

A Day in the Life



of an Autoimmune Arthritis Patient

Created by the International Foundation for Autoimmune Arthritis

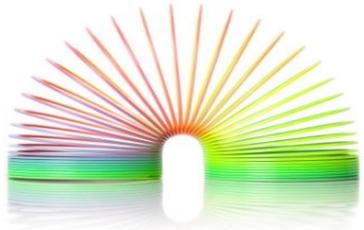


Providing support for someone with Autoimmune Arthritis diseases can be a challenging, yet rewarding experience. Autoimmune Arthritis diseases offer unique circumstances and are very different than dealing with other more consistent illnesses. Knowing when to offer help, what kind of help, and when to step back can be tricky. Here are some tips to help you gauge how to best support your friend or family.

Supporters & Caregivers

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Supporting Your Friends & Family



At some point, every support person has questioned how provide the best mental and emotional help for their loved ones. Providing for someone with Autoimmune Arthritis is very different than helping people with other illnesses.

Autoimmune Arthritis diseases are ever changing. Every day is different. Pain can change from minute to minute, and different areas can hurt at different times. For example, one day a patients' feet can be swollen and painful, then the next day their arms can stiff and numb. Be flexible and understand that it is common with these diseases for things to shift quickly. ***Being prepared for a quick shift from "feeling fine" to "full flare" is essential.***

Don't assume a patient needs help. Try and let the patient do what they can. They may perform slower than normal, and the task may not be perfect, but it is important they maintain as much independence and freedom as possible. **However, in saying this, if you observe a patient to be struggling, it is completely appropriate to offer assistance; matter-in-fact, if you didn't offer to help during obvious times of struggle your action could be deemed as uncaring and the patient may be apprehensive to ask for your help in the future.**

Don't be afraid to ask specific questions. If you simply ask, "How are you today?" you may get as vague an answer as your question. "Pretty good", "not great", "fine", etc. Patients often deal with chronic pain, which means at some level it does not entirely go away. Try asking specific questions, such as, "How much pain/fatigue are you experiencing today?" Adding a few simple words will show the patient not only that you care, but that you **understand their disease.**

One major misunderstanding is when supports equate a patients symptoms with the symptoms they experience as a result of everyday life. For example, Autoimmune Arthritis fatigue is very different than yours. You might be able to reduce your fatigue with coffee, soda, an energy drink or sleep. Autoimmune Arthritis fatigue does not go away unless the cause is addressed. The cause, unlike your fatigue which may be caused by staying up too late, occurs when the patients' own bodies cells fight one another, causing inflammation. That inflammation typically causes a fever and other flu-like symptoms.

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**But you
don't look
sick?**

A Night Out

Autoimmune Arthritis diseases are unpredictable, to an extent, in that it can suddenly flare up for no obvious reason. While a patient can attempt to manage their activity level to prevent this from happening, it still can. Don't take it personally when we have to cancel plans. It frustrates patients to have to cancel or alter plans, but if this happens understand it's not because they want to, it's because they have to.

Be flexible with your activities. Instead hiking or dancing, consider a movie night. Going out to dinner too much tonight? Order it to go and have a picnic in the living room.

Finally, keep in mind that being spontaneous isn't always as fun as it sounds- especially to a patient who didn't plan for the extra energy consumption. Planning ahead is key to managing these diseases, so it's best to plan the night out days in advance- this way there's time to delegate energy leading up to that special evening!

Autoimmune Arthritis diseases start at a cellular level. It takes years for the internal attacks happening inside of the body to cause enough damage to be visible...but then it's too late. All damage from these diseases is permanent and irreversible, even if the patient goes into remission. Remission means slowed or stopped disease activity. Unlike other diseases that go into remission, it doesn't necessarily mean there isn't lifelong disability involved.

If you have a stomach ache, and we can't see it, does that mean it isn't real?

Don't offer unsolicited advice. If you have information you feel may benefit your friend or loved one, present it in a way that doesn't suggest it is a cure all or will make it all better. Unless something manipulates these diseases on a cellular level, it won't do enough to stop the progression.

Thank you for being a friend or family to someone with Autoimmune Arthritis diseases. We know these situations can be challenging, emotional, and frustrating. Not knowing how to help can be equally mind boggling. Hopefully this answers some of the questions you have.

