

# MOVING BEYOND GRIEF

## Skills to Be Learned

- Understanding the Stages of Grief
- Facing and Coping with Fears about HIV
- Identifying and Prioritizing That Which Has Personal Meaning

**W**hen we think about grief we usually think about grieving over the death of a loved one, but grief is actually a normal human response to loss of any kind.

Grieving is an unavoidable part of living for all of us. No one is immune. We grieve when we lose people and pets who are important to us, we also grieve when we lose things that are important to us (even giving up drugs is a loss that many long-time drug users grieve), and we grieve if we are diagnosed with a potentially debilitating illness that can threaten our lives, impair our functioning, or end a cherished lifestyle.

People who are infected with HIV are faced with a profound sense of loss on many levels. If this grief is not addressed, it can lead to feelings of helplessness, continued high risk behavior, including drug use, and to lack of follow-through with medical care. The purpose this chapter is to understand the process of grieving so that you can begin to move beyond grief into hope. Part of this process involves identifying and facing your fears. This can be a highly creative force in finding personal meaning in life. This may be difficult, so you should go at your own pace. Try to use this opportunity to go a little deeper than you might otherwise, and to trust that within you is a source of strength and wisdom that can handle whatever comes up. Grief is something that people don't often talk about, but it can influence decisions we make in our lives that can affect our own health and the health of others, and so it is very important to address.

## **Stages of Grief**

According to Elizabeth Kubler-Ross, who wrote several books on grief—**grief is a process**—that means that people go through various stages when they are faced with a loss. You may not go through all the stages she describes, and you may not go through them exactly in the order she specifies; however, having an understanding of the different stages of grief and being able to identify where you are in the process can be extremely helpful in moving you forward.

The six stages of grief described by Elizabeth Kubler-Ross are: denial; anger; bargaining; depression; acceptance; and hope. We'll go over them one at a time, and then discuss how they may relate to having HIV.

### **STAGE 1. Denial**

This is the stage when the person thinks, **“No, this just cannot be true.”** We've probably all said this when faced with terrible news. Denying some-

thing is true is a common way of initially dealing with a painful situation. At first, one may feel totally unable to accept the bad news. In this stage of denial we might isolate ourselves in an attempt to defend against the reality of the situation.

Although denial is a normal stage of grief, if we remain in this stage too long we will be unable to make necessary and important decisions.

### STAGE 2. **Anger**

The next stage is anger. This is the stage in which the person acknowledges the reality of the situation, but is filled with rage at the loss and thinks, **“This isn’t fair; why did this have to happen to me?”** When a loved one dies, we may be angry at whatever took our loved one’s life, angry at God, even angry at the loved one for leaving us. Although feeling angry is normal, we may displace our anger. This means taking anger out on other people or things. It may feel as if everything and everyone is irritating us and so we lash out and are completely unaware that this is a manifestation of our grief. Although displaced anger may serve to distance us from the pain and reality of the loss, it can create problems in personal relationships, especially if the people around us do not understand that we are grieving. It can even lead to legal problems if we physically act out our anger on people or property.

### STAGE 3. **Bargaining**

The next stage is bargaining. This is a stage that people sometimes go through when they are facing the loss of their own life or the life of a loved one. They think **“There must be something I can do to change this.”** We may try to make bargains with God by promising to do something difficult (often something that we are unlikely to be able to do), in exchange for removing the threat of loss. For example, we might pray, "God, if you spare my loved one’s life, I promise to be a better person." When feeling powerless, bargaining may provide us with the illusion that we are actually doing something to help, but as with the previous stage, if we remain in this stage too long, it can prevent us from coping realistically with the situation and taking appropriate action.

### STAGE 4. **Depression**

The next stage is depression. In this stage, the reality of the loss has really “sunk in.” Denial, anger, and bargaining give way to despair, and we think **“I cannot handle this pain and I’m helpless to do anything about it.”** We may attempt to withdraw from the world and to "shut down our circuits" in an attempt to defend ourselves against the pain of the loss. Although pro-

found sadness in response to loss is normal, it is important not to get stuck in this stage. Depression can quickly lead to drug use and other unhealthy behavior.

### STAGE 5. **Acceptance**

The next stage is acceptance. This is the stage where we move beyond defending ourselves from the pain of the loss with denial, anger, and depression, and begin to accept reality. We may think **“I have experienced a painful loss, but I can get through it.”** When we are in the earlier stages of grieving, it seems that acceptance is an unattainable goal. However, it is important to keep in mind that acceptance is neither unattainable nor is it the ultimate goal. Acceptance is not the end of the process, but rather a necessary step that will move you beyond grief to the next stage which is hope.

### STAGE 6. **Hope**

We have reached the final stage—hope—when we reflect upon the loss in search of personal meaning. In this stage we may think **“I am ready to learn from this important life experience.”** As we will discuss later, finding personal meaning in a loss involves being willing to identify and face your fears.

Before we talk about fear, let’s consider how the six stages of grieving can be applied to HIV and addiction.

Consider the following:

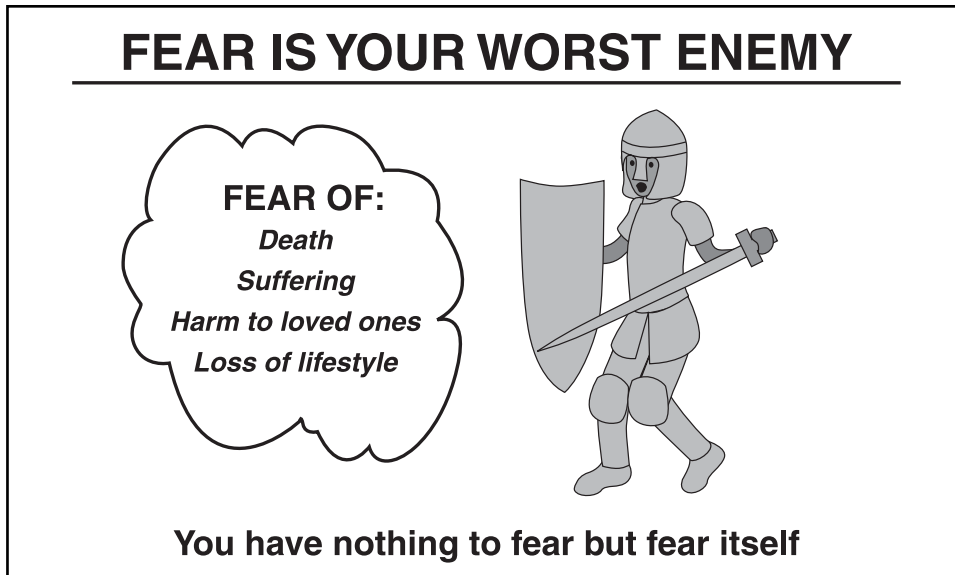
1. Do people grieve when they find out they are HIV-positive?
2. Did any of you go through these stages after you were told you were infected with HIV?
3. Does your addiction keep you stuck in any one stage?
4. What stage are you in now?

Let’s talk now about what keeps us stuck in any one stage and how to move beyond the stages of grief to hope.

## **Fears about HIV**

We talked about the first four stages of grief as providing temporary protection from the reality of being infected with HIV. In fact, what you are really trying to protect yourself from is not HIV itself, but your fears about how HIV can affect your life. Some of these fears may be justified; however,

many fears that people have may not accurately reflect reality. You've probably heard the saying: "You have nothing to fear but fear itself." What this means is **fear is our worst enemy** because it can cause more harm than anything else. Let's consider how fear can impede people who are infected with HIV from moving beyond grief to hope.



As shown in the illustration, some common fears for people with HIV include:

- Fear of death—this may include fear of the unknown, fear that one's life had no meaning
- Fear of suffering—this may include fear of pain, medical procedures, loss of physical, mental, social functioning.
- Fear of harm to loved ones—this may include fear of emotional and financial hardship for family and friends, transmission of HIV to others.
- Fear of loss of lifestyle—this is not the same as fear of death. It can include fear of having to give up old routines, habits, style of coping.

As the illustration suggests, it is important to realize that you can expend a lot of energy trying to defend yourselves against your own fears, putting on layers of armor to protect yourself from harm, when in fact your fears may not accurately reflect reality.

The reality is that focusing on defending yourself from your fears may actually...

- prevent you from taking steps to protect your health.
- prevent you from moving beyond grief to hope

If you become stuck in one of the earlier stages of grief, you may...

- be less likely to protect yourself and others from further harm
- be less likely to follow medical advice, including not taking medication as prescribed
- be less likely to be abstinent from illicit drugs.

So, what is the result of all this? The result is a self-fulfilling prophecy. Your **response** to your fears can actually turn your fears into reality. Let's see how this could happen. Remember our friend Pat from previous chapters? Let's use Pat again to demonstrate self-fulfilling prophecy.



As the illustration shows, Pat's fear about HIV is its potential impact on mental, physical, and social functioning. To defend against this fear, Pat begins a cocaine run and stops taking his HIV medications as prescribed. As we have discussed in previous chapters, cocaine use itself can hasten HIV disease progression, and can contribute substantially to mental, physical, and social impairment. So Pat's response to fear (use of cocaine) caused Pat's fears to become a reality. Pat's HIV disease quickly progressed to AIDS, and Pat also experienced severe impairment due to physical, neurological, and psychological damage caused by chronic drug use. This is an example of a self-fulfilling prophecy. Rather than understanding this, Pat is likely to say "See I told you I was right—look what has happened to me

because of HIV.” In fact, Pat may not have experienced these negative events if were not for the fact that Pat dealt with fear by using cocaine and by not following medical advice.

### **So what do you do if you can't defend yourself from your fears?**

Simply put, you have to have the courage to face your fears in order to reduce the power that these fears have over you and your life.

## **Facing Fear and Reclaiming Control**

Facing your fears allows you to take control—when you do this you take the power out of the fear so that it no longer rules you. Let's go over the ways to face your fears shown in the illustration.



1. If you fear **Death**, face the fact of your death—not because you have HIV, but because you are a human being; therefore your death, like that of all creatures on earth, is inevitable.

Most of us don't want to contemplate the inevitable physical death of our bodies. It takes courage, but the alternative is fear and withdrawal which blocks energy needed for living life fully. One way to reduce the fear of death is to take control of those aspects of your death that you can control:

- a. Have a living will that will inform people if you do not wish to be kept alive by any artificial means. If you don't have an attorney, you can obtain a Living Will in many stationery stores.
- b. Make your wishes known about the disposal of your physical remains. Do you wish to be buried or cremated?

- c. Identify someone you can trust to make choices for you if you can no longer make them for yourself and discuss your wishes with this person.
- d. If fear is an automatic response to thoughts of death, replace the fear with an automatic relaxation response. Do this exercise daily:

Sit quietly and with your eyes closed begin to think about death. As soon as you become aware of feeling fearful, rate your fear on a scale from 0 to 10 (not at all to extremely), and then do one of the relaxation exercises we discussed in a previous chapter. For example, tighten and then relax each major muscle group while continuing to think about death. Then re-rate your fear. Were you able to reduce it? With practice, your body will no longer respond automatically to thoughts of death with fear, but with a sense of peace and relaxation.

- e. If you fear death because you worry that life has had no meaning, remember meaning is found in the present moment. Looking to the future for happiness or living in the past is a set-up for disappointment. Ultimately, we have no assurance of anything beyond this present moment. There really is no future or past—just a continuous progression of **now** moments. We all need to make the most of each moment.
2. If you fear **Suffering**, becoming more informed can help reduce this fear. Become more knowledgeable about HIV. Talk to your health care provider and counselor and read about HIV. Ask about the probability of pain and/or disability due to HIV. Ask how pain is controlled. Ask about medical procedures. Remember that your fears are usually worse than reality. Find out what steps you can take right now to help slow disease progression, and act on it. This includes abstaining from drugs and following medical regimens.
3. If you fear that you will cause **Harm to Loved Ones**, take steps to reduce harm:
- Have an up-to-date will and make provisions for the care of loved ones
  - Talk to your loved ones about your fears and their fears
  - Join a support group with your loved one
  - Engage in harm reduction strategies to reduce risk of HIV transmission to others and further harm to yourself



4. If you fear **Loss of Your Current Lifestyle**, identify what is most important to you about your lifestyle—what do you truly value—investigate alternative ways to meet your needs. For example, if you fear loss of sexual intimacy, learn how to eroticize safer sexual practices.

### **Practice Exercise: Letting Go of Fear**

At the end of this chapter, you will find a worksheet entitled “Letting go of fear.” It asks you to consider what stage of grieving you are in currently and to identify your fears about HIV. It then asks you to select one of the fears you listed and to describe just one specific step you can take during the coming week that will help you let go of this fear. Then make a commitment to take this step on a particular day or days during the coming week.

It also asks you to consider what is really important to you in your life—what do you realistically want to accomplish in your lifetime. Then select one of these lifetime goals and describe just one specific step you can take in the coming week towards accomplishing one of your goals. Make a commitment to take this step on a particular day or days during the coming week.

You might even want to involve a loved one so that you can work together on letting go of fear and setting goals. Commit yourself to getting started right now. You **can** reclaim control. You **can** free yourself from the power your fears have over you. If you do, you **can** begin to live every moment of your life to its fullest potential.

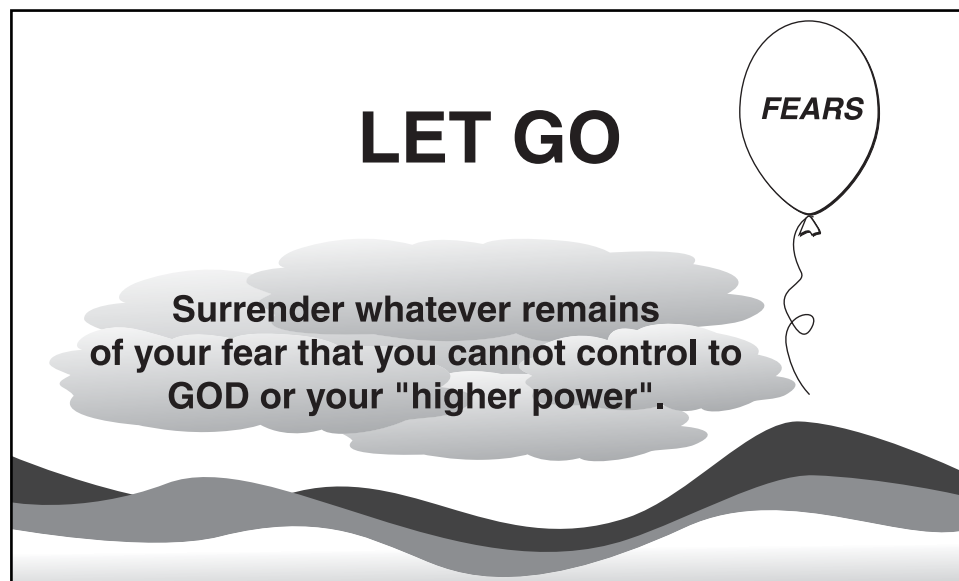
### **Review**

Let’s review what we’ve covered so far. We talked about grief, which is a normal human response to loss of any kind and the 6 stages of grief—denial, anger, bargaining, depression, acceptance, and hope. If you get stuck in the first four stages, you cannot move beyond grief to hope. We talked about how fear can keep you stuck in early stages of grief and how it can prevent you from engaging in behavior that can protect your physical, emotional, and social well-being. Fear can prevent you from taking steps to maintain your health. In addition, even though fears do not always accurately reflect reality, they can lead to behaviors that are unsafe (such as drug use) that can actually cause those fears to become a reality. This is an example of a self-fulfilling prophecy, and explains the saying “you have nothing to fear but fear itself”—fear can actually be your worst enemy. Identifying and facing your fears will help you move beyond grief to hope. This takes courage, and entails identifying what you do, and do not, have control over, and then taking appropriate action. This may include: having an up-to-date Will;

expressing your wishes concerning use of life support systems and funeral arrangements; becoming more knowledgeable about the course of HIV; keeping up to date on the latest treatments; discussing your fears with professionals and loved ones; engaging in risk reduction strategies; and prioritizing what is most important to you in your life so that you can live each moment fully.

Once you have identified what you can control and have taken appropriate action, you are left with what cannot be controlled. This is when you simply need to let go.

You may have heard the saying, **“Let go and let God.”**

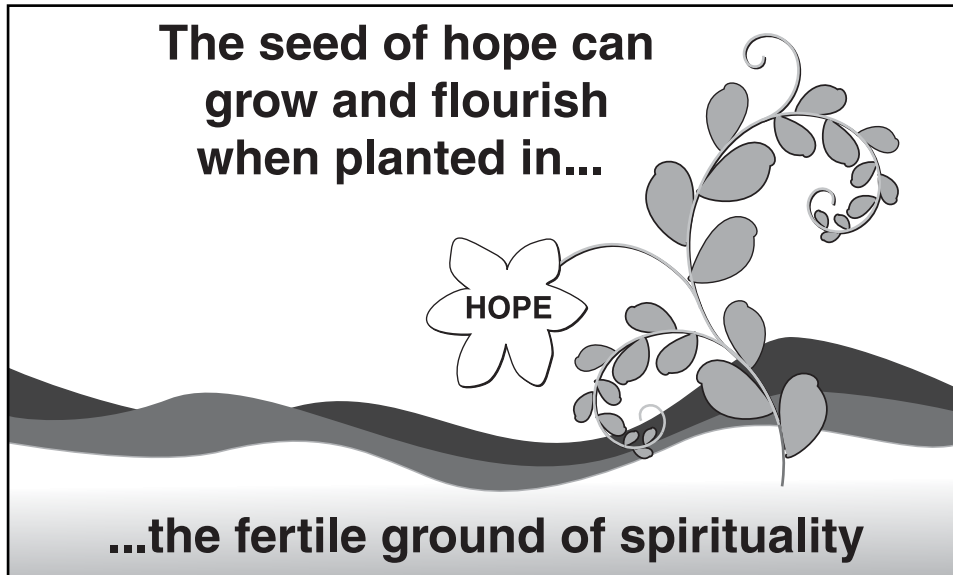


You can replace the word “God” in this saying with whatever concept is meaningful to you. What you need to do is to “turn over” or “surrender” what you cannot control to your higher power, however you interpret that to be meaningful in your life. Remember from the chapter on the 12-steps that “higher power” can mean different things to different people. The primary goal is to let go of what you cannot possibly control. As shown in the illustration, imagine putting what you cannot control in a balloon and then letting it go, allowing it to drift away. If you can do this, you are more likely to attain serenity. This returns us to the last stage of grief—**Hope**.

## **Spiritual Growth**

Mind, body, and spirit are closely interwoven, with each influencing the others. Some people believe that you cannot have healing on the level of the body without healing on the level of the mind and spirit. The term “spiritual”

is often confused with being religious. However, spirituality is not confined to one set of beliefs, doctrines, experiences, or forms. Spirituality is an essential part of who and what we are and what we value. It is therefore profoundly personal, and means something different for every person. Some people experience their spirituality by believing in a power greater than themselves. For some people, spirituality means feeling a connection with all things in creation. Some people believe that their spirit is the very core of their being and that their body is a shell or temporary home for their spirit.



As the illustration shows, whatever spirituality means to you, getting in touch with and strengthening your own spirit **can provide a fertile place in which hope can be planted and can grow and flourish.**

**So, what does spirituality have to do with hope and HIV and addiction?**

Being confronted with a serious health problem, like HIV and addiction, often creates motivation to grow spiritually. When faced with a potentially life-threatening illness, individuals may search for peace and hope and meaning in their lives. There seems to be great wisdom in this for many reasons. There is evidence from research that strong spiritual and/or religious beliefs and optimism are associated with recovery from addiction and with better medical and psychological health. In contrast, if individuals get stuck in the early stages of grief and do not move beyond grief to **Hope**, their health may suffer. This may be due in part to impairment in immune functioning that has been found to occur when individuals grieve and to the neglect of health-promoting behaviors while grieving. As we have discussed in other chapters, keeping your immune system as strong as possible and

engaging in behaviors that protect your health, such as abstaining from drugs and following medical advice, is crucial for people infected with HIV. Therefore, spiritual growth may be an important component of maintaining your physical health.

### **So how do you begin if you want to grow spiritually?**

When you are spiritually starved, you need to begin feeding your spirit.

## STEPS TO SPIRITUAL GROWTH

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**Prayer** Find a source of support in your religious and spiritual beliefs.

**Meditation** Be still. Become aware of your breathing. Be truly present in the moment.

**Imagery** Listen to your inner wisdom. Give it a persona. Visualize this inner guide showing you the path to spiritual healing.

**Ritual** Perform rituals, such as lighting a candle, to symbolize your spiritual healing.

*Choose a special place in your home as your meditation or prayer area. Set aside a time each day to work on your spiritual growth.*

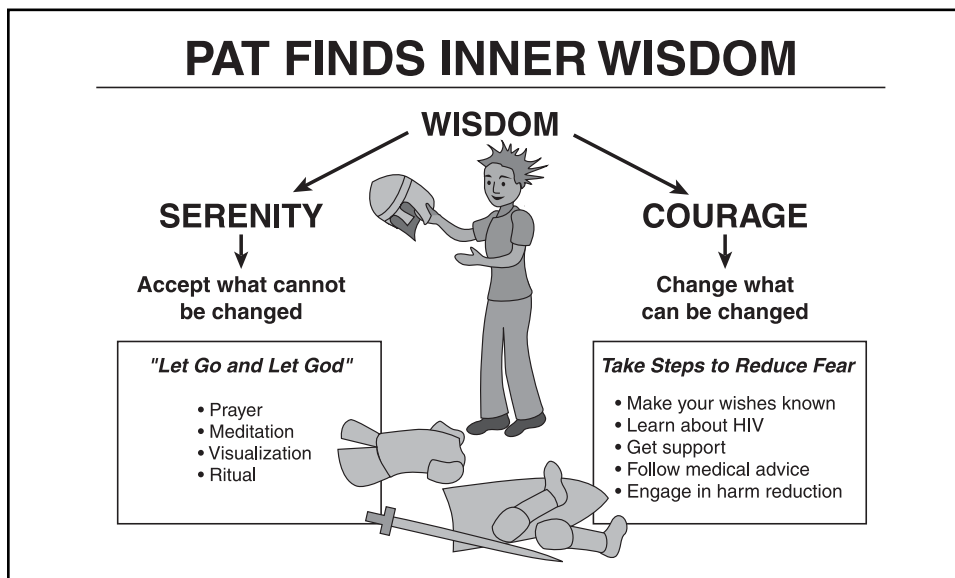
As shown in the illustration, there are several steps you can take to promote your spiritual health. These include engaging in daily prayer, meditation, imagery, and ritual.

- 1. Prayer.** Prayer is any act of communion with God or a higher power. Prayer can take many forms—from recitation of formal litany to an impromptu and brief communication, spoken or unspoken. The content of a prayer may also vary, depending upon the needs of the individual who is praying, and may be a fervent request or the expression of devotion.
- 2. Meditation.** Meditation is the focusing of attention. Like prayer, meditation can take different forms. Some people meditate on a single word or mantra, some chant, some silently become aware of their breathing, or focus on an object, and some simply focus on the present moment. Meditation can be done while seated or lying down, or while engaged in an activity that is repetitive and that limits distractions. By focusing attention, the meditator becomes relaxed, centered, and is able to tap an inner source of wisdom.

3. **Imagery.** Imagery or visualization is the process of forming a mental image (visual and/or verbal). Through imagery you can give your inner wisdom a voice and persona. You can then use this inner spiritual guide to help direct you along the path of spiritual growth.
4. **Ritual.** A ritual is a religious or solemn ceremony repeated faithfully and regularly. Rituals have been used in every culture throughout the ages to inter-connect mind, body, and spirit. Identify a ritual that is particularly meaningful to you that is used by your church or synagogue, or create a ritual that you can perform at home, such as lighting a candle or burning incense, hitting a gong, arranging flowers. As you perform this ritual, let it symbolize your spiritual healing, and take a moment to reflect on this.

**Choose a special place in your home to set up a meditation or prayer area. You may also want to set aside certain times of the day for spiritual healing, such as morning upon awakening and evening before retiring.**

The next illustration summarizes what we have covered so far and shows what our friend Pat could have done to cope more effectively with fears about HIV:



We refer frequently to the Serenity Prayer. Can you see how it applies to what Pat could have done to cope with HIV?

God grant me the serenity  
to accept the things I cannot change,  
the courage to change the things I can,  
and the wisdom to know the difference.

Now Pat has the **Wisdom** to know the difference between what can and cannot be changed about HIV. Pat has found the **Serenity** to accept what cannot be changed, by “letting go and letting God.” Pat has also found the **Courage** to change what can be changed by taking action. Now our friend Pat is able to work effectively on physical, emotional, and spiritual healing.

## **Humor and Healing**

Many people have suggested that laughter may also promote mental, physical, and spiritual health. It is recommended that you make a list of movies, comedians, books, and cartoons that make you laugh. If you have access to the internet you also have access to sites that give you a joke a day and other humorous materials. Humor can also be a healthy way to temporarily defend against fear. You can reduce the power of fear by learning to laugh at yourself and your fears. So, watch, read, or listen to something you find funny every day to bring laughter into your daily life.

At the end of this chapter are some amusing epitaphs found on tombstones in graveyards across the country and around the world.

## **Practice Exercise: Remember Me by What I Valued**

The purpose of this exercise is twofold: 1) to help you reflect on what you value in your life; and 2) to help you let go of fear of death using humor and self-reflection.

### **Instructions:**

1. Turn to the worksheet at the end of this chapter entitled “Remember me by what I valued.”
2. Pretend that your house is on fire and you have time to save **the three things in your house that are most important to you**. All your loved ones and pets are safe so you don’t have to worry about saving them. Write these three things in the space provided on the worksheet.
3. Now write an amusing epitaph for yourself based on the three things you selected to save from the burning house. Be creative. Let go of your fear and try to have fun with it. Invite a friend or loved one to help you.

## Quiz

- 1. Grief is a normal human response to loss of any kind.**
  - a. True
  - b. False
  
- 2. The stages of grief include:**
  - a. denial and anger
  - b. bargaining and depression
  - c. acceptance and hope
  - d. all of the above
  
- 3. Which of the following statements about fear is true?**
  - a. Fear can ultimately lead to self-fulfilling prophecies that are harmful.
  - b. Fears may not accurately reflect reality.
  - c. Fear can prevent you from protecting your health.
  - d. All of the above statements are true.
  
- 4. Healthy steps to reduce the power of fear about HIV include:**
  - a. pretend you are not infected with HIV
  - b. use drugs or alcohol whenever you feel the fear coming on
  - c. become knowledgeable about HIV and its treatment
  - d. all of the above
  
- 5. Ways to grow spiritually include:**
  - a. prayer
  - b. meditation
  - c. imagery
  - d. ritual
  - e. all of the above

## Practice Exercise: Stress Management/Relaxation

We recommend that you conclude each chapter by doing a 10-minute relaxation exercise. Use this time to practice meditation or deep breathing, or to play an audiotaped relaxation or visualization technique. Dim the lights, get comfortable in your chair, uncross your legs, and sit quietly with your eyes closed. Remember that learning to relax is a skill that takes practice, so if you feel restless at first, just remind yourself that this is a 10 minute gift of quiet time that you give to yourself. With practice, you can use meditation and relaxation in many areas of your life. For example, you can use this time to let go of your fear by visualizing yourself planting the seed of HOPE, and watching it grow. By doing this you can help yourself to move beyond grief.

## “Letting Go of Fear” Client Worksheet

### Stages of grief:

Place an “x” in one of the boxes below to indicate the stage of grief you are currently in with regard to HIV infection:

Denial  Anger  Bargaining  Depression  Acceptance  Hope

### Fears about HIV:

In the space below, list the three things you fear most about HIV:

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

### Step toward letting go of fear:

Select **one** fear from those you listed above and, in the space below, describe **one** step you can take **this week** to begin letting go of that fear (e.g., make an appointment to talk to your health care provider or counselor, go to a support group meeting, go to the library and read about HIV). **Be specific.**

This week I will do the following: \_\_\_\_\_  
\_\_\_\_\_

I will do this on:

Mon.  Tues.  Wed.  Thur.  Fri.  Sat.  Sun.

### Lifetime goals:

List three things that are important to you to accomplish in your life. **Be realistic!**

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

### Steps toward accomplishing lifetime goals:

Select **one** goal from the goals you listed above and, in the space below, describe one step you can take this week toward accomplishing this goal. **Be specific.**

This week I will do the following: \_\_\_\_\_  
\_\_\_\_\_

I will do this on:

Mon.  Tues.  Wed.  Thur.  Fri.  Sat.  Sun.



## ***Amusing Epitaphs: R.I.P. (Rest In Peace)***

Here lies a man who while he lived  
Was happy as a linnet  
He always lied while on the earth  
And now he's lying in it

Here lies an Atheist  
All dressed up  
and no place to go

I made an ash of myself

*A contented man:*  
Here I lie snug as a bug in a rug.  
*The contented man's relative  
in a nearby grave:*  
Here I lie snugger than that other bugger.

Here lies  
**Ezekial Aikle**  
Aged 102  
The Good Die Young

*John Dryden's epitaph for his wife:*  
Here lies my wife  
Here let her lie!  
Now she's at rest  
And so am I.

She lived with her husband of fifty years  
And died in the confident hope  
Of a better life

Here lies Ned  
There is nothing more to be said—  
Because we like to speak well of the dead

*A widower placed two messages, one  
year apart, on his wife's tombstone:*

*In 1890, he wrote:*  
The light of my life has gone out

*In 1891, he wrote:*  
I have struck another match

Here lies  
Johnny Yeast  
*Pardon me  
For not rising*

Here lies Lester Moore  
Four slugs from a .44  
No Les No More

*W. C. Fields:*  
On the whole,  
I'd rather be in Philadelphia

*On a dentist's tombstone:*  
Stranger,  
Approach this spot with gravity  
John Brown is filling his last cavity

Here lies the body  
Of Jonathan Blake  
Stepped on the gas  
Instead of the brake

*Epitaph found in a Georgia cemetery:*  
I told you I was sick!

*Found in Hookstown, PA,  
on tombstone with an etching of a  
marijuana plant on it:*

Hi!  
Stay high  
Bye

## Remember Me by What I Valued



### **PART I. The house is on fire—what do you save?**

Imagine that your house is on fire. All your loved ones and pets are safe. You have three minutes to select just **three** items from your house that you would want to save. Write your choices below:

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### **PART II. Epitaph.**

Write an amusing epitaph based on the three items you chose to save. Be creative, let go of your fear, and have fun.

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