New Health Partnerships
Information for People with Chronic Conditions

Self-Management Support:
Information for Patients and Families
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About This Document

The information in this document is intended as a resource for patients and family members dealing with chronic or long-term conditions; the information is not intended to substitute for medical or other professional advice. Patients and family members should always speak with a health care professional about symptoms, specific medical needs, and any aspects of their health. Much of the information in this document was adapted from the New Health Partnership website developed by David Spero and Marie Abraham in 2008, with support from a grant to the Institute for Healthcare Improvement from the Robert Wood Johnson Foundation. The credit goes to David and Marie. Errors and omissions are mine alone.

—Laurel Simmons, 2011
Former IHI Director, New Health Partnerships

About New Health Partnerships

The New Health Partnerships initiative sought to use behavior change and health care system models to develop and test the most effective and efficient approaches for providing support to patients of a sort which enables and encourages greater patient self-management, while at the same time stimulating greater patient engagement in efforts to improve the design and delivery of health care services and systems. The initiative is now complete. For more information, visit http://www.ihi.org/offerings/Initiatives/PastStrategicInitiatives/NewHealthPartnerships/Pages/default.aspx.
Collaborative Self-Management Support: Information for Patients and Families

What is Collaborative Self-Management Support (CSMS)?

To maintain healthy lives, people with chronic, or long-term, conditions and their families have to manage their condition from day to day.

Self-management often involves medical treatments and therapies. It can also mean making lifestyle changes, such as eating better, reducing stress, or increasing exercise. You might also need to make changes in your life, like improving work or family relationships or changing how you interact with health care providers.

Collaborative self-management support (CSMS) means that everyone works together to help you manage your condition. Medical care is often focused on the doctors and prescriptions. CSMS health care is centered on your needs, abilities, values, and preferences. Families and others in your support network are welcomed as partners in care. You, your family members, and providers respect each other. You share information, and create a plan together to guide care of your condition.

Patient Voice Helps Improve Care for Others

Meet Ruth-Jean, a patient advisor, who is helping her clinic change how they work with individuals with long-term conditions. When Ruth-Jean Francois has an appointment with her doctor, Laura Obbard, MD, at the Cambridge Health Alliance Adult Medicine Clinic, in Somerville, MA, they are meeting as partners in care. Ruth thinks joining forces with the medical team is a win-win situation.

Ruth-Jean came to the Boston area from Haiti in 1980. She speaks English well, but French is her native language. Ruth works as a home health aide. Read more.

Excellent Self-Management Guides

Living a Healthy Life with Chronic Conditions by Kate Lorig, Halsted Holman, David Sobel, and Diana Laurent Bull Publishing 2006. The original book on self-management, with specific information on heart disease, lung disease, arthritis, diabetes, chronic pain, and more.

The Art of Getting Well: Maximizing Health when you have a Chronic Illness by David Spero RN, Hunter House 2002. A holistic view of self-management, considering your whole life, not just diet and exercise.
Patients and families have to take a central role in their own care. We need to have a team, but we need to take as much control of our team as possible. We can’t stay passive; we have to be active.

In chronic conditions, doctors can only do so much. If they could cure you, the illness wouldn’t be chronic. It’s up to patients and families to maximize their health.

You can be active in your care in many ways. This section provides information and resources for some of them.

- **Understanding Your Condition.** You don’t need a medical degree. There is plenty of information out there and lots of ways to get it.
- **Physical Movement.** Finding comfortable, enjoyable ways to get moving.
- **Healthy Eating.** Finding, fixing, and enjoying the foods that are right for you.
- **Making Medications Work for You.** Having a chronic condition often requires that you take a medicine. Learn how to take them properly.
- **Self-Monitoring.** Keep track of your symptoms, treatments, self-management efforts and lab results. Bring your logs and medicines with you to appointments.
- **Stress Reduction.** Coping with the tensions and pressures of life.
- **Dealing with Pain and Fatigue.** Learn ways to maximize your energy and your comfort.
- **Using Complementary and Alternative Medicine (CAM).** Finding, researching, and safely using herbs, bodywork, acupuncture, and other therapies.

**Successful Self-Management: A Pound, A Bite, and a Step at a Time**

When Ruth Cody had weight loss (“bariatric”) surgery, she had to change everything about the way she ate and drank. “It wasn’t easy,” she says. “I could only eat a little. Some things I ate caused ‘dumping’ or pain. I had to learn what those were.” Ruth learned what to eat through self-monitoring. Read more.

**Understanding Your Condition**

Doctors and other health care providers can be great sources of information, but there are many other ways to get good information about your condition and healthier living. If you know more about your condition, you will know what to expect. You will be better able to take care of yourself and explain your condition to friends and family. You will also be better prepared to be an active member of your health care team. Don’t be afraid to tell or ask your doctor about what you have learned!
There are many sources for useful information including your care provider, national or local organizations that focus on your condition, local community centers, health and medical libraries (sometimes called resource centers). If you are a member of a patient or family support group, other patients or families can also help you find information. Ask for books and magazines at your public library. Often organizations publish magazines with health and practical information for people with long-term conditions. Information about resources can usually be found on the organization’s website.

**Finding Health Information and Resources on the Internet**

Here are some reliable and comprehensive sources of information on the Internet.

- The [National Institutes of Health](http://www.nia.nih.gov) includes valuable info on drugs and treatments, as well as basic health information.
- [Medline Plus](http://medlineplus.gov) includes information on hundreds of specific conditions and symptoms. Search by age, question, and condition.
- The [American Academy of Family Physicians](http://www.aafp.org) provides a very reliable and user-friendly site for almost any condition.
- There are some reliable commercial health websites such as WebMD and Health.com.

**Evaluating Health Information and Resources on the Internet**

The Internet can be a great resource for finding out information about your condition. How can you be sure that the information you are finding is accurate? Many organizations offer tips to consumers for evaluating health-related websites. The list below contains the most commonly recommended questions to ask when evaluating health information on the Internet:

- Who runs the website? Can you contact them?
- How is the website paid for? Are any advertisements clearly labelled?
- Why was the website created?
- Where does the content come from that is included on the website?
- How is new content selected?
- Do experts review content included on the website?
- Is the content up-to-date?
- Does the website ask you to share personal information? If so, what is done with this information?
- Are consumers encouraged to talk to their health care provider about the information they find on the website?

**Websites That Help You Evaluate Health Information**

- National Cancer Institute
- MedLine Plus - Evaluating Health Information

**Let’s Get Moving**

What if there was a drug that prevented or treated diabetes and heart disease, reduced pain, made you happier, raised your energy level, helped you sleep, improved bowel function and promoted weight loss? Would you take it?
Well you can’t, because there is no such drug. The only thing that will give you all those benefits is physical activity. Yet people don’t do it. Why not?

Most of us face barriers to physical activity. We may live in places where walking is dangerous or impossible. We may work at jobs that leave us exhausted without making us move our bodies. Travel, work, school, religious worship, even most entertainment is done sitting down.

Mel’s Story

Mel was 56 when he had his first heart attack. His job—operating a fork lift at a big box retailer—left him exhausted each day, without giving him any physical exercise. He had given up bowling (too tired), and now mainly watched TV and did crossword puzzles for recreation. His doctor had told him to start walking, but he hated walking alone. It was boring.

One day, Mel’s neighbour Ira told him about his own problems with high blood pressure and pre-diabetes. Ira had just joined a gym, and he told Mel he was enjoying resistance training. They started going to the gym together and hanging out afterwards. After a few months of strength training, Mel had more energy. He and Ira and their wives started double dating to a folk dancing program at a community center. Mel’s weight, cholesterol, and blood pressure are all down, and he feels (and looks) better than he has in years.

Our society creates all kinds of reasons to avoid activity. Kids used to play basketball; now they play video basketball. Developers build suburbs without sidewalks or crosswalks, so you have to drive. Some office buildings lock stairways, forcing people to take elevators instead.

Still, every day, people do overcome these barriers and get moving. The important thing is to make activity a source of pleasure, not a chore you have to do at the end of a long day full of other tasks. Here are some easy steps to getting active.

Make It Fun
Do something you enjoy. It might be a sport, walking a dog, playing with children, splashing around in the water, or any movement you happen to like. If you walk, can you walk somewhere beautiful or interesting, like a park? Window-shopping or mall-walking can be a good way to move, kind of like going to a museum without an admission charge.

Make It Social
Most people find it easier to move if they do it with other people. You can join a group or a gym or just recruit a friend, relative or neighbor to walk or work out with. Perhaps you could start a group at your church or your job.

Start Slow and Build Up Slowly
If you jump into too much action, too fast, you’ll wind up sore, tired, and fed up with the whole thing. Start slowly and build up slowly—baby steps will get you there quicker.

Make It Convenient
If you have to drive 20 miles to the gym, you’re going to stay home most days. The best activities are the easiest: taking the stairs instead of the elevator, walking or running in the neighborhood, stretching before you get out of bed. Even housework can be a good way to get active.
Make It Comfortable and Safe
Get comfortable shoes for walking or dancing. If you’re riding a bike, you can buy wider seats if the one it came with is too narrow. If you have diabetes, check your sugars before working out, and have glucose drops or gel with you.

Be Creative
You don’t have to limit yourself to walking. Strengthening with weights or resistance training is great for glucose control and depression. Martial arts are too. Gentler exercise like yoga and tai chi are great ways to stretch and feel better.

Use your imagination and ask for advice and help. You’ll be amazed at how far you can go and how much better you can feel.

Healthy Eating
Everywhere you look, you find advice on how to eat. Sometimes the advice helps, and sometimes it makes you crazy. It may seem to conflict with other advice, or with your tastes and culture. It may seem healthy eating means giving up everything you like.

But actually, healthy eating is not difficult. Avoiding junk food may be difficult, but finding, preparing, and enjoying tasty, healthy food is quite doable. Here are some strategies. Some you have heard before, but they’re easy to forget in the strain of daily life, the flood of diet books and advice in the media.

Eat Breakfast
Eating a large breakfast with protein will keep your body on track all day. Skipping breakfast or eating too much sugar at breakfast will leave you hungry by mid-morning, and you’ll be snacking all day.

Eat a Balanced, Varied Diet
Make sure you emphasize fruits, vegetables, whole grains, and beans. If you’re giving up something you like, try some new things, there may be something you will like better.

Enjoy Eating
Eat slowly. Enjoy your food, chew it, taste it. Pay attention to your food. Don’t bolt it down while watching TV or reading. Breathe or take a drink of water between bites.

Drink More Fluids
Also replace unhealthy drinks like sugary soft drinks with a healthier choice like water.

Eat with Others
When possible, eat together with your family or friends. You’ll tend to eat less.

Avoid Emotional Eating
When you’re angry, sad, lonely, or tired, you’re likely to hit the junk food. Have some healthy snacks, or better yet, someone to talk to during emotional times.
How Do You Know What to Eat?
The fact is that no one diet is right for everyone. Different individuals with different conditions do better with different foods. But most people can eat most foods, so there is usually no need to obsess about everything you eat.

Many of the problems with our diet come not from foods but from additives, especially in packaged foods. Most of them have nasty things like partially hydrogenated oils (trans-fats), high-fructose corn syrup, sugar, and all kinds of preservatives. The only way to avoid these completely is to stop eating all packaged food. But you can help protect yourself by learning to read food labels. Learn more in the box below.

### Read Food Labels

Food labels have two elements. A nutritional information box tells you how much fat, cholesterol, sodium, carbohydrates, fiber, sugars, protein, and some vitamins and minerals are in each serving. An ingredient list tells you exactly what is in the product.

You can learn how to read and use these labels from the Food and Drug Administration (the people who created them).

If you're interested in healthier eating, you first want to know what you're eating now. A great way to start is keeping a food diary, where you write down everything you eat for a week or so. The diary will show you where you are now and will help you keep track of changes as you make them. Your doctor might be interested, too. Information about food diaries can be found at the American Academy of Family Physician. A meal planner can also be downloaded from the Meals Matter website.

#### Reliable Dietary Advice on the Internet:
- Dietary Approaches to Stop Hypertension (DASH)
- American Diabetes Association
- Advice from WebMD: Eating Right with Limited Mobility

### Medications and Treatments

#### Making Medications Work for You
For most people with long term conditions, taking medications is part of self-managing. Although medications can be troublesome, their proper use is a huge factor in our health and our lives. Some medicines have side effects. Some may not work as well as we would like. Some may cost too much or interfere with eating. Sometimes, it’s hard to remember to take them, especially if we don’t really want to.

#### Learn about Them
Read drug company information sheets and package inserts. Look on the web or ask your pharmacist or health care provider. You’ll want to know what the drug is supposed to do, what side effects it may have, and what other drugs or foods it interacts with. You also should know how long it will take to start working and what lab tests you need to make sure it’s safe for you.

#### Take Them Properly
All drugs have one thing in common – they won’t work if you don’t take them. If a drug is taken with meals, it’s usually easier to remember. If it can’t be taken with food, you need some other reminder.
One strategy is to link the timing of taking your medication to something you do every day, like brushing your teeth or walking the dog. Another is to ask a family member or friend to remind you, or get a watch with an alarm setting.

**Pay Attention to How They Affect You**

Ask your health care team what to expect, and then try to observe what happens. Do you notice a change in symptoms? Some drugs aren’t supposed to relieve symptoms, just keep you from getting worse. Some conditions don’t have any symptoms, so you won’t feel any change, even if the drug is helping. What else do you notice? Are there new symptoms? How is your energy level?

**Keep a Log and Share It with Your Health Care Providers**

Whatever happens, write it down and tell your provider! It’s especially dangerous to stop a drug without telling. They’ll think you’re still on it and might make bad decisions about what to do next. For the same reason, always tell all your health care providers what medicines, herbs and supplements you are taking. Bring a written list of all of these or the actual containers to your visits. Your care providers won’t have all the information they need if you don’t share information with them.

**Self-Monitoring**

One of the best ways to learn what is good for you is to keep track of your own symptoms. What makes them worse? What makes them better? How do medications, foods, activities, people, and stresses affect you?

Keeping track of your health is called “self-monitoring.” Self-monitoring can also show you how the different things your doctor orders, or that you do for yourself, are working.

You can record symptoms you are tracking (such as pain, fatigue, insomnia, nausea) on a “symptom log.” Write down the date and time, the symptom, and rate how bad it is on a scale of 1 – 10, with 10 being the worst. There should be another column where you can note anything you think may have contributed – medications, foods, events, anything. You can keep track of more than one symptom on the same form.

You can and should also keep track of numbers that affect your condition, like blood pressure or glucose readings. Bring your logs to appointments and share them with your professionals and with family if you want.

**Symptom Log**

Keeping track of symptoms on a regular basis can help patients become more aware of their symptoms and understand how other factors in their life may be affecting symptoms. Symptom logs also encourage patients to make healthy changes and observe how these may affect their health. The sample log was developed by a person with a long-term condition (who is also a nurse) for recording symptoms and can be shared with health care providers.

**Stress Reduction**

Too much stress increases disease symptoms of chronic illnesses and sometimes adds to the disease itself. But what is stress exactly, and what can we do about it?
Stress is often called the “fight or flight response.” It’s our bodies’ way of responding to a threat or challenge, like when a deer senses a mountain lion hunting for game. When we feel stressed, our bodies produce about 30 different chemicals that raise blood pressure, cause muscles to tense up, and pour more sugar into our blood. They do this so our muscles will have plenty of fuel for running away from or fighting that lion. Stress “turns off” parts of our body that aren’t used for fight or flight, including the digestive system and the immune systems that protect against disease and heal damage.

It’s a great system for escaping a predator. And in small doses, stress feels good. It makes us feel more alive, more energetic. But it doesn’t work well at all for the kinds of threats we face in modern society. When we have economic problems, job stresses, or family issues, there’s no way to fight or flee. We just sit there and worry.

And modern stresses don’t go away in a few minutes, like that hungry lion. They stay with us 24/7, often for months at a time. Over time, too much stress makes symptoms worse and causes our bodies to break down.

Strangely, our bodies can react to good things, like a child’s wedding or a job promotion, with the same reaction as to bad things. That’s because good stresses put demands on our bodies, too. Learning to reduce and cope with stress is a major part of managing a chronic condition.

Reducing Stress

Limit Stressful Situations
Easy to say, isn’t it? But sometimes we can. If being struck in traffic makes you want to scream, can you leave earlier or later to avoid the rush? Can you plan your life so as not to have to drive so much? Can you take the bus, or do things closer to home?

If a particular relative drives you crazy, can you arrange to see them less? Or see them in less stressful situations, perhaps with other people around?

Change the Way We Think About Situations
In a stressful situation, ask yourself “What am I really afraid of? What’s the worst that could happen?” Perhaps an argument with your spouse leaves you frightened, angry, or depressed. Can you remember that you’ve had arguments before and gotten over them? Nobody will leave you over one fight.

We can prepare for stressful situations in advance. What is it about the situation that you find stressful? Before you get to the event, practice how you will handle yourself, what you will say, and do.

Reduce Demands
Decide for yourself what’s really important, and let some less significant things go. You don’t have to be perfect in your career, your housekeeping, or anything else. Is Better Homes and Gardens coming over for a photo shoot today? Is royalty coming to visit? If not, perhaps cleaning behind the refrigerator can wait. People who love you won’t care if your house is spotless.

Get More Help
This is the most effective strategy of all. Can you find someone to give you practical help, like watching your children so you can relax, or take you shopping? Can you get emotional support, someone you can talk to? Just talking about stresses can sometimes reduce them. Can you get on disability or find other sources of financial support? Help can come from professionals (medical, social work, clergy), or from family, friends/neighbors, your congregation, other patients and families. Don’t forget to mention stress...
to your health care provider – they may be able to help. Read more about getting help from others in the "You’re Not In This Alone" section of the booklet.

**Set Limits – Learn to Say NO**

Don’t answer your phone every time it rings – that’s what answering machines are for. Don’t answer every email as soon as it pops up. Set aside time each day to return phone calls or answer emails.

Don’t try to do everything for everybody, all the time. Plan how much time you have to volunteer or do things for others. Say “no” to new projects or volunteer activities until you are sure there is time in your life.

If your workload is too demanding or unrealistic, discuss it with your boss. If you are asked to take on a new project or task, ask for advice on how to set priorities for your work. For example, you can show your boss a list of all the projects you are working on and ask what can be delayed to make room for the new project.

**Change Your Environment**

Can you make the space you live in safer, quieter, more pleasant or more supportive? Are there doors you can close, or can you “get away from it all” once in a while?

But we can’t always avoid stress. Just as important as reducing stress is learning to deal with the stresses we can’t escape. Learn more about coping techniques in the next section.

**Coping with Stress**

In general, there may be ways to reduce exposure to stresses, but we usually can’t avoid them completely. Here are some ways to cope with stress.

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**Breathing Exercises**

- **Abdominal breathing.** Place your hands over your abdomen just below the navel. Breathe into the abdomen so that your hands rise when you breathe in and lower on the out breath. Let the breath relax your lower back as well.

- **Pursed-lip breathing.** Get comfortable in any position. Breathe in through the nose, then gently out through the mouth, with lips pursed together like you’re going to whistle. Don’t push the air out; let it come out slowly and smoothly.

- **Alternate nostril breathing.** Place your thumb and forefinger on either side of your nose, though you’re going to pinch your nostrils closed. Breathe in slowly, then push the right nostril closed and breathe out through the left. Breathe in through the left nostril, then switch nostrils by closing the left and opening the right. Breathe out and then in through the right, then switch to the left and continue. Out, in, switch. Repeat ten times or more if desired. (This only works if both nostrils are clear.)
Other Strategies for Coping with Stress:

- Laugh! Laughter is our natural anti-stress medicine. You can’t laugh and feel stressed at the same time.
- Try progressive muscle relaxation. Start with your toes, and tighten one area at a time – feet, ankles, calves...work your way up your body. Tighten muscles for about five seconds, then relax them.
- Listen to a relaxation tape, recorded nature sounds, or calming music.
- Meditate or pray. By focusing your mind on your breathing or on a prayer, you can stop worrying about stresses for a while and find strength to manage them.
- Play with or stroke a pet, or just watch the fish in a tank or birds outside.
- Give someone you love a hug.
- Get your hands dirty – work with potted plants or better yet, get out in your, or a community, garden.
- Give the people you live with a ten-minute warning, “In ten minutes, I’m going to be doing my relaxation. I do not want to be bothered for 20 minutes, unless it’s an emergency. Is there anything you need me to take care of now?”
- Put in ear plugs, turn down your phone ringer.
- Many religions observe a day of rest and worship each week. Schedule a day of rest and reflection in your week even if you are not religious.
- Have some fun – play a game or spend some time with children or with close friends.

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**Stress Reduction Pioneer**

Dr. Jon Kabat-Zinn studies the effects of “mindfulness meditation” training in people with chronic pain, stress disorders, and a wide range of chronic diseases. The center he founded at the Stress Reduction Clinic is the oldest and largest medical center-based program in the world.

Kabat-Zinn has proved that meditation is not just for hippies or East Indian gurus. He works with a broad and diverse population including mixed ethnic and racial inner city communities. He has also worked with inmates and corrections personnel in the prison system. All of these groups benefit from practicing meditation.

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**Relaxation Resources**

There are lots of great resources for learning stress reduction and relaxation techniques.

Basic information can be found on the Mayo Clinic’s [website](http://www.mayoclinic.org).

For more in-depth, but easily understandable information on relaxation techniques visit [Mind Tools](http://www.mindtools.com).

View a 10-minute relaxation [YouTube video](http://www.youtube.com) at your computer.

View this guided imagery for an example of an extremely relaxing technique.

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**Meditation**

Meditation is one of the world’s oldest spiritual and health practices. It may sound mysterious, but it’s easy to do. It is not associated with any one religion or faith. [Learn about how to get started.](http://www.mindfulnesstapes.com/)
Dealing with Pain and Fatigue

For most people, it’s not the chronic condition itself that makes us miserable. It’s the symptoms, especially pain and fatigue, that come along with it. Pain and fatigue can stop us from doing things, and stop us from enjoying the things that we do. Doctors can help, but usually not as much as we would like. Pain and fatigue contribute to depression, and the feeling that life "is just not worth it."

But pain and fatigue are manageable. There are many ways to address them.

Dealing with Pain

Pain is a big part of many chronic conditions. For many people it’s the worst part. We’re not talking about the intense pain from an injury, pain that goes away quickly. Chronic pain is pain that lasts for months, years, indefinitely. Such pain can interfere with work, with social lives, and even with basic daily needs like dressing and cooking. Medications can help, but they don’t cure. And medications may have side effects that are as bad as the pain itself!

What causes pain in chronic illness? Sometimes it’s the disease itself, but usually, there are other causes too. Muscle tension always comes with pain and makes it worse. Getting out of shape (“deconditioning”) often happens with illness and causes muscles to hurt more when used. Poor sleep, a symptom of many chronic conditions, makes most people hurt more.

But often the biggest pain makers are emotional. Stress, fear, depression, grief, and anger can all make our bodies more sensitive to pain. This is because our minds sense pain the same ways that they sense these painful emotions. They can all get mixed up together. For the same reason, physical pain often makes depression and fatigue worse.

Leon’s Story

Leon is a carpenter. He has been suffering with chronic back pain since a job injury 12 years ago. He hasn’t worked for the last six years and some days he rarely gets out of bed. His doctors sometimes prescribe narcotics and sometimes refuse. One doctor told Leon he was depressed and prescribed fluoxetine, but Leon didn’t think it helped and stopped taking it.

His wife Janet was at her wit’s end. Leon’s depressed moods and the couple’s financial problems made them both miserable. Their relationship suffered and their sex life had stopped. They were considering divorce.

Then Leon found out about an innovative pain program the county had set up. He started meeting every week with a group of chronic pain patients for mutual support and information sharing. He started using biofeedback to control the pain and receiving acupuncture treatments. He learned about non-narcotic medications and asked his doctor for one. He and Janet started going to couple’s therapy. Eventually, he started doing the stretches and heat his physical therapist had recommended. Now he is up doing housework and going for walks and hopes to return to work soon.
What are the Keys to Self-Managing Chronic Pain?

Try Medications
Narcotic pain medicines can help in the short term, but tend to lose effectiveness over time. But anti-inflammatory, antidepressant, anti-seizure, and muscle relaxing medicines can all help with pain. Work with your doctor to find what works for you.

Relax
Relaxation will reduce muscle tension, which often relieves pain. Meditation, prayer, guided imagery, and resting, can all help. So can mental distraction. Focus your mind on something other than the pain, like a puzzle, a book, or your imagination. You might find your pain much reduced.

Exercise
Exercise often reduces pain. Exercise can warm and stretch tense muscles, get more oxygen into the system, and improve circulation. All of these tend to reduce pain and help with depression.

Try Physical Therapy
Apply heat or cold, or alternate them. Experiment and find out what works. Self-massage or a massage from someone else both help, and are usually easy to do. Massage loosens muscles and joints, improves circulation, and gives feelings of pleasure, which compete with pain.

Keep a Log
By keeping records of how different activities, food, people, and medications affect your pain, you can learn better ways to control it.

Get Off the Pain Cycle
Most of us push ourselves until pain makes us stop. Then we take the shortest possible rest. We push until we’re stopped again, and by then we’re usually through for the day. This is called the “activity/pain cycle,” and we need to get off it. Instead, keep a log and determine how long you can go before the pain gets too bad. Then stop BEFORE the pain makes you stop. Take a nice rest before starting again. On this “activity/rest cycle,” people are able to get more done with less pain.

Try Alternative Therapies
Acupuncture, biofeedback, and other approaches may be worth exploring. But like any other area of self-management, pain control is much easier when you get some help.

Emotional Support of Pain
Pain is emotional as well as physical. Emotional support can be a major part of self-managing pain.
Family
Families may not understand what it’s like for the person with pain. They can’t feel the pain themselves, and they may struggle to deal with how the patient’s pain affects their own lives. Pain is a challenge for the whole family.

It’s important for families to learn to communicate honestly about their feelings about the pain. Having a pain rating scale from 1 – 10 is an easy way to let families know how bad the pain is at the moment. Families need to understand pain varies. Pain might stop a person from wanting to go on a picnic one day, but that doesn’t mean the family shouldn’t go! The person with pain might feel better and want to come along next time, so tell your family not to stop asking.

Professional Help
Sometimes a therapist or a clergy person can help patients and families deal with pain. Chronic pain is a major challenge to a person and their family, and it’s okay to get help with it.

Group Support
There’s a saying in chronic pain clinics that, “The group is the medicine.” A person with chronic pain, often feel that nobody else understands, and rightly so. But other patients know, because they are going through the same thing. If pain is taking over too much of your life, you might want to ask for a referral to a pain-management clinic or a chronic pain support group. There are groups for families too.

Social Contact
It’s important to have people to talk to, shoulders to cry on, someone to make you laugh. Try to keep in touch with friends, even if you can’t get out to meet them.

Dealing with Fatigue
Most chronic conditions cause fatigue. Fatigue isn’t just feeling tired after a hard day’s work. It’s a lack of energy and motivation that can last for hours or all the time. Fatigue can be profoundly disabling.

What can you do if you find yourself increasingly fatigued, unable to carry out your daily life?

- Get checked out by a doctor. Don’t assume all fatigue is due to your condition or how busy you are. Thyroid problems, anemia, immune illnesses such as fibromyalgia, and depression are all major causes of fatigue.
- Check with a pharmacist to see if any of your medications could be causing fatigue.
- Start keeping a fatigue log. Several times a day, record how fatigued you are on a scale of 1 – 10. Keep track of what you had to eat, your activities, stresses, and other symptoms. You might notice patterns that show where the fatigue is coming from. Keep the logs and bring them to your doctor.

Here are some things you can do to reduce fatigue and its impact on your life.

### Pain Scales

Rating your pain helps people understand how bad it is. This numeric scale is easy to use.

This 1 – 10 scale will allow you to report to your health care team how pain is affecting your life. It is called the American Chronic Pain Association Quality of Life Scale.
• Don’t overdo. Maintain your best “Activity/Rest cycle.” That means learning how long you can go without getting tired, and remembering to stop BEFORE your body makes you stop. You’ll get more done without wearing yourself out.
• Get adequate, regular, and consistent amounts of sleep each night. Many chronic conditions interfere with sleep, and finding ways to get more sleep may even help other symptoms!
• Eat a healthy, well-balanced diet, including vitamins, and drink plenty of water throughout the day.
• Exercise regularly.
• Learn better ways to relax. Try yoga or meditation. Breathe.
• Change your stressful circumstances, or get help with them.
• Avoid alcohol, nicotine, and drug use.

**Emotional Side of Fatigue**

Fatigue isn’t only physical. If you have chronic pain or depression, treating either often helps address the fatigue. However, some antidepressant medications may cause or worsen fatigue. Exercise and therapy or counseling, with or without medicines, are sometimes better ways to deal with depression. The stresses of living with a chronic illness can cause fatigue. Everything seems harder to do when you have illness or disability, and the increased difficulty of life can wear you out. So make your life easier. Hundreds of good energy saving tips are available.

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**Keeping Records**

It’s valuable to keep a record of your energy level and your pain level. This will help you and your team see what’s working and what’s making things worse.

You might have more symptoms you want to keep track of. This is especially true for conditions like fibromyalgia. Symptom logs can be a valuable resource.

If you are dealing with fibromyalgia or chronic fatigue, this [website](http://example.com), might be very helpful.

Family members, friends and coworkers may have trouble understanding what fatigue is like. They think it’s like when they’re a little tired. They may think you’re lazy or depressed when you’re actually physically worn out. Learn how to communicate your fatigue clearly – maybe on a scale of 1 – 10. Let them know every day is different and often unpredictable. Some days you might be too tired to go shopping with them; other days you might want to. Perhaps invite them to a support group to hear from others who share your condition. Let them know clearly how they can best help you.

**Complementary and Alternative Medicine**

“Conventional medicine” is medicine as practiced by people with MD degrees and “allied health professionals” such as nurses and physical therapists. Conventional medicine is very powerful and effective, but it is not the only kind of medicine.

Medical practices that are not conventional are called Complementary and Alternative Medicine or CAM. Complementary medicine is used together with conventional medicine, while Alternative medicine...
is used instead of conventional medicine. All kinds of CAM are used by some people as complementary and others as alternative.

CAM includes herbal medicine, dietary supplements, flower essences, aromatherapy, homeopathic remedies, and other therapies you can buy over the counter. It also includes skilled practices by professionals including:

- **Chiropractors** work on spinal alignments to treat disease and pain.
- **Acupuncturists** and other practitioners of Traditional Chinese Medicine (which can include herbs and other treatments.)
- **Naturopaths** use herbs, foods, and supplements and sometimes other methods.
- **Massage therapists** may use techniques including craniosacral therapy, Reiki, Shiatsu, and many other kinds of bodywork.

People usually seek CAM because they are not satisfied with their medical treatment. They want more options than their doctor can give. Conventional medicine provides widely accepted therapies, supported by scientific studies. Many non-conventional therapies have not been studied in large studies. Others have been studied, but the results are not well known. That doesn’t mean the treatments don’t work for some people. Many therapies that were formerly CAM are now conventional, such as glucosamine for arthritis.

### Janet’s story

Janet has multiple sclerosis (MS) and it is getting worse fast. She heard about hyperbaric oxygen therapy (HBOT) for MS and researched it on the Web. She found a few studies that showed benefits. People on Internet support groups were recommending it, so three years ago, she tried it. It is expensive ($80 per treatment, 5 treatments a week, for ten weeks) but Janet feels she is walking much better than she was before treatment.

If a treatment has not been studied scientifically, it’s hard to be sure that it’s safe or effective. It could be, but you have to be careful.

You can find information on almost any CAM treatment. Here are some places to find out:

- You can discuss the CAM practice you are interested in with your regular doctor. They may have information or know someone to refer you to.
- Libraries often have books on CAM practices and on your condition.
- If you belong to a support group or know other people with your condition, one of them might have information for you.
- You can find a list of practitioners in the phone book or see their ads in local newspapers. Call and ask them questions.
- An Internet search for specific treatments or just type in your diagnosis and “alternative” on a search engine.
- Before you see a practitioner, you should interview them over the phone. A list of questions you might want to ask can be found at the National Center for Complementary and Alternative Medicine.

### Would you consider using CAM?

Before choosing a particular type of CAM or CAM practitioner, ask:
• Is all or part of the therapy covered by your health insurance? If not, how much does it cost and can you afford it? Are payment options available?
• How good is the evidence that the therapy works? Are there studies? Can you read them? Did the studies have control groups?
• What kind of training does the practitioner have? What certifications do they have? There may be a professional organization you can check with.
• Does the treatment make sense to you? Are there other patients you can talk to who have tried it?
• Do the practitioners seem like a good fit? Have they treated people like you before? Do they specialize in your condition? Do you get a good feeling from them?

**Allen’s story**

Allen has type 2 diabetes and read about use of herbs to control blood sugar. He asked his doctor, who did some research and okayed use of cinnamon powder. Allen checked his sugars frequently and reported to his doctor. The cinnamon didn’t replace his Metformin, but he was able to use lower doses.

• How much trouble will it be? How far do you have to go? How long will appointments be? How much waiting will you have to do? Is the building accessible to you? Will there be a lot of pain or discomfort?
• Do you have the help you need to get through the course of treatment?

**Alternative Types of CAM**

There are many others – learn more about CAM at the National Center for Complementary and Alternative Medicine housed at the National Institutes of Health.

**If You Are Using CAM**

You should tell your medical doctors what you’re doing and ask them if they have any concerns. You should make a list of all your medical treatments and give it to your CAM practitioner. If you are taking prescription medicines and want to start taking herbs, you should tell your doctor and your pharmacist about them. The meds and herbs may not go well together. You might want to keep records of your CAM treatments and how your body reacts to them. You can share these with your doctor.
Self-care doesn’t mean “do-it-yourself” care. One of the biggest skills you need is learning to find, ask for, and accept help.

**Involving Family Members**

Families can make or break your self-management program. Dr. Ann Steiner, a psychologist who works and lives with chronic illness says, "[Long-term conditions] put extra burdens on a whole family. People don’t know what to do or how to help. But everybody can help each other, if they work on how to do it. That takes talking." How do we ask for help? How do we set limits and show loved ones and friends what we need and what we don’t want? How do we let them know how we’re feeling in ways they can understand? Learning to communicate and work together with families and other loved ones makes everyone’s job easier and more rewarding.

**Asking for Help**

Most of us are reluctant to ask for help. We think it makes us weak, or we don’t want to impose on others. But most people want to help. And it doesn't just have a positive affect on you. It makes them feel good about themselves. Family members won't know what to do if we don’t tell them. They may offer help when it's not needed or try to assist in very unhelpful ways. As you work to include healthy habits into your daily routine, it will be easier for you if you can tell your family and friends ways they can be helpful.

**Setting Limits**

How do we react when a friend insists on re-telling her favorite show, line by line, when we are desperately tired and need to relax? What do we say when Aunt Jane wants a ride to the store to buy cat litter, when we need time to exercise? It’s important to learn how to say "No" and mean it. A lot of us are afraid that if we say no, others will be hurt or angry. In reality, people can handle "No", as long as you’re polite, and you can handle their anger, as long as they're not abusive.

**Talking About Emotions and Symptoms**

It's stressful for families if they don’t know how you're feeling. They can guess, but they don't know unless you tell them. Learn to express emotions and describe symptoms clearly. For example, you might want to give your pain or fatigue or depression a number between 1 and 10. Of course, families don't want to hear about your problems all day long, and you have to listen to their problems, too. Such communication can bring your family closer and prevent misunderstandings. Don't forget to talk about your progress and celebrate changes or success no matter how big or small. Seeing your progress may inspire those around you to adopt healthier habits.
Address the Difficult Emotions That Illness Brings
You and everyone in the family may have anger, fear, and grief about your chronic condition. You and they may also become frustrated when things aren’t going well. Each person may feel the other doesn’t understand their situation. Everyone may be afraid of upsetting others by telling them what they feel.

Talking about these issues together will reduce the stress they bring. You may find these conversations bringing you closer together. You don’t have to talk about such feelings all the time, but it’s good to check in about them once in a while.

Working with Your Health Care Provider

Providers have a major impact on our health. But our relationships with them are often not the best. We can help them help us by preparing for appointments (like bringing in our questions and our medications). We need to share information (like what’s been happening with us and what we know about our condition.) We should ask questions (preferably write them down.) We should help them get to know us as whole people without wasting their time on trivia. Learn to communicate and work with them to get the best possible results.

Finding Resources in Your Community
Community resources can make life and self-management much easier. Everything from churches, to YMCA’s, to neighborhood groups, social work agencies, and schools can be helpful. Learn how to find them and use them!

Health Care Providers

Come prepared to share important information about your health. You are your provider. Bring your symptom logs or copies of them with you to visits, as well as a list of your medicines and dietary supplements. Or bring the actual pill bottles, along with records of appointments you have had with other providers. Also bring a written list of questions for the doctor, with the most important ones at the top. Without a list, you’ll forget things, and if you wait until the end of the appointment, the doctor will be too rushed. They may not be able to answer all your questions on the spot, but they should answer the top two or three and get back to you with the other answers within a week.

Preparing for Appointments and Calls

Have you ever left an appointment feeling like you didn’t get all of your questions answered? Time with your health care provider is valuable to you. Prepare for visits or calls like you would for a job interview or a business appointment. Know what you want to talk about, write down your top two or three goals for the visit, and share the list with your care providers. Your care providers may have their own goals too. Visits should meet everyone’s needs.

Don’t Wait Until the Last Minute

Some people wait until the appointment is almost over and the doctor is on her way out the door. Then they ask what’s most important to them. This is a good way to make the doctor late and to not get the answer you need. Even if it’s embarrassing, just bring what’s important to you up early. They’ve heard it all before.
Active Listening
You should ask questions. But how will you remember the answers, or the other things the doctor tells you? Medical appointments can be stressful, which makes it hard to listen and remember. Most health care providers, especially primary care physicians, are rushed, and some speak in medical language instead of plain language. You can help yourself understand in many ways. Learn more ways to communicate better with your health care providers in the next section on “Tips for Active Listening During Health Care Visits.”

Robert’s Story
Robert has type 2 diabetes and high blood pressure. He also has a schizophrenic brother who relies on him for care and causes him constant stress. Because of these demands, Robert never pays much attention to his self-care. His doctors never asked why it is so hard; they just increase his medication and gave him lectures about diet and exercise. Finally, a doctor asked him what was really bothering him, and Robert told him. The clinic was able to help Robert get some respite and ongoing assistance. Now he has been able to walk for an hour three times a week and feels better.

Tips for Active Listening During Health Care Visits

- Bring a trusted family member or friend with you to listen, ask questions, and remind you of things you wanted to talk about.
- Take notes or ask to record the visit so you can review later.
- If your physician’s office uses a computer to record medical information and notes from the visit (electronic medical record), ask if you can have a copy of the summary of the visit. It will have key information for you to review after the visit. It may also help you prepare for future health care visits.
- Ask for clarification – repeat back what the doctor has told you, and confirm that you have understood it correctly. "So I won't see the effects of this new medicine for two weeks, and it might make it harder to sleep for the first few days. Is that what you said?"
- If they're using too much medical language that you don't understand, ask, "Could you put that in plain language, please?"
- Make sure they understand you, too. Review your main two or three concerns near the end of the appointment and satisfy yourself that something is being done about each one.

Build a Relationship
You don’t want to patter on about everything that’s happened to you in the last month. But you do want to let providers know about the big things – changes in your living situation, your relationships, job, or health of course. You can also take an interest in them as people. You could ask about family pictures in the office, for example. Don’t forget to thank them for their attention, especially when they have really been there for you.
Finding Resources in Your Community

Patients know that the doctors can’t meet all the demands of their chronic condition. They can’t help you follow through on daily goals to eat healthy food, get physically active, take medications, or deal with the stresses of life. But there is often help in your community to support you in meeting your goals.

Here are just a few ideas for where to look for helpful programs in your community:

- Churches and other faith-based organizations give practical, emotional and spiritual support. They may also hold exercise programs, healthy living classes, and provide volunteer opportunities.
- Public schools may provide free educational programs for parents and other adult community members in the evening.
- Senior centers may provide good meals, cooking classes, exercise classes, support groups, and other healthy activities. Some hold self-management training classes that help you manage your condition. Support Groups are great sources of information and emotional support. Group members may also give each other practical help and become friends. You can find support groups on the Internet, from an organization that deals with your illness, from your doctor’s office (maybe even from a patient in the waiting room), hospital, church, or library.
- Libraries – may have health books and magazines and may provide access to the Internet. Don’t be afraid to ask the librarians for help!
- Civic clubs (like Kiwanis and Lions’ Clubs) often provide low-cost meals. They may not always be the healthiest, but you can work with them to improve their food choices. Maybe your health care provider would help in this effort. If wanted, you can have social contact by eating at a club.
- Disease-related groups include groups like the Diabetes Association, Heart Association, Cystic Fibrosis Foundation, National Alliance on Mental Illness, and the Arthritis Foundation. They may offer services in your area. They may provide education, counseling, health information, self-management training, support groups, referrals, and more.
- Community activists often take on health issues. Two examples are the Health Conductors, a self-care program operated by the San Francisco Bay Area Black United Fund and the Chicago Southeast Diabetes Coalition. Another is Latino Health Access, which holds classes and promotes healthier environments in Santa Ana, California. There may be such groups in your community.

How to Find Resources

You can use the yellow pages to find community groups. Usually, the “Social and Human Services” pages will have a lot of good ideas. Your doctor or someone in the clinic should have some ideas. Or ask your medical center’s social workers for help. Your local library might have resources. You can ask the librarians for help.

Other people who share your situation might know of resources. Support groups, congregations, and sometime neighbors might have good information. Your local public health department might be able to help. So might your local Senior Services department, or a local chapter of organizations devoted to your illness.
Be patient. One call might lead to another until you find what you need. You can also search the Internet. If you’re not comfortable on the Web, perhaps you have children or other young people who can help. But it’s not hard to learn for yourself.

**Jenna’s Story**

Jenna is struggling. She tries to manage her type 2 diabetes, along with an 8 year old son, a teenage daughter, and a waitress job that barely paid the bills in a good month. No one else in her family has health problems like hers, and she feels really alone. Even in her small town, she figures there must be other people with diabetes, but nobody seems to talk about it.

One night her daughter was surfing the Net, and decided to show Jenna about networking on the computer. She got to a site, My Diabetes Central that listed diabetes support groups in all 50 states. It turned out that a group met monthly in a library 15 miles away. It took Jenna three months to get up courage to go to the group. It helped that the group leader said she could bring her children.

Jenna learns good information in the group, including a less painful way to check her blood sugars. More importantly, she connects with a woman about her age, who lives nearby. They started sharing childcare and taking walks together twice a week, either outside or at the mall. Jenna is getting in shape, and she plans to start dating again when she has lost ten more pounds.

**You’ve Found a Resource. Now What?**

For some of us, finding resources isn’t the problem. It’s actually getting out and using them. We might be afraid of going to a new place, where we don’t know anyone. We might not want to seem weak by asking for help. We might have difficulties filling out forms or understanding the language.

If the resource involves someone coming to your home, you may be nervous about allowing a stranger into your home, or feel bad about how your place looks.

It’s important to get over these fears. If you’re going to a new resource, it helps to have the name of a particular person to see. Perhaps you, your doctor’s office, or someone in your family can call ahead, so...
that your contact person is expecting you. It might help to take someone with you the first couple of times you go.

The same with having people come to you. It helps to talk with them on the phone first to get more comfortable with them. It will help to have a friend or family member with you the first time they come. The bottom line is that you don’t need to be shy or ashamed. Everyone involved in these services is in the same situation you are. You might even make some new friends.

**Helping Herself – Helping Others Self-Manage**

This past year, Edwina Pitt joined the Quality Community Health Care (QCHC) team participating in the New Health Partnerships Collaborative, a national program finding ways health providers and patients work together to help patients manage their conditions. Learning self-management has helped her change her life. [Read more.]

**Communication Skills Will Help You Work with Others**

Assertiveness – means speaking up for yourself and not being taken advantage of. Learn assertiveness skills and take an assertiveness self-evaluation provided [online](#) by the University of Texas Austin.

**Getting Started with Self-Management**

Self-management means taking as much control as you can of your health care and health behaviors. Like people who run a business or take care of a family, self-managers need to be organized. They need a set of useful skills and habits, and they need support. This section will help you get started.

There are four basic strategies to self-management. They can be applied to anything you want to accomplish – from healthier eating to finding a better job. This section will help you find strategies and skills for getting started with self-management.

**Goal Setting**

Most people do better with self-management if they have positive goals to motivate them, ways they want their lives and health to improve. Change is hard, and we need reasons to do it. Goals can be about physical fitness, like walking a certain distance, or they could be about your life, like going back to school or being able to play with your dog. They can be anything you want.
**Action Planning**
Breaking large goals into achievable chunks that we feel confident about is a great strategy for success. Action planning identifies small, specific steps toward larger goals, and strategies to succeed at those steps. The key is to make the plans specific – what, when, where, with whom, how often.

**Tracking Changes**
If you’re trying to make a change in your life, how will you know when you have done it? We tend to forget what we have done or how we have changed over time. How do we remember the way things used to be? It helps to keep a record of your activities. These records (or logs) will help you see what’s working and what’s getting in your way.

**Problem-Solving**
Life has a way of interfering with self-management. Usually people encounter some barriers they didn’t expect when they made their plans. Some basic steps to overcome problems have been studied and verified by social scientists and therapists over the years. You can use these steps to tackle any barrier.

**Goal Setting**
Most people do better with self-management if they have positive goals to motivate them, ways they want their lives and health to improve.

The most effective goals are medium term. This means something that you can achieve in about 3 – 6 months, although you can stretch those limits. Goals can be about physical fitness, like walking a certain distance, or they could be about your life, like going back to school or being able to play with your dog. They could be about work, like going home in time for dinner every night.

Some questions you might want to ask yourself in setting a goal: “Is there something I would like to do that my condition prevents me from doing?” “What would make me excited about getting out of bed in the morning?” “What does my body seem to want from me now?” It’s okay, desirable in fact, to ask for help from loved ones, friends, or professionals in developing your goals.

When you’ve got a goal, write it down and date it. Maybe share it with people you trust. You might want to record how you’re doing in moving toward your goal every week or so.

You don’t try to reach goals all at once. You don’t go from couch potato to runner in one week. Break goals down into smaller, achievable steps and build up. These one-week steps are called Action Plans.

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**PAMF Diabetes Plan**
Palo Alto Medical Foundation created this attractive, intuitive Diabetes Action Plan form to document patient-reported strengths, challenges, and actions plans on a one-page form. This is an example of a form that can be saved in the patient record so that providers can follow-up and offer ongoing support. Patient advisors at the clinic helped develop this form, adding the “I am doing well with:” column. Palo Alto’s patient advisors said that they want to be able to talk with their providers not just about what they were struggling with but also what was going well for them.
Action Planning

Goals are generally too big to work on all at once. But they can be broken down into smaller, more doable steps called action plans. You can post your action plan where it will remind you of your goals and motivate you to continue.

To work best for you, action plans should be:

- **Specific**
  Not, “I will listen more,” but “I will listen to my partner for 30 minutes a day, 5 days a week, without interrupting” (or whatever is appropriate).

- **Realistic**
  Not “I will run five miles,” if you haven’t exercised for years, but “I will walk around the block after dinner, four days a week, with my dog.” Start slow and build up.

- **About Behavior, Not Results**
  Not “I will lose weight.” That’s a goal. An action plan might be, “I will limit ice cream consumption to one cone, twice a week.”

You should be very confident about your action plans. Ask yourself how confident you are on a scale of 1 – 10, where 10 means you are sure you can do it. Your confidence should be at least 7. If it’s lower, brainstorm with someone (family, friends, health care providers), how you can raise your confidence. This might involve problem-solving barriers or making the plan easier.

Action plans usually have a time frame of one week. Keep track of how you do with yours. Then repeat the plan, build on it, or do something new to help you reach your goals.

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Meg’s Story

Meg is 53 years old, weighs 300 pounds, and has type 2 diabetes. She wants to exercise, but thinks she can’t. “I know I need to walk three miles a day,” she tells Linda, the medical assistant at the clinic, “and there’s no way. I haven’t been out of the house except to go to the doctor’s for six months. How am I going to walk three miles?”

“Well,” says Linda, “How far could you walk?”

Meg thought about it and finally says, “I guess I could walk to the mailbox, down by the curb. Then I’d have to rest for a minute and walk back to the house.”

“What’s your confidence level of being able to do that regularly?”

“Pretty high. I can do that. I’d say a 9.”

“How often will you do that, then?” asks Linda.

“I can do it every day,” says Meg.
“If it’s OK with you, let’s start by planning for five days a week, in case of bad weather or something,” suggests Linda. “You want to be sure you can succeed.” Meg agrees.

As it turns out, Meg could do it every day, so for two weeks she did. Then she calls and says, “I’m ready to go further. I’m going to walk to the corner.” And she does that, and over the course of a year she builds up to 3 miles a day. She loses some weight, and her sugars are better controlled. She’s still working on it, one plan at a time.

Tracking Changes

If you’re trying to make a change in your life, how will you know when you have done it? We tend to forget what we have done or how we have changed over time. How do we remember the way things used to be? You wouldn’t try to run a business without keeping records. You will find that recording self-management activity helps you do a better job and avoid wasted effort.

Say you want to start moving more, and you have chosen to walk four days a week. Keeping a log like this example will help you keep on track and recognize your progress. Don’t forget to celebrate when you fulfill a plan or achieve a goal!

You can also keep track of your symptoms with a symptom log, your numbers (like blood pressure, blood glucose, weight), and your medications and treatments. Some patients and families keep track of their health and progress by using a personal health record.

Keeping records of your health and your self-management will help you see where you are succeeding and where you need help. If you show your records to your providers, it will help them understand what you are going through and will probably give them new ways to help you.

Problem-Solving

Life has a way of interfering with self-management. Usually people encounter some barriers they didn’t expect when they made their plans. There are some basic steps you can use to tackle any barrier.

Kate Lorig at Stanford University has developed a very successful program called the Chronic Disease Self-Management Program for patients. The following steps are adapted from this program:

- Identify the problem – this may be the hardest part. For example, you may think your problem is “No will power,” when actually it is “Loneliness.” Writing it down may help clarify your thinking about it. Make a list of things that might work to overcome the problem. You might get help from friends, health care professionals or other sources like the Internet or library.
- Select one of the ideas and give it a try for a couple of weeks. Assess the results. If the problem is solved completely, great! If not...
- Substitute another idea and see how that works. If needed, use other resources to expand your list. Get help from family, providers, or others. If nothing seems to work, go back to step 1. You may not have identified the real problem.
- Accept that the problem may not be solvable right now, but may be solvable later.
If you aren’t successful in solving a problem, don’t get stuck on it. Who has just one problem, anyway? Choose another issue and work on that one instead. There are many ways we can improve our daily lives with chronic conditions.

Example

Rodney is 35 years old, overweight, and has high cholesterol and high blood pressure. He wants to change his diet, and the hardest part is lunch. Every day, he plans to go to the salad bar place but winds up at the fried chicken shack instead.

He starts by trying to identify the problem. Is it just lack of willpower? He decides the problem is convenience. The chicken joint is the closest food to where he works.

Rodney makes a list of possible solutions. He lists: packing a lunch, buying lunch on the way to work, skipping lunch and just resting in the break room at lunch time.

He picks one to try, making lunch. That doesn’t work, because he doesn’t have time in the morning. He finds a deli on his way to work and buys sandwiches there a couple of times. But he doesn’t like them much – sometimes he goes to the chicken place anyway and eats the sandwich on afternoon break. That’s not helping him lose weight.

Getting frustrated now, Rodney expands his list of resources by sharing his frustration with the Medical Assistant at his next doctor’s appointment. The MA suggests he go back to Step 1 – maybe he hasn’t found the real problem.

When Rodney thinks about it, he realizes that what is really pulling him to the chicken shack is that his friends from the office usually go there. He doesn’t want to be left out. “I live alone. I eat dinner alone.” he told the MA. “I don’t want to eat lunch alone, too.”

He and the MA come up with a plan. She gives him several copies of a nutrition sheet explaining the downsides of eating too much fried food and the benefits of a more balanced diet. Rodney shared the information with his friends, and now they go to the salad bar twice a week and a pasta place another day. Those places are farther away, so Rodney gets to do some walking. Fried chicken is limited to Thursdays, and in four weeks, he has lost eight pounds.

Where Self-Management Started

What is self-management?

Patient self-management is a revolutionary change in health care. Its aim is to make sure patients and families have the resources and support they need to stay healthy and make good decisions about their care. Who came up with this idea? How did it get going? Read more.
Living with chronic conditions isn’t a skill you can learn one time and have it all worked out. Illnesses go on, throwing new challenges at you. You make some positive changes, then life puts up roadblocks or problems, and you may feel like you have to start over.

This section will help you learn vital skills to stay motivated through the ups and downs of the chronic illness roller coaster.

You can click on the links in the left hand column to find information about becoming more active in your care and your health, or you can continue reading to preview the information in this section.

**Dealing with Ups and Downs**

Self-management is rarely a smooth process. There will be ups and downs, good and bad days, weeks, even months. It helps to keep an even keel – to get through the rough patches, and not get too excited in the good times. Read some tips for staying motivated and on-track.

Reward yourself for behaviors, not results. You don’t have to wait until your cholesterol drops 50 points to celebrate. Be good to yourself along the way. Do something pleasurable after you exercise (maybe a long bath or a good book.) Use the money you save by not smoking to go to a show or have your house cleaned. As the book *Living a Healthy Life with Chronic Conditions* says, “Rewards don’t have to be fancy, expensive, or fattening.” Use your imagination.

When you seem to get a little worse or hit a plateau, remember that ups and downs are unavoidable. You will get back in control. Problem-solve what is going on, perhaps with your health care provider.

Remember your motivation. Why do you want to get better? To dance at your young grandchild’s wedding, to be able to travel, to enjoy walking your dog, or what? If you don’t have a good reason, can you think of some or create one?

**How Do You Self-Manage When Things Get Difficult?**

Family crises can interfere with self-management. It’s easy to see how job loss, legal problems, a relative’s death or illness, having to move or taking new people into your home would outrank self-care on your to-do list.
Keep self-managing as much as you can, and realize it’s OK if you have to take some breaks. If you do some things you know aren’t healthy, don’t panic or beat yourself up. Don’t let a few slip-ups cause you to give up completely on self-managing. Learn to find and ask for help with tough situations.

**Julie’s Story**

Julie is dealing with chronic fatigue, depression, and high blood pressure (hypertension.) She is doing a good job of taking her medications and getting out for walks every day, which keeps her mood up and even allows her to work part time.

Then, the store Julie worked at closed, leaving her with “no reason to get out of bed,” she says. For a few days she didn’t, and she didn’t take her medications either. "I felt like giving up," she says, "but I remembered what I had learned in self-managing my fatigue. I knew there were things I could do that might help." She thought of a few things she could do for herself, and she did one. She called a friend and asked her over for lunch. It was a nice day and they went for a walk together. With the friend’s help, she comes up with some problem-solving ideas. She started going back to church, and she goes to the city’s employment center. These give her support and hope for the future. She is able to avoid deep depression.

Good things, such as a child’s wedding or a job promotion, can also throw you off. When we’re feeling good, we tend to overdo and pay for it later. Of course you should enjoy yourself, but try to get back on track as soon as possible.

Self-management is a marathon, not a sprint. You don’t do it all at once. You win because you keep going.

**Turning Around Negative Thoughts**

We can’t control all the factors that affect our health. But we can often learn to control our thoughts. And thinking more positively can make a big difference in our happiness and our health. You don’t have to think positively about everything, all the time. What we want are realistic thoughts. We want to change unrealistically negative thoughts into more accurate, positive ones.

You don’t have to think positively about everything, all the time. What we want are realistic thoughts. We want to change unrealistically negative thoughts into more accurate, positive ones.

How can negative, or distorted, thoughts hurt you? Here are a few examples:

- If you believe you can’t do something (like change your diet), you may not even try.
- If you think nothing can help your condition; you will be stressed and depressed.
- If you think physical activity will make your pain worse; you will stay on the couch and get more out of shape and have more pain.

Can you think of others?
Common Unrealistic Negative Thoughts

- **Overgeneralization.** “Always” or “Never” statements – “I never follow through on my plans.” “Nobody cares.”
- **Fortune Telling.** Thinking you can predict the future or predict how other people will react. “If people see how slow I walk, they won’t want to come out with me.” “My father died of cancer. I’m going to, too.”
- **Focusing on the Negative / Ignoring the Positive.** Looking at the bad and not the good. “She didn’t come to my birthday party. She must not like me.” (Ignoring that she sent you a lovely card and a present.)
- **Blaming Yourself or Others.** “It’s my fault I have heart disease. I stress too much.” “It’s my family’s fault I have diabetes – they keep offering me sweets.”
- **All or Nothing.** If it’s not a full success, it’s a complete failure. “I wanted to lose 20 pounds and I only lost 10. I just can’t lose weight.”
- **Magnifying.** “The whole world is against me.” “Self-management would take all my time.”
- **Personalizing.** If someone’s in a bad mood or something goes wrong, it must be your fault. “Oh, Joe’s really in a bad mood. What did I say?”

Steps to Turning Negative Thoughts Around

- **Identify the negative thought.** Write it down or repeat it aloud. Then rate how true you think it is on a scale of 1 – 10.
- **Check the thought against reality.** If your thought is, “I never do anything worthwhile,” ask yourself “Is this really true?” Can you think of any counterexamples, even small ones? If your thought is, “Nobody wants to hear about my illness,” how do you know? Try asking a trusted friend or family member and see how much they want to listen.
- **Make a more balanced thought.** Jane thinks, “I’ll never lose weight,” when in reality she loses weight just fine, but always gains it back. She could change to a more realistic, less hurtful thought like, “I can lose weight any time I want to. I need help in keeping it off, though.” Rate the truth of that thought from 1 – 10. Then go back and re-rate the original thought. You may no longer find the distorted thought so true.
- **Be Your Own Best Friend.** We’re usually harder on ourselves than on anyone else. When you struggle with a negative thought, pretend that your best friend was telling you that thought about themselves. Say Robert can’t find time to walk more than once a week. He has decided, “I just can’t get an exercise program going.” What would he say if his best friend said something like that? He could tell himself, “Look, it’s amazing how you work so hard and take care of your kids so well. I’m really proud of you for walking even one day a week. If you get some help with it, I’m sure you’ll succeed like you have in other areas of your life.”
- **Repeat the balanced thought several times** a day and any time the negative thought starts to come into your head.

Over time, you may be able to make your thoughts more and more positive. You will find yourself less stressed and probably healthier as a result. If you need help with this process, you can see a counselor who specializes in Cognitive-Behavioral Therapy (CBT).
Valerie’s Story

Valerie wouldn’t even try to manage her diabetes. She had seen her mother have amputations and die young, and she knew it would happen to her. A therapist challenged that thought. How could she know the future?

She admitted she didn’t really know, and went over her options with a diabetes educator. She learned she actually had a pretty good chance of living a long life. Her depression lifted and she started going out to dances for exercise and social support.

Dealing with Difficult Emotions

The emotional demands of chronic illness can be even more challenging than the physical, for patients and families both. The good news is that learning to manage difficult emotions can bring us to a more positive outlook on life and better relationships than we ever had before. Learn ways to cope with painful feelings.

Having a chronic illness is hard physically. But the emotional demands can be even more challenging, for patients and families both. The good news is that learning to manage difficult emotions can bring us to a more positive outlook on life and better relationships than we ever had before.

What emotions does chronic illness bring up, and why?

- **Grief** – feelings of sorrow and pain over things we have lost.
- **Anger** – feeling mad at the world or your family for making you sick, at your doctors for not helping, or at yourself for not taking care of your body.
- **Fear** – Worrying about what the illness will bring you. What will I lose next? Will I sink into poverty? Will this illness kill me? How is my illness hurting people around me?
- **Frustration** – Why isn’t anything working? Why can’t I change as my doctor and family want me to do? Why don’t people help more? Why don’t they understand what I’m going through?

All these feelings are normal and can be successfully managed. But if they are not, they can put one at risk for depression. Depression is a complicating factor in most chronic conditions. It makes self-management and all of life more difficult.

**Grief**

“When you lose part of your health, it’s like you lost part of yourself. You have to grieve that loss before you can accept it and move on with your life.”

-Annie, a 42-year-old woman with lupus.

Grief over illness is normal and necessary. You’ve lost some abilities, or you are different from your peers and from your family. You’re no longer the young, athletic self you want to be. These things hurt!

Usually, grief over illness isn’t something you can do one time and get over it. People will want you to, but the illness doesn’t leave. It may get worse. So we may have to grieve new losses and re-grieve old
ones repeatedly. If we don’t, we risk being sad or depressed all the time. We may close down and lose the ability to feel anything at all.

How can we cope with grief?

- Crying is the easiest, most effective way to handle grief. People have grieved this way for a million years. If it’s hard for you to cry, perhaps you know of movies, books, or music that will help you cry. Perhaps you need privacy for tears, or you may do better sharing pain with a friend, family member, or support group.
- Babying ourselves is okay too. You may want to spend a day in bed, or eat some comfort foods, if you don’t overdo it.
- Denial is a common response to loss. We may need to get through pain that seems too great to manage. We don’t want to stay in denial, but a short visit is often necessary.
- Remember the positive things you still have. There may even be some small rewards you’ve earned from illness, like a more relaxed lifestyle or a new way of looking at life.
- It helps some people to compare themselves with people who are even worse off. Others just find this annoying.

Anger

Anger has a bad reputation, but it can save your life. Anger can be the energizing force you need to take charge of your health. But if not used right, it can damage your health and your relationships.

Anger is the emotion our bodies and minds use to motivate us to change something. If you feel that something is keeping a foot on your neck, a feeling of acceptance won’t help. You have to push the darn foot off your throat first. That’s where anger comes in.

If there isn’t anything to change, or if you don’t apply your anger to help you change, it may raise your blood pressure. It may cause heart problems, too, and for no reason. So what can you do to make anger work for you instead of against you?

- First, try to identify what you are actually angry about. Put it into words.
- Communicate your feelings honestly to others. Don’t attack them; just tell them calmly how you feel. Use “I” language—“When you... I feel as if...”
- Forgive those you can forgive, including yourself. The Mayo Clinic offers helpful information about forgiveness and health.
- Figure out what you can change to make you feel better. If you’re angry because your family taught you bad eating habits, can you change them now? If it’s a society that denied you educational opportunities, what do you want to learn and how?
- Exercise! If you want, do something aggressive like kick-boxing or weight lifting.
- Get help! A counsellor, doctor, or anger program may help. But remember, the idea isn’t to get rid of anger. You want to put it to good use.

Fear

Like anger, fear can serve you or block you completely.

Chronic illnesses can do terrible things to you, but usually they don’t have to! It’s largely in your control whether you get complications of diabetes or lose mobility to arthritis. Not completely in our control, but we can make a big difference.
But fear can paralyze us and stop us from self-managing. What can we do about fear?

- Write them down. What are you afraid of, specifically? Think about your fears and write them down. What is it that really scares you? Is there something other than your illness that you are afraid of?
- Educate yourself. Are your fears realistic? How likely are they? What can you do to stop them? Find help from your provider, support group, or on the Internet.
- Understand where your fears come from. Did someone in your family die a terrible death with your condition? Did your doctor give you a gloom and doom picture at diagnosis? How much do these memories apply to your actual case?
- Accept that whatever happens, you will be able to handle it. The changes might be hard, but you will still be a good person. You will still be able to make the most out of life.
- Conquer your fears. Figure out what you can do to keep your fears from coming true. Use them as self-management motivators.
- Get help. Talk about your fears with loved ones, a support group, or professionals. There are lots of ways to find help.

**Frustration**

You can try as hard as you can. You can do what the doctor tells you, and still you don’t see much improvement. Maybe your friends and family don’t seem to appreciate how hard you’re trying. They don’t seem to do much to make things easier. They go on living their healthy lives, and we worry about being left behind.

What can we do to manage frustration? How can we stay motivated to self-manage when things aren’t going well? Here are some ideas.

- Reward yourself for small successes. If you go for a walk like you said you would, maybe reward yourself with a nice long bath or shower. If you stuck with your meal plan today, maybe a relative can give you a massage or backrub.
- Talk to others who are going through similar things – like a support group or another patient from you doctor’s office.
- Devote some time to pleasure or relaxation each day.
- If family doesn’t seem to understand, ask for some time to explain how you feel. Be specific about what you’d like from them, and be open to meeting their needs if possible.

**Depression**

**CAUTION:** Depression can cause thoughts of wanting to hurt yourself or kill yourself. If you have thoughts like these, get professional help immediately! Don’t trust yourself to “get over it.”

All these feelings are normal and can be successfully managed. But if they are not, they can put one at risk for depression. Depression is a complicating factor in most chronic conditions. It makes self-management and all of life more difficult. If you’ve reached that point, read more below about what to do.
Any chronic illness can cause depression. And depression is often more disabling and painful than the disease itself! Learning to manage depression can mean the difference in your course of illness and quality of life.

**What Is Depression?**
Depression is not just feeling down once in a while. It’s a chemical reaction to life’s problems – like carrying a huge weight around on your shoulders and in your mind – a burden that can take all the pleasure out of life and make taking care of yourself seem way too much trouble.

**How Do You Know If You’re Depressed?**
Symptoms of depression can include:
- Loss of interest in people or things you used to like.
- Difficulty sleeping or sleeping too much.
- Loss of appetite or bingeing on junk food.
- Unusual (for you) feelings of unhappiness lasting longer than 6 weeks.
- Loss of energy, feeling tired all the time.
- Irritability, frequent accidents or arguments.
- Difficulty making up your mind about things.
- Thoughts of being worthless, helpless, or hopeless.

Depression may include crying and feeling sad, but not always. Your body can be depressed, even if you’re in a pretty good mood. If you think you may be depressed, talk to your doctor about it immediately.

**What Causes Depression?**
Depression has different causes in different people, but one cause is nearly always there – feeling of a lack of power. We may feel we can’t change our situation. We may feel that changing won’t do any good. Or we may believe that our lives don’t make any difference to anyone, anyway.

Some people inherit a tendency to depression in their genes. Others pick up a sense of powerlessness in early childhood. And others may learn from society or in school not to believe in themselves. If your parents were depressed or absent, you are more likely to be depressed. If you or your family have suffered trauma or discrimination, you are more likely to feel powerless and depressed.

- **Chronic illness can take away our sense of power.** We may have to take medicines, follow orders, and give up some things we really like to do. It can be hard to feel you are still in control of your life.
- **Medications can cause depression.** Check with a pharmacist or your doctor. Alcohol, cigarettes, and street drugs all can contribute to depression for some people.
- **Inactivity.** Lack of movement, or not having anything interesting to do makes people depressed.
- **Unhealthy food.** Junk foods and sugars make some people depressed. Too much or not enough food can, too.
- **Loneliness.** If you’re not seeing other people regularly, you are at risk for depression.
- **Staying inside.** Darkness and lack of fresh air contribute to depression, especially in the winter months.
- **Insomnia.** Bad sleep or lack of sleep can put you at risk for depression. If poor sleep is a problem, consider being checked for sleep problem, such as apnea.
Since feeling helpless, hopeless, worthless, or powerless cause depression, the cure is often finding ways to take more control.

How Can You Manage Depression?
How can we get a handle on depression? By gaining a sense of control. And how can we do that?

- **Exercise.** Physical activity raises your mood and gives you more confidence. Strengthening exercise has been shown more effective for depression than therapy or medications in several studies.
- **Get help.** Seek help from your health professional, a counselor, clergy person, or others who share your condition. A support group can help you see that your problems are not your fault, and that there may be things you can do about them.
- **Talk about it.** Share your thoughts with family, friends, or other patients. Depression is nothing to be ashamed of. Most people deal with it at one time or another.
- **Consider medications.** Although not a cure, anti-depressants can help you get moving again.
- **Get out in the sunshine.** Try to get some sun most days. If the skies are always cloudy where you live, consider getting a full-spectrum sun lamp.
- **Improve your sleep.** If you’re having trouble sleeping, tell you’re doctor about it. Sometimes there is an underlying problem causing poor sleep.
- **Connect with others.** Find other people to be with. If you can’t get to them, at least talk on the phone.
- **Recognize that depression is a family problem.** We pick up on each other’s moods. Talking honestly can be a big help. You may want to get help from a therapist or a counselor for your family.
- **Problem-solve.** See if you can change a situation that makes you feel powerless or depressed. Maybe a change of job or help with childcare would make a big difference. Brainstorm what might work with family, friends, or professionals.

Coping with Special Situations

If every day was the same, self-management would be easier. But life changes, and at certain times, we may have to work harder at it. Read about dealing with sick days, injuries, travel, visitors, holidays and other challenging times.

“I want to take better care of myself. But life keeps getting in the way.”

Have you said this to yourself more than once? If every day was the same, self-management would be easier. But days are different. At certain times, we may have to work a bit harder at it. Here are some examples:

**Sick Days**
If you have an acute illness such as flu, you should not go to exercise class, and you may not feel like eating your normal diet. You may want to check with your doctor to see if you need to change your medications. Specific chronic conditions may require extra attention. For instance, if you have diabetes, you may check your sugars more often. Get all the rest you can.
Injuries
Getting hurt can interfere with exercise programs and other daily activities. It’s important to rest the injured part but to keep your body moving as much as possible. Perhaps you can find other ways to exercise, such as Sit and Be Fit programs. You may need to get some help with keeping up the house or with other demands.

Holidays and Celebrations
Special days usually mean a busier schedule, more visiting, more food (usually sweets), more alcohol, and more stress. Enjoy your holidays, but prepare yourself! If you’re going where there will be lots of tempting foods that you don’t want, eat something before you go. Practice your assertiveness skills so you can say no to things you don’t want. Schedule rest times and exercise times. Know who you can talk to if things get stressful.

Traveling
Long hours on a plane or in a car, eating and sleeping in strange places, being away from your routines can all cause problems. In route, remember to get up, stretch and move around every hour. Pack food with you if the airplane or roadside food isn’t right for you. If the place you’re staying is not healthy for you, can you find another one? Bring extra medication or testing equipment in case something gets lost. If possible, find, in advance, restaurants that serve food you can eat. Ask the people you’re staying with (family or hotel) for what you need to sleep comfortably.

Helping Others Self-Manage
Many people find rewards in helping loved ones, friends, or other patients care for themselves. Family members may find that helping their loved ones self-manage is less exhausting and more rewarding than caregiving. Patients may also benefit from and enjoy helping other patients. You may wind up feeling better about yourself, with the positive feelings that come from doing good work. And whether you are a patient or family member, when you help others, your own self-management skills may improve.

Helping Family Members
When one person in a family has a chronic illness, everyone in the family may need to change. That’s the bad news. The good news is that these changes can bring better health and closer relationships to the whole family. While illness can put strains on a family, helping each other self-manage can strengthen it. The key is often good communication.

Helping Peers Manage
Helping peers is good for others and good for your health. Studies show that those who volunteer their time are less likely to die from any cause, compared to those who do not volunteer. Helpers also report fewer colds and headaches, and reduced pain from chronic conditions like arthritis or lupus.
Helping a Family Member

The best way is to work as a team. Some things can be done only by the patient, but other tasks (such as buying healthy food or doing housework) can be divided up. The person with illness should have as much control as possible, but family members’ needs also have to be considered.

If family members act like police, constantly saying things like “take your medicines,” or “are you sure you should eat that?” the patient is likely to resist and purposely not do what the family wants.

Often the emotional challenges of illness are the hardest. Chronic illness can bring feelings of anger, fear, grief, and frustration. Emotional changes may be unpredictable and stressful for the ill person and for those who love them.

Here are some dos and don’ts in helping family members manage their conditions:

- **DO** offer to do things with them – like exercising, accompanying them to doctors’ appointments, or going with them to support groups.
- **DO** take care of yourself – model healthy behaviors, don’t wear yourself out. Don’t give up your own life and wind up resenting your family member.
- **DON’T** try to do everything for them or treat them like children.
- **DON’T** assume you know what the person needs. Ask them. Make a mutual plan for self-management.
- **DO** make them aware of resources and information you find, but let them decide what to do with this information.
- **DON’T** tempt them with things they shouldn’t have. If a family member is trying to lose weight, you may need to find some place to keep the cookies where he or she won’t find them.
- **DO** communicate how you feel without blaming or lecturing. Many families benefit from counselling to help them communicate better.
- **DON’T** insist that they do things with you (like play a game or go out to eat), but don’t stop asking them if they want to be included. Some days they may feel up to a shopping trip; other days they won’t.
- **DON’T** assume that all the patient’s or family’s behaviors are due to the illness. All the other problems of life keep going after diagnosis. Talk about problems and work them out.

Helping Peers Manage

Living well with chronic conditions is hard. While each patient is responsible for his or her own self-management, most of us need help to succeed. There are many sources of help, but one of the best sources is other patients like you. Nobody understands what you’re going through as well as people who are going through it themselves. This kind of help is called “peer support.”

Peer support helps in at least four ways:
- Emotional support;
- Practical advice;
- Practical help, like an exercise partner or a ride to the doctor; and
- Increased confidence from seeing others like you succeed at self-management.
Helping Peers Helps You
You can provide peer support as well as receive it. You have a wealth of information and experience to share with other patients. You may be able to provide emotional and practical help, too. Studies of peer support show that both helpers and receivers of help benefit.

Peer support can be informal – just you talking with a friend or someone you meet in the doctor’s waiting room. It can also be more organized. Many health care providers have set up programs of “peer mentors” who are paired with other patients to provide support. Others have set up education programs led by patients to teach others about self-management. Any of these approaches can provide you with opportunities to help yourself and help others.

How does providing peer support to others help you? First, helping others is good for your health. Many volunteers report that they eat and sleep better since they started volunteering. Second, the people you support may become your friends. They may help you and enrich your life in many ways. Third, talking about and teaching self-management skills may help you solve problems in your own life and self-management.

How to Be Good at Supporting Your Peers
The key skills in providing 1-on-1 peer support are:

- **Listening** is often the best help we can give.
- **Sharing your story.** Telling others how you got through similar problems will give them hope and ideas.
- **Giving advice** should usually be kept to a minimum. What worked for you might not work for them. But you can present ideas for them to check out. For example, if certain foods make your arthritis pain worse, you could tell another patient about that experience. But you wouldn’t want to say, “Stop eating these foods.”
- **Giving information.** Don’t preach, but if you know of books, web sites, articles that they can read, let them know. If you know of social agencies that might help them, give them the phone number. You don’t want to appear to be the expert; you want them to become their own experts.

- **Do things with them** like exercising or going food shopping, if you want to. Don’t do things that will make you resent them. Take care of yourself.

Depending on your style, you may do better in formal peer support programs such as:

- A support group or self-help group. Join one or start your own.
- A formal peer mentoring program where you talk or meet regularly with another patient.
- A self-management training class that you can teach. The providers will train you.
- A telephone peer counseling program. Many community organizations and health care providers have volunteer peer counselors. They will train you.
A Patient Advocate Transforms Diabetes Care

Lynn Gifford
Patient Advisor
Family HealthCare Center
Fargo, North Dakota

“The single most empowering thing that my doctor did,” boasts Lynn Gifford, “is to hand me my own medical chart. Then I knew we were in this together.” Lynn and six other patients from the Family HealthCare Center in Fargo, North Dakota participated in this “handing over” at the inaugural group visit launched by the Diabetes Clinic.

Lynn, who once described herself on a radio talk show as a “falling-apart, overweight woman with diabetes, gout, hypertension, high cholesterol, and major clinical depression, without any health insurance,” is now on top of her game. A self-proclaimed health care advocate for years, Lynn is also employed part-time as an activity director at a psychosocial rehabilitation center.

Lynn's depression led her to the Southeast Human Services Center, operated by the North Dakota Department of Human Services. There she received medications for her depression, virtually free of charge. But since the Center provides only mental health services, they could only prescribe medications related to depression and she ignored other symptoms she was having because she could not pay for an examination, let alone expensive medications. The folks at the Center repeatedly advised her to check out the Family HealthCare Center and finally, she did.

That encounter changed her life. Lynn is one member of a small group of pioneers who agreed to play a role in the transformation of diabetes care at the Family HealthCare Center. Seven patients agreed to test out a “group visit.” During the appointment, they all visited separate stations (weight, foot exam, vital signs, smoking counseling, lab testing, and verbal review of medications) in a large auditorium-like room. The group then participated in a question and answer session conducted by a nurse practitioner and the attending physician. Anyone who wanted some private time with the doctor got some. Lynn pronounced it as an eye opening experience.

This was a chance to meet other people who struggle with the same issues as she does. The clinic serves distinct populations and their materials are available in Arabic, Spanish, Bosnian, Somali, and English. Many Native Americans receive care here. But regardless of diversity, Lynn felt connected. She appreciated the informal exchange among patients of ideas, concerns, and solutions. And people signed up on a buddy list to continue this peer-to-peer support.

Since her involvement with the diabetes self-management group visits, Lynn has lost thirty pounds, quit smoking, and joined a gym. In her work at the rehabilitation center, she refers many people to the Family HealthCare Center, telling her own story to those she refers.
People Helping Families Cope

Dr. Barry Jacobs, PsyD, is one of the country’s leading advocates for family caregivers. He defines caregivers as people who take care of anyone they love with a chronic illness. Often this is an aging parent or disabled spouse, but it can be a child with mental health problems or other loved one.

A psychologist and family therapist, Jacobs is author of *The Emotional Survival Guide for Caregivers* (Guilford Press 2006). He also trains medical residents in how to work with caregivers.

Jacobs says that family members are often too busy caring for others to care for themselves. “A big issue is self-identification,” he says. “Not to see themselves only as adult children or spouses but as caregivers and therefore worthy of attention. People don’t think of themselves as caregivers, just say “I’m doing what I’m supposed to do.”

As a result, caregivers have a lot of health problems. “They tend to ignore their own health problems,” says Jacobs. Studies show that caregiving spouses with chronic illness have a 63% higher mortality rate than people with the same illness who are not caregivers.”

Jacobs says the key is to get families more help. People may need help with housework, food preparation, respite care, or programs for the ill or disabled family member. These programs are frequently available in the community, but people don’t know about them.

Jacobs encourages people to ask for the help they need, and encourages doctors to refer them. “Primary care physicians are the ideal people to identify those giving care and make sure they’re getting help,” he says.

There are many other good web sites for caregivers – you can find them listed at the end of this document.

Allen Becomes a Peer Mentor

Ten months ago, one of the clinic nurses asked Allen to volunteer helping other patients. He would share his knowledge of self-management and could give patients much more time than the nurses could. He got people started on exercise programs. He went out to eat with them to show them how to maintain a meal plan in a restaurant. Several of these patients became his friends. He says that one morning a few weeks back, “I woke up and realized. I’m not depressed any more. You might even say I’m happy!” He credits his peer mentoring for his improved mood.
Improving Health Care for Others

Few people want to become involved with the health care system. We’d rather our whole family stayed healthy. But for some patients and families, working to make their own health care better leads them in exciting new directions. They can become advisors to the system. They can make a real difference in the health care and lives of other patients.

Most hospitals and health care systems now have patient and family advisors. Advisors can show doctors and administrators the patient’s point of view. They can lead staff through a typical visit or hospital stay, as seen by the patient and family. They can consult and help providers to understand what it’s like for patients.

Advisors often find that they grow and learn from their work. They might learn to express themselves better or become public speakers. They may also gain other rewards. As one advisor said, “What really made me feel good was to see that they were starting to make changes based on what I told them. That made me feel good, because I realized that I was able to make a difference. I feel like ‘this is what I was meant to do.’”

Patient/family advisors are usually paid a small stipend for their work or compensated in other ways. Some become leaders in helping their systems change.

Sharing Your Story with Others

There are so many ways you can work with health care providers to help improve care. You may be asked to be a member of an advisory council for the clinic, serve on a committee looking at better ways to provide support and patient education, speak to community groups, or train staff. Sharing your story is one of the most effective skills you need as you begin to serve in these roles. You may find it to be the most powerful way to inspire change.

Yet, sharing personal stories does not come naturally to many. Telling your story effectively requires training and practice. Training and practice will help you:

- Share your story in a clear and convincing way;
- Maintain your dignity and limit your story to only what you are comfortable sharing with others;
- Keep your own emotions under your control; and
- Model respectful and productive strategies for working together with staff and physicians.

Sharing Your Story: Tips for Patients and Families

The Institute for Patient-and Family-Centered Care has developed resources that provides more ideas for effective storytelling.

New Health Partnerships: Information for People with Chronic Conditions—Self-Management Support
Institute for Healthcare Improvement, 2011 (www.IHI.org)
There are steps you can take to make sure that you are well prepared to share your story.

**Prepare**
Find out as much information as you can about the event you will be speaking at. What is the purpose of the event? Is it an informal meeting with people sitting around a table? Or is it more formal, like a staff or physician training? Who will be there? How much time will you have?

**Practice**
Give yourself time to practice telling your story. A good story does not have to be long. Listening to a few minutes of a well-told story can be very convincing. It is usually best if you come up with two to three main points that you feel are important and then illustrate these with examples from your own experience. Make it real. You can build your skills by audiotaping or videotaping yourself, practicing in front of a mirror, or asking a trusted friend or family member to listen to your story and give advice. If there are other patients and families you know that have experience serving as an advisor in health care improvement, ask them if they are willing to give you feedback.

**Consider Your Presentation Style**
The way in which you tell your story often will have a long-term impact on the audience. For that reason, it is important to share your story in a way that is respectful and helpful. It is okay to be angry about situations and share those feelings, but you want to be in control of your anger. You don’t want anger to alienate others. If you are feeling too upset about an issue that you feel your message may not be constructive, it may be best to find someone to talk to you about your experience and help you resolve the issue before you share your story. When physicians and staff have asked you to help plan changes, to improve care for others, they want to hear both the positive and negative. Again, make sure you can give them concrete examples of what has worked for you and your family and what has not gone so well.

**Bring Supporting Materials**
It helps to have things that will support your story. If you are making a formal presentation, you may want to share photos or provide slides that frame your story for you and your audience. Slides or pictures can help keep you stay focused on your main points. You may want to write down your notes and have them available. But be careful not to read from them for the entire presentation. If you are telling your story in an informal meeting, take along a few things that add some meaning to your story if you need to (such as a new patient informational packet, copy of a bill, messages you see on signs in the waiting room).

If you are interested in strengthening your presentation skills further, you may want to look at the training opportunities offered in your community through local civic organizations or continuing education classes at area colleges.

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**Toastmasters International**
Want to have fun while overcoming your fear of public speaking? Since 1924, the nonprofit organization, [Toastmasters International](https://www.toastmasters.org), has been helping people become confident and competent in public speaking.
Patients and Family Advisors

In primary care practices, hospitals, and health care systems across the country and in many countries around the world, patients and families are being asked to serve as advisors and leaders with physicians and staff in improving and redesigning health care. Patients and families hold a unique perspective of the care and can share this knowledge with providers to improve care quality and safety.

In many primary care practices, patients and families not only serve as advisors but they also provide education and support to other patients and families. Health care providers find that selecting, preparing, and providing ongoing support of patients and families for these new roles are important for success.

Patients and families report a variety of benefits to serving as an advisor in health care.

- Improves care for others.
- Provides a way to bring about meaningful change to health care.
- Increases opportunities to share information with other patients and families.
- Feels good to contribute.
- Offers connections and friendships with other patients and families as well as physicians and staff.
- Expands knowledge and skills.

How do you know if you would make a good patient or family advisor?

Can I Be an Advisor? Important Questions to Ask

At your next clinic visit you see a poster at the registration desk asking for patient and family advisors to help the practice improve the way they provide care. You are interested but don’t know for sure whether this is something you can do. Those who are thinking about becoming a patient or family advisor can ask themselves the following question to decide if the role is a match for their strengths and skills.

- Can I share insights and information about my experiences in ways that others can learn from them?
- Do I see beyond my personal experiences?
- Am I concerned about more than one issue in health care?
- Can I listen well?
- Do I respect and welcome the perspectives of others?
- Can I interact well with many different kinds of people?
- Do I have a positive outlook on life and a sense of humor?
- Can I speak comfortably and openly in a group?
- Do I enjoy working in partnership with others?

Another key source of information to help you decide whether or not to be an advisor is from the clinic or center that is seeking advisors. If they haven’t provided a fact sheet about the advisor role, then you can get more information to help with your decision by asking them for information in key areas.

New Health Partnerships: Information for People with Chronic Conditions—Self-Management Support
Institute for Healthcare Improvement, 2011 (www.IHI.org)
• Mission and goals of the organization and/or particular project you will be working on.
• Expectations for your participation.
• Meeting times, how often, and expected length.
• Expected travel dates if any.
• Expectations for communication between meetings (e.g., do you need access to email or a fax to participate).
• Time commitment expected beyond meeting times.
• Compensation offered (e.g., cost of transportation, parking, child care, etc.)
• Benefits of participation (i.e., what is the clinic or center expecting will result from your involvement).

The Institute for Patient- and Family-Centered Care
Much of the information in this section has been adapted from materials available through the Institute for Patient- and Family-Centered Care, a nonprofit organization dedicated to advancing partnerships among patients, families, and health care providers to improve the quality and safety of care. Various resources that are available include:

• Advancing the Practice of Patient- and Family-Centered Ambulatory Care: How to Get Started
• Partnering with Patients and Families: Recommendations and Promising Practices

Leading Change and Improvement

For several decades, health care has been changing. Health care used to center on the needs of providers and systems. Now it is becoming more centered on patients and families. This box illustrates part of the difference.

<table>
<thead>
<tr>
<th></th>
<th>System- or Provider-Centered</th>
<th>Patient- and Family-Centered</th>
</tr>
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<tbody>
<tr>
<td><strong>Definition</strong></td>
<td>The priorities of the system and those that work within it drive the delivery of health care.</td>
<td>The priorities and choices of patients and families drive the delivery of health care.</td>
</tr>
<tr>
<td><strong>Example</strong></td>
<td>With the help of the nursing staff, the clinical educator plans and runs a weekly diabetes class for newly diagnosed patients.</td>
<td>With the help of the clinical educator, two trained patients with diabetes plan and facilitate a weekly diabetes education and support class for newly diagnosed patients.</td>
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The patient- and family-centered approach began in maternity and pediatric care. It has spread throughout health care, including primary care in recent years. Health care providers recognize that patients and families hold a unique perspective. They can share their knowledge with providers to improve health care quality and safety.

In 2001, the Institute of Medicine published a highly influential report entitled *Crossing the Quality Chasm: A New Health System for the 21st Century*. This report looked at strategies to drastically improve
the health care system. The report stated that collaboration with patients and families at all levels will be essential to address the challenges we face in health care.

In primary care practices, hospitals, and health care systems across the country and in many countries around the world, patients and families are being asked to serve not only as advisors but also as leaders in transforming health care.

As the following short examples show that patients and families can serve effectively in a variety of leadership roles.

**Co-Leaders and Leaders of Peer Education and Support Programs**

When Mike Wade, a patient at Santa Clara Valley Medical Center (SCVMC), took the Options for Healthier Living Program in 2004, he got very excited about it. Led by lay people with chronic conditions, Healthier Living teaches patients and families how to care for themselves and work with health care providers. It is part of the Chronic Disease Self-Management Program developed at Stanford University.

Wade trained to be a Healthier Living leader, then to be a master trainer, who trains other leaders. Working with cardiologist, Pat Kearns, he recruited patient John Pozniak, then others. They started giving the program in the community and at the hospital. They recruited more patients to become leaders. Under patient leadership, Healthier Living has become a major part of SCVMC chronic care. Other hospitals, and the Santa Clara County health care system have adopted it with SCVMC help. Wade has also helped start Healthier Living programs in other California counties.

**Teaching Health Care Providers and Health Care Professionals-in-Training**

Parent to Parent of Vermont began in 1984 to offer peer-led support to Vermont families who had children with special health care needs. It has since become a national leader in family support.

Parent to Parent of Vermont has also earned a reputation for training and supporting families to serve in faculty roles in health care. Their parents have taught in many programs – Medical Student Leadership Groups for first-year medical students; Medical Education Project for third-year medical students; Families in Resident Student Teaching for pediatric residents; and Vermont Interdisciplinary Leadership of Health Professionals for health care providers. Julianne Nickerson, a parent of a child with a congenital heart condition serves as director of the family faculty programs.

**Paid Positions in Health Care-Related Institutions, Agencies, and Organizations**

Based in New York, the United Hospital Fund has a rich history of providing services and improving health care in chronic conditions and geriatrics for well over 100 years. Their program, the Families and Healthcare Project is devoted to promoting partnerships among family caregivers and health care providers. The director for this project, Carol Levine, is a woman with experience as a family caregiver for her husband who suffered a traumatic brain injury in 1980.

**Co-Investigators on Research Projects**

The MCG Health System in August, Georgia, has been integrating patient- and family-centered care in their hospitals for over 15 years. They offer many advisory and leadership opportunities to patients and families. Several years ago, they began to expand their model beyond the hospitals and into their outpatient clinics.
Christine Abbott, a parent of a child with chronic health care needs, was active as a family advisor at MCG Children’s Hospital. After being diagnosed with multiple sclerosis herself, she offered to share her expertise and insights with MCG’s Neuroscience Center. In 2008, she was offered a full-time paid position on a research team at MCG that is studying the effectiveness of patient- and family-centered electronic health records for patients with hypertension.

Advisors and leaders for national health care organizations
The Cystic Fibrosis Foundation has experience in partnering with individuals with cystic fibrosis (CF) and their families to improve care in all of their care centers across the nation. Efforts include:

- In 2003, an adult with CF and a parent of a child with CF were added to the Cystic Fibrosis Foundation’s Education Committee to identify and review CF-related patient and family resources in 2003.
- Since 2004, an adult with CF has served as a member on the CF Foundation’s Quality Improvement Initiative Strategic Planning Advisory Committee.
- An individual with CF and a parent representative co-chair a Foundation Task Force that promotes and prepares patients and families to get involved in quality improvement work at their local CF Care Centers.
- Joan Finnegan-Brooks, an adult living with CF, has been serving as an advocate for the CF Foundation since she was a child. Her efforts to improve care and enhance quality of life for people with CF are extraordinary and inspiring. Read more.

New England SERVE
Established in 1983, New England SERVE is dedicated to promoting partnerships between health care providers and families who have children with special health care needs. In 2004, they launched the Family-Professional Partners Institute to support interested health care organizations in developing paid positions for families to assist in educational activities, program development, research, and improvement initiatives. Their work includes preparing and training the providers as well as the families to sustain these partnerships.

Words of Advice: A Guidebook for Families Serving as Advisors

This workbook is designed to help patients and family members think through the benefits and demands of advisory roles. It includes self-assessment activities to help address strengths, skills, and areas that need enhancement before patients or family members make a commitment to an advisory position. Available from The Institute for Patient- and Family-Centered Care.
Stories of People with Chronic Conditions

Teaching Doctors about Families from a Parent’s Point of View: A Parent Becomes A Leader

Karen Tate
Family Consultant
The Children’s Hospital of Philadelphia
Philadelphia, Pennsylvania

As a family consultant, Karen Tate makes a huge difference at The Children’s Hospital of Philadelphia and in the lives of their patients and families. She didn’t plan on being employed at the hospital, but twelve years ago, her daughter Candace, then 8 years old, suffered a stroke. Karen stayed with her in the hospital.

“I didn’t want to leave Candace there alone” she says. “They wouldn’t know that she was afraid of the dark, or what she liked. They would just leave the TV on, and if a commercial for a scary movie or something came on, I would get up and change it.”

When Candace came home, things got even harder. “It was difficult trying to access different services or finding resources [for a child with new disabilities] once we were at home. It’s hard trying to find it on your own if you haven’t had experience with it,” Karen says.

She gradually learned to navigate the system so well that a social worker from the hospital asked her to come and speak to a group of physical therapists, pediatricians, and other therapists and staff. This was new for her.

“I’ve never been a person who likes public speaking,” she remembers, “but the social worker said it will be like a discussion, they’ll ask you questions. They really want to hear about your experiences. After I did that, it was a really good feeling. They seemed very concerned and really appreciative of having that opportunity to ask me questions and to find out from my perspective the reality of having a sick child.”

Making a Difference
Right away, Karen was able to help physicians and staff appreciate the reality of having a child with special health care needs, particularly with managing care at home. “They were familiar with things they tell parents to do, but not realizing how difficult that is once you get home and you have other kids to take care of. What really made me feel good was to see that they were starting to make changes. When they gave out the home exercise sheets to the parents, they would tell them, ‘We realize that it may be difficult to do all of this, but if you could just focus on this one.’ That made me feel good, because I realized that I was able to make a difference.”

Karen’s work was so valuable that she was asked to apply for one of the family consultant positions at the hospital and was hired. Most recently, she has been serving as the Director of Family Collaboration.
for a program called LEND (Leadership Education in Neurodevelopmental Disabilities). Each year LEND has trainees from different health fields who work with children like Candace.

“I teach family-centered care classes,” Karen says. “One is a family mentorship program. The LEND trainees can go to the home to see what a typical day is like. They might go at dinner time or even go in the community, like to a restaurant or a soccer game or something. Just to see what their life is like outside the hospital.”

Participating families receive an honorarium for opening their homes to the trainees. The professionals respect the families as teachers. But LEND is only twenty percent of Karen’s work as a family consultant. She describes her job this way. “I meet with parents at the bedside to provide family-to-family support. I support staff around issues of family-centered care. They’ll e-mail me or page me or call when they have questions.”

Karen’s work has changed her life as much as that of the people she serves. “It’s great,” she says. “I really enjoy it. It doesn’t feel like a job. It’s more like this is what I was meant to do. The hospital really values having parents as paid professionals, working as part of the team.”

Becoming a Health Literacy Advocate

Archie Willard, who worked in a local meat packing plant in Iowa, only learned about his dyslexia in middle age, and did not learn to read until he was 54 years old. He became a well-respected literacy advocate in Iowa. In his 70s, he still struggled with reading. But he is passionate about helping others and is now working to create a safer, friendlier health delivery system for all.

Mr. Willard serves as a health literacy advocacy leader in Iowa Health Systems and has presented in many national health care conferences. His New Readers of Iowa Literacy Group has organized several well-attended conferences on health and literacy. He consults with health professionals to increase their awareness of the impact of literacy in health care. He advocates for “new reader-friendly” health care materials. He serves as the voice of the patient.

As Mr. Willard explains, “The voice of the person with the problem is seldom heard. But we need all voices at the table. There’s no one person who has all the answers. By coming together we all become stronger. It’s a natural partnership.”

Sincere collaboration with patients with literacy issues helps primary health care organizations and hospitals improve the effectiveness of their patient and health materials, and fosters a higher level of
sensitivity and responsiveness in health professionals to literacy issues and how greatly they affect the quality of health care.

For more information on Health Literacy read:
In Other Words: Health Care Communication From an Adult Learner’s Perspective
By Helen Osborne, MEd, OTR/L

Taking An Active Role: Facing the Challenges of Chronic Illness

Christine Abbott
Patient and Family Advisor
MCG Health System
Augusta, Georgia

For 12 years, Christine Abbott’s life revolved around caring for her chronically ill son. “When Eric was 9 days old, he turned blue and needed an oxygen tent,” she says. “Then he had hernias, bone problems. At age 5, he developed kidney disease. He spent 42 days in the hospital at Medical College of Georgia (MCG). I had to learn to take blood pressures, give shots, and a lot of other skills.”

This was in 1998, and Christine still manages Eric’s care. At some points, that has meant watching and caring for him 20 hours a day. How has she coped with these demands? One thing that helped her was joining MCG’s Children’s Medical Center Family Advisory Council.

“I wanted to give something back,” she says. “I sat on the Council for a year and chaired it for four. I couldn’t make my son better. I couldn’t cure him, but maybe I could make life a little bit better for a lot of people by being on this council. And it really did feed my soul. It gave me a little bit of power back in a world gone totally chaotic.”

New Challenges
But life had other twists for Christine. Just when Eric started getting better, she developed a number of strange symptoms, which rapidly worsened.

“One morning, I found I couldn’t close my right eye. Within the hour, I could not move my right leg at all. My right arm was getting hard to move. I was starting to have trouble speaking.”

Her husband took her to the Emergency Room. Over the weekend, she was diagnosed with multiple sclerosis (MS).

“I thought it would be like when my son was first diagnosed,” she says. “It would be two years in hell, and then things get better. So I refused to allow myself to feel the emotions of being sick. I got into fight mode. I’d have an attack; I’d think what do I have to do? What therapy? I was going to muscle my way through it.”
In late 2004, she had one attack too many. “I couldn’t fight any more,” she says. “It was never going to end. I was never going to get better. In January, I just broke down. I could not stop crying. I had years of emotional strain, and it was now coming up and there wasn’t a thing I could do about it.”

**Overcoming Depression**

Fortunately, the neurology clinic at MCG had just started a depression screening program. “I come in and they say, fill out this survey (a depression screening tool called the Beck Depression Fast Screen). That’s when I found out I was depressed, and also that I could do something about it.”

The clinic was using the Fast Screen partly because patients on the MS clinic advisory council had asked for more psychiatric support services in the clinic. Christine started self-managing her depression the way she had managed her son’s illness. She started on medication and psychotherapy. She kept filling out the Fast Screens so she could monitor her condition. Keeping records of how you’re doing is a basic self-management idea, but it is not usually used for mental health issues. “Each month, I could track how I was doing. After 6 months, my scores came down from 5s to 2s [much better], and I asked Dr. Hughes if I could cut back on my antidepressant and see how I do. Keeping on top of things makes me feel more confident in managing myself and how the clinic is managing me.”

She also gained confidence by joining the adult clinic’s Patient- and Family-Centered Care team, which helped design a new neurosciences unit. Her main job was to teach other patients how to use the online Patient Medical Record called “My Health Link.”

**Helping Others, Helping Herself**

Pat Sadomka, Director of the Center for Patient- and Family-Centered Care at MCG, says, “Christine is a really good match for our work. She’s a good communicator and is comfortable with technology. It was hard to get patients enrolled, trained, and using My Health Link. Staff didn’t have time to do it nor the patients’ perspective. Christine got involved, and everything started to go better. Now she is helping assess My Health Link, how it can be improved. Then we will do a national trial of it. Christine will be the lead patient representative.”

Just as with her son, taking an active role in her care helped give Christine confidence that she could handle MS and depression. “The team valued me for who I was, when I sometimes felt worthless. I was in that depression and it gave me a reason to get up some days. I was going to go in the clinic and teach this program to other patients. And that spurred me on, I needed to do something other than sit at home and wait for the next attack.”

Her work also helped her self-care. “I learned things from the diabetes and the high blood pressure groups that applied to me. I started walking and watching what I eat. I came out of the depression, and I feel I’m back on top of where I am physically and emotionally.”

Learn more about Christine’s work as a patient and family advisor.
Ruth-Jean Francois: A Patient Voice Helps Improve Care for Others (continued)

Continued from page 5...

Nurse Association of Eastern Massachusetts. In addition to her work, she is responsible for her own and her extended family’s health care. And Ruth is a patient advisor to the Adult Medicine Clinic. Because Ruth has diabetes, she worries about medication, diet, exercise, vision, and weight loss. Ruth believes her health is better since she became an active participant in her own care, trading ideas and information with other patient partners, and sticking to the treatment plan that she developed with her physician.

Dr. Laura Obbard invited Ruth to join the Quality Allies Project as an advisor in the fall of 2005, when the idea of a Patient Advisory Committee was in its infancy. Dr. Obbard chose Ruth from “the vast group of savvy patients and possible participants because of her practicality and her attentive listening skills.” Dr. Obbard explains, “Ruth has a valuable point of view; she hears ideas from many different groups of people, and zeroes in on the ones to improve the health center.” When the Clinic wrote useful brochures for patients, the newly formed Patient Advisory Committee tackled its first official project. Committee members reviewed all the articles and made suggestions, changed wording, and added or subtracted information before it was printed and given to patients. Ruth logically said that while these materials are helpful, not everyone is a skilled reader, especially if English is their second language. She suggested that they be available on audiotape.

The Clinic now has written materials, in English and Spanish, and computerized slide shows with audio. A computer and headphones are available in the reception area to patients who want to view the shows. Topics include weight loss, medication administration and side effects, preventive health measures, diet, and important information about how the clinic functions. The Clinic relies on the Advisory Committee to review all patient items to make sure that they are patient-and family-centered.

At an Advisory Committee meeting, Ruth said that because of her new understanding about diabetes she wanted to start exercising and lose some weight. Even prior to being an advisor, she had thought about joining a work out program, but didn’t know how, when and where she could go in her community. The Committee realized that if one neighborhood resident had a need to know, then the whole community would benefit from knowing! They put together a Community Resources brochure, listing neighborhood exercise programs that welcome people with chronic illnesses, nearby stores that sell healthy, not too costly “allowed” foods, and reader-friendly disease specific websites. The Committee knows that many patients don’t have home computers, so they spread these pamphlets all around the Clinic, local churches, libraries, health departments, and at places where computers and the Internet are free or inexpensive.

Being a patient advisor has helped Ruth lose weight. She joked, “How can I tell people to take their medicine on time, watch their diet, and get exercise, if I don’t do it myself?” She feels confident giving advice to others because she has learned and uses reliable ways to measure and show her progress towards the goals she has set for herself with her doctor.
She respects and feels respected by Clinic staff, believing that both she and they have begun to see themselves as partners in care. “Letting me talk honestly about my care in the Clinic, asking my family about the care, hearing what others have to say, and seeing the reaction to all of it, makes me feel valuable and valued.” She sees her role as patient advisor as a natural progression of the Clinic’s commitment to quality of care.

This partnership has not been limited to Ruth’s health care, but reaches throughout the Clinic. Patients’ self-confidence has increased, bringing about greater dedication to medical routines, adding to patient and provider satisfaction, and resulting in a clinic-wide sense of improved care.

Ruth’s advice to others wishing to partner with their patients: Teaching must fit the person’s interest level, understanding, desire, and ability to learn new information. Rather than explaining everything about a specific disease, focus on what this patient needs to know to be a real partner in care. Respect your patients, listen carefully, share information—and watch the benefits come rolling in for everyone!

Successful Self-Management: A Pound, A Bite, and A Step at a Time

When Ruth Cody had weight loss (“bariatric”) surgery, she had to change everything about the way she ate and drank. “It wasn’t easy,” she says. “I could only eat a little. Some things I ate caused ‘dumping’ or pain. I had to learn what those were.”

Ruth learned what to eat through self-monitoring. “I started a spread sheet,” she says, “and everything that went into my mouth, I documented. It was great. I learned what I couldn’t have, like diet sodas. I found I was eating about 800-1000 calories a day, which was perfect.”

Surgery isn’t a cure for obesity. Her surgeon told her it was a tool, a kick-start, but where she wound up was up to her. She has taken this challenge seriously. “For the past year, I have faithfully gone to the gym every day before I go to work,” she says. At first, I HATED it. But I kept doing it, and now I kind of like it.”

Ups and Downs
Ruth has lost 90 pounds since surgery, but it hasn’t been easy. “When I had surgery, I was at 290 pounds. I lost quickly at first, but then every time I started to get close to 200, I gained.” She realized she was sabotaging herself, and she made the right choice. She got help. “I joined Weight Watchers at work to help me to learn to eat again,” she explains. “I went back to my therapist and we
are trying to sort out what it is about 200 that scares me. I went back to writing things down and using my spreadsheet. I started on antidepressants. I didn’t know how unhappy I really was until I became happy. It makes a big difference.”

Looking at the Positives
Ruth motivates herself by focusing on the rewards of being fitter. “I am 48 years old and this year, for the first time in my life, I have gone snorkeling, horseback riding and most recently snow skiing.” She knows her family also benefits. “My husband has never commented about my weight, but I know it had to make a difference,” she says. “We have been married for almost 28 years. The romance is back. And my children (age 24 and 22), had only known me as fat. I know they must have been ridiculed because of my weight. I can do more with them now. I have so much more stamina. I even look years younger. Go figure.” Perhaps even more important, she has gone from needing 100 units of long-acting insulin a day, to being diabetes-free.

The other thing that keeps her going is her work as Bariatric Coordinator at Chesapeake Regional Medical Center. She is teaching providers about sensitivity to the obese patient, from her own experience. “I personally have suffered the prejudices of being overweight. So has my mother. I am on a mission now.”

Life-Long Commitment
Ruth knows that self-management is a life-long commitment. She has gone from a size 28 to size 18, but she wants to get fitter. She knows she can’t do that all at once. “I have learned that I can’t look at the whole amount that I have to lose,” she says, “but a pound at a time, a bite at a time, a step at a time.”

Helping Herself, Helping Others Self-Manage

Edwina Pitt
Patient Advisor
Quality Community Healthcare, Inc.
Philadelphia, Pennsylvania

Edwina Pitt was born and raised in North Philadelphia. Many people there have tough lives, including her. At 50 years old, she has raised two children and now helps care for her two grandchildren. As an active patient at Quality Community Healthcare (QCHC), she helps a lot of other people too.

She couldn’t be so helpful if she didn’t take care of herself, and she hasn’t always done that. For the last nine years, she has had high blood pressure, diabetes, and depression. But she’s doing much better now.

In April, Edwina joined the QCHC team participating in the New Health Partnerships Collaborative, a national program finding ways health providers and patients work together to help patients manage their conditions. Learning self-management has helped her change her life.

“They have exercise programs out in the clinic; I go to them,” she says. “I walk every other day. I ride my bike in the neighborhood with my sister. Everyone waves and calls me “Miss G.” When it’s too hot to

New Health Partnerships: Information for People with Chronic Conditions—Self-Management Support
Institute for Healthcare Improvement, 2011 (www.IHI.org)
ride outside, I ride a stationary bike in my house for about an hour. Sometimes I go walk in the mall with my girlfriend, Janet.”

Edwina works closely with QCHC to manage. “They have classes for high blood pressure and diabetes a couple of times a year, and I go to them,” she says. “I go to a support group for people with depression, and that really helps.”

“I’ve lost 24 pounds since April. I listen to the nutritionist. I’m eating wheat bread, brown rice. No fried food — I’m grilling on the stove top. I cut way back on the soda drinking. I’m eating more raw vegetables. My diabetes has been excellent; I have improved so much. I take medicine for high blood pressure, and the pressure has been wonderful, too. I’m really proud of that.”

She spends a lot of time helping QCHC. “When there’s something going on at the clinic, I always join in.” She helped develop a survey for patients. “Was your doctor informative, how long did you wait, did they call you and check up on you, are you doing the right things, questions like that,” she describes. “I am in the clinic all the time. I come in and talk to the patients in the waiting rooms or outside the clinic and tell them about the survey and ask how the clinic is working for them. We learned a lot.

One small thing that made a big difference, was that we learned that the signs need to be bigger; Signs on the wall that tell what the clinic offers, psychology, things like that. People couldn’t read the signs because they’re too small. So they made them bigger.”

QCHC Chief Financial Officer Georgette Dukes-McAllister appreciates Edwina’s input. “She brings insight into what patients are thinking, which adds another dimension to what we’ve been doing,” she says. Executive Director Marcella Lingham adds that, “We have several collaboratives going. Edwina was able to put all the pieces of the puzzle together. She has been part of the depression collaborative, the diabetes collaborative, and the obesity collaborative. Each time we work with a patient, we gain insight into our operation. In many cases it’s an eye opener for us. What is a high priority for us isn’t necessarily a high priority for the patient.”

Edwina Pitt likes the Collaborative’s focus on self-management. “We’re learning how to help patients set goals,” she says. “What type of goals they should pick. People have strong areas and weak areas. You have to work with each person’s strengths and weaknesses.”

Working on the Collaborative isn’t always easy, but she says the team helps each other. “Khalil Evans, Outreach Specialist, is so sweet, so good to me,” Pitt says. “When I can’t understand all the language they use, he breaks it down for me. I work with Bethany, Bashera, and Geogette. All of them are really nice. They answer all my questions. I’m not scared to ask questions.” The team meets twice each month and has a conference phone call once a month, and Edwina is a full participant. “If you got something to say, you just jump in and say it.”

Succeeding at self-management and helping the QCHC team have made a big difference for Edwina. She is now busy getting her Graduate Equivalency Diploma (GED). Her girlfriend Janet is helping her, and QCHC leadership is glad to hear it. Marcella Lingham says, “We’re very proud that we’re often a first employer for people in the community who have gotten their GED and go on and start their career.” Perhaps some day Edwina will work for QCHC, too.
Useful Websites

General Health Information

Family Doctor
This website is operated by the American Academy of Family Physicians (AAFP). All of the information on this site has been written and reviewed by physicians and patient education professionals. It includes a "smart patient guide", explanations about medical conditions, and ideas about healthy living and disease prevention. The site offers health tools such as a medical dictionary, BMI calculator, drug information, search by symptom, and website reviews.

Healing Well
HealingWell is an on-line community and information resource for patients, caregivers, and families coping with chronic conditions. The website offers health resources, interactive tools, and community support. The site features health articles, doctor-produced video web casts, community message boards and chat rooms, professional health care resources, and resource link directories.

HealthFinder
US Department of Health and Human Services
This Federal website has a Consumer Guide section, which gives background on health care providers, ratings of hospitals and nursing homes, guides to health insurance, how to report fraud or make a complaint, and privacy issues. It offers a drug database and information about chronic diseases.

Mayo Clinic
This website provides useful and up-to-date health information and health improvement tools that reflect the expertise and standard of excellence of the Mayo Clinic. Includes a first-aid guide, healthy living section, treatment decision guides for many conditions, and an "Ask a Specialist" forum, with Mayo Clinic doctors.

Medline Plus – Health Topics
This National Library of Medicine site features a medical encyclopedia and a medical dictionary, health information in Spanish, information on prescription and non-prescription drugs, and links to thousands of clinical trials. Online tutorials from the Patient Education Institute explain over 165 procedures and conditions in easy-to-read language.

National Institutes of Health – Health Information
This National Institutes for Health website provides information about a wide variety of health topics including health conditions, mental health, alternative medicine, herbal medicine, and healthy lifestyles. You can sign up to receive their weekly Health Information Newsletter that can be sent directly to your computer free of charge.

WebMD
Includes resources that help consumers make informed decisions about treatment options, self-care, health risks and health care providers. WebMD provides detailed information on a particular disease or condition, analyzes symptoms, helps locate physicians, publishes periodic e-newsletters on topics of individual interest, offers online educational videos and message boards to connect with peers and health care professionals.
Health Information for Different Chronic Conditions

American Diabetes Association
The ADA website has comprehensive information on diabetes as well as self-management. Use the Message Boards to share ideas and opinions on a variety of topics with others. In addition, the Diabetes Learning Center promotes better diabetes self-management in the sections entitled Nutrition, Exercise, and Weight Loss. The Virtual Grocery Store focuses on healthy food choices and meal planning. Much of the information is offered in Spanish.

American Heart Association
Find videos, articles, booklets for download, patients stories, podcasts and more, including pages in Spanish, Vietnamese, and Chinese.

American Lung Association
Extensive information and self-management guides for asthma, hay fever, COPD, and lung cancer. Includes a Profiler Tool that can help you make decisions about treatments and monitor your progress. Also has relevant news stories.

Arthritis Foundation
Get information, advice, services, referrals, and resources for advocacy for all different varieties of arthritis, from the nation’s largest and oldest arthritis organization.

Association of Cancer Online Resources
ACOR provides information and support to cancer patients and those who care for them through Internet mailing lists and web-based resources. These are free, non-moderated discussion lists for patients, family, friends, researchers, and clinicians, to discuss medical and non-medical issues. Topics include patient experiences, psychosocial issues, new research, clinical trials, and discussions of current treatment practices as well as alternative treatments.

National Alliance for the Mentally Ill
NAMI provides information and support to people affected by mental illness. The community areas offer a place to share knowledge and find support for living with mental illness in general or specific mental health conditions.

National Cancer Institute
This website offers patients and health care professionals access to credible, current, and comprehensive information about prevention, diagnosis, treatment, statistics, research, clinical trials, and news, as well as links to other NCI websites.

National Multiple Sclerosis Society
This site has the latest information about research, treatments, events, and news. Includes personal stories, educational programs and self-management information. Chat rooms and other ways to connect with others are offered in the MS World site. Ways to Wellness provides information on alternative ways to improve health beyond medication.
Sharing Information and Making Decisions with Health Care Providers

Foundation for Informed Medical Decision-Making
The site offers evidence-based information about treatment options, interviews with patients, tools to guide decision-making, and other tools on a variety of conditions. Their motto is: “The care you need and no less. The care you want and no more.”

Patient Decision Aids
This section of the Ottawa Health Research Institute offers a variety of tools for patients to use to become involved in decisions about their care. Resources are available in French and English.

Learning about Self-Management

The Art of Getting Well
David Spero, a nurse who lives with chronic illness himself, specializes in promoting and enabling self-care. He trains health care providers and leads wellness groups and support groups for patients. Article and other resources are included on this site he has founded. Mr. Spero is a contributor to New Health Partnerships.

Patient Powered: Patient-Centered Health Care in Whatcom County
This site was created by patients as part of a program sponsored by the Robert Wood Johnson Foundation to improve chronic illness care. They believe that increased patient self-management is achievable and improves the quality of care. Viewers can download resources.

Self-Management: Taking Charge of Your Health
This section of Familydoctor.org provides information about the basics of patient self-management through a simple Question and Answer format.

Patients and Families as Advisors and Leaders

Beach Center on Families and Disability
Based at the University of Kansas, this organization has over fifteen years of experience in partnering with families in conducting disability research. The site includes stories, references, and resources about this research framework, called Participatory Action Research.

Center for Medical Home Improvement
A "medical home" is a model for providing comprehensive primary care to children with special health care needs. This site has practical tools and resources for providers in community practices and for families serving on improvement teams. Includes A Guide for Parent and Practice "Partners" Working to Build Medical Homes for CSHCN.

Consumer Quality Initiatives - Participatory Action Research Center
This organization’s mission is to prepare and support patients and families to partner with professionals in planning, implementing, and disseminating the results of research and evaluation projects.

Family Voices
Researchers to improve services for children.
Institute for Patient- and Family-Centered Care
IFCC is dedicated to building partnerships among patients, families, and health care providers to improve health care. IFCC provides articles, tools, resources and training for leaders, providers, patients and families. IFCC has been involved as an affiliate and contributor to New Health Partnerships.

Institute for Healthcare Improvement
IHI offers resources and training to health care providers and others to help them improve care. Several resources on self-management are available for both patients and providers.

Research and Training Center on Family Support and Children’s Mental Health
Based at Portland State University in Oregon, this organization concentrates on supporting community-based, culturally competent, and family-centered services for children with mental, emotional, or behavioral disorders and their families. They have resources for anyone interested in research partnerships among families and researchers.

Tools

Action Plan
This short form helps you develop and record changes you plan to make or goals you want to achieve. Planning specific activities will help you make a general plan real and achievable. An example of a completed form is included.

Depression Self-Screener
How do you know if you are depressed? This questionnaire, provided by Mental Health America, allows you to determine whether you have symptoms of depression. This confidential screening consists of nine questions that ask you to evaluate your thoughts, feelings, and behaviors over the past two weeks, and helps to indicate whether or not you should seek additional help from your health care provider.

HowsYourHealth
Get a two-part “10-Minute Health Checkup." Part one is a survey that includes questions about health, habits, knowledge about disease prevention, and satisfaction with health care providers. Part two includes a summary of your responses to the survey and recommended readings, an action form with a summary of responses to share with a doctor, and condition management forms to keep track of health and progress.

My Shared Care Plan
“My Shared Care Plan” was developed by health care professionals in partnerships and patients and families. The tool offers patients with long-term conditions and their families a way to keep track of their health and health care.

The PAMF Diabetes Action Plan
Palo Alto Medical Foundation created this attractive, intuitive Diabetes Action Plan form to document patient-reported strengths, challenges, and actions plans on a one-page form. This is an example of a form that can be saved in the patient record so that providers can follow-up and offer ongoing support.
A Brief History of Patient Self-Management

In 1978, Kate Lorig, RN, Doctor of Public Health, began a low cost, community-based arthritis education program for the Stanford Arthritis Center. Dr. Lorig lined up help from rheumatologists, health educators, physical and occupational therapists to write the first Arthritis Self-Management Program (ASMP), also known as the Arthritis Self-Help Course.

ASMP was a radical departure from many previous health education programs. “In traditional care,” says Lorig, “professionals are the experts who tell patients what to do. Patients are passive. In the self-management approach, expertise is shared. Professionals are experts about the disease; patients are experts about their lives.”

To help empower patients, the program creators decided to use people with arthritis, rather than health professionals, as leaders. Lorig remembers, “I had worked with community health workers in Native American and Hispanic communities in the States and also with lay midwives and other lay health workers in developing countries, so using lay leaders was a natural extension of my previous work. People have always been skeptical about it, but our research shows the lay leaders are at least as effective as professionals.”

Dr. Lorig is a tireless researcher who has published over 80 scientific papers and several books. (She co-wrote Living a Health Life with Chronic Conditions among others.) As soon as the first ASMP classes were completed, the authors started studying the results. In several studies, they found that participants had better health status, increased knowledge about arthritis, and did more exercise and relaxation than they had before the class. Encouragingly, these benefits were maintained through 20 months of follow-up.

Not content with demonstrating that the program worked, Lorig and associates wanted to know why and how it worked. So they asked, and they were shocked at the results. They found that improved behaviors were not the most important thing. The people who exercised and relaxed the most were not necessarily the people who got the most benefit! So what was causing the improvement? The researchers found that the key factor in the improving health of ASMP participants was increased self-confidence (or self-efficacy, to use a technical term). In other words, people who thought they could control their arthritis were able to. Those who believed arthritis was out of their control were usually right, too.

Now raising patients’ self-efficacy has become a central part of self-management support. That’s why NHP promotes the action plans and goal setting. It’s why we support peer mentoring and other programs that bring patients and families together.

Dr. Lorig and her associates have since spread the self-management courses to many other conditions. They are taught all over the world. It’s a movement that is growing each year. Self-management has moved far beyond the original six-week courses. Hundreds of studies have been done, and new techniques and strategies are being developed all the time. New Health Partnerships is part of this movement. You may be, too.

To learn more about the self-management courses, see here.
Resources and Tools: Getting Started with Self-Management

Self-Monitoring Symptom Log

Keep track of your symptoms. What makes your symptoms worse? What makes them better?

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Describe Symptom</th>
<th>How Bad Do You Feel?</th>
<th>Is There Anything Else Going On?</th>
</tr>
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<tr>
<td></td>
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<td>Pain, fatigue, gas, anxiety, or whatever — including BP, blood sugars, etc.</td>
<td>Rate from 1-10 (1=worst/10=best) Can include your BP, glucose, etc.</td>
<td>(Think of any changes in food, activity, medications, emotions, stress or anything that may be affecting you.)</td>
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See if you notice any patterns. Try to make a healthy change and log the results. Have the log with you at appointments and phone calls.
| Date | Time | **Describe Symptom**  
Pain, fatigue, gas, anxiety, or whatever – including BP, blood sugars, etc. | **How Bad Do You Feel?**  
Rate from 1-10  
(1=worst/10=best)  
Can include your BP, glucose, etc. | **Is There Anything Else Going On?**  
(Think of any changes in food, activity, medications, emotions, stress or anything that may be affecting you.) |
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**Action Plan (short form)**

This short form helps people with chronic conditions plan changes to achieve their goals. The form can be used during a health care visit and then copied so the patient has a copy to take home. It can also be included in their chart to support follow-up. An example of a completed form is included.

**Action Plan**

1. **Goals:** *Something you WANT to do:*

   ______________________________
   ______________________________
   ______________________________
   ______________________________

2. **Describe**
   
   How: ______________________________
   Where: ______________________________
   What: ______________________________
   Frequency: ______________________________
   When: ______________________________

3. **Barriers:** ______________________________

4. **Plans to overcome barriers:** ______________________________

5. **Conviction ___ & Confidence ___**
   
   Ratings (0 - 10)

6. **Follow-Up:** ______________________________
Action Plan (short form — completed example)

1. **Goals:** *Something you WANT to do:*
   Begin exercising

2. **Describe:**
   - **How:** Walking
   - **Where:** Around the block
   - **What:** 2 times
   - **Frequency:** 4 x/wk
   - **When:** after dinner

3. **Barriers:** have to clean up; bad weather

4. **Plans to overcome barriers:**
   ask kids to help; get rain gear

5. **Conviction 8 & Confidence 7**
   Ratings (0 - 10)

6. **Follow-Up:** next visit – 2 months
Action Planning Form

An action plan is one specific activity that you are going to do in the coming week. An action plan must be:

1. Something you WANT to do.
2. Something you reasonably CAN do. It’s better to say you’ll walk 3 days this week and do it, than to plan for five days and do four.
3. Behavior-specific – “I will stop eating ice cream,” not “I will lose weight.” What, where, how often, when, with who? The more specific the better.
4. Be something you are very confident of doing. On a scale of 1 to 10, your confidence should be at least 7, preferably 8 or higher that you will complete the whole plan. If your confidence is lower, re-work the plan – make it easier or get more help with it – until your level reaches 7.

Example: This week I will walk four times for 30 minutes at a time, around the block, after dinner, with my dog.

SAMPLE ACTION PLANNING FORM

Date: ___________________

This week I will ____________________________

I will do this ____________ times for ____________ (time or amount of activity)

I will do this when, where, with whom? (The more specific the better)

On a scale of 1 – 10, my confidence that I will complete the entire plan is: _____

Things that might get in the way of this plan are:

Ways I might overcome these problems are:

LOG: I carried out my plan on the following days:

<table>
<thead>
<tr>
<th>SUN</th>
<th>MON</th>
<th>TUES</th>
<th>WED</th>
<th>THUR</th>
<th>FRI</th>
<th>SAT</th>
</tr>
</thead>
</table>

NOTES: (anything interesting that happened)
**Doc Talk Card**

Patient and family advisors from the MCG Health System in Augusta, Georgia, developed the “Doc Talk Card,” a simple form to help patients and their families organize their thoughts and information in preparation for a health care visit. The forms are printed into notepads and are available in the reception area of ambulatory clinics.

![Doc Talk Card Image](image-url)
**Conviction Confidence Ruler**

This tool helps patients and providers discuss and rate two issues related to goal setting and healthy changes – how convinced a patient is that the change is necessary or important and how confident they are in their ability to achieve the goal.

**Conviction Ruler**

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<th>3</th>
<th>4</th>
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<th>8</th>
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<tr>
<td><strong>Totally Unconvinced</strong></td>
<td>Unsere</td>
<td>Somewhat Convinced</td>
<td>Very Convinced</td>
<td>Extremely Convinced</td>
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**Confidence Ruler**

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</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td><strong>Totally Unconfident</strong></td>
<td>A Little Confident</td>
<td>Somewhat Confident</td>
</tr>
</tbody>
</table>

Adapted from rulers developed by the Rhode Island Chronic Care Collaborative 2003
Self-Management Support Tool

The Self-Management Support Tool, developed by the Improving Chronic Illness Care program in Seattle, Washington, helps people with chronic conditions develop a personal plan to learn a new behavior, such as starting a program to increase their physical activity. The Healthy Changes Plan form may be used by patients either at home or during their office visit to plan their self-management goals for managing their chronic condition.

**Self-Management Support Tool**

**HEALTHY CHANGES PLAN**

Organization Name: ________________________

Name: _______________________________ Date: _________________

Phone: __________________

The healthy change I want to make is (very specific: What, When, How, Where, How Often):

My goal for the next month is:

The steps I will take to achieve my goal are:

The things that could make it difficult to achieve my goal include:

My plan for overcoming these difficulties includes:

Support/resources I will need to achieve my goal include:

My confidence that I can achieve my goal: (scale of 1-10 with 1 being not confident at all, 10 being extremely confident) ________

Review date: ___________________ with _______________
**Other Resources for Getting Started**

**Evaluating Health Information on the Internet**
The section on evaluating health information above gives people with chronic conditions guidance on navigating information found on the Internet.

**Family Doctor**
This website is operated by the American Academy of Family Physicians (AAFP). All of the information on this site has been written and reviewed by physicians and patient education professionals.

**Foundation for Informed Medical Decision Making**
The mission of FIMDM is to strengthen the ability of patients in making decisions about their health care. The site offers evidence-based information about treatment options, interviews with patients, decision-aids to guide decision-making, and other tools on a variety of conditions.

**HowsYourHealth**
Get a two-part "10-Minute Health Checkup." A survey that includes questions about health, habits, knowledge about disease prevention, and satisfaction with health care providers.

**Mayo Clinic**
The mission of this website is to empower people to manage their health. This is accomplished by providing useful and up-to-date health information and health improvement tools that reflect the expertise and standard of excellence of the Mayo Clinic. Sections include information on workplace stress, work-life balance, how to handle medical emergencies first-aid guide, and treatment decision guides for many conditions. In the "Ask a Specialist" section, Mayo Clinic specialists answer select questions from readers.

**MedLine Plus - Evaluation Health Information**
MedLine Plus is a service of the US National Library of Medicine and the National Institutes of Health. The “Evaluating Health Information” page lists a wide variety of resources available to patients and families to help them find credible information. Several of these resources are available in Spanish.

**My Shared Care Plan**
My Shared Care Plan was developed in partnership with health care professionals and patients. The tool offers patients with long-term conditions and their families a way to keep track of their health and health care.

**National Cancer Institute**
This website offers patients and health care professionals access to credible, current, and comprehensive information about cancer prevention, diagnosis, treatment, statistics, research, clinical trials, and news, as well as links to other NCI websites. The main content categories include General Cancer Topics, Clinical Trials, Cancer Statistics, Research and Funding, and News.

**National Center for Cultural Competence**
Sponsored by the Georgetown University Center for Child and Human Development, the National Center for Cultural Competence promotes culturally and linguistically competent health and mental services through providing training, consultation, research, and resources.
National Institutes of Health
This section of the National Institutes of Health website provides information about a wide variety of health topics including health conditions, mental health, alternative medicine, herbal medicine, and healthy lifestyles. You can sign up to receive their weekly Health Information Newsletter that can be sent directly to your computer free of charge.

National Library of Medicine: Health Topics
The National Library of Medicine, part of the National Institutes of Health, created and maintains MedlinePlus. There are lists of hospitals and physicians, a medical encyclopedia and a medical dictionary, health information in Spanish, information on prescription and nonprescription drugs, health information from the media, and links to thousands of clinical trials. The Medical Encyclopedia brings health consumers an extensive library of medical images as well as over 4,000 of articles about diseases, tests, symptoms, injuries, and surgeries. Online tutorials from the Patient Education Institute explain over 165 procedures and conditions in easy-to-read language.

National Multiple Sclerosis Society
Learn from others whose lives are touched by multiple sclerosis, whether it be from living with MS, caring for a loved one, or supporting the mission of NMSS. The site has the latest information about research, treatments, events, and news about MS. The "Living with MS" section is designed for patients and their families and includes personal stories and information about how to self-manage. Listen to inspirational stories or add your own in the Personal Connections section. Chat rooms and other ways to connect with others are offered in the MS World site. Ways to Wellness is the newest addition to the Resources section, providing information on alternative ways to improve health beyond medication. Online educational programs about MS are also available.

WebMD
Contributions include access to health and wellness articles and features and decision-support services that help consumers make informed decisions about treatment options, health risks and health care providers. WebMD provides detailed information on a particular disease or condition, analyzes symptoms, helps locate physicians, publishes periodic e-newsletters on topics of individual interest, offers online educational videos and message boards to connect with peers and health care professionals.

Resources for Caregivers
Caregiving and self-management can go together. Caregivers need to learn to take care of themselves, help loved ones self-manage, and deal with the health care system. Here are a couple of books and web sites that can help.

- *The Emotional Survival Guide for Caregivers* by Barry Jacobs. Covers dealing with the emotional, physical, and practical demands of caring for a disabled, sick, or demented loved one.
- *A Family Caregiver Speaks Up: It Doesn't Have to Be This Hard* by Suzanne Mintz. Tips for dealing with the health care system, self-help ideas, emotional guidance for individual family caregivers, and an inspirational call to arms for health policy change.
- National Family Caregivers’ Association
- National Alliance for Caregiving