

## Document your family medical history.

Take an inventory of your family's health problems, expanding your research beyond your immediate family to cousins, aunts, uncles, and other relatives. Since current research points to a genetic component in most autoimmune diseases, you should know the health histories of your first-degree relatives, including grandparents and cousins, if possible. In a family with a history of autoimmune disease, an individual has a higher risk of developing autoimmune diseases in general, rather than a specific autoimmune disease. Once you know your family history, you can communicate it effectively to your doctor who can then assess the possibilities with a degree of accuracy and order appropriate tests.

## Keep a symptoms list.

People with autoimmune diseases often suffer from a number of symptoms that, on the surface, seem unrelated. In addition, they may have suffered from other seemingly unrelated symptoms throughout their lives. It's important, therefore, to make a list of every major symptom you've experienced so that you can present it clearly to your doctor. List and date the symptoms in order of concern to you. Don't leave out any symptoms that you think are insignificant. Keeping a daily journal of symptoms can help to pinpoint what they are, how long they have been bothersome, and the time of day they usually occur.

When the nurse calls you into the exam room, review your list – or, better yet, give the list to the nurse to record in your chart. When you see your doctor, be sure to mention the symptom that bothers you most. This is often the problem to which your doctor will pay the most attention. Unless your problem list is lengthy, or the doctor notes a serious problem which takes higher priority, she/he usually will be able to answer all of your questions.

## Getting a diagnosis can be a challenging journey.

For people with autoimmune disease, getting a proper diagnosis can be one of the most difficult challenges they face. AARDA conducted a survey of autoimmune disease patients and found that the majority of those eventually diagnosed with autoimmune diseases had significant problems in getting a correct diagnosis. Many were incorrectly diagnosed with a variety of conditions that have no specific blood test to confirm the diagnosis. Many were told that their symptoms were “in their heads” or that they were under too much stress. Furthermore, the survey revealed that 62 percent of autoimmune disease patients had been labeled as chronic complainers or were told that they were overly concerned with their health in the earliest stages of their illnesses. On average, autoimmune patients see four different doctors over a three-year period before an accurate diagnosis is made. Since many autoimmune diseases have confusing and unrelated symptoms, AARDA urges patients to follow the steps in this brochure to arrive at a timely and accurate diagnosis.

# Tips for Getting a Proper Diagnosis of an Autoimmune Disease



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## Ask about the doctor's and hospital's experience in treating autoimmune disease.

All patients want to receive the highest quality treatment, but it is difficult to evaluate the physicians and hospitals to whom you entrust your care. It's a good idea to ask the physician whether he or she treats patients who have the specific disease that has been diagnosed. Generally speaking, the larger the number of patients being treated by the physician for a particular autoimmune disease, the better. A specialist should be adept at managing the therapies used to treat a particular autoimmune disease.

## Obtain a thorough clinical examination.

Tests vary for different autoimmune diseases. A diagnosis usually is reached through careful analysis of laboratory test results combined with a patient examination and history. When facing test situations, a patient might ask the following questions:

- What is the purpose of this test?
- Are there any alternatives?
- Is this an outpatient or inpatient procedure?
- Can I anticipate any pain, discomfort or claustrophobia, and if so, can I take medication to make me more comfortable?
- How much does the procedure cost? Is it covered by my health insurance?
- Can I get a copy of the test results? (You will need a copy of lab test results to give to other doctors if you are going to seek a second opinion.)
- What will they tell me about my condition?

## Get a second, third and fourth opinion, if necessary.

Sort out your treatment options at the beginning before symptoms worsen, but check first to see whether your insurance will pay for a consultation. Since autoimmunity has just begun to be recognized as the underlying cause of more than 100 known autoimmune diseases, and because symptoms can be vague and not visibly apparent, many doctors don't think to test for autoimmune diseases. If a doctor doesn't take your symptoms seriously, dismisses them as stress-related (when you do not feel as though you are under any excess stress), or refers you to a psychologist, find another doctor. You know you are not feeling well – don't be intimidated. When trying to get a correct diagnosis, it is important to be assertive.

## Partner with your physicians to manage your disease.

Once you have settled on your treatment plan, keep in mind that your health is best managed through a partnership – you and your medical team. If more than one medical specialist is treating you, select one to be the “main” provider to manage your medications. This physician will need to agree to take the lead role. Establish a dialogue, a give-and-take where there is mutual respect. Don't be afraid to ask questions, including:

- What are the treatment options?
- What are the advantages and disadvantages of each?
- How long will the treatment last?

## Learn to deal with the long-term effects of autoimmune disease.

The complicated process of obtaining a diagnosis and developing an appropriate plan of treatment, may mean that you will be subjected to a great deal of uncertainty. Accept that patients with autoimmune disease and their families very likely will need to adapt to a different lifestyle.

Sharing your situation with others can have enormous benefits, including eliciting the kind of emotional support that is so necessary for people with undiagnosed autoimmune diseases. Some people use the Internet to research their symptoms and ask questions. Doing so might help advance your personal research, provide clues to what disease you are experiencing, and be a means of discovering resources. Because the Web can also be a source of misinformation, be sure to evaluate what you read. Be especially cautious when using online chat rooms because they can be full of misleading and inaccurate medical information. If you don't have your own computer, many libraries now provide free access to the Internet. Ask your librarian whether this service is available. You might also contact your hospital community education department, your health department, or a nonprofit disease-specific organization to learn more or to connect with a support group.