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Managing your fatigue: Energy conservation for people
with autoimmune disease

Most people who have autoimmune diseases like multiple sclerosis, rheumatoid arthritis and lupus (SLE or systemic lupus erythematosus) struggle with tiredness and fatigue, at least at times. It can be one of the worst symptoms of the disease, because it can interfere with leisure, social activities and tasks that people need to do every day. Severe fatigue can also make it hard to cope physically, mentally and emotionally with the disease.

Energy conservation management for people with autoimmune diseases was developed by occupational therapists. It has been proven to reduce fatigue in people with multiple sclerosis. Energy conservation programmes involve teaching you about your body and energy, your disease, and how you can manage your activities to get the most out of your day. If there is no energy conservation programme available in your area, an occupational therapist who specialises in your disease may be able to help you.

Here we summarise some of the main elements of energy conservation. You can read more about the research into this and other non-drug options, especially exercise, for reducing fatigue in autoimmune diseases here (URL: <http://www.informedhealthonline.org/index.407.en.html>).

Education about fatigue management and energy conservation

Occupational therapists can teach you the basic facts about managing fatigue. This may include, for example, how to predict how much energy you will need for everyday activities and how to plan in advance so that you can cope better with your fatigue.

Energy conservation education for autoimmune diseases generally involves one-to-one sessions with an occupational therapist, but some therapists also hold group classes and provide self-study materials. It might take 12 hours overall - so with one hour per week, it takes about three months to complete.

Some of the topics that would be covered are the basics of, in effect, "budgeting and banking" your energy and pacing yourself:

- The value and role of rest during the day for people with autoimmune diseases, and how to incorporate it into your daily life

- Learning how to communicate about your energy and rest needs to other people
- Body mechanics and what good posture means for you
- Energy-saving movement principles and postures
- Modifying your environment to save you energy, including developing "stations" where you can do things more easily, perhaps sitting down
- Separating fatiguing tasks into single components
- Setting priorities as well as goals for the middle term and longer term - including already planning your day the evening before, so that you get the most out of each day
- Activity analysis
- Making sure you get enough leisure and enjoyable activities in your day

The basics of energy conservation management are about how to live a balanced lifestyle when you have an autoimmune disease. This kind of information is not likely to make a difference to the progress of your disease or how much pain you experience. But it could help you reduce your fatigue. Research so far has shown that energy conservation management could have a long-term impact on your fatigue: a year after participating in programmes like this, people with multiple sclerosis still showed less fatigue than people who had not had this kind of education.

When you are thinking ahead about the next day, you could, for example, ask yourself these questions:

- What do I need to get done tomorrow, and what would I like to do?
- How much energy am I going to need to carry out those plans?
- What time of day will I have the most energy?
- How am I going to make sure that I get some quiet rests in the day, and when can I take breaks?
- Are there any particular devices that I should take with me to make the day easier tomorrow?
- What would be the best order to do these things in?

Autoimmune diseases have flares and better times. It can be a real rollercoaster, physically and emotionally. Learning how to adapt your life to these changes can make the worse days less exhausting and easier to cope with.

Glossary

fatigue

Fatigue is a term used to describe paralyzing mental and physical exhaustion that may also be accompanied by heightened emotional sensitivity. In contrast to usual tiredness, fatigue only responds to rest or sleep to a very limited extent.

Sources

Lamb AL, Finlayson M, Mathiowetz V, Chen HY. The outcomes of using self-study modules in energy conservation education for people with multiple sclerosis. *Clin Rehabil* 2005; 19: 475-481. [PubMed summary (URL: <http://www.ncbi.nlm.nih.gov/pubmed/16119402?dopt=Abstract>)]

Mathiowetz VG, Finlayson ML, Matsuka KM, Chen HY, Luo P. Randomized controlled trial of an energy conservation course for persons with multiple sclerosis. *Mult Scler* 2005; 11: 591-601. [PubMed summary (URL: <http://www.ncbi.nlm.nih.gov/pubmed/16193899?dopt=Abstract>)]

Mathiowetz VG, Matuska KM, Finlayson ML, Luo P, Chen HY. One-year follow-up to a randomized controlled trial of an energy conservation course for persons with multiple sclerosis. *Int J Rehabil Res* 2007; 30: 305-313. [PubMed summary (URL: <http://www.ncbi.nlm.nih.gov/pubmed/17975450?dopt=Abstract>)]

Neill J, Belan I, Ried K. Effectiveness of non-pharmacological interventions for fatigue in adults with multiple sclerosis, rheumatoid arthritis, or systemic lupus erythematosus: a systematic review. *J Adv Nursing* 2006; 56: 617-635. [PubMed summary (URL: <http://www.ncbi.nlm.nih.gov/pubmed/17118041?dopt=Abstract>)] [Informed Health Online summary (URL: <http://www.informedhealthonline.org/index.407.en.html>)]

The German Institute for Quality and Efficiency in Health Care (IQWiG)

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Evidence basis of our health information

Our information is based primarily on systematic reviews of the effects of health care. Systematic reviews are necessary to gain an objective picture of health care. In order to do this, a clear question is formulated. Researchers then find all the relevant studies that could answer this question. They then evaluate those studies.

You can find a list of the evidence and other scientific literature on which this information is based at [**www.informedhealthonline.org**](http://www.informedhealthonline.org)

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