
*The Guide to
Living with
HIV Infection*

Developed at the
Johns Hopkins AIDS Clinic

SIXTH EDITION

*John G. Bartlett, M.D.
Ann K. Finkbeiner*

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Baltimore and London

Note to the Reader

This book is not meant to substitute for medical care of people with HIV infection, and treatment should not be based solely on its contents. Instead, treatment must be developed in a dialogue between the individual and his or her physician. Our book has been written to help with that dialogue.

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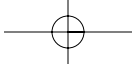
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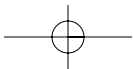
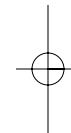
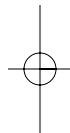
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Chapter 4

HIV Infection and Its Effects on the Emotions

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- Depression and hope
- Fatigue and accommodation
- Fear and realism
- Uncertainty and optimism
- Guilt and self-worth
- Change in perspective

Nearly everyone with HIV infection has, to varying extents and at different times, reacted to the disease with anger, depression, uncertainty, fatigue, fear, and guilt. These feelings do not occur in stages; they come in no order. Some people have several or all of the feelings at once. All the feelings are part of human nature and are reasonable reactions to HIV infection.

They are also more or less unavoidable. That doesn't mean you need to live in the grip of, say, depression. It only means that the emotions are as real as the virus, and that no one has a solid gold, 100 percent rule for curing unpleasant emotions. Though the mental health professionals can be of invaluable help in learning to live with these feelings, the real experts here are the people with HIV infection. Much of this chapter, like chapter 1, is in the voices of those experts.

Anger and Energy

Lisa Pratt: My husband had a lot of anger, which he first directed at me. He criticized, lashed out, once threatened to kill me. At first he refused to use a condom. He said, "Why did some jerk donate blood and now I have to use a condom?" He'd beat his fist on the table.

Alan Madison: I am not particularly angry.

Lisa Pratt's husband received an infected blood transfusion in the late 1980s, and like a lot of people could easily admit and express anger. Other people feel anger but do not acknowledge it. Alan Madison was infected by a lover, is doing well on the drugs, and isn't angry at all. Whatever the case, anger is a perfectly reasonable response to HIV infection.

Reasons for Anger

One reason for anger is the unfairness of the situation. In the first place, being singled out by the virus at all is unfair. No one, regardless of how he or she became infected, asked for or deserved this infection. Steven Charles, who became infected through sexual intercourse, said: "Why me? I didn't do anything wrong, I never hurt anyone, I was doing what seemed right to me. I know people who are more promiscuous and they seem to be getting out without a scar." Helen Parks had found a good job in the post office of the small town in which she lives; she had stopped using drugs by injection before she found out she was infected: "I hadn't been getting high any more. I was earning good money," she said. "Why bother to work hard and do good now? I had a rage of fire that wouldn't go out."

In the second place, being sick when you are young is unfair. "I feel gyped," said Rebecca Wolfe, who had been infected by a former boyfriend. "I don't like to dwell on the unlikelihood. I don't like to think about that." Alan Madison became infected with HIV just as he was beginning to reach success and stability in the banking business, and now he wonders whether he should change his long-range goals.

And finally, the social stigma, rejection, and even abandonment this particular virus seems to provoke are unfair. People's anger is particularly intense when they feel they are badly treated by those they thought they could count on most, their ministers and doctors. When Lisa Pratt's priest could not respond to her request for help, she said she was hurt and angry. People are angry that hospital clinics make them wait for hours, that the clinic doctor they felt rapport with last time has been replaced by someone else and the clinic clerks are rude. Edward Carroll's doctor wouldn't believe Edward had pneumonia and couldn't breathe; he told Edward he was hysterical and sent him home. Edward had to go to the emergency room to get treated. "Because of this disease," Edward said, "I've met some great people and some people I wish I'd never met."

Besides unfairness, another reason for anger is frustration at occasionally losing the sense that you're in control of your life. People get angry about having to live with medications that are complicated to take and can have unpleasant side effects. Dean Lombard was taking a drug whose side effect was diarrhea: "Once I messed the bed like a baby. I got

so frustrated and angry at not being able to do what I wanted to do, I cried.”

And anger at the social service agencies is perennial and universal. People complain that government medical assistance requires that they first become impoverished before they can get help, that they must fill out an amount of paperwork equaled only by the IRS, that even then the outcome is uncertain, and that the clerks are unhelpful and rude. “The workers just mess things up,” said Helen. “The people who take your applications are horrible and hateful. They act like they want to keep people from applying for help. It’s demeaning and dehumanizing.”

Expressing the Anger

Some people express anger directly and openly, usually in private, though Dean has cried in church. “Tremendous anger wells up in me,” Dean says. “I cry during hymns, reading those words. At home alone, I lose my temper, bang doors, throw things, yell. It’s important to me to release my anger, but I try to be careful not to hurt anything.” Rebecca uses almost identical words: “I feel anger building up on a weekly basis. I want to run up and down the road and cry. When I’m really angry, I beat on the bed with a book, which is noisy and very satisfying. Or I go in the bedroom and jump up and down and yell.”

Other people express anger more obliquely. “I’d cry every morning and night in the car on the way to and from work,” said Helen. “Sometimes I’d have to pull over to the side. And I went through a period where I snapped at my customers in the post office. When they asked why, I’d say, ‘Oh, the stupid Xerox machine won’t work.’” In fact, people often express anger not at the true causes, at unfairness or at loss of control. Instead, like Helen and the Xerox machine, they get angriest at little things: “My husband expressed a lot of anger about things so small, they were all out of proportion to what he was angry about,” said Lisa. “I’d fix him oatmeal, and it was not what he’d wanted, or it wasn’t hot enough.”

This infection has a lot to be angry about. Some people turn their anger toward the medical system. They say the drugs have unpleasant side effects; tests are painful and invasive, and so are the procedures. Hospitals do not allow a sense of control and privacy. Doctors seem impersonal and inattentive, nurses too slow. The rooms are too hot or too cold. Rebecca got furious at a friend who volunteered with her doing HIV/AIDS education and who got pregnant: “She was single,” Rebecca said, “and got pregnant. You know she was having unsafe sex. It’s like she thought what happened to me was for nothing.”

Some people say they are not particularly angry, and they truly are not. Other people truly are angry but say they are not because they are

uncomfortable expressing an emotion that is, after all, overwhelming. They worry that giving in to anger means losing face or losing self-control. Their anger at unfairness and loss of control, however, often has not disappeared. Instead of getting angry at co-workers or the medical system, these people turn their anger on themselves. They feel depressed or guilty or they dislike themselves. Some eat too much: Lisa gained twenty pounds after her husband's diagnosis. Others rely too heavily on alcohol or drugs. Some continue the behavior that put them at risk for the infection in the first place: for a while, though she denied doing it, Helen went back to injecting drugs. In general, when people are depressed, they quit taking care of themselves.

Dealing with Anger

Anger is a justifiable response to this infection. People need to be allowed to be angry. Sometimes directing anger at the wrong target—like Helen at the Xerox machine—just helps you blow off. But sometimes it's ineffectual and at worst harmful. Obviously, it can deprive you of needed friendship and support. "Some people express their anger at everybody and everything else in their lives," said Edward, "and people stay away from them."

Anger turned on yourself is recognized as a form of depression. Those who feel hopeless or isolate themselves or eat or drink too much or continue the behavior that put them at risk for the infection are hurting themselves. Usually people realize they are treating themselves badly; before too long, they stop of their own accord. Sometimes a friend or relative notices that the person is drinking a lot or seems unhappy and recommends getting help. If you do not seem to be stopping on your own, get help from a psychiatrist, psychologist, or social worker. These mental health professionals will help you identify and understand the anger and will help the anger find its proper target. If necessary, they can also recommend alcohol- or drug-treatment programs.

Even anger turned outward can be overwhelming. Certain actions and attitudes help people deal with anger. First, separate the anger from its target. Lisa's husband, after talking to a psychiatrist, understood he was angry at the circumstances, not at Lisa for serving him oatmeal. Steven, who had been furious at the doctors he saw in the clinic, was able to say, "The doctors aren't the people I'm mad at. I can identify the feeling now and separate it out."

Second, find mechanisms that discharge anger. These will be different for different people. Helen screams; she also takes long walks through the fields around her small town. Steven jogs and works out in

a gym. Edward writes out his anger in a journal, and talks to his partner, parents, and relatives.

Directing Anger

Much of people's anger about HIV infection is entirely appropriate. After you've figured out what you're truly angry at, after you've separated your anger from its target, you still have to figure out what to do with it. People find ways to direct their anger at its most appropriate targets, and in doing so, sometimes change their whole lives.

Lisa was angry at the social stigma her husband's illness had brought her. She began a newsletter for people in her city with HIV infection, so that others would feel less isolation than she had felt. Steven, who was angry at the medical profession, volunteered for a research study to test drugs. Alan Madison, upset about his career in the banking business, formed an organization that raised money to help local people with HIV infection pay for their rent, medicines, and food. Edward also helped found a money-raising organization for which he single-handedly puts out a newsletter on AIDS research, taught himself immunology, and took over editorship of a local newspaper for which he wrote a regular column on AIDS. "I want to leave behind anger and despair," he said, "and want to keep my desire to spread the word. You teach yourself things and—oh, God—I have so much to learn."

Lisa, Steven, Alan, and Edward are not exceptions. Anger holds an immense amount of energy. All over the country, people affected by HIV have used the energy from their anger to found buddy systems, political action groups, telephone hotlines, newsletters, fund-raising groups, and newspapers. They have successfully influenced medical guidelines and treatments, not to mention the workings of the Food and Drug Administration. Directing anger puts that frightening energy where it will do the most good; it returns to you a sense of control over your own life; it also returns a sense of hope. Sometimes it accomplishes near-miracles.

Depression and Hope

Helen Parks: Sometimes I'm in my room, in my chair, and I think about the people in all the stages of this disease and the people who have left the world with this disease. And I wonder what I'm going to do if I get sicker. I get confused. I get drastic thoughts. I sit in my chair and cry. I get real depressed.

Steven Charles: It feels like I'm caught in a muddy ditch and the walls are mud, there's nothing to grab on to and I can't climb out.

What Depression Feels Like

Depression is one of the most painful feelings a person can have. People say they feel alone and helpless in an indifferent world. They say they lose interest in things, have no energy, feel generally tired. They feel empty and uninterested in things they are normally interested in. They feel lonely and alienated from their friends, relatives, neighbors, co-workers. They doubt themselves or blame themselves or feel they have failed. They quit taking care of themselves. Like Helen, they have "drastic thoughts": they think about dying, sometimes about killing themselves. "When I'm home and completely alone and start dwelling, that's when I'm in trouble," said Edward. "It paralyzes me, I can't do anything. I just lie in bed."

Sometimes depression affects not only the mind, but also the body. Some people report that they cannot think as clearly or quickly as they used to. Some stop eating; others eat too much. Some cannot sleep, especially in the early morning; others sleep too often. In general, people dealing with depression say they are mostly sad and lonely, and they often cry a lot: "For a while, I cried all the time," said Rebecca Wolfe. "I didn't want to cry in front of my husband. I cried when I was alone—in the car, in the shower."

At bottom, depression seems to be the absence of hope. Hope is the sense that life is good, that it holds comforts and delights, that what you do makes a difference, that one way or another things will be all right. Sometimes, for a while, this sense of hope fails you. Faced with hopelessness, people feel helpless. They feel they have no alternative but to continue feeling depressed. They feel they no longer have the power to change how they act or how they feel. They feel that nothing they do matters or ever will matter. Some people, especially early in the course of the infection, consider suicide.

Depression varies in intensity and duration. Sometimes it is a mild feeling of being "down," or devoid of pleasure, or demoralized. Sometimes it is severe, and feels like despair, deep apathy, or true hopelessness. For most people, depression comes and goes: "I get bouts of these depressions," says Steven. The bouts can last a few hours, a few weeks, a few months. Edward, even though he says he has had trouble with depression for much of his life, also says, "I spend a few hours or maybe a day depressed, but that's all."

Causes of Depression

One cause of depression is a sense of being stuck in a frustrating, disheartening situation. Such situations are everywhere in life. Most people at one time or another must face something that they cannot fix, to which they can only adjust. HIV infection is certainly reason for depression: Edward said, “It’s in my dreams. It can just percolate—you have this hopelessness. This is not the best thing that ever happened to me.” For people facing HIV infection, depression, like anger, is a reasonable response.

Other causes of depression are the inevitable accompaniments of any disease. People get depressed when they go to the clinic for treatment and see other people with HIV infection worse off than they are. “We withdraw when we’re sick,” said Edward. “We’re ashamed when we’re sick. And the stigma of HIV isn’t gone. It’s difficult to stay strong. For a while, friends would call and say ‘Let’s do something,’ and I’d say, ‘Why?’ If I’d gone to see a therapist, I’d have been diagnosed clinically depressed.”

Still other causes of depression are all of life’s ordinarily depressing vicissitudes. Steven had a job out of state when, by coincidence and on the same day, two close friends died, one by accident, the other by suicide. “Talk about grief and despair,” he said. “I couldn’t work, and worked anyway and made mistakes. I was goo, I was slime on the ground. Finally I packed up my dog and drove home and we’ve been here since. I didn’t understand how two people who were young and who I loved could die on the same day. I just worked and took care of the dog, that was my whole life.”

Another cause of depression is predisposition: people who have been depressed before their diagnosis might be more likely to be depressed afterward. Another cause is medications: many of the medications used to treat HIV infection and its complications can have depression as a side effect. For example, a small risk of depression is attributed to the long-term use of efavirenz; talk it over with your doctor. Alcohol, which is a depressant, is a particularly treacherous cause of depression because it can start a cycle. To feel better about their depression, people drink, which makes them feel depressed and out of control. So to feel better, they drink some more, get more depressed, and so on and on.

Occasionally, depression may be caused by the virus itself. That is, depression can be a symptom of dementia, a condition that results when the virus enters the brain (see chapter 6).

Finally, depression can be caused by unexpressed anger. Anger is hard to express, especially if it is directed at something as vague as fate, or something as personal as your own body or your behavior. People

who do not express such anger either consciously restrain it or unconsciously ignore it. In either case, they unknowingly turn their anger inward on themselves and become depressed.

What to Do about Mild Depression

Depression that is unexpressed anger will disappear if the anger is recognized and dealt with. Depression that is a reasonable response to HIV infection almost always runs its course within days or weeks, and then goes away. For some people, this happens without their intervention. Others need to be more active in dispelling depression. One way to lessen or end depression is with physical activity: get outside, go for walks, cook a wonderful meal, go boating or driving or fishing or bowling, go shopping and buy yourself a little treat. “When I get depressed,” said Steven, “I eat Ben and Jerry’s coffee Heath Bar crunch ice cream.”

Try to accomplish something you want done. A sense of accomplishment can come from doing something small, like cleaning out a closet, writing a letter, or polishing your shoes. No matter how small, a sense of accomplishment is a great weapon against depression. One small accomplishment can give you the hopefulness to embark on the next small accomplishment, and so on until you recover your normal habits of life.

Another way to lessen or end depression is with mental activity: read novels or biographies or philosophy or poetry. Go to the movies or the theater or the opera. Go to an art gallery and really look at the pictures. Talk to your neighbors or friends or family. Play a musical instrument or draw a picture or take some photographs or write a poem. Plan your garden or a trip or a fancy meal. Learn archaeology or medicine or Civil War history or art history. Write your memoirs; write essays about your political opinions or your philosophy of life. The possibilities of emotionally satisfying activities are endless. “I’m not one of those people who immerse themselves in the sickness,” said Steven, who is a technician in a scientific laboratory. He takes in stray dogs, operates a ham radio, and reads up on scientific discoveries in astronomy. “I keep my regular life going,” he says, “keep on working.”

When Helen gets depressed, she has a list of things she does: “I usually notice depression when I hit the house after work. Then I find things to do, to keep my mind relaxed. I dig in the dirt. I walk, anything physical. Clean the closet, walk through the mall and window shop. I take a bubble bath. Read the Bible, help someone else.” Lisa’s husband did the same: “For months,” said Lisa, “my husband sat in a chair and stared. Nothing interested him. Then he got into his workshop and started making crafts, carving wooden ducks.” Dean gardens; he says it gives him a

great sense of peace and beauty. Edward asks his friends to come visit—“I have a circle of wonderful friends,” he said; “they buoy my spirits”—and writes his newspaper column. “I really battle,” he said. “I really try to engage myself in something, try to do some work. Work is the answer, it just is.”

What such activities do is redirect your attention away from yourself and your very real problems, to other things in life and their very real pleasures. “I do get depressed,” said Rebecca. “But I don’t set my mind into that. If I sit at home and think, I get depressed. So every day I tell myself, ‘Good morning. Have a good day,’ and keep myself busy. I go to the museum, go shopping, volunteer at the Aquarium.” Alan, who found the clinic depressing, decided to do something about it: “I talk to people at clinic—they feel isolated, too. I’ve become more of an outgoing individual and I really want people to feel not alone. It’s so great to see eyes light up, that they’re not the only ones.”

These and other activities will not make your life wonderful again, but they do seem to dissolve depression, at least temporarily. Sometimes, during a walk, the balance between hope and hopelessness seems to shift back toward hope, and you feel more yourself again. Don’t be too impressed by your depression; you have felt it before and you will feel it again. And when the next bout of depression moves in, you, like Helen, will have your list of accomplishments and activities and distractions and small pleasures handy. “The only thing is to keep busy and find things I want to do,” said Edward. “I haven’t been put out of commission by worry or anxiety. I have on occasion, I have taken to bed for a day. But next morning I’m right up and at ’em. I think ‘Ok, I’m going to take care of this.’”

A lot of people, maybe almost all people, get tired of handling depression on their own. Seeing a mental health worker, like a psychologist, and just talking through thoughts and feelings can be a relief, can reassure you that your problems are more or less normal and you’re not going crazy after all.

What to Do about Severe Depression

Sometimes, for some people, depression is too severe or it lasts too long. They feel alienated from everyone, deeply apathetic, profoundly hopeless. Severe, persistent depression is often best treated with medication. Talk to a doctor. If medication taken for another condition is causing depression, the doctor can change the drug or lower the dose. If the depression is part of dementia, the doctor will prescribe medications that ease the symptoms. Most of the persistent depression in people with HIV infection, however, is simply the natural reaction to knowledge of a

frightening disease. Depression can be successfully treated with appropriate support and medications. In this case, the doctor will recommend a psychiatrist, who can prescribe medication that restores sleep, appetite, and mood. The drugs currently used for severe depression can be nearly miraculous. They do for depression what penicillin does for pneumonia: about 80 percent of severely depressed people with HIV infection get better, and about 50 percent are cured. For most people, treatment of depression is critical but temporary.

In addition to or instead of medication, you might want professional help. Either the doctor or the psychiatrist might recommend professional psychological help (see the section on mental health professionals in chapter 11). Psychiatrists, psychologists, and social workers can help you talk through whatever is blocking the healing process, though only psychiatrists are trained medically and can prescribe medications. Psychotherapy may concentrate on the overwhelming problems people must face and feel they cannot solve: How can I face rejection? How can I deal with anger? How can I feel less guilty? How can I have sex without hurting myself or anyone else? Why me? Am I a good person? Why now? By helping you confront problems you feel are unsolvable and find new perspectives on those problems, a psychotherapist will help you take control of your life. He or she will help you deny, not the fact of your infection, but your own helplessness and hopelessness in the face of it.

Thoughts of suicide are usually only temporary. When Lisa's husband said he was considering suicide, Lisa asked him to first talk to a psychologist. She also told him she thought he owed it to her not to act without talking to her. He agreed and made those promises. Eventually, he decided against suicide. Like Lisa's husband, many people find their interest in life is stronger than their desire to die. In fact, the suicide rate among people with HIV infection is low. Researchers say that people seem to consider suicide mostly as a means of regaining a feeling of control over their lives. And that makes sense—it is as though people were saying, "This disease does not control whether I live or die, I do." If that choice seems to be in your hands, you feel less helpless, more in control.

Nevertheless, if thoughts about suicide persist, and if thoughts of taking pills become plans to collect specific pills, and if these persistent, concrete thoughts are coupled with an increase in guilt and a sense of punishment, then get help. Call your doctor or psychotherapist.

Fatigue and Accommodation

The Causes of Fatigue

Fatigue for people with HIV infection comes from anything from the stresses of everyday life, to the drugs against the virus, to the virus itself.

Fatigue often accompanies depression: people dealing with depression lose not only a sense of hope but also their physical energy. They are tired, sometimes exhausted, sometimes apathetic. Fatigue can also have physical causes, which can be sorted out by a medical evaluation (see chapter 6, under “Causes of Constitutional Symptoms”).

Fatigue is a subjective symptom; it cannot be objectively verified or quantified like a blood count. Fatigue is also common to everyone; up to 25 percent of all people without HIV infection complain of being chronically fatigued. For people with HIV infection, a medical evaluation needs to review factors that cause fatigue but that are treatable: depression, anemia, medicines, and infections. Most people just learn to live with and around fatigue.

The Effects of Fatigue

Although the causes of fatigue may be physical, the effects are psychological. In fact, depression not only causes fatigue but is also caused by it. Dean said he has good days and bad days. On the good days, he has more energy. After a rough night and diarrhea, he will be tired the next day: he said, “Those are the crying days.”

Another psychological effect of fatigue is irritation. Lisa Pratt’s husband “had always been a go-getter,” she said, and resented his fatigue. “My husband,” Lisa said, “had to give up little things he liked because he had no stamina. For years, he had been an actor in our local community theater. He couldn’t keep up with the rehearsal schedule and thought he was going to have to quit. It hurt to not go. And it made him mad to give in.” Dean said that until he learned to pace himself, he regularly worked fourteen hours a day running a small newspaper, came home angry, then “got the blues.”

Accommodating to Fatigue

Whether its cause is psychological or physical, fatigue cannot be ignored. First, talk to your doctor so that what’s treatable can be treated. After that, the best way to deal with fatigue may be to accept it and go on from there. Decide what you want to do most, be sure it is possible, plan it out, and pace yourself. Lisa’s husband stayed in the community theater

but tried out only for small roles. Dean kept his job but cut back his hours and tried to have meetings in his office rather than in offices across town.

In general, try to find ways to accomplish what you want with less energy. Lisa's husband's fatigue also affected their social life: "Socially, we didn't go out as much. But then we redefined 'socially.' Instead of going out drinking and dancing, we entertained at home. Our social life didn't disappear." People who find driving tiring can often take public transportation. When they want to buy clothes or household supplies or presents, they order from catalogs or the Internet. To buy groceries, they find a store that delivers, or ask their friends. They get their medication from pharmacies that deliver.

Do what you can; don't give up before you need to. Steven says, "I keep pushing myself. I do wake up tired and don't like that. I make myself get up. I get out of that bed." If you know you've done your best, then relax and rest. Try not to let fatigue affect your good opinion of yourself. You've done what you could. Just take care of yourself.

Fear and Realism

Alan Madison: I'm scared as hell at different periods. I wake up at night and cry a little.

People fear what they do not understand and cannot control. People who are feeling good on the new combinations of drugs fear that the drugs may stop working and worry about the results of each blood test. They worry about their finances: the drug regimens are expensive and they worry about whether they'll be able to continue to afford the drugs. People worry about symptoms that may or may not be serious. They fear being a patient in a hospital, or undergoing painful medical tests and procedures. They fear rejection: Alan was afraid that people would treat him as though he had leprosy; Helen said she was fearful of telling her sons. Rebecca said she'd gotten past her initial fears of being damaged goods, but still "I get little echoes of it when I disclose my HIV status. I hate that conversation." People with HIV infection are afraid they will give someone else the virus.

All these fears are realistic. The point is not to live without fear, only to live without being unduly troubled or hindered by fear.

Sometimes what people feel is not fear but anxiety. That is, they have feelings of fear that are unrealistic. People who are anxious say they feel as if something terrible were about to happen. They cannot say what exactly they fear, only that they have a sense of underlying uneasiness. They feel restless and uncomfortable wherever they are. They are irritable,

tense, and preoccupied with their bodies. They have trouble breathing, are nauseated, break out into cold sweats, have racing pulses. Some have periods of feeling panicky.

People whose feelings of anxiety persist too long or are too severe should see a mental health professional or a doctor who might in turn recommend a visit to a psychiatrist. Persistent anxiety takes a tremendous amount of energy, and it is often curable. Psychiatrists can prescribe medication to relieve anxiety. Mental health professionals can teach techniques that help you relax. Physical relaxation usually makes people feel calmer and more themselves again.

Dissipating Fear with Information

Many fears do not hold up in the cold light of reality:

If you fear sickness, find out which symptoms you should see your doctor about and which you should ignore (see chapter 6). “I found out what’s what,” said Alan, “and now I don’t worry about every little cough.”

If you fear medications, tests, and procedures, educate yourself about them. Read what you can find, ask your doctor, ask people who have had the experience. Learn about drugs and their side effects. Talk to someone who’s had a bronchoscopy, who’s gone through a scanner, who’s had a lumbar puncture. The fear of such things is often much worse than the things themselves.

Put the fear into perspective. Alan said, “I went to a therapist for a while. Then I had a big gigantic turning point. I was taking a shower and realized that all my problems were coming from the fear itself. Fear was creating all the problems, even the fear. Realizing that made the fear dissipate in a gush. Of course, it came back again, but it kept going away again too.”

Uncertainty and Optimism

Everyone with HIV infection faces uncertainty about the future whether they’ve been sick and didn’t improve until the triple therapy was introduced, or whether they’ve been well on the triple therapy all along. For those who were sick, the drugs work wonders physically: people feel well and energetic. “I look good,” said Dean. “My muscle tone is back, it’s great to look in the mirror and not cry. That’s a real wonderful thing. But there’s a whole new game to play here and it’s not all that easy.” Dean’s test results are good; his CD4 counts have been climbing and the virus in his blood—his viral load—is at undetectable levels. But he wor-

ries about the next round of tests: “I’ve had a year now of undetectable virus. As long as I can keep it that low. But it’s like a time bomb—you’re always waiting for something to happen.”

Reasons for Uncertainty

Everyone taking the new drugs feels this disconcerting mixture of uncertainty and hope. Both feelings are accurate reflections of the reality: at the present, the drugs restore people to health; for the future, the drugs could hold HIV in check forever or they could lose their effectiveness. This kind of fundamental uncertainty about sickness and health is not like anxiety, which is an unrealistic response or a response to something unreal. This uncertainty is entirely realistic. HIV infection, in the virulence of the virus and effectiveness of the medical response, has been a remarkable disease, and we are at a remarkable point in its history. The only certainty is, the situation is infinitely better than it once was.

The uncertainty is all the more nagging because many people with HIV infection know exactly what they’re up against. “A year ago I was preparing my funeral,” Alan said. “I had pancreatitis, couldn’t take drugs, was grey, my skin was hanging in folds. My CD4 count was 180 and viral load was 650,000. Now my CD4 is 1,115 and I’m undetectable. I’m 12 years out, alive and kicking and working full time. But in a way, it’s easier to resign yourself to dying than to living.”

Rebecca had nearly the same experience: “My counts started going up and my doctor was bouncing out of his skin. I said, ‘Forget it. I mean, great, I’m going to live a long life. But what am I going to do with it?’ Though I feel like an ungrateful patient. I say to myself, ‘It could be worse.’ But you know, it really might *get* worse.”

Adding to the uncertainty is the scrupulousness with which people have to take the new drugs. “I recently missed a dose,” said Rebecca. “One day I was busy and the dish was full as if I hadn’t taken a dose. I’ll take blood work in a couple weeks. My doctor said, ‘Did you miss a whole day?’ I didn’t, only the morning dose. He said, ‘I really don’t think you’ll have to worry.’ But after the test, I’ll know how exacting I have to be.”

For Helen Parks, the drugs aren’t working well; her viral load is down but not undetectable. “My biggest issue is,” she said, “will I be spared? My doctor says he doesn’t know, he doesn’t have a crystal ball. If my viral load were undetectable, if the pills were actually working as they were supposed to according to the newspapers, I’d be feeling better.”

Managing Uncertainty

People manage uncertainty partly by accepting it and partly by investing, cautiously, in the future. People who have been extremely sick and have faced the possibilities others only fear, are particularly aware, not only of the uncertainty but also of the investment. Alan, who said that living might be harder than dying, added, “My partner and I just bought a house with a 30-year mortgage.”

They do what could be called “bracketing”: suspending consideration of sickness, living in the present, planning for the future. “It’s possible to separate yourself from having AIDS now,” says Steven. “I’m not thinking about it as much.” They remain scrupulous about their drug regimens and their doctor appointments. And like Edward and Alan, they make plans, pursue friendships, fall in love. They think about what to do next. “I also want to start a college course in theater,” said Alan. “I was always interested and never did anything about it. Also watercolor lessons. And piano lessons again—I used to play.” Rebecca would like to have children: “I hope to, when this is all over. I want an end to this. I’m looking forward to my future.” They work hard at being ready for the positive alternative, being ready if the drugs keep HIV down forever, being ready to return to life’s normal uncertainties. “I live my life like everything’s normal,” said Steven, “like I’m going to do everything I planned to do. I bury myself in work. It helps.”

Some people have to decide whether to work. Their decisions depend on their individual circumstances. “For now, I’m ok financially,” said Dean, “but what am I going to do? Start working? Give up disability? I had friends who sold their life insurance and now they have to start over. My family says, ‘You’re healthy, why don’t you go back to work? Why don’t you?’ I think when my doctor says, ‘It’s a cure, there’s no HIV left,’ then I’ll go off disability.”

Rebecca, who is also on disability, volunteers at several jobs; she’s thinking about going off disability and seeing if one of her jobs will hire her full-time. Alan had friends who stopped putting money into retirement funds and who passed up promotions. Alan himself qualified for disability at one point, but when the new drugs gave him more energy, he went back to his banking job. “AIDS is not your whole life now,” he said. “It’s there and you’re worried about it. But it’s not everything.” Alan decided he’d take the risk of going off disability, even though he worried about what would happen if he got sick again. “I guess I’d rather die with my boots on,” he said. “I mean, how disabled would I let myself be?”

Guilt and Self-Worth

What People Feel Guilty About

One of the many peculiarities of HIV is the amount of guilt it seems to inspire. People feel guilty for having become infected. They feel they are somehow to blame for having gotten the virus, that they brought it on themselves. “I feel a little guilt,” said Steven. “I should have known to practice safer sex, even though at the time I got infected, no one even knew the virus was around. I know how stupid that sounds, but I feel guilty anyway.” They feel guilty about bringing HIV infection into the lives of other people: about putting their partners or spouses at risk, about telling their children they have HIV infection, about distressing their parents, their families, and their friends.

Many people also feel guilty about the behavior that put them at risk in the first place. “I felt guilty over my period of promiscuity when I first came out as gay,” said Edward. “I justified it at the time, but I knew it was wrong.” The behaviors that exposed most people to the virus—gay lovemaking and injection drug use—are behaviors of which society often disapproves. For many people, social disapproval is distressing, and they feel isolated and punished. Sometimes they unconsciously take social disapproval on themselves as guilt. “A lot of us took society’s view,” said Dean, “and felt guilty about being gay.” The same is generally true for injection drug users: “I was real upset with myself,” said Helen. “This disease makes me feel like I’ve been a dirty person, and I’m not. I’m a clean person.”

Even those whose exposure to the virus came through conditions society does not disapprove of—blood transfusions, hemophilia—still feel guilty. Even people whose infection came through heterosexual sex worry about social disapproval: “I got infected by an old boyfriend,” said Rebecca, “but I worry that people will think I had been a slut.” They feel they are to blame for involving their families in a disease that is socially isolating, and for putting their spouses at risk. Lisa said her husband had been afraid their daughters would say, “What did you do to our family?” “I felt guilty when I was diagnosed,” said Dean. “I thought ‘I killed my partner.’” Like Dean’s partner, Rebecca’s husband remains uninfected, but Rebecca worries about the consequences to him if her infection becomes public: “I cannot let my husband be hurt by this. His career would be jeopardized by them finding out about me. Maybe they’d be understanding, but I can’t take that risk.”

Even caregivers feel guilty. Steven’s mother feels that if she had been

a better mother, Steven would not have been gay and come in contact with the virus.

Causes of Guilt

Guilt does not necessarily have a cause. Guilt, like fear, is a feeling that may or may not have anything to do with the facts. Some people knowingly did something they should not have done. Perhaps they knew they ran a risk when they became infected. Others are accepting blame for something over which they had no control. Perhaps they knew nothing about the virus or they thought they were taking appropriate steps to avoid infection or they unknowingly received infected blood.

Guilt, like all other reactions to this infection, is a natural human feeling. Sooner or later in their lives, most people feel guilty about something, sometimes justifiably, sometimes not. Alan, for instance, remembers stealing a plastic toy from a dime store when he was seven years old, and though he does not feel like a criminal, he does feel a vague sense of shame and is not able to forget the incident.

Perhaps guilt comes from a sense that good behavior deserves reward and bad behavior deserves punishment, and since the virus feels like a punishment, they must have behaved badly. Perhaps social disapproval operates the same way: people feel isolated and punished, so they feel they must have done something wrong to deserve it. Both of these possibilities are built on bad logic and are just plain wrong.

What to Do about Guilt

First, separate the virus from a sense of punishment. Lisa states: “What I say is, it’s a virus, not a punishment. I didn’t get the virus and my husband did. Does that make me good and him bad? That’s ridiculous. Everyone got this virus like my husband did: being in the wrong place at the wrong time.”

The virus does not set out to “get” anyone. It has no brain, no judgment, no ability to pick out who is worthy and who is not. The virus has nothing whatever to do with punishment. Nor does anyone set out to get infected with the virus. The conditions that put most people at risk for the virus—homosexuality and drug addiction—may well be directed by biology and, in any case, are not the result of a conscious intention. No one makes a conscious, informed decision that they will become gay or will use drugs.

Understand that guilt, except when it keeps you from repeating mistakes, is a remarkably useless emotion. Feeling guilty means worrying

about something you cannot change. Whether people knowingly ran a risk or not, the past is beyond anyone's power to change. Guilt keeps people captured in the past and prohibits them from doing what they can to improve the present. Guilt uses emotional energy that would be better used on the real problems of life.

Balance guilt by understanding your own worth. Ask yourself, outside my worries, who am I? A pastor who has had experience with people with HIV infection asks people, "What else besides the things you feel guilty about are you? What do your friends like about you? They tell me 'that I helped them move the piano, that I had some good kids, that I was a good friend.'" Steven told himself, "You just have to focus. You're worth something. You're not scum, you can make a difference."

In the process of focusing on your own worth, guilt usually fades away. People come to like themselves for who they are. Some people speed up the process by getting help from a therapist. During therapy, they deal with the attitudes and behavior, often left over from childhood, that make them feel guilty. They learn to feel comfortable with themselves and free themselves of their old, useless burden of guilt.

Sometimes, however, guilt is not particularly personal, that is, people aren't feeling punished or ashamed or responsible or bad. Their worry is more general, more religious or philosophical. They're trying to make sense of their HIV infection, to fit it into their mental worlds, to understand why they got infected.

Helen is an eloquent example. The drugs are less effective with her, her viral load is detectable, and she has trouble not taking it all personally. "So what did I do wrong?" she said. "I can't make it out, to tell you the truth. If it's true that bad things happen to bad people, I'm ruined. People say to me, 'How could this happen? You're such a good person?' I guess maybe I'm not. Or maybe I'm not really a bad person and I'll be spared. For me, usually, reading, getting involved in stories, is a great way to stop worrying. The problem is, in most stories, bad things happen to bad people—it's just there all the time. I don't know how to get around it, even though I'm convinced in my deepest core it's wrong. You can see I've thought about it."

For Helen and others, guilt actually seems to be the first step in making sense of their new lives. Their reasoning goes like this: Why did I get this virus? Did I do something wrong? If I didn't and the virus isn't a punishment, if it's simply a random biological fact that's affecting my life, then what do I do? How do I make sense of that? The question has been addressed by every theologian and philosopher since the Book of Job. The answer is going to be deeply felt, carefully thought out, unique to everyone, and completely beyond the scope of this book or the expertise of its authors.

Change in Perspective

Often the answer to questions like Helen's and Job's involves a change in perspective on life. "Change in perspective" is a vague term that everyone uses and no one defines; it probably means something like, "When you stand in a different place, you see things differently." HIV infection is certainly a different place, and after years of adjusting to these changes, people come to see their lives differently.

"Before I got sick," said Rebecca, "the world was normal. I knew I had a virus in me, but I was living the life I wanted to lead. I was dating, having fun, being me. But when I got sick, I prepared to die. I wrote my last will and testament, made funeral arrangements, did a living will, and fixed up my house to die in—I wanted a pretty place to die in. I had 12 CD4 cells, PCP, esophageal thrush, anemia, had lost over 10 percent of my body weight, and my hair fell out. So I know what it's like to be sick." But Rebecca improved drastically on the medications, and once again, her life changed. "Life before I got sick was very good. I got sick and it all changed. For a long time I thought I should never have taken the meds. I should have just let it go. It almost pissed me off not to be able to die gracefully and beautifully. I don't really want to live. I don't want to die either. So I'll make the best of it. You don't just resume life. And you don't have any hope of ever resuming your life. It's changed. The hand I hold is totally different now, and I have to play this hand I'm dealt."

Faced with their new knowledge, people change their priorities. Accordingly, some people begin thinking how they might change their lives. Rebecca will go back to school, to go into social work. Alan is a banker, but his training was in music, and now he thought he would like to go back to playing the clarinet. Steven, who worked as a technician for a scientific laboratory, had always wanted to teach, and volunteered as a teacher in a community adult education course.

Many people now place greater priority on other people. "When I almost died," said Rebecca, "I realized at that time the most important thing is my relationships. With my time now, I want to spend time with the people I love." Some people begin tidying up relationships: Lisa's husband called his brother more often, and they began going to ball games together.

Somehow or other, such changes in priorities answer people's deep questions about whether life makes sense, whether it has meaning, whether it's good. Dean volunteers at a hospice, and explains himself this way: "Before I got this virus, I had this feeling about God, that I lived a charmed life, that God looked out for me. And this was a wake-up call. I couldn't believe in God the way I did. I thought, 'There's no



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orchestrating force in life, it's just random. I've spent my life in the best way I can, doing as little harm as possible. Nothing justifies this.' So I had to think where I had ever found meaning before, where I ever had a sense of God. I realized these times were when I cared about someone as much as myself. I needed to get that back. If I could care for those people at the hospice, I could come back. My conception of God has changed. I do see the world as more random. And whoever I was before is gone. But I'm trying to find where God was and where there's meaning. And that's in caring for someone. That's what keeps me going."

