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■ Living With Chronic Illness

Coping With Chronic Illness

More than 90 million Americans live with some form of a chronic illness, such as cardiovascular disease, cancer, lung disease, arthritis and diabetes. A chronic illness is a medical problem that lasts a year or longer, limits what a person can do, and requires ongoing care. The course of illness and level of disability from chronic diseases varies widely. Some have mild but manageable discomfort and few physical limitations. Others have persistent and debilitating pain and decreased quality of life.

Diagnosis and adjustments

With diseases such as cardiovascular or lung disease, while very serious, the diagnosis and treatment is relatively straightforward. However, with conditions such as autoimmune disorders, thyroid disease, chronic fatigue or multiple sclerosis, the diagnosis is anything but straightforward. It can take months or even years for an accurate diagnosis and viable treatment plan.

Feeling sick or tired and not knowing the cause makes some people question their sanity. Many of these people are relieved to finally have a diagnosis. "At least I know that I am not crazy" is a common response to the frustration associated with a lengthy diagnostic process.

When a diagnosis is made, an individual must adjust to the realities and demands of the illness and the treatments. When illness interferes with a person's mobility and independence, feelings of despair, loss and sadness are normal. They are usually resolved by family support and encouragement. However, in many instances chronic illness is associated with the onset of depression.

Depression

Any chronic condition can trigger depression but the risk increases with the severity of the illness and the level of life disruption it causes. Approximately 25 percent to 33 percent of individuals with a chronic condition will become depressed, significantly higher than the general population.

The rate for depression occurring with chronic illness is quite high. For example:

- **heart attack:** 40 percent to 65 percent
- **coronary artery disease (without heart attack):** 18 percent to 20 percent
- **Parkinson's disease:** 40 percent
- **multiple sclerosis:** 40 percent
- **stroke:** 10 percent to 27 percent
- **cancer:** 25 percent
- **diabetes:** 25 percent

Depression often aggravates the illness, especially if the illness involves pain or fatigue or disrupts social and family functioning. Depression can also intensify pain and cause fatigue that can worsen the loss of energy associated with chronic medical conditions.

Trusting your medical providers

Millions of people who cope with chronic illness are faced with agonizing decisions every day. And they may struggle with a health care system not designed to meet their medical needs or provide necessary information or adequate support.

Having a chronic condition almost always requires many visits to doctors and clinics. Believing in the competence of the medical team can provide much needed peace of mind. The concept of patient and family-centered care is essential in modern medical practice but even more important in managing chronic illness. It is important that you feel comfortable with your care provider.

Learn about your condition

Access to medical information has never been greater. There are countless professional medical resources available on the Web and through your health care provider. Ask your doctor where you can learn more about your condition. Learning about your illness allows you to collaborate with your doctor and take an active role in your treatment. Don't be afraid to ask your doctor questions.

Emotional and spiritual support

Having family and social support improves the perceived quality of life for individuals with chronic conditions. Even during the darkest hours of an illness, just knowing that someone cares and that you are not alone can make all the difference in the world. Nontraditional approaches to illness—including prayer, meditation, relaxation, medically-approved exercise and rhythmic breathing—have been shown to lessen the intensity of some symptoms and improve quality of life.

If you or a family member has a chronic condition, take heart because you are not alone. Ask for help and support from family members, friends or clergy. You may also call the toll-free phone number on this site to find available resources in your community.

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Helping a Child Cope With Chronic Illness

Many parents initially feel overwhelmed and helpless when their child is diagnosed with a chronic illness. The parent might not know information about the illness or understand the disease, and the child might not comprehend why he has been stricken with the disease. However, it is possible for parents to help their child cope successfully with his condition. These tips can help.

- **Learn about your child's disease.** Knowledge is power, and what you know about your child's condition can make

a big difference. Start by asking your doctor for information. Libraries and national organizations also may be helpful.

- **Teach your child about his disease.** Young children may not understand why the disease occurred and may assume it is a punishment. Help your child understand the illness by giving him honest, accurate and age-appropriate information.
- **Set up a regular schedule.** It is important to work with your doctor and form a regular treatment schedule. Arrange medication schedules to minimize doses during school hours. Teach your child to promptly report symptoms and to participate in her treatment as she gets older.
- **Contact the school.** After a treatment plan has been reached, especially if it involves routine and episodic medications, brief the school nurse and the child's teachers. Make sure that they understand the support your child needs to manage the illness and provide a plan of action for emergency situations. Ask for a teacher who is willing to stay in contact with your child and offer encouragement during hospitalizations and absences.
- **Consult the school nurse.** Parents often overlook the school nurse as a potential ally. The school nurse deals with chronic conditions, such as asthma, nearly every day and has a great deal of hands-on experience. She will be familiar with medication schedules and may be able to suggest coping strategies.
- **Maintain normalcy.** It is important for parents to help their child maintain as normal a routine as possible. Keeping this in mind, encourage physical and social activity within your child's limits.
- **Join a support group.** It often is helpful for a child to be in contact with others who have successfully adjusted to living with a chronic illness. Many organizations have local chapters with support groups for children and teenagers, as well as parents.
- **Maintain a positive attitude.** Qualities such as self-discipline and personal responsibility are learned through struggles with a chronic illness, and your child will gain confidence as he learns to cope with his disease.

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Pain and Depression

It seems obvious that persistent or chronic pain and depression would be connected. After all, nobody is happy when in pain.

But we are just beginning to understand the ways they are linked. Simply stated, pain causes depression, and depression causes pain.

The research shows that:

- Thirty percent of people with persistent pain conditions also suffer from clinical depression related to their pain.
- About 40 percent to 60 percent of patients being treated at pain clinics have symptoms of depression, including serious bouts of sadness, fear and despair.

Common chemical pathways in the brain

Some research shows that pain and depression share common chemical pathways in the area of the brain where our emotions originate. This helps explain why pain and depression often co-occur.

The presence of a chemical messenger called norepinephrine is linked to depression. And we now know that norepinephrine also affects how we experience pain. Depression seems to increase an individual's response to pain, or at least the perception of suffering associated with it. Conversely, chronic pain is stressful, debilitating and depressing in itself, creating a vicious cause-and-effect cycle.

How pain can disable, depress

Consider the example of an active 35-year-old who develops moderate low-back pain and is forced to abandon many of the activities he previously enjoyed. This increases stress, diminishes health and physical stamina and creates isolation from people associated with his active lifestyle.

Persistent pain keeps people from many of the things that make their life enjoyable. Genetics, family functioning and stability and social support also contribute to whether or not someone develops depression.

Fibromyalgia and depression

Fibromyalgia is a chronic condition characterized by widespread pain in the soft tissues (muscles, ligaments and tendons), fatigue and depression. It is perhaps the best example of a medical condition where pain and depression conspire. There is much debate among experts about the disorder's cause(s). Some experts argue that muscle and joint pain are symptoms of depression. Antidepressant medicines that work on norepinephrine (a brain chemical) reduce both pain and depression in some patients.

Shared symptoms

Pain patients treated at pain clinics report some of the signs and symptoms related to depression, including:

- decrease of physical conditioning, energy and endurance
- sleep problems
- decreased sexual activity
- increased family stress
- financial burdens and worries
- decreased self-esteem
- worry about further injury or sickness
- loss of self-efficacy (the belief that one can take care of oneself)
- mood swings, including irritability, anxiety and anger

Unfortunately, many people with chronic pain and depression do not seek appropriate care and often minimize the emotional impact when talking with their doctors.

Treating depression and pain

Telling your doctor about all your symptoms, including sadness and fear, is the first step in the treatment process. Your doctor will work with you to develop a treatment plan to reduce your pain and improve your physical functioning, emotional well-being and quality of life. Your treatment plan may include 1 or more of the following therapies:

- physical therapy
- pain medications
- antidepressant medications
- cognitive-behavioral therapy
- stress management activities such as: relaxation techniques, hypnosis and biofeedback
- supportive counseling
- family counseling

Chronic pain and depression are debilitating, but highly treatable conditions. Because pain and depression are multifaceted, a team of health professionals may be involved. Primary care doctors often refer patients to pain management specialists, particularly for complicated cases. If depression persists, a psychiatrist may be consulted to evaluate and prescribe medications as necessary.

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Managing a Chronic Illness During a Disaster

Surviving a natural or man-made disaster is no small thing, especially for those who have a chronic illness. During a disaster access to health care, personal support and medication are lessened. This leaves people with chronic medical

conditions at risk for serious medical complications—even to the point of death.

What is a chronic illness?

A chronic illness is a medical problem that lasts a year or longer, limits what a person can do, and calls for ongoing care. More than 90 million Americans live with some form of chronic illness. Examples of common chronic illnesses include:

- diabetes
- chronic obstructive pulmonary disease (COPD)
- heart disease
- chronic pain syndromes
- inflammatory diseases, such as rheumatoid arthritis

Prepare for an emergency

Because we seldom know when disaster will strike, it is important for those with chronic conditions and their caregivers to make specific plans and arrangements. Here are some tips to help you plan for and manage a chronic medical condition during a disaster.

1. **Let your family, friends, and others in your support network know of your condition and how to help you in an emergency.** Be specific. Get commitments from others to help in an actual emergency.
2. **Pack an emergency kit.** Have a bag that is readily available that contains:
 - an identification and medical information card with your name, address, phone number, insurance information, physicians' contact information and emergency contact person
 - a list of your specific illnesses and medications. The list should also include information about dosages and any allergies you may have.
 - an adequate supply of your medications—at least a week's supply if possible
 - any special equipment you require, for example, portable oxygen canisters
 - your personal hygiene products
 - special foods or supplements as required by your condition
3. **Talk to your doctors about emergency medical plans.** Ask specific questions about your medical care and what you should do if disaster strikes and your doctor cannot care for you.
4. **If you need regular treatments, determine who could provide this for you if the clinic or health professional is not available.** In some cases a family member can learn how to give medications and treatments during an emergency. For example, some patients with lung disease require breathing treatments that are usually performed by a respiratory therapist but can be easily learned by a nonprofessional. In the case of more complicated treatment, contact the local or neighboring hospital emergency department to arrange treatment during an emergency.
5. **If you are not able to walk, be sure to notify the local authorities and disaster response agencies, such as the Red Cross.** Give them specific information about your condition so that disaster workers know how to contact you, and let you know about their disaster, rescue and evacuation procedures. Let them know of any special needs you have.
6. **Plan where you will go and which health care providers will care for you if you have to leave your community.** Your doctor can advise you of clinics and specialists in other communities.

7. **In the event of a disaster, don't panic.** Simply carry out your plans and keep your wits about you. Use your energy to stay focused on the solution, not the problem.

Planning is the single best thing you can do to prepare for an emergency. Seeking the wisdom and support of your family and friends in preparing for disaster and making emergency plans is time well spent.

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The Robert Wood Johnson Foundation. Partnership for Solutions. Better Lives for People With Chronic Conditions, www.chronicnet.org.

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Maintaining a "Normal" Lifestyle With Diabetes

Living with diabetes means living with certain limits and paying more attention to your day-to-day health than most other people. Complications can make those limits even tighter. You also may face a certain level of discrimination on the job or at school—though federal law aims to make treatment of people with diabetes as equal as possible.

Does this mean people with diabetes can't lead what most people consider a "normal" life? No. But to do so takes some planning and attention to detail.

When you travel

Anticipate diabetes-related risks and make sure you can get medical care if you get sick.

- Get a thorough check-up before you leave.
- Experts advise assembling a travel folder with all your relevant medical information, prescriptions, and a detailed description of how to manage your diabetes.
- You'll need to pack blood-testing supplies (including extra batteries for the glucose meter), insulin and syringes or oral medication (as appropriate), snacks to help you control your blood sugar if a meal is delayed and, as always, your medical ID bracelet or necklace.

Eat carefully

The recommended diabetic diet, in general, isn't much different from the kind of healthy diet that everyone should have—low-fat and high-fiber, with limited alcohol. Carbohydrate control is made easier with non-caloric soft drinks and non-sugar sweeteners.

Eating out at restaurants or friends' homes may require some advance work, such as telling the host ahead of time about your meal plan requirements and taking along some form of fast-acting sugar. In restaurants, try ordering a la carte, and stick with plainly cooked, familiar foods. Never eat unacceptable foods to avoid offending your host or cook.

Let the people around you know you have diabetes

Diabetes doesn't take a break for your work or social life. You should tell coworkers and friends about your diabetes and what you must do to deal with it. By giving up some sense of your privacy, you'll be repaid many times over in understanding, cooperation and encouragement. And if the world looks at you a little differently knowing you have diabetes, you can use this to your advantage by setting an example of how competent and successful someone with diabetes can be.

June Biermann and Barbara Toohey, diabetes educators and authors who have published a number of books on the disease, say diabetes can make you live a healthier life—with the right food, sufficient exercise and self-discipline—than you would have led without it. By forcing you to change and develop good habits, they say, diabetes teaches you how to look after your overall well being. "If you can change in one area, you are capable of change in other areas," they say. "You can improve not only your health but your whole life."

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