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Lupus: How to make friends with the enemy

Dian Syarief , Jakarta | Sun, 05/10/2009 12:47 PM | Opinion

I know very well that the The Jakarta Post normally dedicates its Opinion pages to strategic issues such as political, social and economic issues. Some readers may protest to the editors for allowing an article on Lupus disease to appear in this section. But, believe me, discussing this issue is no less strategic than issues of our presidential election, or the ongoing global economic collapse.

For anyone, including politicians who are losing their power or business people who are seeing their companies collapse, this article is about hope, about the need for self-healing, and to accept the most bitter parts of life and live with them happily.

Let us get back to the main issue. Systemic Lupus Erythematosus (SLE) is widely known as "the Great Imitator", causing doctors to misdiagnose it and thus prescribe the wrong treatments.

In facing a chronic disease, where the cause and cure are unknown, the best approach is not to make the disease into an enemy, but to make it a friend. That way, people living with Lupus, "Lupies", can maintain their energy for fighting the disease, stay wise and rational, and retain the ability to find blessings behind the adversity. The key words here are: Befriend Lupus.

Ways that we can live with Lupus and make it into a friend can be categorized into two dimensions: those in the physical/medical dimension and those in the spiritual dimension.

The ultimate aim of a human existence is to be happy here in the world and in the hereafter. Happiness can be defined as freedom from rejection, anger, depression in the form of sadness, unease, anxiety fear and other negative feelings. For those living with Lupus, the ups and downs of their physical condition affect the psyche. For some, this can really affect their psychological condition.

For instance, someone with a previously upbeat psychological condition can decline as their physical health deteriorates (accompanying a prolonged physical disease), resulting in a prolonged sadness. This condition should be avoided. Those with low spiritual and psychological conditions feel an emptiness and cannot experience happiness even when their physical health is good or there is no physical pain. In this condition, emptiness and unhappiness can still show.

Conversely, some whose psychological and spiritual condition is very good are not robbed of their happiness but their physical condition deteriorates. Although "the body is sick, the soul is healthy". Those who have good psychological and spiritual conditions are serene and remain positive even when their physical condition is low. Therefore, for Lupies whose health is always in yoyo, it is important to aim to keep in a good spiritual condition.

It is clear that Lupies need to synergize their efforts in maintaining these two dimensions - the physical and the psychological/spiritual - in a balance to achieve happiness and quality of life.

First, accepting the fact that we live with Lupus is the first step to befriending the disease. Questions such as: "Why me?", "Why Lupus", "What did I do to deserve this?" will only increase denial, frustration and anger, without making the situation better. Lupies only have two choices: To let the disease have them and make their lives miserable, or to control their disease and make it into a friend and arrange a new life pattern with it.

Second, the relationship between Lupies and their doctors is a long term relationship. Good communication is very helpful during the treatment process. In Indonesia, non-medical treatments, which are usually referred to as alternative medicine, is a phenomenon itself. However, Lupies and their families need to be cautious; they need to examine and select offers of alternative treatments critically.

Third, avoid physical exertion, psychological stress and exposure to direct sunlight. Lupies need to embrace a healthier lifestyle and adjust to their limitations in order to reduce risks of aggravating their disease.

Fourth, join support groups. Fighting diseases together is easier because we can share our feelings, experience and knowledge. Group members and volunteers work well in supporting and motivating each other.

Fifth, increase your spirituality. You need all the strength you can get to face the challenges life has given to us, including chronic diseases such as Lupus. This strength can be drawn from our faith in God. Some

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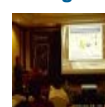
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important spiritual conceptions are: Illness is a form of God's love toward His servants; God never tests His servants beyond their ability to endure; illness wipes away sins; patience has no boundaries; and there is always a blessing behind any misfortune.

Sixth, find financial support and do good financial management. Burdens will certainly increase when one has Lupus. Priorities in household spending must be adjusted because the costs of treating Lupus may eat up a large portion of the budget. Take advantage of Support Groups that offer discounted rates for Lab tests, prescriptions and others. Some Support Groups may also offer financial help with certain conditions and limitations. Talk to your doctors about generic brands of medicine. Some hospitals also provide help for needy patients through government programs. Help from extended family is sometimes needed for patients to afford medical treatments.

In the end, it is Lupies themselves who determine the success or failure of this process. No matter how much attention, love and support they have in their families, without strong determination to continue fighting and never give up, it is very difficult to achieve the desired results. Let's hope the spirit always burns in the heart of all Lupies.

The writer has been living with lupus since 1999 and now lives with only 5 percent of her vision. She has dedicated herself to supporting friends living with Lupus through Care for Lupus and Care for Low Vision support group under the umbrella of the Syamsi Dhuha Foundation, of which she is the chairwoman.

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