

Finding Balance

What Happens When You Go Home

You don't get to choose how you're going to die, or when. You can only decide how you're going to live now.

—Joan Baez

You're home from the hospital—maybe you're lying in bed or sitting at your kitchen table or taking a shower, and suddenly it hits you, the full weight of what you've been through. And you ask yourself, How do I come to terms with all of this?

Reflecting on your experience, it's as if you're seeing the world in time-lapse photography. You can see yourself going through the chaos of the emergency room—test upon test, one procedure after another, doctors and nurses hovering over you—and then your hospital room with all those tubes and IVs attached to your body. These images seem surreal and disconnected from your real life. You feel like you've been trapped in a scary movie, and you just want to leap off the screen and go home. In the wake of such events, it's not uncommon to experience a sense of shock or feel emotionally numb; these are completely normal reactions to a heart event. And even after you go home, these feelings of shock and numbness may stay with you for a while.

I was terrified when I came home from the hospital. I felt very insecure and fragile. My home didn't feel safe any longer. I felt alone. I was afraid to travel away from home for fear that I would have another cardiac event and my doctor wouldn't be there to "save me." Every now and then I think about the fact that I had a heart attack and will live with the uncertainty of heart disease for the rest of my life. It's all rather overwhelming.

—Joann, Huntington Station, NY, age 59

A heart event isn't just a physical experience. It affects you emotionally too. And once you go home from the hospital you'll begin the task of adjusting to your illness. For most heart patients, this is a time of transition, a time when you're adapting to the new realities you face. Every woman's experience is different. Some women find that their lives will change significantly. Others find that, over time, their daily routines pretty much get back to normal. The degree of change you face will depend on factors such as the severity of your illness, the level of responsibilities you have to take on, and your age and stage of life. But, for just about every heart patient, the process of adapting raises emotional issues. This chapter will touch on those issues. I'm hoping that knowing what's ahead will help you to negotiate these early stages of recovery. I'll also share some advice on how to deal with some of the feelings and experiences you may have, and insights on how to take those first steps towards your emotional and physical recovery.

Things Are Different

[My friends and family] tend to remind me not to overtax myself, which gets irritating. I don't like them making a fuss over me. Sometimes I try to listen to them and slow down a little bit. But can't they just let me be?

—Betty, Zanesville, OH, age 58

At some point during or following your hospitalization, you come to know that somehow your life has changed. The realization can feel overwhelming. All of a sudden, you see yourself, your body and your life differently. No matter how you defined yourself before—as a mother, a homemaker, a businesswoman, a lawyer, a doctor, or a salesperson—you've transformed. Redefining yourself is an unexpected challenge you suddenly have to face.

Many women experience a sense of loss. Looking in the mirror, you may ask yourself: "Who am I now?" The reflection tells you that this experience has changed your life in ways that are not welcome and not always easy to process. Whether you're forty-five or sixty-four, before you got sick, you probably felt like a teenager on the inside. Like most people, you took life for granted; you felt invincible. That's what most of us believe. It's a healthy, constructive way to go through life. But now, all of a sudden, you've confronted your own mortality and those internal bubbles filled with images of yourself have burst. Losing your sense of invincibility disrupts your sense of security and sense of self, and that can leave you feeling unbalanced. It can be scary. You tell yourself this is not a club you want to be a member of. These initial feelings and experiences are normal. Don't worry, over time you will regain your footing and your hope will be rekindled.

Okay, so that's what's happening inside of you. Then, to make matters more complex, you're confronted with a flood of mandates from doctors, health-care providers, and even, at times, from your family and friends: Take your medications. Go to cardiac rehabilitation. Visit your doctor regularly. Adjust to your physical limitations. Eat right. Exercise. Stop smoking. And find ways to reduce your daily stress. How can anyone reduce stress, you wonder, when these instructions and changes are making everything so stressful?

The truth is most heart patients feel overwhelmed at first. As you begin to accept your heart disease, these changes you're being asked to make won't be as overwhelming as they may seem at first. You'll find ways to incorporate them into your routine and they'll just become part of your daily life. Ultimately, you'll accept the new image of yourself as a heart patient and regain your own internal sense of security. But it's going to take some time and patience. Recognize that change is difficult for everyone. It's a process of ups and downs. You'd never expect toddlers to crawl one day, pull themselves up the next, then begin to walk and even run without difficulty the following day. Well, you can't be expected to change overnight either. It has to be a gradual process; even adults have to take courageous baby steps to achieve their goals. You have to take all these steps one at a time, at your own pace.

There are two ways of meeting difficulties: You alter the difficulties or you alter yourself to meet them.

—Phyllis Bottome, Author

Try to Set Realistic Expectations— of Yourself and Others

I was depressed because of my inability to care for myself and household in the manner in which I was accustomed. I am a worker, have always been. There was a great stress in my not being able to handle things the way I like them handled.

—Billie, Las Vegas, NV, age 44

It's normal for you and the people who care about you to want things to stay the same—to be the way they've always been. So it's not unusual for your friends and family to set expectations too high. They might hope or even expect that once you're home again, things will go back to normal. And it's not unusual for women heart patients to go home and set the bar too high for themselves. If you set your expectations too high, it can lead to added stress at home and personal disappointment. Everyone's expectations—yours and theirs—can be so unrealistic that you can't possibly meet them.

Here are a few tips to get you through the first weeks at home:

- Go easy on yourself. Don't expect to be able to get right back on track. And don't try to do too much too fast. Studies show that, following a heart attack, women may take on the burden of too many household chores too early in the rehabilitation process. And that can pose a risk of recurrence.¹
- You'll probably have to change the way things are managed at home and that too will take some time and adjustments. Start small. For example, maybe your partner can get up early once a week to feed the kids, so you can sleep late. Or maybe your kids can take on a daily chore they haven't done before—emptying the dishwasher, taking out the garbage, folding laundry, or even helping with dinner. If everyone pitches in, it will also serve as a daily reminder that you need a little extra support.
- Listen to your body and pay attention. Rest when you need to. Take a nap to rejuvenate during the day. It might be a ten-minute rest or a sixty-minute nap, but do whatever feels right to you. And don't feel guilty about resting.
- Let other people know how you're feeling. If you're tired or feel weak or dizzy, be honest with yourself, your family, and your friends. Don't be afraid to lie down when you need to, even if you have visitors. You need to tell people what your limitations are. You have nothing to gain by overtaxing your body.
- Don't be afraid to ask for help when you need it. Recognize that asking for help is not a sign of weakness. It's a sign of your ability to take control of your life and adapt to new circumstances.
- This is a good time to learn how to say No when you can't do something or need to rest. In fact, setting these limits for yourself and others is an important step toward your full recovery.

Relating to Your Friends and Family

Some friends and family are still in disbelief and even denial about my condition. Some have lashed out in anger and rage over my not being the same. I think I was viewed as being very capable. When I appeared ill and became vulnerable, this shook their foundation. I was their glue, the stabilizing force, if you will; then I became unglued.

—Billie, Las Vegas, NV, age 44

Here you are just beginning to deal with your new diagnosis and trying to process the feelings that accompany that experience, and you find relating to your friends and family is at times a struggle. This is a challenge many heart patients face when they go home—how to deal with the other people in their lives; family and friends, the people we all look to for support. To compound the problem, many newly diagnosed patients don't know how to accept support or empathy from others. They have difficulty accepting emotional support because they see it as a sign of weakness or feel that they're being pitied. In fact, people are most likely to tune out empathy from others at those times when they're feeling most vulnerable. In part, it's because those words of comfort and support only serve to confirm the fact that they are sick and they may not be ready for that.

On the flip side of this issue is the ability of friends and family to give appropriate emotional support. Although everyone needs support at times like these, not everyone knows how to be supportive or empathic in a way that may be the most helpful to you. Most people in our lives have good intentions but have never been taught those skills. It's not easy when someone we care about becomes ill and it's also hard to know what to say or what to do to be helpful in that situation. So, sometimes the people who love you the most may fumble a bit in giving support and empathy.

You may not be ready to accept support and empathy; or the people who care about you may have difficulty giving you the support you need. Either way, it can create issues for heart patients—feelings of loneliness and isolation, even distance from the people who care about them the most.

Here's an approach that can help the situation. Recognize that your feelings are pretty raw right now. They probably range from shock and denial to anger and sadness. Most likely your friends and family have not been where you are right now and can only relate to a limited extent to what you are going through. Try gaining some emotional distance from your experience by seeing the situation from the perspective of the people who care about you. Recognize that they're experiencing deep emotions—just as you are. They've been down this frightening path with you; they too wish everything could just be the way it used to be. Their own feelings of helplessness and frustration may be getting in the way of their ability to be supportive, at least supportive in the way you want them to be.

These times are difficult and when your interactions with others break down, the first thing to do is to take a step back and breathe deeply. Take time and think about the fact that you and the people who are close to you are really all in this together. Their experience might be a bit different from yours but it's a loss to them, just as you're experiencing a loss. In all likelihood, your feelings of helplessness and lack of control are what they are experiencing as well. Understanding where they're coming from can help diffuse some of the tension you're feeling and in the long run will make it easier on everyone.

Here's another problem a heart patient encounters. Sometimes, either in response to their out-of-control feelings or in an attempt to be sweet and thoughtful, the people who care about you make comments that make you feel worse instead of better—although that's not their intention. They may think they're showing you that they care by giving you advice, but it doesn't sound that way to you. One of my nurse friends once told me while I was continuing to have chest pain after procedures that my problem could be emotional. She said, "Kathy, I think your heart problems could be in your head instead of your heart—maybe you should get therapy." A few weeks later I ended up with bypass surgery and of course our relationship has never been the same. Other well-meaning comments can also be painful to hear. "Are you sure you should be eating that?" may sound like "Why don't you take better care of yourself? That's how you got into this situation in the first place." Or a statement like "Don't lift that! Please get some rest," implies that you aren't taking proper care of yourself. At times like these, you may think their comments suggest you're the cause of your medical condition—and that your behavior alone will determine whether you get better. What's meant to be supportive and encouraging instead sounds condescending and judgmental, even if their suggestions make sense.

In fact, heart patients know that they're sometimes blamed for their illness and treated quite differently from people with other types of life-threatening diseases. While people with other illnesses are perceived as victims, heart patients may hear comments that suggest they brought it on themselves: "You knew better—why did you smoke?" or, "Gaining weight isn't good for you." For obvious reasons, comments like these aren't terribly helpful and only make you feel worse. Sometimes, the people around you aren't actually coming out and saying such things, but you perceive a lack of empathy or, because you may already feel guilty about your personal habits, you might even imagine they are thinking these things. And these experiences just compound the self-image problems that women face as they age. These feelings can make you feel alone—as if you're not getting the support you need, as if there's no one on your side. Many women heart patients report such feelings.

How should you handle those feelings? First of all, it's important for you to know that the genes you inherited likely played a role in what happened to you. You should not be blamed for your condition. Much of your heart disease was likely beyond your control or you didn't see yourself at risk. But now that you know that you have a heart problem, you will have to work to reduce the risks that you can control. Second, it's important to communicate with the people who love you. Your friends and family will need to learn to be patient with you and let you take responsibility for your condition at your own pace. Most newly diagnosed heart patients recognize that they need to change their lifestyles and certain habits. But the people who care about you need to let you grieve about your illness before you can even begin to hear what they have to say.

Learning to Communicate

So how do you effectively respond to these well-intentioned comments? Ideally, you do so by talking to them, by clearing the air, by clarifying things—clarifying what they're really saying and explaining how it makes you feel. Sometimes heart patients are so emotionally vulnerable from their experience and overwhelmed with feelings that any comment feels like negative criticism. At these times, it is easy to become defensive. Remember that the people who love you are making these comments because they care about you and want you to take care of yourself. They want you to get better. So you need to open up the lines of communication. That means telling them how you feel and hoping they'll be more sensitive. But it also means being aware that you may be emotionally sensitive right now and have a limited perspective.

All that said, a word of caution: Take time to think about the potential consequences of sharing your feelings and thoughts with the person you want to communicate with. Make sure you weigh the pros and cons of having an open discussion with that person. Sometimes no matter how well you communicate your feelings or thoughts, the other person may not accept your openness in the way you had hoped they would. You could be misinterpreted, a conflict could arise or you might not get the kind of response you anticipate.

Remember: Communication is a skill. If you are not a person who communicates your feelings easily, the first time can feel a bit awkward and somewhat scary. To get past the fears, try reminding yourself that communicating with those around you will help you in your healing, recovery, and ultimately with your life. Of course, some people in your life will be easier to talk to than others. You know who they are. They're the good listeners, the ones you feel emotionally close to, the people you can always communicate with. But there will be people who care about you that are not as capable of hearing and understanding your concerns. Those conversations will take more time and patience.

Here's one way to make it easier: Try communicating with "I" messages instead of "you" messages. People tend to respond better if they're not being told that they did something wrong—as in "you're always telling me what to do" or "you're acting like all of this is my fault." Using "I" messages is more constructive and it's much harder for people to argue with them. For example, you might say: "Dad, I know you're concerned about me and I know you're trying to help. But I'm feeling overwhelmed right now. I'm trying to adjust to all the things that the doctor says I need to do. And it makes me feel more overwhelmed when everyone else starts telling me what to do. I just need time to process all of this and figure it out for myself." If you use "I" messages like these, it's more likely that your dad will hear you and not be put on the defensive.

Once you begin the process of communicating, try to learn from it and improve your skills. Ask yourself a few questions. How did your dad respond to your feedback? Did he hear you and acknowledge what you were trying to say? Did he react defensively or did he understand your point of view? From that one conversation, you can learn a lot about your communication style and his listening style.

Even if your first attempts to communicate don't go exactly as you'd hoped, give the communication process time. When it comes to communication, practice really does make perfect. In time, you'll get better at voicing your concerns and the people who care about you should begin to understand how you feel and respond more appropriately. Ultimately, communicating with others will bring you closer to them, so you can work through problems that come between you in the future. Chapter 6 contains more advice on dealing with your family and how to communicate better.

Becoming Part of a Support System

The isolation and feelings of being alone are real. I did not think that I could talk to other women who had been through what I had been through. I did not think that I could talk to anyone about my problem. My health-care provider is too busy with other patients to give me the time that I need. Even the cardiologist and specialists are too busy to give their attention. All I get is twenty minutes with the doctor/cardiologist/specialist. That's it. I'm examined like an object and that's it.

—Lila, Juneau, AK, age 58

Your support system can profoundly affect your recovery and reorientation. And often, support seems to elude our grasp. Adjusting to an illness takes time and can be an emotional experience. That's why it's so important to reach out to others who have been where you are right now rather than remain isolated. Reaching out to others is not always easy nor is asserting yourself with those who care about you. But the reality is this: There are millions of women who are experiencing feelings similar to yours. Support groups, group counseling, and connecting to other heart patients via the WomenHeart Internet site can help resolve some of these feelings and give you a way to heal and recover with other women heart patients. And the anonymity of the Web site helps you to feel more comfortable initiating communications with other women. Visiting the WomenHeart Online Community at <http://womenheart.clinicahealth.com> is one way to hear what other women have to say about their experiences, and for you to share your own.

(See the Resources section for more options.)

Taking the First Steps Toward Addressing Your Risk Factors

Doubtless your doctor has talked to you about your risk factors—those habits and characteristics that put you at risk for heart disease. They range from smoking to being overweight to diabetes. You know your risk factors. In upcoming chapters, I'll talk about long-term strategies for addressing your risk factors, such as diet and exercise. But in the first weeks home, the crucial first steps toward addressing your risk factors involve cardiac rehabilitation and medication management. Those are important first steps you must take to get back on track physically and emotionally.

Cardiac Rehabilitation Is a Must

The very first thing that I made the most use of was cardiac rehabilitation. I think it is the best tool to use right away. The education classes, the monitored exercise, talking with other patients, it all helped me to accept my diagnosis and treatment.

—Diana, Des Moines, IA, age 55

One of the most important things you can do for yourself after a heart event is to go to cardiac rehabilitation. The basic goal of cardiac rehabilitation is a permanent change in lifestyle choices—a change that will directly affect your risk factors, whatever they may be. Keep in mind that all of us have risk factors. In fact, according to Dr. Nanette Wenger of Emory University School of Medicine, “The majority of middle-aged and older women in this country have at least one coronary risk factor but they don’t know it.” There’s nothing to feel guilty about, but you may have some work to do to address those risk factors and stay healthy—both physically and emotionally. Cardiac rehabilitation is the first step toward addressing their impact.

Dr. Wayne Sotile, clinical psychologist and author of *Thriving with Heart Disease*, sums up the need for cardiac rehabilitation this way: “Participating in formal cardiac rehabilitation is one of the surest ways to thrive with heart disease.” Unfortunately, according to Dr. Sotile, research has shown that women patients are referred less often for this life-saving intervention than men. Yet because of the unique challenges they face, women stand to benefit from cardiac rehabilitation just as much as, if not more than, men.

Dr. Sotile encourages women to assert themselves with their health-care providers by calling their offices and getting the necessary referrals to attend cardiac rehabilitation. I asked my cardiac surgeon for a referral to cardiac rehabilitation and he didn’t follow through until I contacted his office and made it happen. I can’t tell you how many women I have spoken to over the years who have had the same experience. Just think what happens to all of those women who don’t assert themselves! The sad fact is that, as a patient, in many cases, if you don’t make the effort to make things happen with your own health care then it won’t happen.

After my heart attack, I did my own research and had to ask my doctor to send me to cardiac rehabilitation. Going through cardiac rehabilitation was my security blanket. I had this fear after the heart attack that any exertion at all and I would drop dead on the spot. Had it not been for the rehabilitation, I believe that I would have gone through a deep depression that so many other women go through. Instead of depression, I came out a fighter, determined to beat the odds and be a role model for other women going through the initial fears of heart disease.

—Tasha, Hot Springs, AR, age 40

There is no question that there are tremendous psychological, social, and medical benefits for women who attend rehabilitation after their heart event. Readjusting your schedule, getting that referral, and participating in rehabilitation is worth the hassle of getting there.

REHAB, REHAB, REHAB!!!! Rehab provides not only exercise, but social interactions, education concerning diet, and more. They also monitor your heart, which provides a sense of comfort and confidence.

—Judy, Kenai, AK, age 63

Think of cardiac rehabilitation as an investment in you!

Medication Management

One of the biggest obstacles I've had to face is accepting the fact that heart medications are necessary to maintain my "quality of life" and not a form of weakness that I need to try to wean myself off of.

—Ellen, Beverly Hills, MI, age 53

One of the simplest and easiest things you can do for yourself immediately to reduce your risk factors is to take your prescribed medications. Whatever your doctor has prescribed is designed to help manage your blood pressure, cholesterol, other heart conditions, and/or diabetes. You probably have many different pills that need to be taken at various times of the day. It's really important that you know what each pill is, what it does, the amount of that medicine you're supposed to take and how that physician wants you to take it.

Sadly, over half the people who use medications don't use them correctly. They may be using the wrong over-the-counter medicines or ignoring drug interaction precautions by using one medication that shouldn't be taken with another. Maybe they're taking the right prescription medicine, but they're not following the instructions properly. They're taking too many, or too few, or self-medicating when they decide they need it. Any one of these errors can have serious—or even fatal—consequences. Remarkably, of all hospital admissions, one-tenth of them are due to medication misuse.²

That's why it's so important to have direct and open communications not only with your physician but also with your other health-care providers, including your pharmacist. Being your own best health-care advocate is the way to avoid problems. Here are some strategies you can use:

- Stay informed. Write down your questions for your doctor or pharmacist before your visits, and then write down their answers, so you don't forget. You want to know: What are the potential side effects? What are potential drug interactions? Should I take this with or without food? Before or after meals? What about alcohol precautions? What do I do if I skip a pill or forget my medication?
- Avoid mistakes. Make sure your prescription labels are easy to read and that they state what you're taking the medication for. If not, ask the pharmacist to include this information. Make a list of all the medications you're taking and the dosages, even the ones prescribed by different doctors. Include any vitamins, herbs, and supplements you're taking. Keep this information in an accessible place.
- Keep your doctor informed. Be sure to tell your doctor and/or pharmacist about all the medications or supplements you may be taking, including vitamins, minerals, or herbs. Be open and honest about everything you're taking. Let your doctor know about all of your medical conditions or illnesses. And tell your doctor if you're allergic to any medications or have had a problem with any medications that have been prescribed in the past.

- Don't be afraid to talk about costs. Let your doctor know if you're concerned about the cost of your medication. Some medications cost less than others. Generic medications may be a less expensive option.
- Organize your medications. Buy a plastic pill sorter to help you keep track of your medications. They're inexpensive, available at any drugstore and designed so you can put all of the pills you need for each day in the container. Try to get a size that fits in your purse, so you can keep your pills with you when you're on the go. Your pharmacist can give you advice about the best system for you to use.
- Use a single pharmacy. Make sure you go to only one pharmacy for your prescriptions; that will reduce the chance of complications and confusion.
- Develop a daily routine. Take your medications at the same time and in same place, if you can. That will help you remember to take pills as prescribed. You'll be less apt to forget to take your pills, which could be dangerous. Like anything else that's new, taking pills is a learned skill—and practice makes perfect. After a while, taking your medications will just become a part of your daily routine. If you forget a pill, call you doctor's office and ask what to do.

What happens if I get side effects from my medications? Should I just stop taking them? The answer is a big No. Stopping your medications abruptly can be harmful if not dangerous to your health. If you are experiencing side effects contact your health-care providers immediately. If they don't get back to you right away, call them as often as necessary to get them to respond to you. Do not delay! It might be a simple matter of adjusting the time of day when you take your medication or you might need to take your medications with food to reduce the chance of nausea. But these are all solutions that need to come from your health-care provider.

For information on clinical trials, online pharmacies, and drug indexes see the Medication Management Resource Guide in the back of this book.

What's Next?

This chapter has given you guidance and support in navigating those first weeks at home and how to take steps towards regaining some of your balance and footing. Now, let's turn our attention back to what's going on inside of you, back to that person looking in the mirror who's asking herself, Who am I now? You may be at the point where you are just realizing it: You've experienced a loss—the loss of your previous perception of yourself. All of these changes and losses are normal and can bring up strong emotions, some akin to grieving, others that are linked to mental health concerns. In the next chapter, I will guide you through how to check your emotional pulse.