Take Charge of Your Health

Self-Care and Self-Management Information for Individuals, Families, and Caregivers





The information in this document is intended as a resource for individuals and family members dealing with chronic or long-term health conditions; the information is not intended to substitute for medical or other professional advice. Individuals and family members should always speak with a health care professional about symptoms, specific medical needs, and any aspects of their health.

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Or visit our website: Adrc.kenoshacounty.org and click on the Health and Wellness tab.

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.

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. When it comes to 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.

Excellent Self-Management Guides

Living a Healthy Life with Chronic Conditions by Kate Lorig, Halsted Holman, David Sobel, and Diana Laurent Bull Publishing 2012. 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.

Understanding Your Condition. You don't need a medical degree. There is plenty of information out there and lots of ways to get it.

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.

Living Well: A Self-management Workshop - https://sites.google.com/site/livingwellinkenoshacounty/

Held in Kenosha County, Living Well is a 6-week workshop that helps you to manage pain and fatigue, reduce frustration and depression or anxiety, strengthen your body and mind, increase energy and be more in charge of your life. Living Well is a program created by Stanford University and is made up of six 2 ½ hour weekly sessions that take an innovative approach to teaching techniques and strategies for better health management. There is no charge for this workshop in Kenosha County.

Finding Health Information and Resources on the Internet

- Who runs the website? Can you contact them?
- How is the website paid for? Are any advertisements clearly labeled?
- 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?

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

- The National Institutes of Health includes valuable info on drugs and treatments, as well as basic health information.
- <u>Medline Plus</u> includes information on hundreds of specific conditions and symptoms. Search by age, question, and condition.
- The <u>American Academy of Family Physicians</u> provides a very reliable and user-friendly site for almost any condition.
- There are some reliable commercial health websites such as <u>WebMD</u> 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:

Websites That Help You Evaluate Health Information

- National Cancer Institute
- MedLine Plus Evaluating Health Information

Physical Movement. Finding comfortable, enjoyable ways to 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?

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 neighbor 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. Mel's weight, cholesterol, and blood pressure are all down, and he feels (and looks) better than he

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.

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.

Healthy Eating. Finding, fixing, and enjoying the foods that are right for you.

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

Eat Out and Eat Healthy

Eating out poses special challenges for healthy eating, see a useful page of ideas from the USDA ChooseMyPlate.gov, titled

When Eating Out Make Better Choices
(http://www.choosemyplate.gov/)

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.

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 Web MD. (Web MD. (Melp-you-lose-weight) A mellose-weight) A mellose-weight) A mellose-weight) Mellose-weight of the mellose-weight of th

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 <u>learn how to read and use these labels from the U.S. Departments of Health and Human Services and Agriculture</u>. (http://www.choosemyplate.gov/downloads/NutritionFactsLabel.pdf)

Reliable Dietary Advice on the Internet:

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

Making Medications Work for You. Having a chronic condition often requires that you take a medicine. Learn how to take them properly.

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. Keep track of your symptoms, treatments, self-management efforts and lab results. Bring your logs and medicines with you to appointments.

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?

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 (see appendix) 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.

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.

Stress Reduction. Coping with the tensions and pressures of life.

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

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.)

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.

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.

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

<u>View</u> a 10-minute relaxation YouTube video at your computer. (https://youtu.be/Xz-KDXWsepl)

http://www.mindfulnesstapes.com/

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.

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.

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.
- Take a Lighten UP! class. If you live in Kenosha County, are 60 years or older or are 18 years or older with a physical disability this class can help you to increase your happiness and manage your day-to-day in a more positive way. To find out more: go to http://adrc.kenoshacounty.org and click on the Big Red button for workshop details.

Dealing with Pain and Fatigue. Learn ways to maximize your energy and your comfort.

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.

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-

American Chronic Pain Association (ACPA)

ACPA has more than 600 chapters around the world, run by people with pain and physicians who treat it. Their site gives information about all kinds of chronic pain for providers and for people with pain.

http://www.theacpa.org

A government study of chronic pain programs shows they provide a great improvement in life function and a good improvement in reported pain.

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.

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 its 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, and 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.

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, might be very helpful. http://www.cfidsselfhelp.org/

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

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.

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.

Using Complementary and Alternative Medicine (CAM). Finding, researching, and safely using herbs, bodywork, acupuncture, and other therapies.

"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.

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.

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. (https://nccih.nih.gov/health/tips/selecting)

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?
- 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?

You're not alone in this

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 effect 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!

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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.

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 provider in the next section on "Tips for Active Listening During Health Care Visits."

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

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.

How Assertiveness Reduces Stress

Active listening – Learn to focus on who you are listening to, in order to understand what he or she is saying. Active listening helps you remember what was said and lets the other person know they have been understood.

http://www.studygs.net/listening.htm

Tips for Working with Your Doctor

The National Institutes of Health give <u>advice and tools</u> for having the best possible relationships with doctors.

(http://www.medicareinteractive.org/)
The Dana-Farber Cancer Institute
has information tailored for cancer
patients online.

(http://www.dana-farber.org/)
There is also additional information specific to teens.

(http://kidshealth.org)

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 <u>San Francisco Bay Area Black United Fund</u> and the <u>Chicago Southeast Diabetes Coalition</u>. Another is <u>Latino Health Access</u>, 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.

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,

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.

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 holds true 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.

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. 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.

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, and healthcare 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.

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 <u>Chronic Disease Self-Management Program</u> 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.

Staying On Track

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.

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 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. on your to-do list.

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.

We can't control all the factors that affect our health. But we can 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.

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).

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.

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 – 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.

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 <u>helpful information</u> about forgiveness and health. (http://www.mayoclinic.org/healthy-living/adult-health/in-depth/forgiveness/art-20047692)
- 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 counselor, 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 – 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?

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 – 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?

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-mange 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.

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.

Depression

Take a Lighten UP! class in Kenosha County

Lighten UP!, because life is all about learning. The Kenosha County Aging and Disability Resource Center is working with the University of Wisconsin-Madison to promote well-being. We are inviting you to take part in this exciting program that looks at ways to help you: enjoy happy experiences, find things that get in the way of feeling happy, use new tools to help you feel better, get to know new people, and enjoy life's journey. There is no charge for this class.

<u>Lighten UP!</u> -<u>https://sites.google.com/site/adrclig</u> <u>htenup/</u> **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. 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 your 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.

Useful Websites

General Health Information

Family Doctor - http://familydoctor.org/familydoctor/en.html

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 - http://www.healingwell.com/

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 - http://www.healthfinder.gov/

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 - http://www.mayoclinic.com/

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 - http://www.nlm.nih.gov/medlineplus/

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 - http://www.nih.gov/

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 - http://www.webmd.com/

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.

Centers for Disease Control Healthy Weight - http://www.cdc.gov/healthyweight/healthy_eating/recipes.html

A healthy lifestyle involves many choices, among them, choosing a balanced diet or healthy eating plan. This site includes recipes for various conditions such as heart disease and diabetes, as well as a searchable database of healthy recipes.

Mayo Clinic's Healthy Recipes - http://www.mayoclinic.org/healthy-lifestyle/recipes

If you're like most, you're looking for ways to make meals healthier yet still enticing. Get your juices flowing to plan healthy menus by browsing healthy recipes online and in cookbooks.

Health Information for Different Chronic Conditions

Diabetes Self Management - http://www.diabetesselfmanagement.com/Blog/

The Diabetes Self Management website has comprehensive information on diabetes as well as self-management. Get tips and insights from health-care professionals and people with diabetes, share your thoughts, and ask questions on their blog.

American Diabetes Association - http://www.diabetes.org/

They fund research to prevent, cure and manage diabetes, deliver services to hundreds of communities, and provide objective and credible information about diabetes.

American Heart Association - http://www.heart.org/HEARTORG/

Find videos, articles, booklets for download, patient stories, podcasts and more, including pages in Spanish, Vietnamese, and Chinese.

American Lung Association - http://www.lung.org/

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 - http://www.arthritis.org/

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 - http://www.acor.org/

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 III - http://www.nami.org/

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 - http://www.cancer.gov/

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 - http://www.nationalmssociety.org/

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.

Nutrition

The Nutrition Source - http://www.hsph.harvard.edu/nutritionsource/

This website, through the Department of Nutrition at Harvard School of Public Health, provides timely, evidence-based information on diet and nutrition. Expert faculty from the Department of Nutrition and other invited experts review all content before it is posted on the site, and all content is re-reviewed regularly.

Dietary Approaches to Stop Hypertension - http://dashdiet.org/default.asp

The DASH diet is based on research studies to stop hypertension, and has been proven to lower blood pressure, reduce cholesterol, and improve insulin sensitivity.

Tools

Depression Self-Screener - http://www.mentalhealthamerica.net/mental-health-screen/patient-health

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 - http://www.howsyourhealth.org/hc/

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 - https://www.sharedcareplan.org/HomePage.aspx

"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.

Workshops Offered in Kenosha County, WI

For all workshops offered in Kenosha County, you can visit our website at adrc.kenoshacounty.org and click on the big red button or call the Aging and Disability Resource Center (ADRC) to register and get more detailed information.

ADRC: 262-605-6646 Toll Free: 1-800-472-8008

Living Well: A Self-management Workshop - https://sites.google.com/site/livingwellinkenoshacounty/

A 6-week workshop that helps you to manage pain and fatigue, reduce frustration and depression or anxiety, strengthen your body and mind, increase energy and be more in charge of your life. Living Well is a program created by Stanford University and is made up of six 2 ½ hour weekly sessions that take an innovative approach to teaching techniques and strategies for better health management. There is no charge for this workshop.

<u>Healthy Living with Diabetes</u> - https://sites.google.com/site/livingwellinkenoshacounty/healthy-living-with-diabetes-1

A 6-week workshop that helps you to manage pain and fatigue, reduce frustration and depression or anxiety, strengthen your body and mind, increase energy and be more in charge of your life with diabetes. Healthy Living with Diabetes is a

program created by Stanford University and is made up of six 2 ½ hour weekly sessions that take an innovative approach to teaching techniques and strategies for better diabetes self-management. There is no charge for this workshop.

Stepping On Falls Prevention - https://www.jotform.com/form/10113124225

Stepping On is a seven-week workshop using adult education to develop the knowledge and skills needed to help older adults prevent falls. It focuses on how strength and balancing exercises, medication management, home safety, footwear, vision, and mobility all play an important role in fall prevention. There is a minimal charge for this workshop.

Lighten UP! - https://sites.google.com/site/adrclightenup/

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