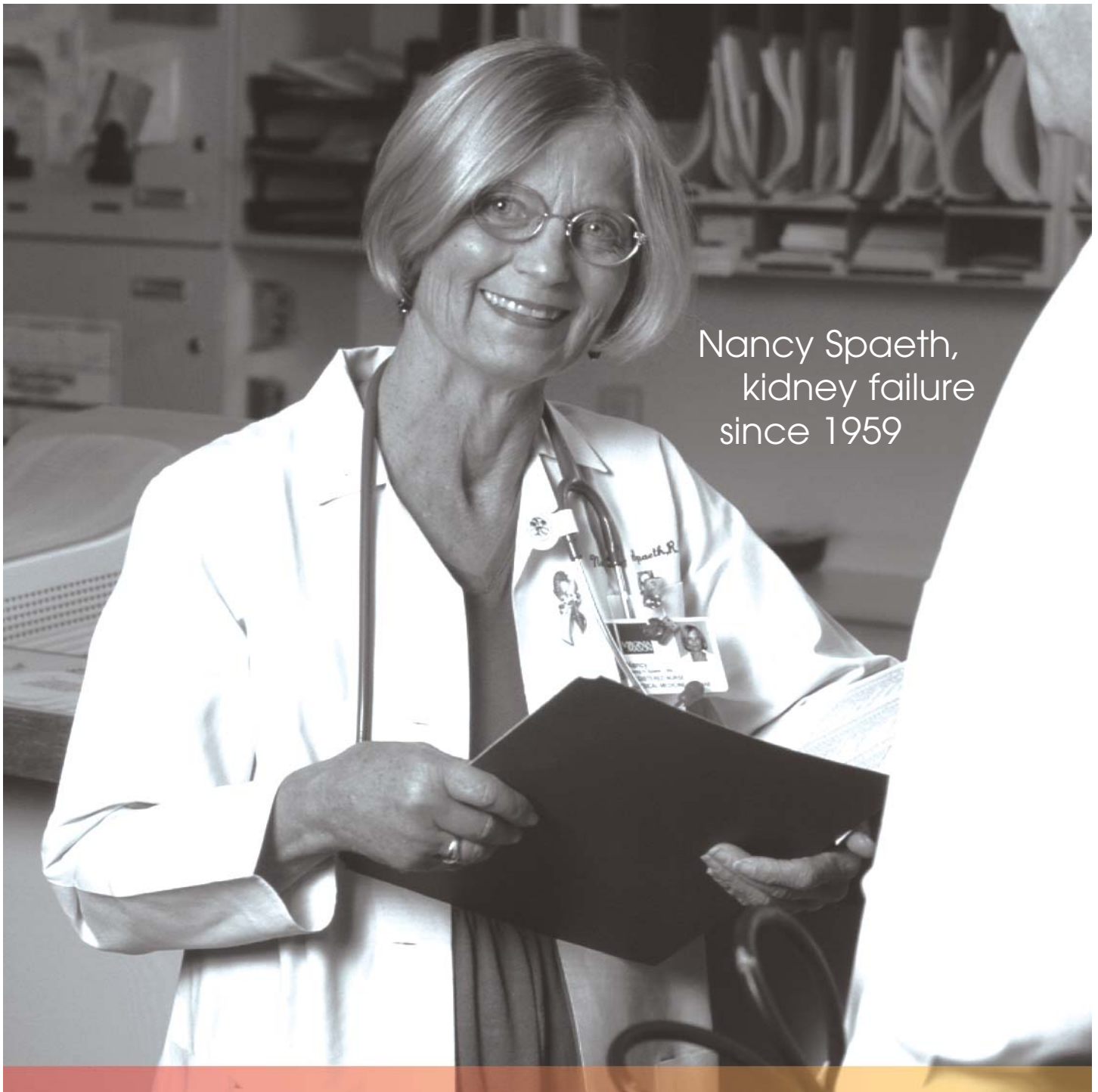


Kidney School™

Module Five: Coping with Kidney Disease



Nancy Spaeth,
kidney failure
since 1959

About Kidney School

Welcome to the print version of Kidney School! Kidney School will help you learn to take an active role in your healthcare decision making. Research suggests that kidney patients who become active partners in their care are more likely to live long and live well.

Kidney School is an on-line learning program designed to help people understand kidney disease and its treatment, adjust to kidney disease, make good medical choices, and live as fully as possible. You decide which modules to read and when—so what you learn is entirely up to you.

Kidney School was developed to:

- Offer free, up-to-date, research-based information, at your own pace.
- Help you learn what to expect and what questions to ask.
- Provide the tools you need to self-manage your care so you can stay healthier and keep doing the activities you enjoy.

Kidney School is a project of the **Life Options Rehabilitation Program**. Sponsored by Amgen Inc. and administered by the non-profit Medical Education Institute, Life Options is a program of research and research-based educational materials to help people with kidney disease live long and live well.

All Life Options programs, including Kidney School, are guided by the Life Options Rehabilitation Advisory Council (LORAC), a national expert panel of patients, doctors, nurses, researchers, social workers, dietitians, physical therapists, and administrators.

All content for the Life Options program and for Kidney School is developed by Life Options staff and reviewed by members of the multidisciplinary LORAC and by additional patients and kidney professionals. Life Options and Kidney School content is entirely independent of and not influenced by its corporate sponsor(s).

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Module 5— Coping with Kidney Disease

It was Groucho Marx who said, “I’ve had a wonderful time, but this wasn’t it.”

Many people with kidney disease could say the same thing about life with kidney disease. You may learn from it and you may find meaning in it. But it probably doesn’t rank up there with your best life experiences.

You don’t have to like having kidney disease. But you *do* need to learn to live fully with it—since this is your life. And that part can be challenging.

One person described the emotional journey with kidney disease this way: “I do pretty well at following my treatment plan and working closely with my healthcare team. That’s the easy part. But my emotions are like a roller coaster that won’t stop. If I could make sense out why I’m feeling like I do on a given day, I could manage my whole life a lot better.”

At times you may struggle with anger, fear, confusion, or other feelings related to kidney disease—if so, you’re not alone. Most, if not all, people affected by kidney disease go through a wide range of emotions. Some are mild but others can be paralyzing, making it hard to stick to the treatment plan—and endangering health.

By making sense of your emotions, you can use them for your benefit—even the stubborn feelings that don’t want to go away. This will help you stay on course with your treatment plan, improve the quality of your life, and maintain the relationships most important to you.

In this module of Kidney School, we will walk you through the most common emotions that people with kidney disease and their families experience.

We believe you’ll find this journey through the emotional landscape of kidney disease enlightening,

encouraging, and empowering. At the end of the module we will sum up the key points in a personal plan that you can print and use as a reminder.

To help you understand the common feelings you might face with kidney disease, imagine that you own a large house with many rooms.



Each room serves a different purpose. Some rooms contain things that you’ve wanted to throw away for years. Other rooms you’ve avoided because the contents or décor make you sad, angry, or afraid.

There are two important things to remember about each of the rooms in your house:

- Each room brings out a different emotion. But there is nothing in any of the rooms that can actually hurt you. So you need not be afraid of entering them.
- The doors to each room are always open. This means that you can come and go from one room to the next as you please.

Let’s take a closer look at the floor plan. Here are the rooms in the order we will walk through them:

- The **Red Room** (Crisis)
- The **Empty Room** (Isolation)
- The **Woodshed** (Anger)
- The **Blue Room** (Depression)
- The **Workshop** (Rebuilding)

So, let’s get started.

The Red Room (Crisis)

The red room is a place that few people forget. It's the first stop for most people with kidney disease.

Your first visit here may have been when your doctor first told you your kidneys were failing, when you had to choose a form of treatment, or when dialysis or a transplant were needed. Some people enter this room slowly, others are whisked in by an emergency. Regardless of how you get here, it is usually a crisis.

The heart of a crisis revolves around unwanted change. Before, your life looked predictable and



under control. Now, everything seems to have a question mark on it: your health, your relationship with your family, your freedom, your work, your dreams. You may have been given information

Fear of the Unknown: the Common Thread of Crisis

People we have talked to have told us what it felt like to be in a crisis about kidney disease:

“Emotionally, it threw me into a terrible loop, because I had no clue what it meant. You know, am I going to live or die, and what’s going to happen next?”

“I was scared. I was just, I didn’t know what was going to happen to me.”

“At the time, I felt of no use. I thought I was just going to die. I didn’t know you could live with this.”

“I had lost a leg, and was already handicapped. Now I had to go and have surgery limiting my life more than it was already limited.”

“All I had ever heard [about dialysis] was horror stories. That’s why it bothered me. But I was so sick at the time they put me on, I really didn’t give a damn what they did, as long as I felt better. I was in the hospital when they decided to do it, and I went down, they

put the access in, they gave me a treatment the same day, and I started to feel better.”

“I did triathlons at the time, and she [MD] said, ‘you will never be able to do that again,’ and I kind of took that like I wouldn’t be able to walk at all. So that was kind of misleading and really shook me up. I just thought my whole body was going to deteriorate, and I’d be—I would die within a few months. It is a couple of years later now, and I’m fully functional. I mean, for the most part. I can’t do triathlons, but I can walk or I can drive.”

“I remember sitting with the most incredible terror. Four o’clock in the morning used to be the time when I’d wake up and worry about things. And the fear of dialysis....”

What do all of these people have in common? Fearing the unknown—and expecting the worst. Seeking information to help you learn what you can really expect may help you move beyond a crisis stage.

about your health that raises questions you don't have answers to. The future seems very shaky. You may be worried about what kidney disease will mean for your life. Here are some of the most common emotions people feel during a crisis. Check those you or your family members felt during that time:

- Fear
- Confusion
- Overwhelmed
- Numb
- Sad
- Hopeless
- Other emotion:

The shock you feel at having your life turned upside-down can cause you to be upset for days—or even weeks or months—following the news. But, as you find answers to your questions, you can start acting on what you know. This evens out the turmoil and helps you feel more in control so you can start to adjust to life with kidney disease.

That's not to say you never feel other intense emotions related to your health. We'll talk more about these as we explore other rooms.

Some people, though, become stuck in crisis mode. They can't move past the fear, or don't want to admit that their kidneys aren't working properly or that their lives will change. Right now, do you think you have worked through the crisis? Or, are you still in crisis mode?

It's common to be in crisis mode, possibly for a while. Your best and fastest way to move out of this stage is to *get answers*.

How Can I Meet Other People with Kidney Problems?

“What’s the best part about a support group? Meeting other people in the same boat, because you don’t feel so alone and isolated. My husband isn’t diabetic and it’s really hard managing the food at home when he wants to barbecue his steaks and have whatever he wants, and have chocolate cake piled on with ice cream, and not gain an ounce.”

Support groups for people with kidney disease may be available in your area. The National Kidney Foundation (NKF) has a Patient and Family Council, with affiliate chapters in many states. Membership is free, and you will receive free subscriptions to the NKF's *Family Focus* newspaper, and *Transplant Chronicles*. To find out if there is a chapter near you, call (800) 622-9010 or visit the NKF website at <http://www.kidney.org>.

The American Association of Kidney Patients is a membership organization you can join. For \$25/year, you receive a membership packet, *aakpRENALIFE* magazine, *AAKP Renal Flash* monthly e-mail newsletter, and opportunities to attend local meetings (if there is a chapter in your area) and an annual meeting. Call (800) 749-2259, or visit the AAKP website at <http://www.aakp.org>.

If there is no group you can go to in your area, you can still get support from other people who have kidney problems. Many on-line support groups are available, and members “talk” to each other through e-mail. To subscribe to *Dialysis Support*, one on-line support group, send an e-mail to dialysis_support_subscribe@yahoo.com or go to their website at groups.yahoo.com/group/dialysis_support.

Realistic information about what to expect can help you see that life will be different, but it can still be good. Talking to other people who have been through what you are going through can help. Your care team can answer your questions and ease your fears. A mental health counselor or a social worker (if you are on dialysis) has special training to help you learn to cope with kidney disease.

Try to make one of these contacts within the next week. If you can't make the call, ask a family member or friend to call for you. Time, on its own, will probably not get you where you want to be. The sooner you ask for help, the sooner you can begin to feel some relief.

People handle tough times differently. For example, “crisis” may or may not seem like the right word for what you went through. The main idea is that a big change—especially a life-altering change—*should* cause us to feel some emotion.

Sometimes bad news is too much to handle and we block it out, minimize it, or even *deny* the importance of what we learned. As one patient put it:

“Denial is a really big thing and you have to break through it before you can realize that you can control things. I didn't take care of myself until I came out of denial that, ‘I'm going to die, and this is going to be the reason why.’ It's your life, not the doctor's; they go home and they're okay.”

Could you be denying a “crisis” relating to your kidney disease? Sometimes we don't know how to deal with a hard time, and think that avoiding the truth will somehow make it go away. Seeing that you may not be fully dealing with what is going on in your life is a step in the right direction. Working through your feelings instead of trying to avoid them is part of coping with kidney failure. The rest of this module will show you how.

The Empty Room (Isolation)

Once you leave the red room of crisis, you may return again at some point, but chances are good that you will spend most of your time in other rooms of your house. Often the next place you will go is the empty room of isolation. Let's take a look at why this can happen.

A crisis tends to mobilize people to action. Family and friends may rally around you offering their help, support, encouragement, and empathy with your struggle. As much as you hate being in a crisis, it is a comfort to have people show concern.

But once the crisis settles, the visits, phone calls, meals, or other forms of support often stop. People begin to focus their energy on other things, which may leave you feeling very alone or isolated.

You may feel that your loved ones don't really care about you. Or that they only helped out at first because they felt sorry for you. The chances are very good that neither of these is true.

It's very understandable that you might feel this way, though. Little has changed from the crisis phase until now. You still wake up each morning with kidney disease and all the worries that go with it. You might think your family and friends can see how obvious this is, and wonder why they no longer seem concerned about you.

But, a crisis demands a lot of physical and emotional energy from those helping. By the time things begin to be stable, family and friends may be exhausted from juggling your needs and trying to lead their own busy lives.



You're Not Alone in Feeling Alone

Not wanting to seem different from everyone else is another reason that some people with kidney disease don't ask for the support they need. As patients have told us, they may not even tell people they have kidney disease:

"I didn't want to tell anybody. I felt like I was sick, diseased, that I wasn't clean, that people wouldn't like me if they knew."

"I haven't talked about it in years, actually. We're so focused on everybody has to be super-human that any kind of defect...it's almost like it's contagious."

"I really haven't told anyone. Well, my mom. But I haven't told anyone else because I like positive energy coming toward me, not people saying, 'Oh, you poor thing.' I just want all positive thinking."

"I just want to be seen as healthy and whole. I have a reputation for being in good health. You don't want to be mollicoddled, or you don't want to be pampered or have sympathy. You like to try to help people, but try to keep it as private as possible on a need-to-know basis. Even some immediate family members, try to be overprotective. It's like you're constantly under a microscope, where they're watching what you eat, 'Well, you can't have that!'"

Who you tell about your kidney disease is up to you. Maybe you don't want the whole world to know, and that's okay. But if you can share the news—and your needs—with people you trust, you'll start to feel less alone.

Their need to pull back may not be a lack of concern for you—but simply a need to get back to their own routines.

Feeling needy and alone can be very hard. Sometimes the way out of this dark tunnel is easier than you might think. The solution? *Learn to ask for help.*

This is easily said, but hard for most people—with or without chronic conditions—to do.

One of the biggest barriers to asking for help is often our strong feeling that it is wrong or weak to need help. Our culture tells us to be independent and self-sufficient. You may not want to “be a burden” to your loved ones.

But we all need other people, chronic illness or not. Because you do have a chronic illness, you may need more help than the average person. But you can't expect even those closest to you to read your mind about the kind of help *you* need.

There are many kinds of help. Mowing the lawn or getting you to the clinic or carrying groceries—that's one kind of help. People who spend time with you and help you see that *you're still you*, even with kidney disease, offer another kind of help. Making you laugh and taking your mind off your troubles for a while is a kind of help, too. And there are others.

You may need to find new sources of help and support, besides your loved ones. Some people with kidney disease feel alone because they feel *different* from everyone else they know, or even *embarrassed* or *unclean* because they are sick. Nobody really knows what it feels like to have a kidney problem except someone else with a kidney problem. So, it may help you to talk with other patients.

A counselor, therapist, social worker, or clergy may also be able to help you—if you can bring yourself to ask for the help you need.

By asking those most able to help, you have the best chance of getting what you need and feeling connected in relationships. Most people are willing to help if asked, but be mindful of the person you're asking. If you're too demanding or insensitive to the needs of your loved ones, you may push them away even if they want to help you. If you're in doubt, ask them if they feel taken for granted or imposed upon. If they say "yes," talk with them about how you can make your needs known in a way that is better for them.

On the lines below, write the first names of at least two people that you would be willing to ask for help when needed. Then, list at least one need you have that they could help meet.

Name 1: _____

Need: _____

Name 2: _____

Need: _____

Name 3: _____

Need: _____

Allowing others to help you is an art that must be learned and practiced. But it is the exit out of the empty room of isolation.

The Woodshed (Anger)

The woodshed is a room where anger is felt. While anger is a valid feeling, it can be either a positive or negative force in your life. We aim to make it a positive one.

When you have a chronic disease there are no days off. If this were a paying job, and your boss insisted on you being at the workplace 365 days a year, you would be angry!

Add to that tiring schedule:

- Kidney disease is a job you dislike and never asked for
- It makes you change your lifestyle to fit your work schedule
- You're on call 24 hours a day—every day
- The responsibility can feel like too much at times
- You must depend on people to help you
- When you add up all the time and energy this job can take, both physical and mental, it may seem like you don't have much of a life

If you ever feel angry, we don't blame you! You didn't ask for or want this disease. But you do have to live with it.



Anger is usually directed at someone or something—like God, the doctor, or even yourself. Let's take a look at these feelings.

God

When something goes wrong, the desire to blame someone—anyone—is normal. And when there is no one else to blame, you may even feel like God has let you down. “Why me?” you may ask. “Why am I being punished?” It may help you to talk to a religious advisor about this test of your faith.

The doctor

Maybe your doctor did not catch your kidney disease early. Maybe he or she didn't tell you that you were at risk, or didn't listen when you said something was wrong. As one patient said, *“Right now if I could see that lady [MD] I would choke her! Because I kept on to the point where I couldn't walk. I was incontinent at home. I was by myself, I had to almost crawl to the bathroom. And I told this lady that there's something wrong with me. ‘Oh, there's nothing wrong with you.’ She didn't check me or nothing.”*

You may feel it's not fair that your life is changed forever due to someone else's mistake. Changing doctors and finding a therapist or grief counselor to help you work through your feelings are steps you can take.

Yourself

Could you have taken your blood pressure pills more regularly? Kept your blood sugar in better control? Drank more fluids? Seen a doctor sooner? Showed more faith? Even if there was something you could have done differently, blaming yourself now will not change anything.

Spinning around in a cycle of self-blame will keep you from moving forward in your life.

Breaking the Cycle of Regret

Whenever life takes a bad turn, it's only natural to wish you'd taken the other fork in the road. Here's what some of the patients we've talked to said about blaming themselves for their kidney problems:

“I was a little upset with myself because I used to make jokes whenever like, when I was younger and eating food, I'd say, ‘I'm still getting more salt, getting my pressure a little higher.’ I didn't know what I was actually doing was really, you know, killing me. It was dumb, I could think about all the times I could have, just, cut that out.”

“One of my feelings was, ‘You did it,’ that I did it, from not having the control that I should have had. Saying, ‘Well, you know what diabetes does, you know better than anybody. You had it longer than your mom, longer than your brother, you know what it does.’ And by having poor management.”

“It doesn't have to kill you. We have more control than we think we do. I did a whole lot of mismanagement, a whole lot of things that I shouldn't have done, a lot of rebelling. I mean, I'd be in the hospital with candy bars in my drawer, seriously. And so it took a lot of things to happen in my life, so I understand totally what they mean when they talk about living in denial.”

The only problem with looking back at what you did and what it meant for your life is—you can't change it now. Just as you might try to forgive someone else who did you wrong, you need to try to forgive yourself. You'll know you succeeded when you can look forward instead of backward, and do what you can to have the best possible life now.

Talking to a social worker, counselor, or therapist may help you deal with your feelings.

Kidney disease makes your life harder. But it is vital that you seek to move past anger, regret, and feeling like a victim. If you don't, these feelings will act like an emotional prison. They will use up the energy you need to treat your kidney disease—and send you back to the empty room of isolation.

Some people can face major life changes without a lot of emotional reaction. You might be one of them. If so, we encourage you to reach out to other people with kidney disease and their families who are not coping as well as you.

The goal is to express your anger in a constructive way. You don't want to pretend it isn't there, stuff it inside you, or blast anyone with it.

By putting your anger into words, you can make more sense of it and reduce its intensity. But the way you go about this is key. Below are some starting points; check the ones that you would like to work on:

- I will try to avoid using sarcasm, negativity, or criticism as clues to my anger. Instead, I will say, "I'm angry" and explain what I am angry about. (This keeps the other person from guessing what's going on, and helps me sort through details that may not yet be clear.)
- I will try to "own" my anger by using "I" statements. For instance, instead of saying, "my doctor makes me so mad when he talks about dialysis," I'll try saying, "I have a lot of anger in me about needing dialysis." (Because it is my emotion, I can do something about it if I want to. Owning my anger also keeps me from blaming others and putting them on the defensive.)

- I will look for ways to talk out my anger with someone, even if it's not the person I'm angry with. (When I hold emotion inside, it tends to grow larger and more intense. Letting someone in on my anger gets me support and another point of view.)
- I am not feeling angry right now, but I will stay aware of my feelings and share them so I can stay as healthy as possible.

Some people are afraid of anger. Somewhere along the line, they have gotten the message that expressing anger is wrong. But even if you wanted to remove anger from your life, you couldn't. It is part of being human.

Instead, think of anger as a healthy feeling when it is stated in a way that helps your relationships. Anger is also healthy when it moves you to *take action* and make good changes in your life. Using anger—instead of letting it use you—will help keep you out of the woodshed and out of trouble with the people closest to you.

The Blue Room (Depression)

As many as 17 million adult Americans struggle with depression during any given year, says the National Institute of Mental Health. You may already know that people with chronic diseases are even more prone to depression. What you may not know is how to deal with it.



Before we talk about managing depression, let's take a closer look at what it is.

Depression is a broad term that describes a set of mood disorders. Some are long and some are short. Certain types are milder, while others are very strong and paralyzing.

For our purposes, we will clump them into two groups:

- 1 Common mood swings
- 2 Ongoing depression

Everyone has common mood swings. They may look like depression, because you feel sad, discouraged, lack energy, may lose sleep, or doubt yourself over some event or relationship. These moods last from a few hours to a few days, and then subside. Clinically speaking, this is not depression, but a normal response to life changes.

Ongoing depression is more serious. If you have more than one of the following symptoms, for longer than 2 weeks, you may be depressed:

- Persistent sad, anxious, or empty feelings
- Loss of interest in activities you usually enjoy
- Fatigue, loss of energy
- Feeling worthless, helpless, or guilty
- Large weight loss—or gain
- Insomnia—or sleeping more than usual
- Feeling restless and irritable
- Having trouble concentrating, remembering, or making decisions
- Thoughts of death or suicide
- Other symptoms you have that might be related to depression (write them down below):

Grieving for the Life You Had

Some period of adjustment is normal when a major life change happens. It takes time to get used to the idea that life is different than you expected. Figuring out how the hopes, dreams, and plans you had before can fit into your new life is part of adjusting. Feeling sad, cheated, or frustrated is a common reaction. In a very real way, you are grieving for the life you thought you would have—before you can accept the new one.

Besides time, there are two other things you need to accept your new life. One is hope. Why do we think you can still have a good life with kidney disease? Because we know people all over the country who are on dialysis and still travel the world, volunteer or work at jobs they love, and even ride their bicycles across the U.S. Is it easy to rebuild your life? No. Is it possible and worth the effort? Yes. Others have done it, and you can, too.

The other thing is knowledge. By learning all you can, you can prepare yourself to manage your own healthcare, which will help you to stay as healthy as possible so you can go out and live your dreams.

If you haven't reached hope yet, and you're still grieving, here's something to think about: If your kidneys had failed just 40 years ago, doctors would not have been able to save your life. Today they can. So you can compare your life today to what it was before—or you can feel lucky to be alive, and try to make your life worthwhile.

Some of the physical symptoms of depression, like fatigue, loss of energy, weight gain/loss, and sleeping problems, can also be caused by your kidney disease or its treatment. So, before you diagnose yourself with depression, talk to your healthcare team about your symptoms and your concerns.



If you are depressed, know that depression can be treated. And depression can make you feel helpless—and even affect your will to live—if you don't get help for it.

Depression with kidney disease can be serious because it can derail your treatment plan. (For more information, see Module 4 of Kidney School: *Following Your Treatment Plan*.) Depression creates self-talk that can reduce your well-being.

How does depression do this? See the box below and match each of the common mindsets below with a self-talk message it produces. Do you ever fall into these mindsets or follow these messages?

A key to fighting depression is understanding what you do with your feelings. Most people who struggle with depression tend to hold their feelings inside. But, as we've already seen with anger, it is healthier to let your feelings out.

Over time, these pent-up feelings begin to feel like heavy weights on your shoulders and “depress” your mood, draining your motivation and energy. You may start to feel like you're walking through molasses just to get through your day—everything is harder to do, even just getting dressed or fixing something to eat.

Here are some tips to fight depression. Check the ones you would like to work on:

- Instead of trying to pretend I am not sad, discouraged, or frustrated, I will try to admit it to myself and feel the emotion. (Emotion will not hurt me, although it may feel uncomfortable.)
- I will try to share my feelings with someone—a friend, family member, or counselor. (This will help me to gain some perspective and reduce the burden that I'm carrying all alone.)
- I will try to focus on right now, instead of overwhelming myself by worrying all the time about what the future holds, and what my health will be like a year from now. (What I decide today will help to make my future. If I live in the moment and focus on making good decisions for the present, the future will arrive when it is time.)

Depression Mindset

Incompetence ____

Low self-worth ____

Hopelessness ____

Lack of motivation ____

Self-talk Message

A. I'm not worth taking care of.

B. I'm too tired to do all that self-management.

C. I can't handle this responsibility.

D. It doesn't matter what I do, the outcome will be the same anyway.

Correct answers: Incompetence - A, Low self-worth - C, Hopelessness - D, Lack of motivation - B.

Positive Self-talk

Self-talk isn't only negative. Life Options has done research with long-time dialysis survivors. We interviewed patients who have lived for more than 15 years on dialysis—some of them more than 30 years. The question we wanted to answer was: Why are some people able to live long, full lives on dialysis?

What we found is that these patients coped with their changed self and changed lives, in part by using self-talk, or “affirmations:”

- “I want to live”
- “I am still me”
- “I am still valuable”
- “I am in control”

Are these statements true for you?

- I will start an exercise program, after talking with my healthcare team. (Exercise has proven to help fight depression. Setting small goals—and reaching them—will help me see that I *can* change my life for the better. Exercising is a good decision I can make today that will improve my future.)
- I will reach out for support. (Research has shown that people with chronic illnesses who have good support systems manage their health better—and even live longer—than those who don't. If I don't have a good support system now, I will talk to my social worker or a counselor about how to build one.)

Some people manage their mood swings and feelings themselves with the kinds of choices we just talked about.

But for many others, more direct help is also needed. Depression is a brain sickness, just as kidney disease is a body sickness. It can be treated.

The two most common forms of professional help for depression are:

- Drugs (antidepressants)
- Counseling (talk-therapy)

Usually a combination of both works best. If you are feeling depressed, tell your doctor! Many drugs are removed from the body by the kidneys. So, it is also vital to talk with a pharmacist about which antidepressants are safe for you—especially with other drugs you are taking.

Most people feel better within weeks to 2 months.

The Workshop (Rebuilding)

Our last room is the workshop. This is where a life changed by illness and struggle goes through a transformation. The veneer is stripped away, the weakened joints are made stronger, and rough edges are sanded. It is a long, slow, and sometimes painful process of rebuilding.

With time and perseverance, a new life takes shape that resembles the old, but is stronger, wiser, and more fully human.



Of course, this room describes your journey with kidney disease. It has taken you down a path you would have preferred not to go. It has caused changes you don't like. It has put pressures on you and your family that seem at times too weighty to bear. Whether your life stays in this shape, or becomes something new, is in the hands of the craftsman—*you*.

You can build a new life that is full and meaningful if you want to. Your tools to do this are emotional.

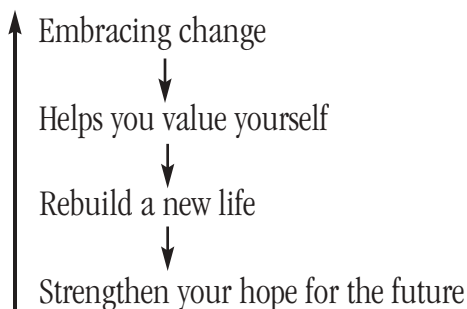
One tool you can use is to *embrace* your life changes as being good for you.

Not that having kidney disease is good for you. But you or someone you care about *does* have kidney disease. So the life changes needed now or in the future, such as diet and fluid limits, drugs, and dialysis or transplant, are good *in light of having* kidney disease, because they keep your body healthy.

When you embrace these changes, you affirm your value as a person by saying you are *worth* taking care of. This fights that negative self-talk we talked about before.

In contrast, people who fight these changes take poorer care of themselves. As their quality of life declines, so does their hope.

The progression looks like this:



As you embrace change, it affirms your worth and helps you practice healthy physical and emotional self-care. The better you feel, the more hopeful you become about your life, and how it can be good.

Embracing change means trying to do better—not to be perfect. No one can be consistent 100% of the time. No matter how committed you are to managing kidney disease, you'll have days when all goes well, and days when nothing goes right—just like everyone else.

A better target to aim for is growth. When you shoot for growth, you not only embrace change, but you take it one step further. You *actively look* for ways to improve your health, avoid isolation, express your feelings, handle conflict, and so on.

Any time you make a change yourself, it means taking risks. But the payoff can be so big for you, that any challenge you run into (and it will be there) will seem a minor barrier in comparison.

Growth can empower you in ways you can't yet even imagine. But for this type of growth to begin, you need to take action, and refuse to give up.

Start now by suggesting one change you would like to work toward and one area of growth you would like to start for yourself.

Change to work toward:

Growth to start:

Positive Attitude and Coping with Kidney Disease

Embracing change successfully, as you can see below, involves finding a way to a positive attitude:

“Just think very, very positive.... Do not dwell on, ‘well, I’ve been diagnosed with kidney failure and I have to go to this machine because I feel like dying.’ Not with me, but if you get...yourself in that type of a mode, you’re just hanging on, you’re going to dread it. So if you can find any other activities...try to go on with the most closest normal life that you can, and you’re going to be alright.”

“I am a 64-year-old woman, diagnosed with lung cancer 5 years ago. Since then, I have had bladder and kidney cancer, had a kidney removed, and due to the effects of chemo having damaged my other kidney, have been on dialysis a little over a year. I volunteer 5 days a week at the Cancer Center, putting in 25 hours a week. Generally, I rest in the afternoon. I do not feel sorry for myself, nor am I bitter, because I am so grateful to be alive. Also, I wholeheartedly do believe a positive attitude takes you a long way. It doesn’t cure cancer, but it does make life worth living. I have seen cancer patients do better when they have a positive attitude...as well as dialysis patients. I think we all need to put laughter in our lives, enjoy the things we have, and accept the things we cannot change and ‘stop to smell the roses.’”

Having a positive attitude doesn’t mean being happy every minute, or even every day. But, in the long run, being glad to be alive and making the most of the time you have are attitudes that can help you to be as healthy as possible with kidney disease—or any other chronic illness.

Each room in your emotional house with kidney disease has a purpose: to help you develop the skills, motivation, and support to live a full life. If you do not avoid those places, but learn what they have to teach you about yourself and others, you will leave each room more whole than when you entered.

This is the goal of Kidney School: to help you be whole and live a full life with kidney disease. It is possible! You, as craftsperson, must shape your life to how you want it to be.

Before we end this module, we want to give you a personal plan to sum up the main points we covered. Use it to help you toward your goals of coping with kidney disease.

Educating yourself about kidney disease is one way to help yourself or a loved one live long and live well with kidney disease. We hope this module has been helpful to you and your loved ones, and we hope you’ll read other modules.

Personal Plan for _____

Coping with Kidney Disease

The places most commonly visited as I adjust to kidney disease are:

- The Red Room (Crisis)
- The Empty Room (Isolation)
- The Woodshed (Anger)
- The Blue Room (Depression)
- The Workshop (Rebuilding)

Crisis

Unpredictable change can create a crisis for me and my loved ones.

Isolation

It's not uncommon to feel alone after the crisis passes and those who were supporting me go back to their own lives.

If I want someone to help or support me, I need to ask, instead of expecting people to know my needs.

It is not wrong or weak to need or ask for help.

Anger

Anger is a valid feeling and one that every person has. My goal is to use my anger in a constructive way.

Depression

Depression describes a number of mood disorders.

- Common mood swings are normal for most people and last a few hours to a few days.
- Ongoing depression lasts for more than 2 weeks.

Depression creates self-talk that is destructive. Common messages include:

- 1 Incompetence—I can't handle it.
- 2 Low self-worth—I'm not worth it.
- 3 Hopelessness—I can't do anything to change it.
- 4 Lack of motivation—I'm too tired to try.

The two most common forms of professional help for depression are:

- Drugs (antidepressants)
- Counseling (talk-therapy)

Usually a combination of both works best.

Rebuilding

I enter the rebuilding phase in my journey with kidney disease when I:

- Embrace new changes
- Strive for growth instead of perfection

I will be willing to take risks to rebuild my life.

I will learn what I can about others and myself from my feelings, using them as teachers instead of avoiding them.

Take the Kidney Quiz!

You'll see how much you're learning if you take our quick kidney quiz. It's just 10 questions. How about it?

- 1. The heart of a crisis involves changes that are:**
 - a) Predictable
 - b) Unpredictable
 - c) Certain
 - d) Deliberate
- 2. The best healthcare provider to call when you are in an emotional crisis may be a:**
 - a) Social worker
 - b) Dietitian
 - c) Counselor
 - d) Nurse
 - e) Secretary
- 3. When support people stop helping after a crisis, it usually means they don't understand what living with a chronic illness means *and* they:**
 - a) Don't care
 - b) Are going on vacation
 - c) Have found someone else who needs them more
 - d) Have their own lives to care for
- 4. One of the biggest obstacles to asking others for help is:**
 - a) Our culture's emphasis on self-sufficiency
 - b) Feeling it is wrong to impose
 - c) Being seen as weak
 - d) All of the above
- 5. One reason that people who have kidney disease may feel angry about it is:**
 - a) It's all their parents' fault
 - b) They would have rather had liver failure
 - c) It's a "job" they don't like and never asked for
 - d) They have to carry an oxygen tank to breathe
- 6. The best response to the emotion of anger is to:**
 - a) Keep it inside you
 - b) Express it constructively
 - c) Pretend it isn't there
 - d) Yell at someone
- 7. Someone who is clinically depressed has symptoms for at least:**
 - a) 6 months
 - b) 4 weeks
 - c) 2 weeks
 - d) 1 week
- 8. All of the following are classic symptoms of depression, except:**
 - a) Fatigue, loss of energy
 - b) Weight gain or loss
 - c) Migraine headaches
 - d) Feeling worthless or guilty
- 9. Professional help for depression typically includes which options:**
 - a) Counseling and diet
 - b) Community service and exercise
 - c) Medication and counseling
 - d) Acupuncture and retail therapy
- 10. One tool you can use to make a successful adjustment to kidney disease and rebuild your life is:**
 - a) Getting used to living with chaos all the time
 - b) Embracing change as a positive force
 - c) Wishing life could be the way it used to be
 - d) Ignoring kidney disease and living as if you don't have it

There, you've finished the test! We'll show you the correct answers so you can see how you did:

- | | |
|--------------|---------------|
| 1.) b | 6.) b |
| 2.) a | 7.) c |
| 3.) d | 8.) c |
| 4.) d | 9.) c |
| 5.) c | 10.) b |

Thank you for completing Module 5 of Kidney School! Learning about kidney disease is one way to help yourself or a loved one live long and live well with kidney disease. We hope this module was helpful to you and we invite you to look at other Kidney School modules:

Module 1—Kidneys: How They Work, How They Fail, What You Can Do

Module 2—Treatment Options for Kidney Disease

Module 3—Working with Your Healthcare Team

Module 4—Following Your Treatment Plan

Module 5—Coping with Kidney Disease

Module 6—Anemia and Kidney Disease

Module 7—Understanding Kidney Lab Tests

Module 8—Vascular Access: A Lifeline for Dialysis

Module 9—Nutrition and Fluids for People on Dialysis

Module 10—Getting Adequate Dialysis

Module 11—Sexuality and Fertility

Module 12—Staying Active with Kidney Disease

Module 13—Heart Health, Blood Pressure, and Fluids

Module 14—Patient Responsibilities and Rights

Module 15—Alternative Remedies

Module 16—Long-term Effects of Kidney Disease

Additional Resources

In addition to the free Life Options materials you can find at www.lifeoptions.org/combined/materials/indexpa.shtml, the resources below may help you learn more about the topics in this module of Kidney School.

PLEASE NOTE: Life Options does not endorse these materials. Rather, we believe you are the best person to choose what will meet your needs from these or other resources you find. Please check with your local library, bookstore, or the Internet to find these items.

Books:

- 1 ***A Delicate Balance: Living Successfully with Chronic Illness***, by Susan Milstrey Wells
The author follows 21 people, including herself, who have chronic illnesses. She talks about such questions as finding a diagnosis, choosing a capable and caring healthcare provider, treatment options, making sense of emotions, strengthening bonds with family and friends, making career decisions, and thinking about how illness changes one's life. She also presents research on the mind-body connection and tips on topics such as using the Internet for advice and support.
- 2 ***After the Diagnosis: From Crisis to Personal Renewal for Patients with Chronic Illness***, by Joann Lemaistre, PhD
Lemaistre, a psychotherapist with multiple sclerosis, identifies six stages in the emotional process of dealing with chronic illness: crisis, isolation, anger, reconstruction, intermittent depression, and renewal. Each chapter focuses on a stage, beginning with a story of someone coping with chronic illness, followed by the author's analysis of how the person handled the issues.
- 3 ***The Chronic Illness Experience: Embracing the Imperfect Life***, by Cheri Register
This book probes the emotional aspects of chronic illness and reveals how those who endure hardship achieve meaningful lives.
- 4 ***Chronically Happy—Joyful Living in Spite of Chronic Illness***, by Lori Hartwell
This motivational book helps people living with chronic illness create joyful, fulfilling lives. The author, who developed kidney disease at age two, fills the book with stories about her own experiences, as well as others coping with chronic diseases.
- 5 ***Coping with Kidney Failure: A Guide to Living with Kidney Failure for You and Your Family***, by Robert H. Phillips
This book looks at the psychological and emotional aspects of living with kidney failure.

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- 6 *Dialysis: An Unanticipated Journey***, by David L. Axtmann
The author was 26 years old, married, the father of two young children and going to college when he was told his kidneys were failing. Axtmann shares those days of doubt and fear and explains how he coped with low blood pressure, sleep problems, lack of energy, and even change in his sexual needs and desires. He also explains his reason for choosing dialysis over a transplant. At the writing of this book, David has been on dialysis for 32 years. He has seen his two children make it through their graduation days, and is now a grandfather of three.
 - 7 *Kidney Failure: Coping & Feeling Your Best***, by Anna K. Hollingsworth
This book looks at the psychological and emotional aspects of living with kidney failure.
 - 8 *The Life of Illness: One Woman's Journey***
(Sunny Series, the Body in Culture, History, and Religion), by Carol T. Olson
One woman's account of life with kidney disease, which includes surviving her siblings, who also had kidney disease. This book is an inspiration for others with long-term diseases, and an insight for health professionals into the patient's perspective.
 - 9 *You Are Not Your Illness: Seven Principles for Meeting the Challenge***,
by Linda Noble Topf, Hal Zina Bennett (Contributor), Bernie S. Siegel (Contributor)
The author, who has lived with multiple sclerosis most of her adult life, talks about her own experience of regaining emotional and spiritual wholeness.

Audiovisual materials:

- ***A Meditation To Help With Dialysis***, by Belleruth Naparstek
Guided imagery designed to be listened to before, during, and after treatment to promote relaxation, ease pain, reduce fear of needles, reinforce optimism, help stabilize blood pressure, increase energy, and support a positive outlook. Positive affirmations on side B. (Running time approx. 60 minutes)

Other materials:

- ***Coping Effectively: A Guide for Patients and Their Families***, by the National Kidney Foundation (NKF)
If you would like more information, or to obtain this item, please call the NKF at (800) 622-9010, or visit their website at www.kidney.org/general/atoz/.

Support groups:

- 1 National Kidney Foundation (NKF)**
To find out if there is a chapter near you, call (800) 622-9010 or visit the NKF website at www.kidney.org.
- 2 American Association of Kidney Patients (AAKP)**
To join their membership organization call (800) 749-2259 or visit the AAKP website at www.aakp.org.
- 3 Dialysis Support**
To subscribe to this on-line support group, send an e-mail to dialysis_support-subscribe@yahoogroups.com or go to their website at groups.yahoo.com/group/dialysis_support.