

MAKING PEACE WITH THE UNWANTED COMPANION--FIBROMYALGIA

Ellen[not her real name] leads a double life. Just like Superman.....well, sort of.

Some of the time, she can't keep an appointment, or locate her car keys, or find her way out of a store or to her friend's house in Cherry, or remember names, or sleep for more than a few hours at a time, or even make herself get off the sofa. She's moody, sensitive to sounds, confused by simple directions, and has mild to wild pain in at least 6 different body parts. But she can deal with all of that---as long as she can isolate herself enough to keep her secret life hidden from as many people as possible.

It's only during her 'other times,' that most of the world sees Ellen. That's when she goes about her day getting things done, feeling, looking and acting pretty much like everyone else out and about. And worrying whether she'll be able to pull it off long enough to make it to the back to the 'safety' of her car or home.

But most of the folks around her have no idea that Ellen has fibromyalgia. And even if they know, they don't really 'get it.'

How can they? Even the medical community has about scratched its head raw over this mysterious set of symptoms—or syndrome. It's not even a disease—most often nothing to point to in an ex-ray or a test result. Meanwhile those symptoms mount a full-scale dramatic production within the body. The main characters are pain, fatigue, depression, and confusion ("fibro fog")---with bladder infections, brittle nails and hair, and numerous others rounding out the minor roles.

Sometimes Ellen has no symptoms at all for 10 minutes, or an hour, or even a day. She never knows when or for how long, and she dares to be optimistic. After six years of sharing her life with fibromyalgia, she still often has the expectation that she can do what she wants for as long as she wants and not be tired or sore. Then reality sets in and she reminds herself, "No, not today."

When she was first diagnosed, Ellen used talk a lot about it and all the ailments—because it was new and strange. But when she started feeling like a broken record, and bored with her own conversations....she stopped talking and started problem solving.

Both Ellen and her family have to cope with the household and life they share with fibromyalgia—the invisible family member, the uninvited guest, the unwanted companion. Relationships are strained because friends and family can't possibly understand Ellen's on-going triple roller coasters of pain, fatigue, and mood swings. They are never quite sure when she can concentrate on discussions, and when she just needs a sympathetic ear or some space and time to herself.

Over the years, and despite the frustrations, Ellen has learned to cope, to get by, to identify and avoid specific triggers of the symptoms. She makes lists, notes events on a prominent wall calendar, and has posted a "do and don't" list her husband can refer to when she's having a bad day. She makes routines of eating, relaxing, and moving. She's become more patient and respectful of her body. She spends time with family and friends, does things to help others—or just for fun, and tries not to expect too much of anyone.

She has done her best to just ignore her unwanted companion, and thought that was enough....until recently.

This past summer, Ellen attended a week-long fibromyalgia wellness workshop at the Mayo Clinic, with other participants just like her...who she had the pleasure of relating to completely. Not only was it a refreshing affirmation of

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so many of the coping skills she'd developed.... It was also an invitation to take the next step: to consistently focus on the positive, to document it, to celebrate it, to set goals, and to dare to believe she could reach them. She's now driven to engage body, mind, and spirit – more convinced than ever of how important it is for those three 'voices' to sing in harmony. She moves, she creates, she meditates or prays. She's ready to make peace with the unwanted companion.

[Ellen is a composite of two area' Superwomen' on their quest for peace with their fibromyalgia.]

--by Carol Zakula, freelance marketing copywriter at www.carolzakula.com