

Welcome to the CFS Blogosphere!

By JENNIFER SPOTILA, CFIDS ASSOCIATION BOARD MEMBER



Many people with CFS and computer access are using cyberspace to reduce isolation and share information through blogging. Learn what it is, why it works and how to tap into the benefits.

FAST FACTS ►►

- Blogging refers to online communication through weblogs, where authors write posts the public can read and reply to right on the author's website.
- People with CFS are using this technology to connect with others, regardless of their physical limitations.
- If you have Internet access, you can be blogging within minutes or even start your own blog.

Weblogs, better known as blogs, have recently exploded in popularity.

Not surprisingly, people with chronic fatigue syndrome (CFS) are using this online tool to communicate, reduce isolation and expand awareness of the illness. Though some with CFS do not have access to the Internet or are not able to tolerate computer use, many others are discovering blogging as a lifeline. So read on and take a peek into the CFS blogosphere!

The lay of the land

In its most basic form, a blog is a website where regular entries are made, similar to a journal or diary. Blogs first emerged in the early 1990s,

but in the last few years they have become so accepted by the mainstream that authors of leading news and commentary blogs have earned media spots at national political conventions and press conferences. One blogtracking website, Technorati, currently tracks over 45 million blogs, and in 2005 it was estimated that a new blog is created every second.

Blogs cover every imaginable topic, including news, politics, travel, food, knitting, music and celebrity gossip. The content of a blog is a reflection of its author, a "blogger." Some blogs are deeply personal, revealing the most intimate details of the blogger's daily life, while others focus on editorial commentary and factual reporting. This diversity is a result of the wide range of different people participating as bloggers and a prime example of the democratizing effect of the Internet.

But a blog is more than a static website containing the author's posts. A key feature of blogs is the interactive element of commenting. Visitors to a blog can read the author's posts and then respond by adding their comments to that post. The comment process enables a conversation to take place among the blogger and

readers, enhancing the value of the original post.

CFS blogs can be loosely defined as blogs written by people with CFS. Some of these blogs are limited to chronicling the illness experience, and others are more like online journals covering all aspects of the person's life. These blogs provide unique insights into the many aspects of life with CFS in a more personal way than is possible from reading medical articles. Bloggers with CFS have found the process to be very positive for them in many ways.

The benefits of blogging

One of the greatest benefits of writing a blog is reducing the feelings of isolation that CFS sufferers encounter. "I really would have been more lonely during my years of being housebound without this outlet," says Kristine Beeson of the blog Kadyellebee. People with CFS frequently lack the energy to maintain regular contact with far-flung friends and family, and a blog is an easy way to stay in touch. Cynthia Armistead of the Fibrant Living blog and podcast (a type of online broadcast) says, "I can

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connect with people through my blog when I don't feel up to talking on the phone." In fact, friends and family can read a loved one's blog each day and leave comments of encouragement. This is a big benefit to blogger Pris Campbell of Songs to a Midnight Sky, who has a regular group of blog followers who offer support during the rougher times.

Blogs also help people with CFS connect with each other. Blogger Sandy Robinson of Fighting Fatigue says, "I have found out that I am not alone, and I know my feelings and symptoms are not unique to just me. There are many other people feeling the same."

Many bloggers also agree that even though you may be blogging alone at home, reading and posting to

blogs can connect you in a way that might not be possible otherwise. "It's much easier to make a blog entry than it is to go out to a [support group] meeting," notes Armistead. "I have met people I wouldn't have ever encountered otherwise, and developed some wonderful relationships." Since blogs are available around the clock, a person with CFS can check in on friends when insomnia strikes. A laptop even makes it possible to blog from bed on the days when no other activity is possible.

Many CFS sufferers find the act of blogging itself to be therapeutic. "I think blogging can be a great way of expressing yourself, irrespective of physical limitations," notes Ciara MacLavery of the blog Seats for Landing. Robinson has also found blogging to be therapeutic. "I have been able to vent, get my frustrations out and offer advice to others."

Blogger Sharon Brogan of Abide says that blogging is key to her well-being. "I'm too ill to do anything else. When one's limbs are lead and the world is foggy, it's tempting to just give in, intellectually as well as physically. Blogging has challenged me to continue to learn new skills, and given me a reason to do so."

Betsy Bradfield of the blog Beebes also uses her blogging therapeutically. "Since my memory is so impaired,

ON BLOG READING

Blogs are, by their very nature, individual expression, so be careful when reading and commenting on the sites. Some blogs may contain language or content that a reader may not be comfortable with. In addition, there is no way for a reader to know for certain if the blogger is who he or she claims to be, or whether what the blogger says is fact.

Comments posted on a blog are public and available for everyone to see. It may or may not be possible to comment anonymously, depending on the blog. And your e-mail address may be available to others as well. Be mindful of protecting your privacy if you choose to leave a comment. Most bloggers provide a way to e-mail them privately, and a reader may prefer that method of communication in some circumstances.

it's nice to have a record to return to and remind myself where I've been and where I'm headed." Campbell, on the other hand, says that though blogging about life with CFS can be cathartic, she also uses her blog "to forget about being ill awhile."

From the blogosphere to the world at large

Blogs by people with CFS perform an important function of educating both friends and strangers about the seriousness and complexity of the illness. While many people with CFS started blogging for fun, Bradfield said she wanted to do something to increase awareness of CFS. "I am tired of the blank stares and quick remedies I get from people who don't have a clue about the serious loss of what our lives were before and after we became ill." Australian blogger "Greenwords" of Greenwords Growing started her blog for just these reasons. "A decade into my illness I was still constantly hearing misinformation and myths about ME/CFS, even from people who knew me well. It was so frustrating. I wanted to give voice to how some severely affected sufferers live. I believe [those with CFS] need to tell our own stories, and keep telling them until people start to listen and change starts to happen."

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HOW TO FIND CFS BLOGS

There are many ways to find blogs by people with CFS. Several search engines are devoted exclusively to blogs and can be searched by subject area. Another easy way to find blogs is to check the links on a blog you've already read. Many bloggers link to each other through their navigation bars.

Blog Search Engines:

Blogdigger (www.blogdigger.com)

Feedster (www.feedster.com)

PubSub (www.pubsub.com)

Technorati (www.technorati.com)

CFS Blogs to Check Out:

Abide (<http://abide.sbpoet.com>)

Beebs (www.bbdesignsbeebs.blogspot.com)

CFSsquared (www.cfssquared.com)

Fibrant Living (www.fibrantliving.com)

Fighting Fatigue (www.fightingfatigue.typepad.com/my_weblog/)

Greenwords Growing (www.greenwordsgrowing.blogspot.com)

Hidden Words (www.hiddenwords.net)

Kadyellebee (www.kadyellebee.com)

Learning to Live with CFS (www.livewithcfs.blogspot.com)

Seats for Landing (www.ciaramaclaverty.blogspot.com)

Songs to a Midnight Sky (www.poeticinspire.blogspot.com)

Two Wooden Sticks and a Ball of Wool (www.twowoodensticks.blogspot.com)

TumblyDay (www.tumblyday.com)

Velo-Gubbed Legs (www.velo-gubbed-legs.blogspot.com)

started researching remedies and concerns beyond her own in recognition of the scope of the illness. This type of information can be informative to healthy blog readers as well. Ann Beutel, a professor of sociology, has been reading the blog of a childhood friend who has CFS. "I knew people with CFS can suffer fatigue so great that they are unable to hold jobs, have children or do other things that people without the disease can do," she says. "But. . . I had no idea how much pain people with CFS can suffer and how

STARTING A BLOG

Would you like to start your own blog? It's surprisingly easy. A number of online services provide free server space (hosted platforms) and templates to would-be bloggers. Blogger.com is just one site that has free blogging templates to help get you started.

Using a hosted platform does not require technical knowledge of web programming, and account space is usually free. Some sites may also provide the option of "locking" blog entries so that only specific friends can read them.

See the online bonus (at right) to get started!

difficult it can be to find the right combination of medications. I also have learned how people with CFS manage to enjoy life in spite of the limitations of the disease. By reading my friend's blog regularly, I have a much fuller picture of what life with CFS is like."

Entering a brave new world

Blogging does take energy, but it can give CFS sufferers a sense of accomplishment and purpose too. Blogger "Greenwords" enjoys the instant gratification of blogging. She says, "I hit the publish button and can see something for my efforts. I feel like I've actually done something."

Blogs offer unique opportunities to people with CFS and their loved ones. Blogging about life with CFS not only educates others about the illness, but provides the sufferer with a way to meet new people and give or receive support. If you have access to the Internet, it's also easy and fairly inexpensive to start and maintain a blog.

See you in the CFS blogosphere! ■

Jennie Spotila is a member of the board of directors of the CFIDS Association. She blogs about CFS and other topics at www.tumblyday.com.

TWO ONLINE BONUSES!

■ Learn the basics and find reliable resources for starting your own blog. See www.cfids.org/bonus/su06.pdf or call the Association's Resource Line at 704-365-2343.

■ Read one blogger's personal story of discovery and growth as she launched her own CFS blog called Hidden Words. See www.cfids.org/cfidslink/2006/blogger-jo.asp

TIPS FROM CFS BLOGGERS

"If you have [CFS] and you're thinking about blogging, go for it! The more the merrier. There's an audience for every blog. I constantly battle with thinking mine is boring, and it might be to a healthy person, but at the end of the day nobody has to read it who's not interested. Don't feel daunted by the technical side of things. If you can send an e-mail or post to an online forum, you can blog."

- Greenwords (Greenwords Growing)

"Start slowly and don't feel as though you have to be a professional writer to do this. It is a great hobby for me, and I only spend a few minutes a day, so it's not physically or mentally draining on me."

- Sandy Robinson (Fighting Fatigue)

"Be aware of the balance needed in dealing with the demands of blogging (such as visiting blogs, leaving comments, posting, answering comments, the development of online friendships, etc.) and one's ongoing fluctuations of energy and health crises. I am still trying to not feel guilty when I am "on" for a couple of days, get all caught up and then can't deal with it for a week or so."

- Cynthia (Two Wooden Sticks and a Ball of Wool)

"I would definitely suggest blogging as an outlet. Not only is it a way to meet people, but it's a terrific log of your life, including your healthy and poor periods. If [you are] intimidated with public blogging, maybe use a smaller forum with a tool that's able to only post to friends."

- Kristine Beeson (Kadyellebee)

"The great thing about blogging is that you can do it when you want to. You can write as much or as little as you want. You do not have to write every day. When you do plan on writing, set a timer for 15 or 30 minutes or whatever you think is doable, so you don't tire yourself out too much or get overwhelmed."

- Laura Bzowy (CFSsquared)

"Blog only when you feel up to it. Try to make it fun. Blog about things you enjoy. If you have a craft or hobby, use your blog to showcase it. The biggest thing is to enjoy the experience."

- Pris Campbell (Songs to a Midnight Sky)

"I like to keep my own entries short. I think people like punchy, concise entries rather than huge rambles; one or two chocolates rather than the whole box."

- Ciara MacLavery (Seats for Landing)

"My body is no more respectful of blogging schedules than it is any other sort of schedule! Don't push yourself to write daily. If you can, that's lovely. If you can't, don't punish yourself."

- Cynthia Armistead (Fibrant Living)

"I advise that you blog for yourself, and let yourself discover what that means for you."

- Sharon Brogan (Abide)