

PRACTICAL HELP

"If a friend is in trouble, don't annoy him by asking if there is anything you can do. Think of something and do it."

(E.W.Howe 1853-1937 American writer.)

HERE ARE SOME IDEAS:

1. Housework

Food shopping (or even setting this up on the internet)

Doing a load of washing and hanging it out

Making a casserole or soup every now and then

Changing the sheets on beds/ turning the mattresses

One -off cleaning & tidying not done by home help or cleaner eg defrosting fridge, cleaning out cupboards, taking "junk" to opp. shop or load to the tip

2. Gardening and maintenance

Watering the garden

Taking pets to the vet

Washing the car

Walking/washing pets

Pruning/weeding

Clearing the guttering

Mowing the lawn

Washing the windows

3. Advocacy

Accompanying CFS'er to appointments with doctors, council, etc

Organising a roster of friends who can shop or garden etc so that one person isn't doing all the helping

"Researching" the options/prices when something new has to be bought eg a new microwave

Facilitating activities-helping with preparations, transport etc

4. Time-out and care

Reading to someone who is bedridden

Exchanging library books

Minding a child

Getting out a video to watch together

Remembering to ask how appointments and treatment went

Going around for a 15 minute "cuppa"; don't forget the dishes!

If visits are too difficult, phoning or emailing are good options

CFS AWARENESS DAY - MAY 12TH.

Florence Nightingale (1820-1910) was born on May 12th.

It is now believed that she probably suffered from CFS. Having been close to death from fever during the Crimean War, she returned to London where she was bedridden for over 10 years. Her campaign for public health & hospital reforms was conducted primarily through letters to parliamentarians.

Watch the media for information on CFS around this date.

Joy Sandford, supported by the Tortoise Project© March 2003

UNDERSTANDING CFS

A GUIDE FOR FAMILY & FRIENDS



CHRONIC FATIGUE SYNDROME (also known as ME Myalgic Encephalopathy) is a severe and debilitating illness. It is unexplained, persistent exhaustion for six months or more, together with a cluster of other symptoms. The name can be misleading. Often, people think that CFS is just being tired. This is incorrect. Sufferers are sick, not simply exhausted. Some people have the illness severely and are bedridden. In its mildest form, some people may be able to continue work and do other activities with care. Most people are somewhere in between, perhaps being capable of 3 or 4 hours of very light activities, with rests in between. Rest does not cure the illness, but it is essential in order to prevent exacerbation of the symptoms. "Payback"/crash/relapse (ie the worsening of symptoms because of doing too much) is not always immediate; it could be 24-48 hours later. Activities and domestic chores which most people consider mundane can become major jobs, even obstacles for the CFS'er. This means that sufferers need to change their lifestyles considerably.

Not everyone has the same symptoms but there are many common ones. These symptoms can vary by the hour, by the day, by the month. CFS'ers relapse often. This may be due to a) physical activity, b) mental activity, c) emotional strain or stress, d) infections, allergies, illnesses. CFS'ers may sometimes look well, but this is **NOT** an indication that the illness has improved; more than likely it means that symptoms are not so severe at that particular time. **Remember this is a chronic illness.**

SYMPTOMS

Below is a list of symptoms associated with CFS. Your friend or family member may have highlighted or ticked the ones which affect her/him the most. This is an attempt to explain to you (in non-medical terms) the day to day realities of living with CFS.

- Sleep disturbance, including sleep which does NOT refresh or relieve symptoms
- Severe exhaustion after physical or mental activity and /or emotional strain eg Hanging out a load of washing may be very difficult. Going to the supermarket is usually a nightmare! A disagreement with someone may bring on severe symptoms.
- Muscle and/or joint pain, sensitivity to touch
- Eye problems eg blurred vision, sore eyes
- Headaches
- Nausea
- Inflamed and sore throat which happens with any activity, not just talking
- Swollen glands
- Digestive problems eg food intolerances or allergies, Irritable Bowel Syndrome etc
- Difficulty with balance and co-ordination eg Some sufferers find it difficult to judge going down steps.
- Mood swings, panic attacks, anxiety, depression (who wouldn't be depressed with all this going on!)
- Heightened sensitivity to light and noise - This makes going to restaurants, shopping malls, films etc and being with a number of people extremely stressful, and is likely to bring on more symptoms.
- Chemical intolerances eg Perfume, hairspray, paint fumes, petrol etc can be enough to send some people to bed for days.
- Food intolerances eg gluten, sugar, alcohol (damn it!)
- Sensitivity to even small amounts of medication
- Intolerance of upright positions - Standing and sitting upright for any length of time (even as little as 30 seconds) is a great strain and for some, impossible. It may produce heart palpitations, nausea, fainting, sudden aching legs. This is one reason why CFS'ers lie down a lot!! Sitting at the computer may be very difficult. And the definition of a queue is "one person in front of me"!
- Cognitive difficulties, including poor concentration and short term memory problems - This can make even reading difficult. Forgetting thoughts and/or words mid-sentence is common. Don't ask a CFS sufferer to get the milk on the way home!!

LOSS

CFS sufferers have to make changes to their lifestyles, and treat the symptoms in order to manage the illness, since at present there is no cure, nor even consensus about the cause(s). Although some people do recover and others improve, many have this illness for years. Lifestyle changes mean that a great deal is lost from people's lives, so grief and its associated feelings of frustration, anger, denial, disappointment, sadness, guilt etc. have to be dealt with. Not being able to continue with life and its activities as before can also cause social isolation. There may be the loss of:

- Work - status, self-esteem, being the "bread -winner"
- Education and the opportunities and experiences this brings
- Income and all that this entails
- Sport, hobbies
- Travel, holidays
- Social events, family gatherings
- Friends, workmates, colleagues
- Identity and self esteem which goes with life before CFS
- Independence
- **Be aware that as a friend or family member of a CFS'er, you may experience feelings associated with grief too. The loss of someone as s/he used to be may be difficult to come to terms with.**

HOW YOU CAN HELP

"Do the one thing that makes a difference; imagine what it is like to be someone else..." (Christopher Reeve, actor and quadriplegic activist.)

Make time and space in your life for this person.

Be aware that the activities you did together may not be possible now. Learn to recognise the small signs which indicate how the person is feeling (when they sink low into the couch, maybe it's time to leave!)

Try to notice the jobs that need to be done.

Look out for your friend or family member. Remember that different people have different needs. CFS'ers need different help at different times because symptoms and their severity change.

Don't forget that this person is your friend or family member, not an illness. They need to feel useful and valued as a person.

Finding sympathetic and knowledgeable health professionals, and learning how to pace activities can be a long, frustrating journey. Be patient with the CFS'er throughout this process.

Be mindful that you won't be asked for help if you spend all your time talking about how busy and stressed you are.

Think about gifts you give. Who's going to dig the hole for that plant???