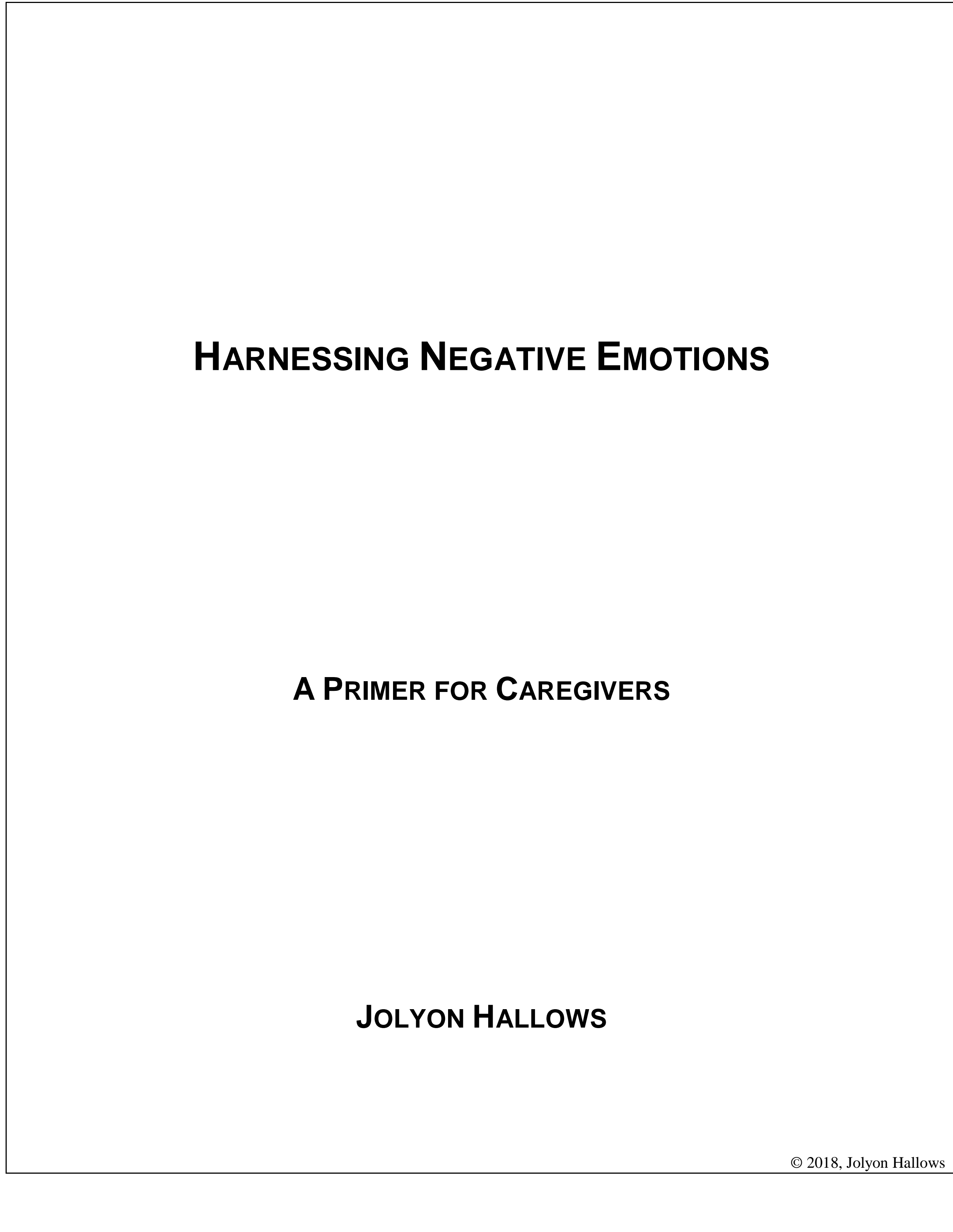
Harnessing Negative Emotions

Allowing them to Guide You

Jolyon Hallows



HARNESSING NEGATIVE EMOTIONS

A PRIMER FOR CAREGIVERS

JOLYON HALLOWS

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The Emotional Turmoil

"I'm conflicted. I need to keep my sanity."

"It's only 8 a.m. and I am exhausted from his dementia and delusions."

"I feel trapped."

"Saying goodbye is hard but she can't fight anymore."

These are a small sample of online comments on just one website devoted to helping caregivers. I've edited them to protect the people who posted them, but the sentiment is there. Always present, always painful.

Caregiving can be an emotional pit. Anger, frustration, despair, grief, depression. We live with those and more. Part of this quagmire arises from the effort that caregiving imposes, effort that shatters a normal life of work and play. Part of it is because our life plans have been shredded and we don't know what will happen next. And part of it is the dismay that the caree, usually someone we love, is declining and is no longer the person he or she was.

Some of us have to fight against our carees. Their slow slide into dementia or their loss of independence can turn even the most loving people to anger or despair. Nobody wants to lose a driver's license. Nobody wants to have to be dressed by someone else. And nobody wants to be a burden to the people they love. But becoming dependent is the reality of chronic, progressive diseases.

Some of us struggle with grief watching those we love gradually fade away to be replaced by someone we don't recognize.

And some of us succumb to exhaustion and hopelessness in the face of an unrelenting attack on our resources.

How do we handle it?

We caregivers are often advised of the need to find calm, peace. It's common to find advisors citing the Serenity Prayer:

> God grant me the serenity to accept the things I cannot change
> Courage to change the things I can
> And wisdom to know the difference.

When I first encountered this, I didn't give it much thought. But then I wasn't immersed in the tribulations that caregiving imposes. Then things changed. One day, my wife, Sandra, was diagnosed with Parkinson's disease. That day, although I didn't realize it at the time, I became a caregiver. I looked after Sandra as she gradually slipped away from me. Our retirement plans dissolved, our activities faded, our hopes evaporated, all in the crush of the disease and what it meant.

Her battle, and mine, lasted for over twenty years before she succumbed to the disease. As part of my process of grieving, I attended a seminar in which the speaker spoke of finding calm and peace amidst the turmoil of caregiving. One of his tools was the Serenity Prayer. I appreciate his intentions, but when I thought about it, it struck me that this advice was terrible. I saw it as a fancy way of saying, "suck it up." If anyone had told me, while I was gripped by anger or despair, that I needed to accept the situation and to become serene, I would have reacted badly. Implying I lacked serenity because I wasn't wise would have been to invite an

indictment for criminal assault. To those of us caught up in anger or despair, advising serenity is futile. Implying a lack of wisdom is infuriating.

Yet negative emotions, played out over a long time, are dangerous to our health and well-being. They do need to be dealt with, so counselors offer tactics to ease them. Some advise venting. “You’ll feel better getting if off your chest.” Others advise suppression. “Take a deep breath, relax, and count to ten.” Still others suggest action. “Go for a run. Go to the gym. Work it off.” And there are those that advise refocusing. “Look at the problem from your caree’s point of view.” “Things could be worse.”

These tactics may seem divergent, but they all have one attitude in common: negative emotions are bad. They are an affliction that we must somehow banish. Our job is to discard them so we can get on with our lives and our responsibilities.

But I have an annoying question. If negative emotions are bad for us, why do we have them? After all, we are the products of a billion years of evolution. Every characteristic we have, every physical feature, every mental or emotional state has survived those millennia because they have served us—or at least they served our ancestors.

You don’t believe in evolution? Then our characteristics must have come from the deity you believe created us. Unless you think your deity is capricious, our emotions were given to us for a reason.

Whatever your view of how we got here, our emotions, negative and positive, have a purpose. They exist to serve us.

So the best way to deal with negative emotions is not to impose some standard of calm in order to get rid of them, but to acknowledge their purpose and to use them to make our lives and those of our carees easier. That is what I mean by “harnessing” them.

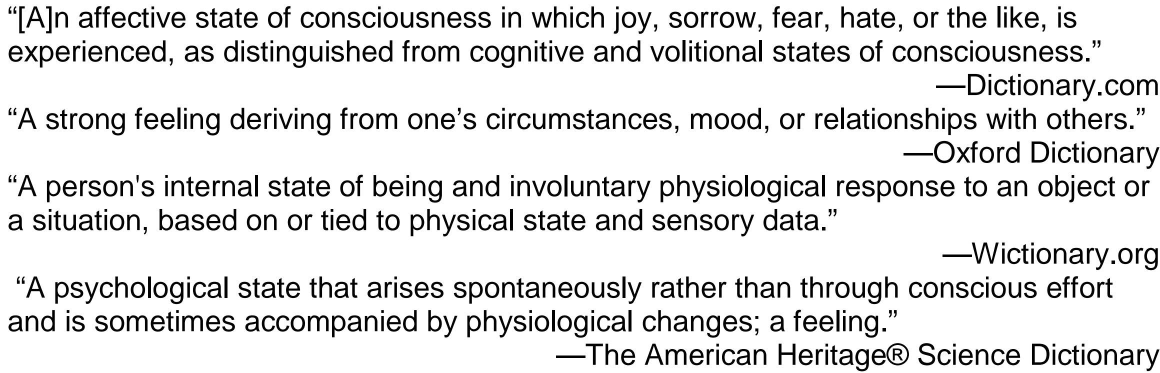
A Disclosure

The information I present here arises from my experiences in caregiving, from many conversations with other caregivers in person and online, and in seminars I’ve attended and delivered. This paper is not an academic review and I’m not a therapist. It is my attempt to describe some of what I’ve learned and to pass it on. If it helps you, that’s my goal. If not, I wish you well in finding whatever will benefit you.

What is an Emotion?

Before we look at negative emotions, let's ask what emotions are. If you research that question, you can be drawn into a quagmire of competing theories, each with its own terminology, and each requiring a graduate degree in psychology to grasp.

But let's start with some dictionary definitions.



"[A]n affective state of consciousness in which joy, sorrow, fear, hate, or the like, is experienced, as distinguished from cognitive and volitional states of consciousness."

—Dictionary.com

"A strong feeling deriving from one's circumstances, mood, or relationships with others."

—Oxford Dictionary

"A person's internal state of being and involuntary physiological response to an object or a situation, based on or tied to physical state and sensory data."

—Wictionary.org

"A psychological state that arises spontaneously rather than through conscious effort and is sometimes accompanied by physiological changes; a feeling."

—The American Heritage® Science Dictionary

Here is my summary of the key points from these definitions.

An emotion is an involuntary, subconscious, instant evaluation of a situation or event that affects us. The emotion is positive or negative as the event supports or threatens what we value.

From these definitions, three aspects of emotions stand out.

1. Emotions are involuntary. We don't decide to have them and we can't avoid their onset. If I'm on a hike and a bear rears up, I don't think, "There's a bear. What emotion should I feel. Oh, yeah. Fear." The fear slams me the instant I see the bear.
2. Emotions signal a situation that affects us. If I see a police car on the other side of the freeway, lights flashing in pursuit of someone, I may check my speed, but otherwise I don't care. If I see a police car, lights flashing in my rear-view mirror, I'll probably have a spasm of fear or anxiety. These two events are the same, except that one of them matters to me.
3. Emotions tell us whether a situation or event supports or counters what we value. Of the spectators leaving a stadium or arena after a sports event, some will be elated, others dejected. They both saw the same game, but the outcome had different meanings for them.

Emotions have no content. They don't tell us what triggered them, just that something did. It's up to our reason to figure out the cause. Often that's easy. "I'm mad at that jerk who cut me off in traffic." But sometimes the reasons are not so obvious. "I don't know why I'm so angry. This shouldn't bother me that much." But something is infuriating you and you need your cognition to figure out what that is.

Just as negative emotions don't tell us what the problem is, they also don't tell us what to do. That's the function of reason. Imagine a primitive man in a loincloth armed only with a club or spear walking across a plain when he sees a bush move. The instant emotion is a pang of

fear. Is it a predator, prey, or just a puff of wind? The emotion says, “Alert.” It’s his reason that must evaluate the situation and decide whether to flee, attack, or shrug.

Dealing with an emotion, therefore, means recognizing that it is telling us something important. Then using our minds to figure out what that is and what to do about it.

Tactics in Harnessing Negative Emotions

From here on, I'm talking about negative emotions. Few people need help in dealing with happiness or pleasure.

Before I get into the tactics for dealing with negative emotions, I need to emphasize one thing. I agree with all the counselors and advisors who want us to shed them. Long-term, they can lead to health and behavioral problems. But they exist to warn us of something. If we don't resolve whatever triggered them, they will persist. Harnessing them does not mean avoiding them, it means recognizing what they're telling us and then taking care of whatever that is so they will go away on their own.

The steps in doing this means accepting the emotion, determining what kind of emotion it is, then taking action to deal with it.

Accept the Emotion

One of the damaging responses to an emotion is, "I shouldn't be feeling this. There's something wrong with me." The unfortunate corollary is when someone else says, "<u>You</u> shouldn't be feeling this. There's something wrong with <u>you</u>." But remember, emotions are involuntary. You have no control over their onset. So here's a principle: there is no such thing as an emotion you shouldn't feel and there's no emotion that indicates something is wrong with you. The ideas of "should" and "wrong" belong to the arena of behavior, of actions. I will even extend this principle to thoughts. There are things you shouldn't do, but there are no things you shouldn't feel or think, even though some of them may shock you. You may want to ram your car into the jerk who cut you off. Feeling angry is fine. Thinking about doing it is okay. Doing it is not.

So the first tactic is to allow yourself to feel the emotion. It's telling you something about the world. It is not an affliction, it is part of you. And it exists to serve your interests. Far from fighting it, welcome it. Allow yourself to experience it. It's on your side.

But there is a problem with negative emotions in that their grip makes analysis hard. If I'm mad and someone says, "Let's examine why you're angry," my response won't be placid. So you may need time for the emotion to die down. Sometimes, of course, you don't have that luxury. Again, if you're hiking and encounter a bear, it would not be wise to think, *I'm in the grip of fear, so I'll wait until it passes before I figure out what to do*. But in caregiving, most of the triggers that set off an emotion aren't urgent. You do have time to let them pass and allow your mind to clear before you analyze them and decide on a course of action.

Determining the Kind of Emotion

Determining the kind of emotion means classifying it. That simplifies dealing with it and provides a framework for analyzing it. However, there is a critical caveat. Putting anything into some slot implies that thing is independent of anything else. For example, books are either fiction or non-fiction. While some books may be hard to classify—for example, a book may be based on real events and real people but have elements that the author created—but once we've classified it, that's it. The same book can't be both fiction and non-fiction. That's not true of emotions. It is possible, for example, to feel anger and despair at the same time. Classifying them is useful, but not always conclusive. Nevertheless, classifying emotions makes them easier to think about.

The Categories of Negative Emotion

There are two categories of negative emotion and one exception that falls into both. I call these categories “spurs to action” and “thieves of ambition.”

The spurs to action are emotions that demand we do something. They include hate, rage, frustration, and anger. When we’re gripped by them, we feel the urge to act, even if it’s hitting something or screaming or going for a power walk. They don’t tell us what to do, only that some action is necessary. What that action is requires us to evaluate the emotion, consider our options, and pick one. The emotions are like goads. We may choose to act, or we may opt to suppress the emotion and do nothing. That decision belongs to our reason.

In contrast to the spurs to action, the thieves of ambition squelch behavior. These emotions include grief, apathy, sadness, guilt, depression, and despair. They are the emotions that cause us to want to just lie down and let the world go on without us. Like the spurs to action, these emotions don’t tell us what actions we should (or in this case, shouldn’t) take, and whatever we do, we do because we have overridden them and forced ourselves to act.

Before I go into detail about these categories, I’ll deal with the exception. That’s fear.

Fear

Fear is a response to a threat. Its role is to alert us. The threat may be immediate, such as the bear on the trail or a police light in your rear-view mirror, or it may be distant. If your caree is declining and will need to be placed in a home, you may feel fear at the looming decision you’ll have to make. Or if you experience pain when you go to the toilet, you may feel fear at whatever has caused it. An acronym for this kind of fear is Future Events Appearing Real.

The value of fear is obvious when the threat is immediate. It’s a motivation to action. Such fear triggers what psychologists call the “fight or flight response.” The fear releases adrenaline to our muscles preparing them either to go into battle or to flee.

Fear has the same purpose when it’s longer-term. It’s meant to motivate us to do something. In that sense, it’s a spur to action. But fear that is long-term allows us the luxury of procrastinating or avoiding doing anything. That’s when it can become a thief of ambition.

Fear as a Spur to Action

As a spur to action, fear pushes us to think about what the threat is and to figure out how to deal with it.

Let’s look at an example. If my caree is declining and the demands of care are becoming too severe for me to handle, my fear of the future can be overwhelming. Do I put her into a care home? I know she doesn’t want to go. Will she get angry at me? What if she becomes resistant or aggressive? What if there are no care home beds available? Can I get additional help so I can keep her at home? What about finances? We’re not wealthy. How can I pay for this? Will some social services agency place my caree into a subsidized home on the other side of the province or state?

One of the characteristics of this kind of fear is ignorance. This is not an indictment. We just don’t have the information we need. So we keep hammering ourselves with these questions until we get dizzy. Of course, we never get answers, because we’re asking someone who doesn’t have them.

Here’s a thought: ask your questions of someone who does.

Write out a list of your questions, all of them, then make an appointment with someone who may be able to help. This could be a social worker associated with an organization specializing in the disease, your doctor, a lawyer, your caree's case manager, or a spiritual advisor. You have two purposes in this. First, for each question, you want an answer. The person may not be able to answer all your questions, so for those he or she can't answer, ask for a referral to someone who can.

The second purpose in asking the questions is to find someone who can help you prepare a plan. A jumble of information is not much value even if you now have all the answers. You need to pull together what you've learned into a set of actions. So when you pose your questions, one of them will be, "Can you help me put together a plan, or can you suggest someone who could?"

Your plan will consist of a set of activities such as researching care homes, registering for social programs, investigating care aides, and if appropriate, exploring financial assistance.

Even though your plan may be hard to carry out and even though you probably will encounter barriers and problems, you now have a course of action. Your plan not only prepares you for what might come, it is also a signal to your fear that it has done its job and that it can retire. Elements of fear may still arise from time to time. Think of them as pokes asking if you have thought of something that could affect your plan.

Fear as a Thief of Ambition

The actions we've just discussed, gathering information, creating a plan, and carrying it out, are the result of using your fear as a spur to action. But fear can also be a thief of ambition, quashing action. If you respond to a fear with something like, "I don't want to think about that right now. I'll deal with it when it happens," you are, in effect, ignoring the message your fear is trying to deliver. But delaying a response doesn't cause the fear to go away. It will lurk there in your mind, continually upwelling and assailing you with the problem. Even worse, the more you ignore it, the more it will exaggerate the consequences. That's one of fear's tactics. To jolt you into action.

For example, consider how you might respond if you experience pain during urination. You have a spasm of fear. You might think, *bladder cancer*. Of course, you should see your doctor immediately, but that's treating your fear as a spur to action. Allowing it to become a thief of ambition leads to denial. *It's nothing. It'll go away*. But fear will magnify the problem, making it more serious than it probably is. You may wake up at night in a sweat convinced you have cancer. It's in stage 4. You're about to die. If that leads you to call your doctor, your fear has finally succeeded in getting you to act. But if you ignore your fear, it can turn into dread, which may be even more debilitating. One principle that may help you take action is to recognize that your fear's strategy is to convince you that things are the worst they could be. That just might get you to act. But that means that the actual problem will never be worse than your fears. To be sure, it may be just as bad. You may really have stage 4 bladder cancer. On the other hand, it's more likely just an infection that antibiotics will cure.

Dealing with fear means recognizing what your fear is telling you, then creating a plan to deal with the problem. That plan could be as simple as calling your doctor or as complex as researching care homes. But building a plan is the best way to acknowledge your fear and allow it to step back, having done its job.

A Complication

In the following sections, I will describe the negative emotions that are the spurs to action or the thieves of ambition. But first, an acknowledgement that life isn't always simple.

A major complication is that the same trigger can result in an emotion that's a spur to action or one that's a thief of ambition. For example, if an insurance company denies a claim, I may respond with anger ("How dare these people do this to me?") or despair ("Why does nothing ever work out well?") Because the trigger is the same, the tactics for dealing with the emotion are the same, regardless of which one we experience.

So recognize that a given trigger can lead to different emotions as we'll see in the following discussion.

The Spurs to Action

The spurs to action include hate, rage, frustration, and anger. What is the difference between them? Are they shades of the same thing or are they different emotions entirely? Here, I hope to convince you of the latter. They're different and you handle them differently.

Hate

Hate is a perceived threat to something you value. In that sense, it's like fear, the difference being that fear yields to a plan of action, even if that plan is just to flee. Hate is longer-term and too often festers.

My focus is on emotions that arise from caregiving, not from other sources. A lot of hatred is directed toward groups based on ethnicities, religions, races, or atypical social behaviors. That kind of hatred is outside the scope of this document.

Hatred can be directed at family members or co-workers who have offended you. If the hate, or sometimes disgust, was there before you became a caregiver, it's not an emotion that is relevant here. However, sometimes it can arise from caregiving. Some family members may challenge the level of care the caree needs or accuse you of overstating the problem. They may refuse to offer help. Co-workers or employers can dismiss your concerns and even deny you any leeway in working hours. Having to face these kinds of attitudes while at the same time dealing with giving care, can lead to anger, disgust, and hate.

I have heard people say things like, "I hate this disease" or "I hate the way the system works." Here, I suspect the word hate is being used in the more general sense of wishing things were different rather than being the hatred that consumes some people and leads them to commit acts of violence.

However, sometimes hate does arise from caregiving when the threat may be to your caree or to your ability to give care. As an example, sometimes strangers would compliment me on how well I was taking care of my mother. Now I know that my wife's Parkinson's had stooped her and given her a flattened expression making her look older than she was, but I found the comment hateful. If I was alone, I was curt but polite when I corrected the person who made it, but if my wife was with me, I was savage. I have said, "This is my wife. Do you make it a habit of insulting people or did you just decide to attack her?" I know they meant well, but my wife could hear what they said. It was painful to her and I hated the anguish it caused her. She couldn't defend herself. I could.

This situation illustrates how emotions can combine. My reaction to the comment was hatred, to the speaker, anger.

It's been said that hate is the opposite of love. But the opposite of love is indifference. Hate arises because of an attack, real or perceived, on us or on what we love. Had I been looking after someone as an act of duty, I wouldn't have had a negative emotion. I might have said something like, "Oh, I'm just filling in." I might have thought of the speaker as an unobservant fool, but the heat wouldn't have been there.

Harnessing hate means assessing it. Here are some questions.

- What is it you hate? Is it a person? An action? A situation?
- What do you love that is being threatened?
- Is the threat real or could it be a misunderstanding?
- How can it be neutralized? What defenses can you set up?

Most commonly, the hate that arises from caregiving is directed at a person. You may hate a family member who minimizes or ridicules your efforts. You could hate a co-worker or supervisor who criticizes you for having to take time off or for complaining about the effort of giving care. Or you may hate someone you have to deal with such as an unsympathetic doctor or insurance agent or even a stranger with whom you have casual contact, like those who referred to my wife as my mother.

The emotion of hate is warning you of a threat. It's up to your reason to evaluate that threat, determine if it's real, and if so, to figure out how to counter or neutralize it. Or whether you can dismiss it as the blather of a blockhead and let it go.

Here are some tactics for dealing with hate.

- If you can sway the source of the hate, do so. For example, if a family member dismisses your efforts as an exaggeration, have a conversation. You may recruit a friend or another family member to help. Prepare a list of everything you do in a typical day or week along with the time each activity takes. Then present it to the family member and ask for suggestions on how to whittle it down. Or invite the offending family member to spend a few days with you and let him or her experience the effort your caregiving demands.
- If you cannot sway the source of the hate, perhaps you can avoid it. Let the offending party know you will no longer deal with him or her. No visits, no phone calls, no Christmas cards. That may be painful, but you have your hands full giving care. You don't need any extra emotional drain.
- At work, meet with your boss, explain the situation and explore how you can adjust your work to the demands of caregiving. Can you reduce the hours? Do some work at home? Work on weekends when someone else can fill in for you at home? Employers are often flexible and willing to adjust employment conditions. Or if you can't get any cooperation, can you find another job?
- And as a last resort, an angry response can sometimes jerk an insensitive person into an awareness that might even become supportive.

Rage

Rage is an uncontrollable negative emotion. It's not anger. We control anger. I may get angry at my boss, but I don't quit my job—at least not before I've found another one. I may get angry at my spouse, but I don't hit her or walk out on her. I may get angry at the jerk who cut me off in traffic, but I don't pull out a gun and shoot him. We control our anger. Rage is beyond our control.

It's hard to see how rage serves us. How does being out of control help? Perhaps in a more primitive time when every village was at war with its neighbor and the only weapons were clubs or swords, rage was useful in combat. The warrior who held back or who paused to consider the consequences of his actions probably wouldn't have lived long enough to pass his cautious genes on to his offspring.

Today, we don't face that situation. Even in battle, modern armies rely on judgement and assessment skills. So perhaps rage is like the appendix. It was useful once.

Episodes of rage are a signal that you are slipping into a state that needs professional help. It's not an emotion that anyone in its grip can handle. Therefore, once it has passed, a

critical question to ask yourself is, "Was I out of control?" If so, you need to get help. The culmination of rage is either prison or the morgue. Later, I'll talk about recruiting a friend to serve as an "early warning sentinel." Rage is one of the emotions to be on that person's radar.

Getting help means talking to a professional counselor or therapist. Entering therapy is a step many people are reluctant to take because doing so implies they can't handle their own problems. But that's what rage is, a problem you can't handle yourself. And if you resist getting help, you risk doing serious harm to those around you. Getting help means taking steps to avoid becoming a story on the evening news.

Frustration vs. Anger

Frustration and anger can feel similar. In both cases, there is an impulse to lash out or to scream. But there are two important differences.

First, frustration usually arises from a problem. Anger is usually directed at an entity such as a person or an organization or, in some cases, at "the system" or the world or God.

Second, when the trigger is dealt with, frustration disappears. Anger remains.

So when you emerge from a state where you want to scream or hit something, ask yourself these two questions:

1. What was the focus of the emotion? Was it some problem I couldn't solve? If so it was probably frustration. Or was I upset a person or an organization? In that case it was probably anger.
2. Now that the cause has diminished, do I still feel the emotion? If not, if it has dissipated, it was most likely frustration. But if it persists, if you still feel it, it was likely anger.

Harnessing Frustration

Frustration is the emotion we feel when we're faced with a problem we don't know how to solve, particularly if the problem is common. If we do know how to solve it, it's no longer frustrating, it's just a task. The task may be unpleasant, but, like any chore, it's a job to be done. So when we feel frustration, it's because we are facing a problem that we haven't figured out. And as this problem recurs, it becomes even more frustrating.

Now you may be thinking that's obvious. You don't need someone else to tell you you've got a problem. But if your problem is ongoing, why does it persist? Why haven't you solved it? It could be that you're not defining it correctly. Here's an example of what I mean.

In giving care to my wife, one of my principles was that I wanted her to do as much for herself as she could. It was a way of helping her maintain a semblance of her independence. One of my frustrations was when I'd transfer her into her wheelchair, then put down the footpads. I'd say, "Feet on the footpads." When she didn't respond, I'd say, "Put your feet on the footpads." On the third or fourth time, I was adding a few adjectives to the request and getting frustrated by her lack of compliance.

Now I know this problem is minor, but caregiving presents us with endless minor irritants which build up and create a tsunami of problems. Resolving them before they erupt into something more serious is one key to a more composed caregiving experience.

My breakthrough with the footpad problem came when I mentioned it to one of her doctors. He explained that because of my wife's Parkinson's, the connection between the part

of her brain that generates the intent to act has been severed from the part that acts. She thinks she is putting her feet on the footpads. His advice? If she doesn't do it, I should do it for her. In that instant, I realized the problem wasn't that she didn't position her feet, it was my attitude that I wanted her to be independent and do it for herself. Realizing she could no longer do that and that I had to place her feet for her was sad, but it was no longer frustrating.

Dealing with frustration means analyzing the problem that triggered it. Here is a set of questions to ask yourself when the heat of the frustration has passed.

- What is the problem? (No feet on the footpads.)
- Why is that a problem? (Because her feet have to be on the footpads so she won't be hurt.)
- Is there another way to solve it? (Sure. I could do it myself.)
- So why aren't you doing it yourself? (Because I want her to be independent.)
- Could your insistence on her independence be the problem? (Oh!)

In this analysis, you will need some help because if you could solve the problem yourself, you'd have done so by now. You might talk to a friend or a counselor or a doctor and work through these questions with them.

But many frustrations don't yield to this kind of analysis. For example, I get frustrated at the heavy traffic I sometimes have to deal with. Here are the questions for this problem.

- What is the problem? (The stop and go traffic. Mainly stop.)
- Why is that a problem? (I've got better things to do than sit here.)
- Is there another way to solve it? (Sure. I could stay at home.)
- So why aren't you staying at home? (Because I have to get to this appointment.)
- Could getting to the appointment be the problem? (No. The problem is the traffic!)

In such cases, the only solution is to live through it. And maybe make future appointments for times when the traffic isn't so bad.

Harnessing Anger

Anger is a negative emotion directed at a person or an organization that has harmed or threatens to harm you or someone you love. In that respect, it is similar to hate, but while hate may simmer, anger warns you of a threat and spurs you on to do something.

While we're immersed in anger, it's hard to think rationally about it. Just as with frustration, we need distance to assess it. But anger does dissipate and once it does, that is when you can analyze it.

Start by categorizing the target of your anger. There are three possibilities.

1. The target is <u>specific</u>. Your anger directed a person or an organization with which you have to deal.
2. The target is <u>misplaced</u>. You are angry at an entity like the government or the unions or the oil industry that have nothing to do with your situation.
3. The target is <u>generalized</u>. You are angry at the disease or the system or the world or even God. We will deal with generalized anger when we look at despair.

You deal with these differently.

Anger at a Specific Target

Let's look first at anger at a specific target: a person or an organization. In this section, I will give four steps and, to help clarify, I will refer to two examples.

- I had heard of a specialist doctor who others had recommended as being superb at dealing with Parkinson's patients and I wanted my wife to see him. But her doctor wouldn't give her a referral. He told us he'd tried to refer other patients to this specialist, but he had declined the referral because he was overloaded. I asked our doctor to reconsider and at least try, but he refused.
- In the other example, my wife's case manager at the home care service told me they had upgraded their policy ("upgrade" means make it more convenient for them, less for you). Under the new policy, their care aides would no longer give medications. Since I often used their services for times my wife needed her medications, this was a problem.

Step 1 – Identify a person as a target for your anger

For this analysis, the target of your anger must be a person. If it is an organization, ask who represents it. Whether you are angry at that person doesn't matter as long as there is someone who stands in for it. In the first of my examples, I was angry at my doctor. In the second, at the home care organization. The person who represented it was the case manager. I wasn't angry at her—she didn't like the policy either. But I needed a person to stand in for the organization and she was it.

Step 2 – Can the person change the situation?

Determine if the target of your anger is able to change the situation that has triggered it? Don't ask if they will, but whether it is within their power to do so.

In my examples, the doctor could change his mind and issue the referral, but the case manager couldn't override the organization's policy.

Step 3 – Negotiate

If the target can change the situation, this now becomes a matter of negotiation and persuasion. Marshal your arguments. Arrange them logically. Avoid heat or blame. And practice presenting them. Find a friend or someone you respect for their ability to express themselves clearly—someone who works in sales or public relations is a good source—then ask him or her to help you refine your argument.

Then make it. If the target relents, the situation has been resolved. If not, you are now in the same position that you would be if the target cannot change the situation. In this context, can't and won't have the same consequence.

When I tried to persuade my doctor to issue the referral, my arguments were ineffective. He didn't budge. So now, I had to treat the situation as if he couldn't change things—just as the case manager couldn't change the policy.

Step 4 – Find a workaround

If the target cannot or will not change the situation that triggered your anger, you need to find a workaround. What can you do to deal with this situation? In the case of the doctor's referral, I was able to ask another doctor my wife was seeing—Parkinson's often involves

several specialties. I girded myself to argue for the referral, but it was unnecessary. The second doctor said sure. And my wife did see the specialist. A friend had a similar strategy. Her doctor gave her a referral to the same specialist, but he declined to accept it because he was busy. So she sent him a letter explaining why she wanted to see him and asking him to reconsider. He did. That's another kind of workaround.

The workaround for the medications was more complicated and involved different tactics. One was to schedule appointments or meetings for times my wife didn't need medications. But sometimes I had courses or meetings I couldn't reschedule. In such cases, I resorted to giving her medications early just as I left, or late, as soon as I got back home. Specialists in Parkinson's recommend against this. Medications must be given on time. But giving them early or late was better than not giving them at all.

But there were occasions I would be away all day. My wife received her medications three times during the day: 10:00 a.m., 1:00 p.m., and 4:00 p.m. My workaround was to engage a home care aide from 8:00 a.m., when I left home, to 10:00 a.m. Then I booked a nurse from a private nursing agency (they had no restrictions on giving medications) from 10:00 a.m. to 1:00 p.m. The nurse would give those two sets of medications. Then I had another home care aide come in from 1:00 p.m. to 4:00 p.m., when I got home and could give the last set of medications myself. Having to hire a nurse from a private agency was more expensive, but it got the job done and it transformed my anger toward the home care service into contempt.

Misplaced Anger

Some anger is not directed at a specific target but is misplaced toward entities that have nothing to do with the situation. Some people are constantly angry at something. They rail against the government or the system or foreigners or corporations. If that describes you, let me say I admire your passion even as I wish you'd calm down. I have no advice to offer you because your anger is part of your character. While the demands of caregiving no doubt worsen it, caregiving didn't generate it and the solution, if you want one, lies somewhere else.

On the other hand, some people are normally calm. Anger is out of character, so when it happens, it's startling. If that describes you, I suggest you are actually angry at something else but are constrained from displaying it. Here's an example.

An example of misplaced anger

I was visiting a friend who, despite having strong opinions, was normally even-tempered. But one day, he erupted. He powered up from his chair and stormed back and forth across the room, gripping his local newspaper and cursing. When I asked him what was wrong, he said the city council had voted to install parking meters near a park he and his wife frequented and he would now have to pay a dollar every time they visited the park.

I understood why he was upset, but his reaction was out of proportion to the offense. Yes, the new policy was annoying, but it wasn't serious. The extra cost wouldn't make a dent in his finances.

At the same time, I also knew the root of his anger. His wife had a medical problem that needed specialized treatments, but his wife's doctor had classified the treatment as voluntary and his insurance company had declined his claim. He was smart enough to recognize that if he stormed into the insurance company's offices to vent, or into the doctor's office to spew his

contempt, he would only harden their positions or risk having them cancel the policy or even, if he yielded to his impulses, call security. He knew he needed tact and restraint, so his life was focused on forcing himself to stifle his anger and deal with the doctor and the insurance company professionally. But some seething part of him wanted to abandon discretion and express his outrage in a more direct form. City council was a safe focus. Allowing himself to vent protected his wife's interests by providing a safe release for his anger, calming him enough to deal with her treatment in a lucid manner.

Dealing with misplaced anger

Here are three key questions to ask yourself if your anger is misplaced:

- Who am I really angry at?
- What would be the consequences of expressing my anger at that person?
- What value am I protecting by deflecting my anger onto something else?

In my friend's case, his answers to these questions would have been:

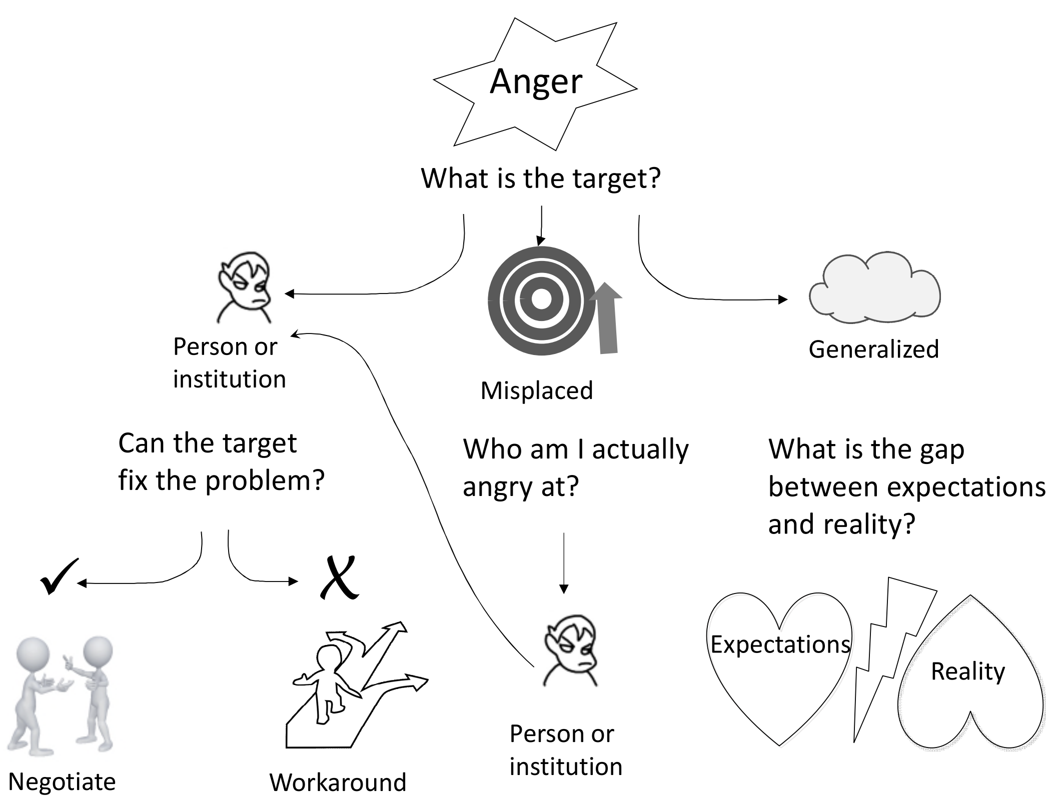
- I'm angry at my wife's doctor and the insurance company.
- If I expressed my anger to them, my wife would lose any hope of her claim and she wouldn't get the treatment she needs.
- By deflecting my anger, I'm allowing myself to vent at an anonymous target and protect my wife's health and wellbeing.

How can you handle this kind of anger? Once you have done the analysis and answered the key questions, you are now able to shift the anger from generalized to specific. When my friend thought about it, he realized that the real culprit was the doctor who had classified the treatment. The insurance company was just following its standard policy of not paying for voluntary services. If the doctor would change the classification, something that was within his power, the insurance company would cover the costs. Once my friend understood this, he was able to look beyond his emotion and think, "Negotiate. If that doesn't work, get a second opinion. Find another doctor."

Generalized Anger

Generalized anger is directed at the system, or the disease. It has no specific focus. We will deal with generalized anger when we look at despair

Here's a chart that summarizes the three types of anger.


Anger
What is the target?
Person or institution
Misplaced
Generalized
Can the target fix the problem?
Who am I actually angry at?
What is the gap between expectations and reality?
✓
X
Negotiate
Workaround
Person or institution
Expectations
Reality

The Thieves of Ambition

The thieves of ambition, those negative emotions that rob us of our motivation to act, include grief, apathy, sadness, guilt, depression, and despair.

Grief

Grief is the emotional response to a loss. When someone we love dies, nobody questions the grief. It's a process we all have to work through, and it's triggered by a sad event. But in caregiving, particularly for conditions that, like Parkinson's, are progressive, the loss we are experiencing is continual and hits us in small increments. The person we love is fading away, being transformed into someone we don't know and the grief from that loss can pervade everything we do. When my wife and I were married, she told me she knew she wanted to spend her life with me when she realized that fifty years later, we'd still be having great conversations. Her Parkinson's robbed her of that ability and that loss was unrelenting.

Grief as it's normally conceived, passes. Time removes the sting. But caregivers' grief hangs on because the loss is not finished. Every day, we're reminded of what we're losing, what we've already lost, and what loss will come. It's relentless and it hurts.

Grief is the flip side of love. Without love, we wouldn't experience grief. Counselors sometimes speak of the stages of grief, but those stages assume the person for whom we're grieving has passed on. When that's not true, we're stuck, unable to proceed to the next stage.

People in grief handle it differently, but one approach stands out. We need to talk about it. We may talk to a friend, to a counselor, to a spiritual advisor, or to a support group. Talking helps us deal with the pain.

How do we identify grief from other emotions? That's a complex question because our emotions come in bundles and it can be hard to separate them. But if you find yourself thinking of what you've lost, that's a sign of grief. Another sign is an increase in your emotional response to situations that don't affect you. For example, I watched a news report on a funeral for some police officers who had been killed on duty. I had no connection to these officers or the event and I would normally have let it pass, but I found myself getting emotional. That was a manifestation of my grief.

The loss can encompass several parts of your life.

- The relationship. We can no longer talk, joke, argue like we used to.
- Activities. We can no longer golf or ski or buy season tickets or travel.
- Plans. We can't retire or visit family or work together on our business.

When you find yourself regretting the loss of any of these, that's a sign of grief. Find someone to talk to. The grief will not abate but talking about it eases the pain.

Apathy

Apathy is often associated with lassitude or passivity, but apathy just means "I don't care." More formally, it is indifference, a lack of interest, enthusiasm, or concern. We call people who don't vote apathetic, but their refusal to vote often doesn't arise from sloth, they just don't see the point to it. As such, apathy is not an emotion as much as it is an attitude. But in demanding situations such as caregiving, apathy can also reflect depression. More about that below.

In caregiving, apathy reflects itself in a lack of concern for the person being cared for. Why would a person who doesn't care for the caree take on caregiving? Perhaps it's out of a sense of responsibility or maybe it's in hope of a future gain. *If I look after my aunt, maybe the old biddy will name me in her will*.

Nowhere is it written that caregiving must be based on love. Caregivers who don't care about the caree are still providing care. The only caution is that anyone who takes on the role of caregiver has to be thorough in providing it. If apathy leads to neglect, the caregiver is now at risk of legal action. If you take on the role of caregiver, you are obligated to carry it out fully, regardless of your attitude toward the caree.

Apathy is a signal that you don't care. Again, you may say that's hardly a revelation, but if you don't care, then why are you taking on all this work? That question is the key to harnessing apathy because whatever the answer, you will not be apathetic to that. If you are hoping for a payoff or recognition from your family or kudos from society, those are valid goals and they are what drives you.

Harnessing apathy means recognizing that it's okay not to love the caree, but that it's not okay to abandon or neglect her while you've taken on the role. The response to apathy is to remind yourself of why you're doing this. And that's a purpose.

Sadness

Sadness, as opposed to despair, is more a mood than an emotion. There are days we feel sad, others where we're happy. What causes these moods? It could be diet, sleep, the weather, or just some random neural activity. Moods are part of life. They don't require intervention and they're not alarming or something to worry about as long as they're sporadic.

When you're sad, ask yourself when was the last time you were happy. If you can't answer that, be careful because that's a sign your sadness is becoming chronic. That's despair or depression. Those need attention. More about them below.

But in the meantime, if you have sad days and happy days, good moods and sour ones, welcome to the human race.

Guilt

Guilt is the response to what we perceive as a personal failure. It can arise from things we did that we shouldn't have, from things we didn't do that we should have, or from things we did but not to the standards we expect of ourselves. For caregivers, guilt is an ever-present drag, so dealing with it is critical.

Guilt arises from two components. One is an ideal of behavior, a standard. The other is an evaluation of how well we met that standard. So if you feel guilt, congratulations. You have principles of proper behavior and you have a conscience. People who don't have such principles are considered amoral or immoral, those without consciences suffer from what psychiatrists call an antisocial personality disorder—psychopaths or sociopaths. Guilt is a sign you've escaped those fates.

Okay, you may say, but that still doesn't stop the grungy feeling. I still messed up. I should have known better or done better. Yes, you feel bad and how you deal with it depends upon what caused it.

Guilt is one of the more pervasive negative emotions because it can arise from different sources. Before I get to them, here's an approach to dealing with guilt.

Responsibility *vs.* Blame

One of the key words in guilt is "should." I should have done this. I shouldn't have done that. I should have done better. The dismal feeling of guilt arises from that accusing word, "should." How do we deal with it?

When we mess up, there are only two reactions, and you can have both. One is self-blame. The other is restorative. One reaction says, "I messed up." The other says, "How do I fix this?" The difference between these attitudes is one of blame vs. responsibility.

Blame looks backward. Its mantra is "should." It seeks the guilty. And that's you, otherwise you wouldn't be feeling bad. Responsibility looks forward. It seeks to resolve whatever happened. Blame leaves unhealed whatever harm your messing up caused. Responsibility tries to fix it.

Harnessing guilt means turning your back on blame and embracing responsibility. That may mean apologizing, or replacing something you broke, or committing never to make the same mistake again.

However, even after you make amends, the prod of guilt often continues. So here is a strategy to help you overcome it. Let's start with a couple of examples.

- You forgot an important date such as a birthday or anniversary.
- You snapped at a friend or relative who was trying to help, but who triggered some reaction you now regret.

Apologies are valuable in making things right, especially if they're accompanied by some material offering such as chocolates or flowers or a gift card (or jewelry?). But it's better {and probably less expensive) if you can put in place some processes to help you avoid repeating the problem. Here is a basic question to ask yourself:

> Is this mistake I made consistent? Have I made it before? Or is it a one-off, something that is unusual for me?

If it's a one-off goof, ask yourself what you were occupied with when you made it? Were you in an emotional state or tired or had too much to drink? If you can honestly claim that the mistake is unusual for you, recognize that circumstances conspired against you, fix whatever went wrong, and promise yourself and anyone you offended that you won't do it again.

But if the mistake is consistent, if someone could accuse you of always forgetting a birthday or snapping at a friend, you need a strategy to avoid those problems. For example, if forgetting an important date or an appointment is normal for you, get a calendar that will alert you to events. Do some research on electronic calendars, especially ones that run on your cell phone or tablet and that you can set up to prompt you. Most calendars will remind you of an appointment shortly before it's due, but you can set the reminders for several hours in advance or even the previous day. One strategy to remind yourself of an important date such as an anniversary is to set the date in your calendar for the preceding week. That way, the reminder will come in plenty of time for you to buy flowers. If you're a chronic forgetter, put the date in your calendar every day for that week.

If the mistake was that you blurted out something you now regret, and you have to admit that this is not unusual for you, find some strategy to keep your mouth shut until you have thought through what you want to say. You've heard the advice that when you feel a burst of anger, count to ten. That's a good tactic, but try counting out loud. When the person you're dealing with asks you what you're doing, tell him you're resetting yourself to prevent you from shooting off your mouth. Chances are, he'll recognize whatever he said that triggered your reaction and may apologize. He may even laugh at your unconventional behavior. Problem solved.

Resentment Guilt

Some guilt can arise from an inner state that bothers you, one of the most common being resentment toward the caree. That is not unusual, but it can lead to the guilt that you shouldn't be having such feelings. If you haven't done or said anything to be ashamed of, your guilt has done its job by warning you that you may be thinking of actions you'll regret.

One tactic in dealing with this kind of guilt is to remind yourself that emotions and thoughts are never right or wrong. Acknowledge the resentment and affirm to yourself that you're entitled to feel it. You've earned it. In fact, not feeling it would be unnatural. You haven't done anything to feel guilty about. and you can congratulate yourself for carrying on despite the demands that caused the resentment. You're doing well.

Abandonment Guilt

There is one piece of advice that we caregivers constantly receive: to look after ourselves. We're exhorted to take care of our own needs because if we collapse, we don't do ourselves or our caree any good. Taking care of ourselves means doing the things we like to do such as playing a round of golf or meeting a friend for lunch or taking a weekend trip. But doing so can lead to the guilt that we're abandoning our caree. We're putting our own selfish desires ahead of the person who needs us. Even worse, we're doing things our carees would probably enjoy doing with us. The first time I played a round of golf when my wife was in a day program, I felt guilty for the entire game because she loved to play. Doing it without her felt like betrayal.

On another occasion, I put my wife in respite care and went out of town for a break. I lost track of the number of times I wanted to turn around, pick her up from the care home, and beg for her forgiveness. The only thing that kept me going was the knowledge that I needed to get away for a time so that I could continue to give her the care she needed. After all, everyone needs a vacation.

And when the vacation was over, I felt rejuvenated and more capable as her caregiver.

If you are subject to this kind of guilt, ask yourself how effective your caregiving would be if you didn't take a break. Ask yourself what would happen to your caree if you collapsed from the stress of constant care. And allow yourself to realize that the break you're taking is one more part of being a good caregiver. This is not an uncaring act, you're doing it for yourself, and you're doing it for your caree.

Omissions Guilt

Omissions guilt arises when you failed to anticipate something and there were consequences. For example, you and your caree are at the mall and it's time for her medications. But you forgot to bring them with you. Now you either have to abort your plans

and head for home or delay giving her the meds. Both are an indictment of your oversight and can lead to you berating yourself for something you should have taken care of. If this is a common problem, put in place processes to make sure it doesn't happen again. You may put a vial of extra meds in the car or your caree's purse (or yours). Or you could make up a "going out" checklist that includes medications and run through it whenever you leave home. But while those will help in the future, they won't erase the self-blame you're feeling now.

Here's a tactic for doing that. Ask yourself what was happening while you were leaving home. Probably you were getting your caree ready, helping her with her coat, making one last trip to the bathroom, guiding her to the car, getting her seated. In other words, you were busy providing care. Would you blame someone else in the same position for one oversight? If not, give yourself a break. Then put an extra set of meds in the car for the next time it happens.

Depression

"Depression" has two meanings. In general use, it is a synonym for sadness. People will say, "I'm so depressed" because someone they like snubbed them or they were passed over for promotion or their favorite team lost the playoffs. But that's disappointment. It will lift in a few hours or, in more extreme cases, days.

But real depression is beyond unhappiness. People who are depressed feel hopeless, that their lives are without meaning. They lose interest in the activities that once occupied them. Now, nothing motivates them. They often lose their appetites or sleep to excess or neglect their appearance. In extreme cases, they attempt suicide and too often, they succeed.

Depression is not an emotion, it is a psychiatric condition. A disease. Like any disease, it needs to be diagnosed and treated. People rarely emerge from depression without help. And the end point of depression is at best collapse, at worst, death.

There are treatments available including medications, talk therapies, and surgery. But all treatments first require diagnosis and evaluation. That's the job of a professional.

But people who are clinically depressed lack the motivation to act. Even calling a doctor is beyond them. Depression, like rage, needs someone to identify it and report it to someone who can help. That is the role of the "early warning sentinel" I describe below.

Despair

Despair is the emotional signal that we're overwhelmed. We're reaching the point where we cannot cope and we see no way out. The purpose of despair is to warn you that you have to make changes. Of course, this isn't a revelation. But how do we do that? How do we harness despair?

In many ways, despair is the thief of ambition's equivalent to anger or frustration, although it manifests itself as a lack of motivation. Despair tends to be cumulative. It builds up from small irritants until it swamps us. Of all the negative emotions, despair is probably the hardest to deal with, in part because it robs us of our impetus to do something, and in part because it often leads to the attitude of hopelessness, that no help or relief is possible.

The first requirement for harnessing despair is to prod yourself to move. You might say something like, "Enough wallowing in self-pity. Time to do something." Or "I've got to get moving." Or just get mad. Anger is a great antidote to despair.

But one barrier to pulling us out of despair is the idea that we don't know what to do. It's one thing for me to say that I've got to get moving, another to decide how. The risk is that we say something like, "What's the point? I don't know what to do." Or worse, "There's nothing that can be done." That last attitude is a recipe for despondency or even depression.

Harnessing despair takes two steps. First, decide to take some action. Second, figure out what action to take. It's okay to say, "I have no idea what to do, but I know I have to do something." The next step is to say, "Okay, now what?"

There are three types of despair. Your first analysis is to figure out which one your despair is. The three types are problem-based, situation-based, and generalized.

Problem-Based Despair

Problem-based despair is similar to frustration in that it arises from problems that are persistent and that we don't know how to handle. You can tell when your despair is problem-based by asking why you're despairing. If the answer is something like, "Because I don't know how to . . .," or "Because I can't . . .," then your despair is probably problem-based.

For example, I couldn't get my wife to eat enough for her to maintain her weight. Every meal was a struggle to try to get more food into her, but force-feeding wasn't an option. She was becoming more and more frail and nothing I did seemed to work. I consulted with one of her doctors who suggested feeding her high calorie snacks and deserts. I resisted the idea because we're supposed to eat a balanced diet and I saw it as my responsibility to make sure she ate properly. Ice cream and chocolate don't qualify. I was despairing over what I could do, then I recognized that I was dealing with a problem just as if I was frustrated, so I went through the questions for frustration. Here they are with my responses. I've modified the last question.

- What is the problem? (She won't eat enough.)
- Why is that a problem? (Because she's losing weight and it's unhealthy.)
- Is there another way to get her to eat? (Well, I could feed her high-calorie deserts.)
- So why aren't you feeding her those? (Because they're empty calories and not nutritious.)
- Isn't it better for her to get empty calories than none? (I guess so.)

The solution wasn't ideal because she wasn't getting a balanced diet, but I was able to find specialized products that were sweet and high-calorie but that also had nutritional value.

When despair is directed at a persistent problem—and it's the persistence that creates despair—you can harness it by focusing on the problem and searching for solutions.

Situation-Based Despair

Situation-based despair is similar to anger in that it arises more from circumstances related to people or organizations. For example, my wife was referred to a Parkinson's center for evaluation when her disease had progressed to the stage where she had problems with mobility. The staff at the center were thorough and put her through a variety of tests. At first, I was impressed by how comprehensive the testing was, but then I saw the effect it was having on her. In one test, she was shown the outline of a house and asked to draw it. She couldn't, and when she saw the difference between what she was supposed to draw and the scrawl she produced, it made her despondent. This happened on each trip to the center and I became more displeased at each appointment. I couldn't get angry at the staff, they were being diligent.

But the results of their tests drove my wife and I deeper into despair, especially as each appointment loomed.

When I thought about this, I saw two solutions. The first was to consult with the staff and ask them to skip these evaluations and focus on treatments, the second was just to stop going. These two solutions are similar to the approach in anger when a factor is whether or not the person who is the target of the anger can do anything about it. I don’t know whether I would have been able to get them to stop the evaluations, although I doubt it. They were a research center and they were using the results as data for their studies.

The option to stop going seemed extreme, but I asked myself what benefits my wife had realized from her trips to the center. When the answer was none, the decision was easy.

Harnessing situation-based despair is similar to harnessing anger. Can the person whose actions lead to the despair change the situation? If so, negotiate. If not, find a workaround. Our workaround was to stop going to the center which stopped her from being exposed to what was contributing to her (and my) despair.

Generalized Despair

I suspect that generalized despair is the most common. And it’s similar to generalized anger. In this discussion, you can substitute the word “anger” for “despair.” The approach to harnessing the emotion is the same.

Generalized despair is the emotion that arises from the attitude there is nothing you can do. Things will never get better. The situation is hopeless. I once described my attitude toward caregiving as resentful resignation. Nothing would ever improve and even though I was resigned to it, I resented being immersed in it.

Generalized despair is not the same as depression. It is not always present and it does yield to moments of laughter or pleasure. But unless you can harness it, it lurks in the background, ready to emerge at any time.

What is generalized despair telling us? What is its value and how do we make use of it? I suspect that generalized despair is a signal that the circumstances of our lives have been wrenched from those we had expected. My wife and I were looking forward to a fulfilling retirement with travel and friends and engagement with our community and the joy of one another’s company as we grew old together. All that disappeared with her Parkinson’s. The circumstances of my life had become nothing like what I had anticipated.

So generalized despair arises from the gap between expectations and reality. As long as that gap persists, so will despair. Harnessing generalized despair means narrowing or eliminating that gap. It means bringing our expectations in line with the life we now live.

There are two things you need to do to narrow that gap. The first is to bid farewell to the expectations you had. The second is to create new ones. Both may require help, but here are some tips.

Shedding expectations is easier than it might seem. For most of us, we’ve been doing it all our lives. When you were in your twenties, what did you expect your life would be like? How would you be living it? I’ll bet that you in your forties lived a life that was different from the one you had expected. And I’ll also bet that you in your sixties will be living (or have lived) a still different life. Those transitions from what you expected to what you have are constant. You adapted. How did you do it? How did you adjust to not getting your dream job, or finding out

that you and your spouse couldn't have children, or being offered a lucrative overseas assignment, or having to move to another city to find work? All of these uprooted your expectations and forced you to adjust. That's true now.

Part of shedding expectations is acknowledging that you must. The alternative is to hang on to them even though you'll never realize them. When I recognized that our retirement would be nothing like what we had expected, I had to admit that my life had changed. And that gave me a choice. I could bewail that my dreams were dead and spend my life cursing my fate, or I could take a deep breath and reset. My life had changed and I needed to adapt.

But adapt to what? To an endless routine of caregiving drudgery? That's the second part of harnessing generalized despair. I needed to create a new set of expectations, ones that reflected my circumstances.

Creating new expectations is figuring out how to make use of your new situation. If you and your spouse discover you can't have children, you might adopt, seek reproductive technologies, become foster parents, or embrace the freedom of childlessness. If you have to move to another city to find work, you could plan how to explore your new environment, make new friends, or find circles of interest. New circumstances offer possibilities and alternatives.

But what about caregiving? There are two areas in which you can set new expectations. One is in charting your own life, the other is in becoming the best caregiver you can be.

But, you may argue, how can I chart my own life if the one I have is absorbed with giving care? That is where self-care comes in. We caregivers are constantly advised to look after ourselves. If we don't, we risk collapsing from the unrelenting stress. If that happens, we have two problems. Our caree doesn't get care and we have now become patients who need it.

Self-care means taking the time to do the things you want to do. Finding that time is a problem, but there are services to help you do that. Bring in a home care aide in the evenings so you can take that course in ceramics or Lebanese cuisine or square dancing. Register your caree for a day program so that you can attend that program in Cantonese or scuba diving. Put your caree in respite for a few days so you can enjoy that hang-gliding jamboree or writer's conference. Once you decide to take the time for you, you will develop a new set of expectations, ones that you can meet.

The second part of setting new expectations is in resolving to become a great caregiver. With that focus, expertise becomes a goal and competence an expectation. But you may object that excelling at caregiving isn't something you ever wanted to aspire to. That may be true, but that is your role now. Your choice is between sinking further into despair and spending your time going through the motions of providing minimal care or making a choice that you will strive to become the best caregiver you can. And an essential step is to decide that even if your possibilities are limited, they are there.

Being a great caregiver is more than providing the mechanics of care. Any care aide can do that. Excelling at caregiving is helping your caree enjoy life rather than just enduring it. Decide that each day, you will show your caree your love by words or smiles or caresses. Create a list of spontaneous activities you can draw from when the time is right. For example, if it's a sunny day, suggest you hop in the car and stop at that funky antique shop you discovered a few years ago. Or if it's a dismal day, suggest going to that new exhibit at the art gallery or museum or visiting that new outlet shopping mall.

The opposite of spontaneity is planning. Set aside a movie night, one evening each week when you'll go to the theater. And if your caree can't go out that night, download a movie. That gives you and your caree something to look forward to. That's one of life's pleasures. And if your plans have to change, we're all used to that. Caregiving greatness means your caree knows you are on her side. She can rely on you. She doesn't need to fear being abandoned.

When I was immersed in caregiving, I could not say it was rewarding. It was hard work and it was emotionally exhausting. But knowing my wife was comfortable and looked after, knowing she could laugh or listen to me enthuse about some passion or enjoy a day program with others was one of my expectations. To be sure, they were limited, shadows of the ones I had to give up, but just having them meant there was no longer a gap between them and my reality. My despair had done its job of shifting me to my new life. And even if it was a life I would never have chosen, it was the one I now had.

Recruiting Others

Resources

There are a vast number of resources to help you in caregiving. They range from commercial products or services to community programs. Using these resources enables you to become a better caregiver, and in two ways.

First, they ease the workload. Having a care aide frees up your time. Installing a commode makes night-time bathroom visits easier to handle.

Second, relieving you of some of the work of caregiving allows you more time to pursue what you like to do, but it also gives you more time to spend just enjoying being with your caree.

Find a local organization that specializes in the condition your caree has. In my wife's case, that was Parkinson's. Some of these are local branches of national organizations and some are affiliated with medical schools or universities. Most offer a range of services including education programs, support groups, counseling, and seminars or webinars. Medical centers offer specialists, social workers, and physio- and occupational therapists. You can access your local organization by just picking up the phone. For medical centers, you may need your doctor's referral.

Find out how your local health care system works. For us, it's organized into health authorities, but that varies from place to place. Consult with your doctor, or with a local organization that deals with your caree's condition, or even the local community center.

Most jurisdictions have services such as home care, day programs, or respite care. Look for someone who can act as a portal to the services that are available. That may be a case manager, a social worker, or someone with a national organization such as the AARP. Ideally, this person will be responsible for assessing your caree and authorizing a level of services.

Ask for the list of services the organization offers, how you can access them, and what they cost.

Visit your local community center. Many offer specialized exercise programs such as chair exercises for people with special needs. Some have drop-in services or information sessions or seniors' programs or social activities.

Check out transportation services. Some cities have specialized transit for the handicapped or subsidized taxi fares. Ask your doctor or case manager about getting a handicapped parking decal. Some transit systems allow caregivers to travel for free. That's also true of some airlines for certain flights. Some pharmaceutical manufacturers subsidize the cost of their medications or cover the difference in cost between their brand name and generics. Your case manager can help you find out what's available and whether you qualify.

Visit a medical supply store and spend a couple of hours just browsing or talking to sales staff. If you're not part of the medical community, you'll be astonished at the range of products available to help. And even if some of them aren't necessary now, just knowing about them can make it easier when you do need them.

If you have a spiritual advisor, meet with him or her and explain your situation. You need to be careful because while most pastors or priests are trained to be supportive and empathetic, a few tend to be more concerned with your soul. Their job is to judge you and to issue penance if you stray. The last thing you need is to have someone add guilt to the struggle

you're going through, so come to an agreement with your spiritual advisor that on some occasions, you need a counselor, not a judge.

Support Groups

One of the most effective sources of help is a support group. The people in it have been through what you're going through and will be a rich source of information as well as sympathy and advice.

But some people, particularly men, are put off by the idea of support groups. They think of them as touchy-huggy-feely weep sessions and want nothing to do with them. Other people rebel at the thought of revealing personal information, whether about their carees or their own emotions.

That was my reaction when someone suggested a support group. I wanted nothing to do with one. But I realized I needed to talk to someone and I didn't want to burden my friends and family. So I tried a support group. For the first couple of sessions, I kept my guard up. I wielded my skepticism like a shield. When it was my turn to talk, I resorted to the name-rank-serial number school of communication. And the group didn't pressure me.

Over time, I realized there were almost no tears, no boxes of facial tissue, no hugs if I didn't want them. But there was information and the people in the group were going through the same struggles I was. That gave me the confidence to keep going and gradually, to immerse myself in the group and to benefit from the wisdom of the others who are in it. Now, I don't even mind a hug at the end.

The Early Warning Sentinel

Two of the negative emotions I've described are rage and depression. These have two things in common. They are outside your control and they end badly. If you fall prey to them, you must escape. But given that you can't control them, you need help to do so. Where does that come from?

That is the role of the early warning sentinel. Wherever you are in your caregiving role, recruit a friend or relative to be that person. Choose someone who knows you well, cares about you, and whom you see often, then say to that person something like, "I want you to keep an eye on me. If you see me sliding into unusual rages or injuring myself or ranting against things that aren't important, or if you see me becoming slovenly, or not eating or laughing or engaging with you, I want you to call my doctor. Here's his number."

You are not asking this person to intervene. That may not be wise. You are asking him or her to take any concerns to your doctor who will have the resources to deal with them. Of course, you also need to tell your doctor what you're doing, give him the contact information for your friend, and give legal authorization for him or her to intervene. You can even ask your doctor to touch bases with your friend every year or so just to get an opinion on how you're doing.

In most cases, your friend will never need to make that call. He or she can be just a friend. But if you do begin to slide over the edge, there will be someone there to catch you.