Coping with Autoimmune Disease

Take control of your illness

When you are diagnosed with autoimmune disease (AD), it is normal to be overwhelmed with the complications to your life a chronic illness can have.

The following are tips and suggestions we hope that will provide guidance to you for living with your AD.

AARDA's mission is to alleviate the suffering of individuals afflicted with AD though research, education, and advocacy.



www.aarda.org 586-776-3900 Consider the following suggestions to manage your illness better.

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

Follow the treatment plan designed by your physician. If you are unsure ask questions, or get a second or third opinion. Ask about the side effects of medications, medical tests, and the potential impact on your condition.

Let your doctor know if some new symptom is occurring. Do not be concerned about the perception of being a chronic complainer, more medications, or being a problematic patient. Honesty is more important than self-preservation. Communication about your health is vital in getting proper care.





You can expect to have a variety of emotional responses. Newly diagnosed patients can 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 fear of the unknown future.

Dealing with the emotional aspect of having a chronic illness is a challenge. The unpredictability of a serious illness makes you feel out of control of your well-being. This feeling can cause anxiety for both you and your family.

Understanding these responses and their causes will help you determine what works best for you in overcoming them. Be open and forthright with those around you. It is important that you do not blame everything that goes wrong on your illness.

Use "I" messages with others. For example, say "I am not feeling well and I really could use your support." "You" messages are usually interpreted defensively and get in the way of the real issue, which is your need for support. It's okay to lean upon your support system when you need to. Don't be intimidated by the medical professional. Your doctor is your ally in fighting your disease. Be honest with your doctor. You hurt only yourself if you are not upfront with your physician. Play a role in your treatment plan. Once satisfied that is right for you, follow it.

Fatigue accompanies many AD. Learning how to pace your activity level can help put you in control of your illness. Listen to your body and stop before you feel over tired. Pacing your activity to help sustain a relatively normal and consistent energy level. Do not feel guilty for managing your health, take breaks even if your having a "good" day. Do not try to make up for resting.

The cycle of high activity and prolonged rest periods can interfere with managing the disease process, and with some AD, create a need for more medication to control the constitutional symptoms that accompany those illnesses. By learning to spread out your workload, you will be able to accomplish as much while feeling better both physically and emotionally.

For AD that requires a special diet, following it is important. Diet can play a major role in health management and your sense of well-being. Learning about nutrition and healthy food preparation puts you in the control of your diet and management of your disease. Chronic illness often has many ups and downs that it can be emotionally draining. Handling this emotional roller coaster is important and personal. Some techniques include: trying to keep up a normal life-style, pacing yourself and your activities, using relaxation techniques, covering up your pain, and joining support groups. You must find out what works best for you. Understanding that it can fatiguing trying to cope is a step in the right direction.

Give yourself and your family time to adjust. Adjusting to a significant change like an AD diagnoses takes time. Viewing life with AD as one more of life's challenges is helpful. Understanding that it is normal to experience feelings of worthlessness, depression, anger, and self-pity, can help master coping techniques.

Joining a support group for persons with chronic illness is very helpful to many patients. Professional counseling may be in order if you are unable to cope in spite of every effort to do so.

Understand that you did nothing to cause your illness and that life is not always fair. Bad things do happen to almost everyone at some time in a lifetime. It is how we deal with these life changes that make the difference between a life of coping and a life of moping.







Living with an autoimmune disease

Do...

- follow your treatment plan.
- become as knowledgeable about your disease as possible.
- take your medicine as prescribed.
- try, within reason, to avoid contact with infectious diseases.
- keep a record of the drugs you are taking and keep it with you.
- avoid anxiety and tension.
- keep a list of question to ask your doctor.
- get enough rest.
- follow good health habits with regard to smoking and alcoholic beverages.

Do not...

- ignore your doctor's directions or self-prescribe your own drugs or treatment.
- blame all of life's problems on your illness.
- believe every "popular" article which appears in print.
- let your diseases victimize you and your family.
- over exert yourself physically or emotionally.
- hesitate to seek professional counseling if you cannot adjust or if depression lingers on.
- turn control of your disease over to everyone else. You control your illness.
- give up.

