

lupus **FACT SHEET**

LEARNING TO LIVE WELL WITH LUPUS: Preventative Coping Strategies for Emotional Health

Developing preventative coping strategies to live well with lupus can involve learning different ways of thinking, feeling and acting to adapt to the challenges of a chronic illness that affect your entire life. Successful adaptations may involve addressing a variety of areas in your life, including the intellectual, emotional, spiritual, physical and social domains of day-to-day living. Successful coping means minimizing threats to personal integrity and emotional balance, while maximizing body function. The following suggestions may help you learn and develop different ways of dealing with lupus.

- **Communicate needs.** One of the toughest tasks is learning to say “no,” even when doing so is in your best interests. A note by your phone that says “no thanks” can prompt you to say it as needed. Learn to assert yourself when you know that giving in to the wishes of others will cause you emotional and/or physical distress. Assertive behaviour is being honest and open with yourself and others, without placing blame or creating feelings of guilt. Using “I” statements conveys honest feelings and concern for others. An example: “I miss spending time with you and I’d like to go hiking with the group. I will join you at the finish of your hike and maybe we could all have a coffee or drink together. I hope you understand.”
- **Manage your time and your schedule** to avoid overbooking and creating stress. Acknowledging your limitations is difficult. You may not have to give up enjoyable activities. You may have to

learn to do things differently or to delegate parts of a task. Be flexible when you ask for help. Others may not do things exactly as you would or as fast as you would like.

- **Deal with emotions.** Acknowledge your losses. Try and define what you have lost. People with lupus frequently talk about losing friends, independence, energy, confidence, job satisfaction, financial security or their prior healthy selves. These are serious losses and the feelings associated with them need to be recognized and understood as a grieving process. This process takes time, and talking about your feelings will move you closer to emotional healing. Feelings associated with grieving are depression, anger or frustration, guilt and shame, denial and acceptance. Give yourself time and admit to your feelings with supportive friends, family or health care providers. A counsellor, therapist, or spiritual resource may also be consulted for difficulty coping with emotions. Explore creative ways of helping yourself deal with emotions, such as music, exercise therapies, art or journal writing.

Don’t ignore the spiritual elements of your whole-person wellness. Improving communication in personal relationships, optimizing your community networks, involvement with organizations and causes that you believe in, and spiritual practices such as prayer and meditation may all be helpful to you as you learn to live well with lupus.

- Practise positive thinking. Self-talk is the endless stream of automatic thoughts that run through your head every day. Automatic thoughts can be positive or negative. Life after a diagnosis of lupus is different. You are still the same person, but you become aware that there are some things about your disease that you cannot control. Some people with lupus can have recurring negative thoughts, such as “I can’t do my job anymore” or “I won’t be able to take care of myself” or “Nobody will ever want to date me.” These negative thoughts influence behaviour that can sometimes lead to feelings of failure or inability to cope with or alter problems associated with lupus.

Our thoughts and belief systems inform how we think about events in our lives. It’s not necessarily the event that occurs, but the thinking about the event that stirs up the trouble. This can feed into a vision of a sad past, negative present and a bleak future. Negative thoughts are hard to give up because they serve a useful role at times, such as protecting you from risk, such as risk of failure or rejection. Studies have shown that negative thinkers who focus on their inability to control physical symptoms and emotional problems in their life are more likely to become depressed and physically inactive. Changing from a negative to a positive thinker involves developing awareness of negative thoughts. The process is simple, but takes time and practice. Stop and evaluate what you’re thinking throughout the day. Put a positive (reality-based) spin on your negative thought. Be gentle and encouraging to yourself and don’t say to yourself anything you wouldn’t say to someone you care about.

Example:

Negative thought “I can’t do all that I used to. I’m no longer competent.”

Positive thought “I can do much of what I want to. I can be actively involved in life, as long as I don’t overdo it.”

Work on one or two thoughts that you think can change to make a positive difference in your life with lupus

To manage stress and emotions, become aware of such negative thoughts and learn to confront them with reality and you may be able to change them. Work on one or two thoughts that you think you can change to make a positive difference in your life with lupus. Make a list of your negative thoughts. Counter them with the real situation.

Eventually, your self-talk will automatically become positive.

- Challenge your expectations. Some people are perfectionists, constantly striving for excellence. A lifestyle of compulsive perfectionism can become physically and emotionally damaging to a person coping with lupus. Adaptation to new challenges can be encouraging and fulfilling. A new challenge to consider, if you have a tendency to perfectionism, is to perfect the art of adjusting your goals. Be flexible in adjusting your expectations and you may be rewarded with a more positive attitude and increased activity. Keep the outcome secondary and enjoy the process of learning and developing yourself.
- Boost your self-esteem. Maintenance of a strong sense of self-worth is vital to keeping yourself healthy. The better you feel about yourself, the more you’ll care about supporting a healthy lifestyle. All the previous suggestions for learning

to express and manage emotions and controlling negative thoughts will help you feel more confident in your abilities and improve your self-esteem. Follow these simple guidelines if you have days when you need a bit of support and inspiration:

- Structure your day with small goals you can meet.
- Talk to a friend. You know who is willing to take the time to listen.
- Spend time with other people. It helps to feel connected and less alone.
- Help someone. Your life does make a difference to other people.
- Treat yourself to something you enjoy. You are special and you deserve a gift from yourself.
- List the reasons you are liked. People enjoy being with you and it helps to remind yourself of that.
- List the things you do well. Then do one of them.
- Embrace joy and happiness and make laughter a part of your day.

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People who live well with lupus and successfully cope with its challenges share certain characteristics. They have insight and understanding into their personal strengths and weaknesses and have realistic expectations of themselves. They can define their personal goals and find gratification in their accomplishments. Living well with lupus requires a strong sense of self-worth and a feeling of control over their life events. People who live well with lupus believe they can influence their world and shape the course of their illness in their life.

Systemic Lupus Erythematosus is an autoimmune disease that affects thousands of Canadians, mostly women in their childbearing years. Symptoms vary greatly from patient to patient and treatment is highly individualized. Patients are urged to contact their physician or health professional with any questions or concerns they might have. For more resources and information about lupus, visit the Lupus Canada website at www.lupuscanada.org.

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