

Living With Chronic Disease

Living with a long-term (*chronic*) condition can be physically and emotionally challenging. It is important for you to:

- Have an active role in your treatment and your physical and emotional self-care.
- Learn ways to manage the condition and its effects.

What actions can I take to manage my chronic condition?

Manage your stress



Stress is a fact of life and it is often a part of living with a chronic disease. Having a chronic disease increases your chances of also developing depression. Dealing with depression is more serious than dealing with stress. To help manage your stress levels and prevent depression:

- Become aware of what causes your stress to start (*your stress triggers*).
- Practice identifying how your stress affects you physically, mentally, and emotionally.
- Identify the best methods to deal with the current stress.
 - If you cannot directly resolve your stress, try to accept it and move on.
 - If you cannot accept or change your stress, think about what you can do to help yourself feel better physically, mentally, or emotionally.
- Ask for support from people you trust, such as friends and family.
- Take good care of yourself:
 - Be active and exercise regularly. Good physical health helps you deal with long-term stress and helps to prevent physical illness.
 - Develop self-soothing skills, such as meditation, positive self-talk, yoga, or listening to music.
 - Eat a healthy diet.
 - Get enough sleep.
 - Keep following your normal routines.
 - Treat yourself when you feel stressed, such as by getting a massage or taking a hot bath.
 - Avoid overeating, drinking a lot of alcohol, smoking, or using drugs.

Take your medicines

- Make it your goal to take part in all treatment decisions (*shared decision-making*). Ask about possible side effects of medicines that your health care provider recommends, and tell him or her how you feel about having those side effects. It is best if shared decision-making with your health care provider is part of your total treatment plan.
- Take over-the-counter and prescription medicines only as told by your health care provider.
- **Do not** skip any dose of medicine.
- **Do not** stop taking any of your medicines before you ask your health care provider if it is safe to stop.

- Refill your prescriptions before you run out.

Stay close to your loved ones

Having a chronic disease can be difficult for you and for your loved ones. It is important to realize that your loved ones, especially your spouse or significant other, may also be feeling stress. Your loved ones may:

- Worry about you and about seeing you in pain.
- Need to talk with someone about their feelings related to your illness. They may benefit from a support group for caregivers.
- Take on the role of your caregiver. In some cases, this may make you feel angry or you may feel like their care is taking away from your self-care.
- Need clear guidelines from you about how they can be most supportive. Ask them for what you want, such as having their company or being left alone.

How to recognize changes in your condition

- Educate yourself and your family members about your chronic disease. Know what symptoms to watch for, and work closely with your health care team.
- Ask your health care provider what physical and emotional changes need to be reported to him or her. These changes vary based on your specific chronic disease. Some common things to tell your health care provider about include:
 - Sudden weight gain or loss.
 - Shortness of breath while at rest.
 - Loss of appetite.
 - Feeling tired all the time.
 - Emotional changes, such as depression or anxiety.

Where to find support

Finances

If you are taking medicine, you may be able to get the generic form, which may be less expensive than brand-name medicine. Talk to your health care provider to see if this may be an option for you. Some makers of prescription medicines also offer help to patients who cannot afford the medicines that they need.

Community resources



Talking to specially trained people about your condition or emotions can greatly benefit you. Sources for getting this help include:

- Your health care provider.
- A support group for people living with a chronic disease.
- A spiritual leader.
- A counselor.
- Community services that are committed to your chronic disease. Organizations such as the American Diabetes

Association, American Lung Association, and the Epilepsy Foundation may have more information about these services.

- The National Council on Aging.

Contact a health care provider if:

- You have symptoms of depression, such as:
 - Feeling sad, down, or depressed more often than not or every day for more than 2 weeks.
 - Losing interest in activities that you normally enjoy.
 - Trouble sleeping or having a change in sleeping patterns.
 - Losing your appetite or noticing changes in your appetite.
 - Difficulty concentrating.
 - Being irritable or crying for no reason.
- You find yourself often worrying about the future.
- You have headaches, back pains, and abdominal pains.
- You are worried about your alcohol or tobacco use.
- You feel powerless.

Get help right away if:

- You have thoughts about hurting yourself or others.

If you ever feel like you may hurt yourself or others, or have thoughts about taking your own life, get help right away. Go to your nearest emergency department or:

- **Call your local emergency services (911 in the U.S.).**
- **Call a suicide crisis helpline, such as the National Suicide Prevention Lifeline at 1-800-273-8255 or 988 in the U.S. This is open 24 hours a day in the U.S.**
- **Text the Crisis Text Line at 741741 (in the U.S.).**

Summary

- Living with a long-term (*chronic*) condition can be physically and emotionally challenging. It is important for you to have an active role in your treatment and your physical and emotional self-care.
- Educate yourself and your family members about your chronic disease. Know what symptoms to watch for, and work closely with your health care team.
- Having a chronic disease is hard on you and those you care about most. Your loved ones may also be feeling symptoms of stress.
- Seek help if you feel sad, down, or depressed more often than not or every day for more than 2 weeks.

This information is not intended to replace advice given to you by your health care provider. Make sure you discuss any questions you have with your health care provider.

Palliative Care

Palliative care helps to improve the quality of life for people coping with serious and life-threatening illnesses. It involves care of the body, mind, and spirit. Palliative care services are different for each person and are based on the person's needs and preferences. Services often occur in the hospital or in a long-term care setting. Palliative care requires a team of professionals and loved ones. Services include:

- Steps to control pain and other symptoms and to provide comfort.
- Family support.
- Spiritual support.
- Emotional and social support.

Palliative care is a way to bring organized services to a person for comfort and peace of mind. It can be helpful to a person and his or her family and friends during the course of an illness.

What is the difference between palliative care and hospice?

Palliative care and hospice have similar goals. They both aim to manage symptoms, provide comfort, improve quality of life, and maintain a person's dignity. The difference is that palliative care can be offered during any phase of a serious illness, from diagnosis to cure. Hospice care is usually offered at the end of life, often when a person is expected to live for 6 months or less.

Who can receive palliative care services?

Palliative care is offered to children and adults who are seriously ill. It is often offered when a person:

- Is not responding well to treatment.
- Needs pain management.
- Has side effects from treatment, such as chemotherapy, that are difficult to manage.
- Has symptoms from the effects of surgery.
- Has a diagnosis of an advanced disease, or a disease that shortens his or her life.

A health care provider will usually recommend palliative care services when more support would be helpful. Family members and friends may also receive palliative care services to help manage stress and other concerns.

Who makes up the palliative care team?



The following people make up a palliative care team:

- The person receiving care and his or her family.
- Physicians, including primary health care providers and specialists.
- Nurses.
- A social worker, psychologist, or psychiatrist.

Depending on one's needs, the following people may also be included on a palliative care team:

- A pain specialist.
- A hospice specialist.
- A financial or insurance consultant.
- Religious or spiritual leaders.
- A care coordinator or case manager.
- A bereavement coordinator.

The team will speak with the person and his or her family about:

- The person's physical symptoms, such as pain, nausea, vomiting, shortness of breath, and the need for a pain specialist and hospice specialist.
- Life and death as a normal process.
- Advance directives or living wills, health care proxies, and end-of-life care.
- Stress, depression, and anxiety symptoms.
- Treatment options and how to maintain as much function and mobility as possible.
- Spiritual wishes, such as rituals and prayer.
- Legacy and memory-making activities.

The palliative care team helps a person talk about difficult issues and will address spiritual and emotional concerns.

Where to find more information

- National Institute on Aging: www.nia.nih.gov
- National Hospice and Palliative Care Organization: www.nhpco.org

Summary

- Palliative care helps to improve the quality of life for people coping with serious and life-threatening illnesses. It involves care of the body, mind, and spirit.
- The specific services are different for each person and are based on the person's needs and preferences.
- Palliative care is a way to bring comfort and peace of mind to a person and his or her family.

This information is not intended to replace advice given to you by your health care provider. Make sure you discuss any questions you have with your health care provider.