HIV, and many will follow. You don't have to face this by yourself. There are lots of hands reaching out to assist you.

Your Emotional Health

Finding out that you are infected is usually overwhelming. Even if you had suspected it for some time, learning that you are can be a very traumatic experience. Testing HIV-positive has led some people to quit their jobs, quickly write out their wills, and say goodbye to their friends and family, only to discover that they aren't sick and will

probably live for many years to come. It's common to perceive these results as an immediate death sentence, but this is simply not true.

What you are feeling now is perfectly normal. Anger, fear, confusion, numbness, depression -- all are completely natural reactions to the kind of news you've heard. If you've known for even several weeks, you may find yourself having a normal day, then suddenly remember that you are HIV-positive. It's very common for this kind of realization to just "hit you in the face" out of nowhere over and over again. You are not going crazy if this happens to you. Your moods may swing from profound sadness one moment to extreme anger the next. That's normal, too.

The first step to getting through this emotional turmoil is to acknowledge what you are feeling. Don't be surprised to find yourself going through the day in a state of shock. Allow yourself to feel nothing. Your emotions will come rushing back in soon enough. This is merely a way that your mind "turns off" to allow you to cope with a problem.

If you are feeling angry, that's fine. You have every right to be angry and a lot to be angry about. This virus is threatening your very existence. It's okay to express this anger. If you're frightened, acknowledge your fears. You are thinking about things that would make anyone fearful. You are allowed to feel the way you do. Don't be hard on yourself or think you have to be strong. You don't have to be anything.

Fear of Sickness and Death

Almost everyone is afraid of getting sick and dying. If you're young, you may never have had to face the death of someone close to you. We often think of dying as something that happens only when we're old. You may never have really considered the reality of your own death before. Now, suddenly, you are HIV-positive and your mortality becomes very real. You may be afraid of pain, of hospitals, or of becoming unattractive to others through an illness.

Your reaction to the idea of getting sick or dying could go one of two ways. You may decide that you are definitely going to live and that there is no way that this virus is ever going to "get" you. This is a form of what's called denial -- refusing to face some of the possibilities of living with HIV. If you find yourself feeling this way, try to keep in mind that having hope to go on with your life is good. However, it can become dangerous if it keeps you from taking care of yourself.

The other way you might choose to deal with the subject is by deciding that you are absolutely going to die of this and there is nothing you can do about it. If you go this way, you may find yourself fantasizing about your own sickness and death. You have to keep in mind that there are many people who are HIV-positive who are living productive, happy lives, and you can be among them if you choose. It's good to face up to the possible consequences of this infection, but not to the point that living today becomes

less important than your fear of the future. It helps to remind yourself that everyone will die, but that doesn't prevent most people from living today.

Starting Over

One of the truths of testing HIV-positive is that once you know, you can **never not know** again. For better or worse, your life will always be different now. You may be experiencing great feelings of loss about this. You may feel that certain areas of your life are now in the hands of doctors, insurance companies, or symptoms. This can make you feel as though you have less control over your own life and may cause you incredible anxiety.

Know this -- you do not have to give up control of your life. By arming yourself with information and deciding what is right for you, you will soon realize that you are still the same person you were. It is your life, your body, your health, and no matter how well-meaning your family, your friends, or your doctor may be, they have no right to take control of your life. Allow yourself to take time to decide what you want to do. Then go do it.

You may find that many of the priorities in your life change rapidly. If you are considering making major changes in your life, just make sure that you think them through carefully. Many HIV-positive people have made huge changes in the way they live. Many have broken bad habits, such as drinking too much or smoking. Some have gotten out of bad relationships or quit jobs they really hated. Facing the possibility of getting sick or dying has made many of our lives much better because it has made us take action in areas we have previously ignored or repeatedly put off. Mortality can be a great motivator.

Some people blame themselves for being HIV-positive. This kind of guilt and self-hate is very destructive. Regardless of how you were infected, you did not go somewhere or do something with the intention of infecting yourself -- so why beat yourself up about it? You are facing enough right now; you don't need to punish yourself for testing HIV-positive also.

Grief, or extreme sadness, is one of the emotions that most HIV-positive people face at some point. You may be grieving for yourself, facing the possibility of your own death. For many of us, the virus is not only affecting our lives, but the lives of those we love. Many have lost friends and loved ones to HIV, or have many people in their lives who are also HIV-positive. Allow yourself to express grief and fear in some way. Permit yourself to cry. These feelings are valuable and normal; ignoring them will not make them go away.

You may also feel that you are now damaged in some way -- that no one will want to touch you or love you or that you are less desirable because you are HIV-positive. You

may feel that you will never be able to love again, that no one would want to be with you if they knew that you were HIV-positive. These feelings will pass. You are not "damaged goods." You are still a valuable person, as capable of giving and receiving love as ever. You can make your own decisions, relax, and enjoy each day. This may be a struggle and you may have to find new ways of coping with daily life, but it's worth it.

Getting Support

Many of us have been raised with the idea of "rugged individualism," that we must face things on our own, that this is what "strength" is all about. Asking for help or reaching out for support are often considered weaknesses. Consequently, a very common response to testing HIV-positive is withdrawal. We isolate ourselves, hiding the news of our status. This can be very painful.

Your life does not have to be doom and gloom. It is possible to have a very positive attitude as a person living with HIV -- millions are doing it right now -- but it is much more difficult to get on with your life and live happily if you're trying to do it alone.

There's no need for you to handle this by yourself, and it's probably a mistake even to try to do it. You are not the only person facing this. Learn who the others are and what they have to offer. Just hearing how someone else has adjusted to living with the virus can be enough to help you realize that life is still good, that you can still have love and laughter. And you may also be surprised to learn that your own sharing can help others. In sharing the issues that concern us, each of our voices lends strength to the others.

Support groups, like those at Body Positive, are a powerful means of learning to cope with this new beginning. There are support groups offered by HIV/AIDS organizations across the country. If you don't know of an HIV/AIDS organization in your area, call us at (212) 566-7333. If there's no support group in your area, you may be just the person to get one started. Just remember: those millions of people living successfully with HIV are people who've reached out to get the help they needed. Wherever you are, you can find support, or the means to create it. It just doesn't make sense for us to face the same issues without helping each other out. We are not alone. And neither are you.

Michael Slocum and Jim Lewis were editors of Body Positive. HIV/AIDS organizations around the world have reprinted "You Are Not Alone" in their own languages.

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