

Autoimmune Resource & Research

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ARRC



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HOW TO HANG ON UNTIL THE PAIN LETS GO

One of the most difficult parts of having lupus is the constant readjustment of our lifestyles. This may be caused by increased disease activity, but more often by discomfort or chronic pain which may not be reflected in laboratory tests.

Health care professionals get frustrated in their efforts to help relieve this discomfort. After a period of time your doctor or nurse may appear to develop a "deaf ear" to your complaints of pain. After an assessment looking for a "new" cause of the pain finds nothing significant, we are frequently told it is "just lupus" and to "learn to live with it". This only increases our frustration and often feelings that our complaints are not heard or believed.

There are efforts by some caregivers to change this sequence of events. Realising that pain does not always fit into past definitions or expressions, verbal or non-verbal, a new definition describes pain as being what, when and where the patient claims. This definition also eliminates the game of "real" versus "imaginary" pain. Although the changing ideas of what pain really is will help ease our frustration, we still need many techniques to help ease the pain. There are many things available to use. Medication, physical therapy, bio-feedback and TENS are useful in some situations, but all require a doctor's prescription and may not be available at 3 am. It helps to have a variety of options to help us hang on until the pain lets go.

The number one defence is **DISTRACTION**. We can decrease our awareness of pain and increase our tolerance by directing our attention to something other than the discomfort. The distraction can be anything, but enjoyable experiences such as music, humour, TV or movies, hobbies and sharing affection are the most relaxing. Most people utilise this technique but have been unaware of its role in pain management and do not consciously use it to decrease pain.

REST is a highly effective and underrated management technique. Although sleep and relaxation are frequently interrupted by musculo-skeletal pain, they are most effective in minimising this discomfort. Occasionally minor tranquillisers and anti-depressants are prescribed to overcome the sleep disturbance and allow a healing rest to take place. We can rest tender muscles and sore joints by decreasing our activity for a short time. We must guard against the tendency not to resume our activity, as exercise is important to maintain muscle tone and physical condition.

HEAT AND/OR COLD treatments, with or without massage are beneficial. Cold has a numbing effect from a few minutes to a few hours. Heat is soothing and helps promote muscle relaxation. Safeguards must be taken against frostbite or burns, especially if there are circulatory or sensation deficits.

The next defence is **IMAGERY**. Imagining the discomfort while relaxed and using thought to destroy the problem is a proven method. An example of imagery is to think of a headache as a spot on a fabric. The spot is attacked by an enzyme detergent and disappears. Do this for fifteen or so minutes two or three times a day while listening to relaxing music. It becomes more effective with repetition.

RELAXATION AND STRESS REDUCTION are similar methods. Meditation and stress reduction tapes or self-help books are easily obtained to teach these techniques. Generally they use a step-by-step process of learning to achieve the level of relaxation helpful to healing and pain modification.

Membership in a SUPPORT GROUP, such as the Scleroderma/Lupus Support Society, is very helpful. It provides the opportunity to meet others who have dealt with similar situations. Increased understanding of lupus will decrease the anxiety which contributes to pain. Probably for the first time we are able to meet people who understand and have experienced what we are going through. Volunteering and working to help others, promotes a positive outlook and occupies our minds with something other than our discomfort.

These techniques of pain management, as with all aspects of lupus, must be individualised. Each person needs to find that method or combination of methods that are most effective. This may require some practice before you give up on a technique. It is important to be aware of all pain defences because what may not work today may ease the pain tomorrow.

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These techniques are useful for those who have Scleroderma or Sjogren's Syndrome and are troubled by chronic pain.

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