



Gearing Up to *Enjoy the Holidays*

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The holiday season is a time of year that most people look forward to. After all, gatherings with family and friends should be full of enjoyment. So why does the thought of having company in your home or hosting a holiday event conjure up feelings of stress and awkward moments? What can you do so that the holidays will not land you in the dumpster emotionally and physically?

People with fibromyalgia (FM) and chronic fatigue syndrome (CFS) often face special predicaments that keep them from fully enjoying this time of year. Turn a new leaf, and do what you can to prevent your less-than-perfect health from putting a damper on the season's festivities. Gear up to have a ball this year by reading the following common scenarios and advice on how to handle them.

Scenario: *Company is coming, the house is a mess, and you don't have the energy to pick up. How are you going to get your house cleaned? You can suggest that the family gatherings take place at someone else's home, but you believe that year after year of not hosting builds resentment toward you. You feel awful when you have to say NO because you want to see your family too. As a result, the holidays are a time of feeling badly about yourself, and how can you look forward to that?*

I have had the question, "How am I going to get the house cleaned?" every year about this time. (The other common questions are: "How am I going to get the meal prepared for my entire extended family? How am I going to handle my Aunt and Uncle who fight every year at the dinner table? How am I going to handle my grandfather who always gets drunk and obnoxious at dinner?")

My suggestion: Be aware of what triggers "feeling badly about yourself," and try to avoid these situations by working around them. Long before the holiday meal, make your personal situation clear to your family. Say something like, "As you know, I have a chronic illness. I haven't had the holiday party at my house in a long time, and I want to have it this year because I love you all and want to be with you. I may close off a couple of rooms that I won't be able to get ready, and I ask that you don't open the door to those rooms." To people who you are close to and live near you, give each one of them a simple task. You may ask your spouse to sweep the front steps and the back porch a few days before the gathering. To your children (depending upon their ages), you may ask them to make sure all the bedrooms and bathrooms are presentable for this special event. Ask a close sibling to do some major shopping for you.

A few days before the get-together, you may wish to hire a neighborhood teenager (for a modest amount) to help cut and prepare the meals. The day before the gathering, it may be time to spring for some limited professional help in deep cleaning the bathrooms and kitchens

... think of it as a present to yourself!

Scenario: *So much to do! How can you begin to accomplish everything expected of you during this time of year? Having visitors in your home comes with obligations, but how can you make the people you love feel welcome when you can't properly play host to them?*

Patients with FM/CFS often seem to end up in the same role each holiday season: the family caretaker. Whether it's cooking, cleaning, shopping, gift buying and giving, or the many other holiday season activities, the person who has been the nurturing one for many years before the onset of illness has a hard time changing their role in the family. And when they do, they may find their family angry with them.

Coping with chronic illness is about knowing your limits and being confident of your capabilities. The person with FM/CFS who, during the rest of the year, could only function "part-time" without physically crashing, is the same person who demands of themselves 12-hour-days for preparing a Thanksgiving get-together. **Nothing has changed but the calendar; make your limitations clear and request help.** Asking for help may come in the form of assigning tasks, spending that little amount of money set aside for a rainy day to hire a house cleaner, or even purchasing a platter of fruit rather than cutting it.

Be sure not to extend past your average number of "functioning hours." This requires advanced planning with a calendar. If you are preparing a Christmas meal, outline

tasks on a sheet of paper, and when your energy allows, start dividing up what you are able to do and what you will ask others to do. Be sure to give them plenty of notice, and call them a couple of times to confirm. A little humor won't hurt: "You've agreed to pick up the soft drinks. If you forget, you may end up as the next Rudolph the Red Nosed Reindeer and on the roof with Santa." Consider sending out reminder notes, e-mails, or voice mails so people don't forget. A little "nudging" will go a long way in getting things done.

Make a schedule for various tasks at least three weeks in advance. Put "paper to pencil" and note the dates that specific items need to be done by. Allow time for human error and forgetfulness by adding a couple of days if something doesn't get done.

Scenario: *Kids and grandkids want entertainment. This is not the time of year when you drop them off at the local mall or movie theater for a few hours of quiet time for yourself. Youngsters relish the family festivities and want you to be a part of them as well. How do you appease a child who is too young to comprehend chronic illness? What fun activities can you do together to retain your "connection" with the children of the family? Are there ways to pace activities with children to make them feel special throughout the holiday season?*

If you are the aunt, uncle, grandmother, or grandfather of little children coming to your house, there is no reason that your physical limitations should dampen their joy of being in your home and spending time with you. You may not be the energetic entertainer you once were (and neither is anyone else), but you can still be the "focus of fun" or the "prophet of play." Wear a hat, colorful clothing, or anything that sparkles. If you are up to it, you can even wear a costume or paint your face. *Looking*

like fun doesn't take much energy.

Set up a corner of the house as the "toy zone," and leave out whatever games or crafts you want. Lay plastic down so children feel comfortable making a mess, then, just scoop up the plastic and throw it away when they are done (the plastic is cheap and sold with paint supplies). Make sure to have a constant source of "goodies." Children don't care where the food comes from (it can be inexpensive store-bought candy), as long as it's there and you deliver it with love, affection and attention.

Sit with children, read them stories, or listen to their stories. This not only takes minimal energy, but may even be somewhat restorative. Rent videos. (Confession: I watched "Pinocchio" 32 times with my son David when he was 2 years old over the course of a year—I'm not sure who enjoyed it more. I stopped watching it when he started calling me "Gepetto" after I pulled his nose.) Your mind may be fatigued, your body may be in pain, but your creativity can still flourish while you conserve energy.

Scenario: *Perhaps you do not have strong ties to your family, or no family at all. What can you do so that the holiday season does not intensify your loneliness?*

The term "Holiday Blues" is a very real phenomenon. During the holiday season, people remember the past through the lens of longing for warmth, safety and closeness. During

the darkness of winter, you may compare the present with the past, and it may not fare too well. This is especially true if your social support is limited.

Isolation is the worst psychological consequence of any illness. It produces a type of depression that can be hard to break out of. Try to preserve whatever social support you may have by making contact with people from the past. Send a year-end letter highlighting stories from your life or anything you think will be amusing. It can be a form letter photocopied on colorful paper, with a short personal note at the bottom. Many will call or write you back, providing you with a sense of connectivity. Give small gifts—perhaps homemade—to neighbors, just because it may feel good.

Do whatever you can to break out of isolation before the holiday season. Join a church, synagogue, or any other community group ... and enjoy the presence of others. Attend a lecture. Take a class. Go to a concert. Many of these activities are inexpensive or free if you look around. If you are too blue to participate, then enjoy the company of people and listen to conversation. Try to attend to things outside of yourself.

Don't become cooped up indoors; spending time outside of the house helps to combat feelings of isolation. Check out the local mall, if only for the decorations or to "people watch." Staying alone indoors begets loneliness, which breeds depression.

Consider getting a dog or a cat. Some of the best therapy comes from

Keep in Mind ...

You must conserve your energy. Be sure not to engage in activities or get caught up in situations that make you "feel bad." Try to gain self-confidence in what you are realistically able to do and acknowledge the real limitations your illness has imposed, even if it is difficult for you (and your loved ones). The more you can accept your limitations, the more those who love you will do the same. Also, don't view acceptance as a form of giving up, but rather as a necessity for moving on with life.

the devotion and love of a pet. The warmth, affection, and interaction can make you appreciate being alive. But, make sure you have the energy to take care of a pet, especially a kitten or a puppy, who require lots of training and extra attention until they mature. Cost is another factor to consider. Even if you get a pet for free, their care can be expensive. The holiday season may be an opportune time to volunteer to dog- or cat-sit for a neighbor ... a form of “rent a pet” to see how you do.

Remember, the best way to handle isolation is to try to avoid it. Plan NOW to avoid becoming lonely by appreciating the power of being with people and your important need for human contact. Even if fatigue contributes to your feeling that you aren't up to being with others, realize that you have a lot to offer other people (and pets), even if you don't know it right now.

Scenario: Living under scrutiny. It is nearly impossible to hide the medications you take, your mid-day nap or after-work crash on the couch, not to mention all of the proactive things you do to make it through the day (stretching sore muscles, applying heat wraps, long soaks in the tub, etc.). From the perspective of your extended family, you appear obsessed with your health and very much a hypochondriac. However, spending the entire holiday trying to explain your illness to other family members seems self-defeating. It gobbles up energy you don't have and forces you to dwell on the one subject that you want to have a break from. What should you do?

Make it clear that you have a medical condition that forces you to take extra care of yourself. Explain that you don't wish to make someone else uncomfortable, but that you need to make sure you don't over-extend yourself.

And then ... here comes the “white lie” ... tell them you have “arthritis”! Yep, after all these years of trying to get an accurate diagnosis, find the right healthcare providers, and receive the proper treatment, you are going to fib and say, “arthritis.”

Why? Because people don't normally challenge arthritis. Friends and family members have a clear understanding and acceptance of arthritis. They know it causes pain and functional limitations, and usually don't question it. Almost everyone has had a grandmother or aunt with arthritis, and the popular press seems okay with it. If it makes it easier on you, why not simply call it “arthritis” and leave it at that during the holidays?

Now, your job is to say no more. You don't have to explain, justify, share, prove, or compare. You simply have a common medical condition called arthritis. You can only do things in moderation and must take time out to rest. Sometimes, it includes excusing yourself when it's boisterous and loud, or asking for help in clearing dishes when there are plenty of able-

bodied people around. If you aren't able to perform a task, don't complain or explain yourself. Stay within your limits to avoid exhaustion and a painful symptom flare up.

You can be a gracious host, a friendly conversationalist, a welcoming relative, as long as you do things in moderation. If you quietly excuse yourself to go to your room to rest, no one need be the wiser. Plenty of healthy people do this, so why can't you? If you need a cane, use one and don't feel obligated to explain yourself. If asked, simply say, “I need a little extra support,” and then ask them to pass the Christmas cookies. Don't make a public display of needing to recline or a verbal excuse for your inability to lift or carry.

Your body may experience pain and fatigue, but your heart can express joy at this family gathering; your spirit can be welcoming of loved ones; your character can be as charming and as humorous as your limited energy allows. This can be a beautiful and memorable holiday season for you. END



Reprinted from
Issue #71, October 2005

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