



Coping

with Autoimmunity

Mission

Autoimmune Association is dedicated to the eradication of autoimmune diseases, and the alleviation of suffering and the socioeconomic impact of autoimmunity through initiating, fostering and facilitating collaboration in the areas of education, public awareness, research and patient services in an effective, ethical and efficient manner. Autoimmune Association is the only national nonprofit organization bringing a national focus to autoimmunity as a category of disease and a major women's health issue.

Take Control of Your Illness

Being diagnosed with a serious, long-term health condition can be frightening and overwhelming. Often, the unpredictability of such an illness can make you feel out of control. This feeling can cause stress, anxiety, anger and depression for both you and your family. Understanding these responses will help you determine what works best for you in overcoming these feelings

Suggestions to Help You Cope With and Manage Chronic Illness:

UNDERSTAND THE ILLNESS & TREATMENT PLAN

Understand the illness and the treatment plan established by your physician. Ask questions of your doctor about your specific condition, especially what changes and symptoms you can expect to experience.

DO YOUR OWN RESEARCH

Do your own research to become familiar with the disease, symptoms, diagnosis and treatments. Accurate knowledge can help you feel empowered. Some autoimmune diseases are quite rare, and your physician may not be knowledgeable about the disease. Seek out a specialist who is familiar with the disease and its treatment.

FOLLOW THE TREATMENT PLAN

Follow the treatment plan designed by your physician. If you are unsure of the treatment plan, do not be afraid to ask questions or to get a second or third opinion. Ask questions about the side effects of medications and medical tests and the effect or benefit they will have on your condition.

REMEMBER YOUR DOCTOR IS YOUR PARTNER

Don't be intimidated by the medical professional with whom you are entrusting your care. Remember that your doctor is your partner in fighting the disease, but you are your best advocate! Be honest with your doctor and be up front about any concerns you might have when it comes to your care.

BE HONEST HOW YOU FEEL

Let your doctor know if some new symptom is occurring. Persons with chronic illness often feel that their doctors will think they are chronic complainers if they are honest about how they are feeling. They may worry that their doctors will simply give them more prescriptions, adding to the many medications they are already taking. Another fear patients may have is that if they complain too much, their doctors may not want them as patients. It is much better to discuss what is going on and how it might be treated than to worry about what the doctor thinks.

EMOTIONAL UPS AND DOWNS ARE TO BE EXPECTED

Expect to have a variety of emotional responses as you cope with a serious, chronic illness. Typically, newly diagnosed patients feel the "anger, denial, bargaining, depression, and acceptance" cycle identified by Kubler-Ross as a response to coping with a significant loss and major life changes. You may feel isolated from others and experience the fear of an unknown future. Understand that you might experience feelings of worthlessness, fear, depression, anger, and self-pity, and that it is normal to experience these feelings. Chronic illness often has many ups and downs that can be emotionally draining. How you handle this emotional roller coaster is very important and personal.

PACE YOURSELF

Learn to pace yourself. Pacing your activities can help put you in control of the illness. It is important to listen to your body and stop before you feel overly tired. Patients often feel guilty if they slow their pace and, therefore, rest only when they are not feeling well or when they are very tired. This forced rest period can last a few days, which can leave you feeling pressured to "catch up" and accomplish all you were unable to do during the time you were resting. This creates more stress, which can lead to anxiety and depression. The unhealthy cycle of high activity and prolonged rest periods can interfere with managing the disease process, and with some autoimmune diseases, create a need for more medication to control the symptoms that accompany those illnesses. By learning to spread out your activities, you will be able to accomplish just as much while feeling better, both physically and emotionally.

MAKE HEALTHY CHOICES

Make healthy food choices. If you have an autoimmune disease that requires a special diet, following that diet is very important. Doing so can play a major role in the management of your illness and in your sense of well-being. Learning the ins and outs of nutrition and healthy food preparation puts you in control of your diet and can improve disease management. Ask your physician what foods are best to avoid and which to incorporate into your diet.

Coping Strategies & Techniques

You must find out what works best for you. Understand that both your emotional state and coping efforts can be fatiguing in themselves. A positive attitude and approach will have a significant impact on your quality of life and help you to develop effective coping skills.

Healthy Coping Techniques:

Keep your lifestyle as normal as possible (after being diagnosed).

Pace yourself and your activities at home and at work.

Use relaxation techniques (listening to music, coloring or painting, deep breathing exercises, yoga/stretching, taking in nature, meditation).

Keep a positive mind-set, be constructive and optimistic.

Engage in leisure activities or hobbies that make you feel productive and happy (reading, cooking, exercising, journal writing, etc.).

Join a support group, or a community group, or reach out to others for support online.

Give yourself and your family time to adjust and accept the reality of your diagnosis.

Set realistic short-term goals for yourself.

Get involved by becoming an advocate or raising awareness about your illness.

Communicate your feelings to others in a constructive manner.

Seek professional counseling if you are having trouble coping or feeling hopeless and depressed.



Additional Coping Resources

Anxiety and Depression Association of America

8701 Georgia Avenue, Ste #412, Silver Spring, MD 20910
(240) 485-1001 | www.adaa.org

American Psychological Association

750 First St. NE, Washington, DC 20002
(800) 374-2721 | www.apa.org/helpcenter

Center for Coping

12 West Cherry Street, Hicksville, NY 11801
(516) 822-3131 | www.coping.com

Emotions Anonymous

PO Box 4245, St. Paul, MN 55104-0245
(651) 647-9712 | www.emotionsanonymous.org

Mental Health America

500 Montgomery Street, Ste 820, Alexandria, VA, 22314
Phone (703) 684.7722 | www.mhanational.org

National Alliance on Mental Health

3803 N. Fairfax Drive, Ste 100, Arlington, VA 22203
(800) 950-6264 | www.nami.org

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