

**When You're Thrown For a Lup-us...  
Coping with Lupus**

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**What is Lupus?**

- \* Systemic Lupus Erythematosus (SLE) is an autoimmune disease that causes the immune system to develop antibodies that react against the individual's own tissue (NIAMS, 2010).
- \* SLE can affect various parts of the body, especially the skin, joints, blood, kidneys and brain.
- \* Lupus effects of the brain, both neurologically and psychologically. This includes strokes, seizures, psychosis, mental fog and mood disorders.

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**Mood Disorders & SLE**

- \* SLE patients have a 50% chance of developing some form of psychological distress either because of direct central nervous system involvement, compounding systemic complications, effects of treatment, or adjustment related to chronic illness (Kozora, Ellison, et al., 2005).
- \* Sense of helplessness with an unpredictable disease effects the quality of life in lupus individuals (Thumboo & Strand, 2005).




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## Mood Disorders & SLE

- \* Psychotherapy is highly advocated to decrease disease activity and flare-ups (Wallace, 2003).
- \* Depression is the most common coping problem in lupus (Wallace, 2005).
- \* 91% of individuals with lupus report some level of depressive symptoms (Goozee, 2012).
- \* Poor psychological adjustment to lupus correlates with increase physical disability (Hochberg & Sutton, 1988).




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## Stages of Grief

Being diagnosed with lupus can bring up many feelings for individuals, learning to cope with the disease and coming to a place of acceptance is a process. Elizabeth Kubler Ross introduced 5 stages of grief (1969).

- DENIAL
- ANGER
- BARGAINING
- DEPRESSION
- ACCEPTANCE

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## Causes of Mood Disorders

- \* Psychological Factors (stress, sense of failure, unhealthy thinking patterns)
- \* Biological Factors (genetics, hormones, brain chemicals)
- \* Environment (toxic exposure, poor diet, unhealthy relationships)
- \* Lupus (inflammation, pain processing, medication side effects, dealing with a chronic illness)

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## Depression

- \* Feelings of sadness or guilt
- \* diminished interest in activities
- \* insomnia/hypersomnia
- \* poor concentration or decreased memory
- \* weight gain/loss
- \* loss of energy, fatigue or tired
- \* Crying spells
- \* feelings of worthlessness
- \* Irritability or frustration
- \* Reduced sex drive
- \* Slowed thinking, speaking or body movements
- \* Back pain or headaches
- \* Sense of hopelessness
- \* recurrent thoughts of death.

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## Pain & Depression

- \* Depression can cause pain — and pain can cause depression.
- \* Pain and depression create a vicious cycle in which pain worsens symptoms of depression, and then the resulting depression worsens feelings of pain.
- \* 90-95% of individuals with chronic pain will report some level of depression.

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## Anxiety

- \* Highly correlates with depression.
- \* Some anxiety is normal, however for others anxiety is a persistent problem, that interferes with daily activities such as work, school or sleep.
- \* This type of anxiety can disrupt relationships, enjoyment of life, and over time it can lead to health concerns and other problems.
- \* Pain itself can lead to anxiety. The pain may be experienced as dangerous or attacking. It may stir up feelings of vulnerability or loss of control.

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## Anxiety

- \* Restlessness or feeling on edge
- \* Being easily fatigued
- \* Difficulty concentrating
- \* Irritability
- \* Muscle tension/trembling
- \* Sleep disturbance
- \* Sense of impending doom
- \* Palpitations or tachycardia
- \* Shallow/difficulty breathing
- \* Gastrointestinal distress
- \* Chest pain
- \* Chills or hot flashes
- \* Feeling dizzy/lightheaded
- \* Panic attacks
- \* Specific phobias

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## Treatments of Mood Disorders

- \* Best treatment is psychotherapy and medication used simultaneously with healthy lifestyle changes (stress management, nutrition, sleep hygiene, exercise, relaxation skills, spirituality).
- \* Psychotherapy is highly advocated to decrease disease activity and flare-ups (Wallace, 2003).




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## 1. Psychotherapy

- \* Recommended psychological treatment for generalized anxiety is cognitive behavioral therapy (CBT). This includes learning techniques to let go of worries, ways to deal with unhealthy thinking, becoming more present focused and relaxation to reduce chronic tension.
- \* Psychotherapy may also provide pain coping skills including stress management, sleep hygiene, pacing, nutritional counseling and mood management.
- \* Discuss with your doctor, seek referrals, call your insurance or community mental health resources.

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## 1. Psychotherapy (cont.)

- \* Health (Pain) Psychologist – trained and specializes in treating individuals with health conditions and chronic pain.
- \* M.D., Ph.D., Psy.D., L.M.F.T., or L.C.S.W.
- \* Medicare & Medical cover mental health treatments.
- \* State Referral Hotline for health & human services is 2-1-1. Low cost mental health resources are available. [www.211.org](http://www.211.org)

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## 2. Medications

- \* Sometimes psychotherapy and healthy lifestyle changes are not enough to treat mood disorders, your doctor may suggest adding medication.
- \* Common medications include antidepressants and anti-anxiety drugs. These drugs help restore proper function of neurotransmitters in the brain.
- \* Antidepressants are not addictive, will not make you euphoric, have mild side effects for most (dry mouth, sleepiness, etc.), can help with sleep & appetite, FDA approved for pain.

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## 2. Medications (cont.)

- \* SNRI's- Selective Norepinephrine Reuptake Inhibitors are FDA approved to treat depression as well as pain. (2 common brand names include Cymbalta and Pristiq).
- \* SSRI's- Selective Serotonin Reuptake Inhibitors are FDA approved for depression and anxiety, however may also help with sleep and pain. These include Prozac, Zoloft, Paxil, Lexapro and many others.
- \* Must be taken daily, takes weeks to start effect, average patient tries 1-3 antidepressants, SSRI's do not interact with most lupus medications.

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## Self Care Techniques

- \* 1) **Exercise:** Numerous studies have shown that exercise is beneficial for treating depression and anxiety. Regular gentle exercise for at least 20 min three times a week. Start slowly and gradually increase, do on a daily basis, consult physician.
- \* Regular exercise increases energy and promotes healthy sleep.
- \* Exercise also increases endorphins, the body's natural pain reliever.

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## Self Care Techniques

- \* 2) **Socialization:** Even when struggling with social isolation, it is important to be around other people. Regularly schedule socialization at least once a week. Isolation feeds into depression, making it worse.
- \* Choose who you socialize with wisely, avoid stressful or negative individuals. We are sensitive to those around us.
- \* Even leaving the house to sit alone in a café has been shown to be helpful for those with depression.
- \* Laughter truly is one of best medicines, decreasing depression and increasing endorphins.

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## Self Care Techniques

- \* 3. **Relaxation Techniques :** Visualization techniques, guided imagery, body scan, meditation, yoga, tai chi and prayer. Learning to slow down your mind, diaphragmatic breathing and relax your muscles is crucial. Deep meditation increases endorphins.
- \* Guided relaxation CD's are a good resource, YouTube or various websites have several relaxation audio/video tracks with different themes (chronic pain, stress, anger, etc.).
- \* Tai Chi, yoga, and Pilates offer both relaxation training as well as gentle exercise. Check out gyms, Community/ Senior centers or community colleges for classes.

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## Self Care Techniques

- \* 4) **Laughter:** Research shows the average child laughs around 300 times per day, the average adult only 17 times.
- \* Reduces tension, stress, lowers anxiety and irritation which are all factors that contribute to depression.
- \* Laughing has been found to reduce pain. Not only does it distract you, but it releases pain relieving endorphins.
- \* Lowers blood pressure and blood flow, improves breathing, and helps you lose weight.
- \* DVR your favorite sitcom, watch comedians on YouTube.com, call you friend with the witty sense of humor.

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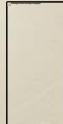
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## Self Care Techniques

- \* 5) **Sleep:** Average adult needs 6-8 hours of sleep. Sleep is important for brain function, managing stress, cardiovascular health and immune system function.
- \* Keep a routine, going to bed and waking at the same time. Avoid long naps, caffeine late in the day, avoid alcohol, reserve the bed for sleep and sex only.
- \* Address sleep disorders, such as sleep apnea and teeth grinding.
- \* Talk to your doctor.




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## Self Care Techniques

- \* 6) **Nutrition:** Maintain a healthy weight through a balanced diet and safe gentle exercise. Extra weight decreases healthy immune system function, decreases restful sleep, decreases energy, and increases joint pain. Malnourishment can decrease muscle mass and increase pain.
- \* Lupus medications and depression can effect your weight. Be proactive surrounding yourself with healthy snacking options.
- \* Many health insurances include nutritional counseling. Talk to your doctor.




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## Self Care Techniques

- \* 7. **Create a Routine:** A regular routine and structure keeps us engaged and focused. Slowly start a routine that includes enjoyable activities, exercise, self-care, socialization and laughter.
- \* Find a balance in life. Work, family, friends, volunteer work, spirituality, doctors and most importantly—you.
- \* Always make time to care of yourself, be active in your self-care.
- \* 8) **Meaning & Purpose:** You are an individual living with lupus, it does NOT have you.

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## Questions




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**Thank you.**




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