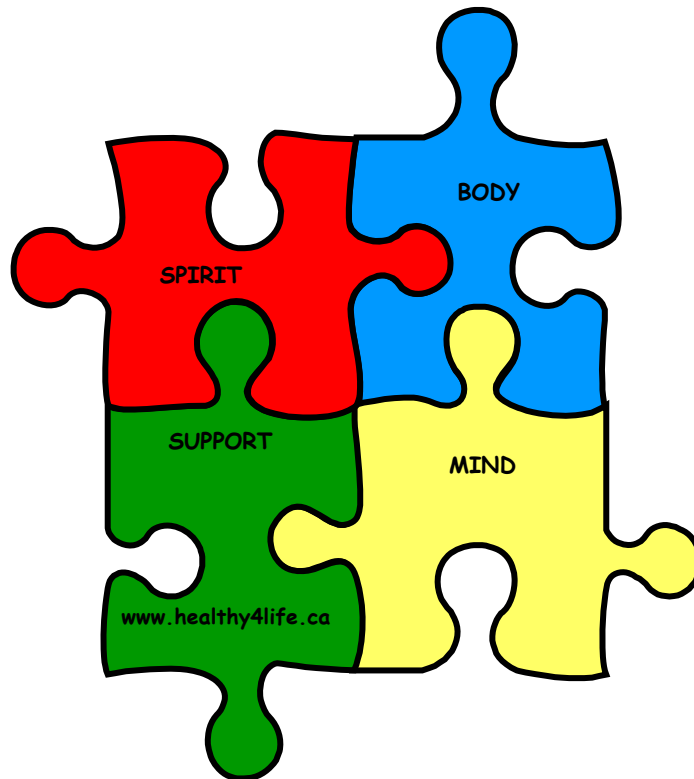


Lupus Etiquette

For people who do not have lupus

**BEING RESPONSIBLE
HELPFUL NOT HURTFUL**



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Life Skills & Health Coaching

Lupus Etiquette

- 1 Do not offer unsolicited advice about my medication, eating, exercise or other aspects of lupus.**

You may mean well, but giving advice about someone's personal habits, especially when it is not asked for, isn't very nice. Besides, many popularly held beliefs about lupus ("you should just get more exercise" "you should just eat properly") are out of date or just plain wrong.

- 2 Do realize and appreciate that lupus, whether discoid or systemic, is hard work.**

Lupus management is a full time job that I didn't apply for, didn't want and can't quit. It involves thinking about what, when, and how much medication I take, supplements I take, while also factoring in nutrition, movement, exercise, stress, photosensitivity, sleep quality and quantity, medication reactions, food allergy and sensitivity and so much more—each and every day.

- 3 Do not tell me horror stories about your grandmother or other people with lupus you have heard about.**

Lupus is challenging enough, and negative stories like these are not reassuring! Besides, we now know that with good lupus management, odds are very good you can live a long, relatively healthy and happy life with lupus.

4 Do offer to join me in making healthy lifestyle changes.

Not having to be alone with efforts to change; like starting an exercise program, eating whole foods, staying involved in social activities, is one of the most powerful ways that you can be helpful. After all, healthy lifestyle changes can benefit everyone!

5 Do not look so horrified when I have conspicuous rashes and sores, patches of missing hair, put on excessive sunscreen or sun protective clothing, have to take medication including needles in public or can barely move.

It is not a lot of fun for me either. Checking rashes and taking medications are things I must do to manage lupus well. If I have to hide while I do so, it makes it harder for me.

6 Do ask how you might be helpful. Be specific with what you can offer to do as lupus cognitive challenges may be flared up that day.

If you want to be supportive, there may be lots of little things I would probably appreciate your help with. However, what I really need may be very different than what you think I need, so please ask first.

7 Do not offer thoughtless reassurances.

When you first learn about my lupus, you may want to reassure me by saying things like, "Hey it could be worse!" This won't make me feel better and the implicit message seems to be that lupus is no big deal. However, lupus is a big deal.

8 Do be supportive of my efforts for self-care.

Help me set up an environment for success by supporting healthy lifestyle and nutrition choices. Please honour my own decision to decline a particular exercise, food or outing even when you really want me to try it. You are most helpful when you are not being a source of unnecessary temptation or criticism.

9 Do not peek at or comment on my lab results and other tests without asking me first.

These numbers are private unless I choose to share them. There are Many reasons for having numbers and other results that are sometimes too low or too high. Your unsolicited comments about these numbers and other results can add to the disappointment, frustration and anger I already feel.

10 Do Offer your love and encouragement.

As I work hard to manage my lupus successfully, sometimes just knowing that you care can be very helpful and motivating.



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