

Mild, Moderate, Severe and Very Severe PVFS/ CFS/ ME in patients' own words

Post Viral Fatigue Syndrome (PVFS), Chronic Fatigue Syndrome (CFS) and Myalgic Encephalomyelitis (ME) are different names for what is probably the same illness. The severity of symptoms varies from person to person, and over time.

The aim of this leaflet is to describe the different severities (mild, moderate, severe and very severe) in patients' own words. People with mild PVFS/ CFS/ ME can usually work part-time or even full-time if they have lots of support at home and severely restrict their other activities. The severely ill are housebound, those very severely ill are bedbound, and people in the moderate category are intermediate. People with moderate to very severe PVFS/ CFS/ ME often struggle to explain what their symptoms feel like. Family, friends and some healthcare professionals can find it difficult to understand how the sufferer feels.

MILD

"Not so much Forrest Gump "life is like a box of chocolates" but "CFS is like a glass of water" (or beer, whichever you prefer). Everything I do involves physical, mental or emotional energy of varying degrees. Once my glass is empty there is no more. We each have different sizes of glasses (mine's usually the pint) and I can tell when I'm getting to the bottom because that's where the cloudy bit is (I can't talk properly when I get there!). It then takes a wee while to refill the glass." Healthy people start every day with, say, a whole basin-full of water to play with. And unless they do something really out of the ordinary (like run a marathon) they will wake up the following day with another basin-full of energy.

"As long as I stay within my limits, I feel ok. If I do too much (say, enjoying a couple of dances at a wedding) I feel normal at the time, but am liable to suffer a week-long hangover that starts within 48 hours of me over-doing it."

MODERATE

"As I recover, I am feeling increasingly normal, as long as I keep my bouts of activity (listening to the radio / seeing a friend / going on-line / cooking) very short. It varies from day to day – sometimes I can only manage 10 minutes of activity before I need to lie down for half an hour of rest, other days I'm good for 30 minutes. The crucial thing is to stop before I need to – if I carry on for 5 or 10 minutes too long, I'm liable to be hit by a crushing wave of fatigue that feels a bit like bad jet-lag. Physically, I'm still very limited in what I can do – emptying the dishwasher has to be done in three stages and putting the wheelie bin out is currently beyond me (though I'm working on it). I'm now able to drive to the local corner shop to buy a few groceries – until recently I was so noise sensitive that I didn't have the brain function to cope with standing in the queue if there was music playing."

"When I first got ill, I had to be horizontal, and often asleep. This got gradually better, with the 'up' time improving from 10 minutes to 2-3 hours. For a long time I didn't have the energy to hold a book, so I couldn't even read. I am unable to work, and have limited capability for work. I feel like I have a virus permanently, without the catarrh etc. of a head cold. When I do get a cold however, it's much worse than before I had the CFS, and lasts a lot longer. I have friends who are in chronic, severe, constant pain, because they live with different illnesses. So although my muscles throb from head to toe after I have overdone things, I wrote this poem to explain a little of what it is like living with CFS/ME day to day:

I'm not in pain like some of my friends;
 I don't have a life-threatening disease.
 But ME sucks, and all I ask –
 Is to have some energy.....please?"

"My analogy is: it's as if someone has left the doors to all my cells open, and energy can't build up. No matter how much I try, through food or rest or whatever, it simply drains out the open doors, and there's no way as yet of shutting them."

"It is very hard to say no to yourself, and others. I still have days where I give far too much and suffer for days after. Frustrating was a word I used to use to describe CFS: my mind would be desperate to do things, but my body would say no, and often be unable to move very much at all."

SEVERE

"To feel so ill for so long is a nightmare beyond most people's imagination. Every day feels like a cross between the first day of flu, combined with a hangover, after 10 rounds in a boxing ring. It's about surviving this dreadful illness. Many days are so difficult it takes everything I've got to focus on getting through each half-hour. Most things healthy people take for granted are impossible for me, for example, watching TV, going on-line, listening to radio or music, sitting up comfortably, looking at a magazine, chatting to a friend relative, enjoying a meal, enjoying the view out the window. It takes every bit of courage I have to get up tomorrow and survive it all again until, I hope, things improve. I feel like my body is full of lead. It's frightening, isolating and disabling. I feel completely exhausted and ill before I even start the day - as soon as I wake up I feel awful. I don't feel okay at any point. Obviously if I do activities I feel worse. One of the most frustrating things is the lack of understanding of this illness from other people."

VERY SEVERE

"It's hard to find words to explain what it's like being affected by very severe ME: horrible, awful, desperate, frightening, suffering, lonely, trapped, painful, isolating, bewildering, relentless, heartbreaking. All seem insufficient somehow, but that's it."

MYTH BUSTERS

What healthy people sometimes think/say	Support Network Response:
"But you look well!"	Many people with PVFS/ CFS/ ME do look normal. The illness does not usually produce visible symptoms.
"It's no wonder you can't sleep at night if you don't do anything all day." Or "You need to learn to relax, then you'd be able to sleep"	When a person has no energy available, they have no choice but to rest during the day. Insomnia is a common symptom of this illness and does not imply an inability to relax.

"You need to spend less time in bed!"	Our members have often discovered by trial and error the best way to manage their illness.
"I haven't talked to you in ages...you must be better by now?"	This illness can be a very long haul.
"So, what progress have you made?"	The sufferer does not always experience progress. Set backs are part of the process – sometimes it is one step forward and two back.
"But I thought people with ME felt okay unless they overdid it?"	In severe and very severe PVFS/ CFS/ ME sufferers feel ill continually.
"You must be depressed as well".	Rates of depression among those with PVFS/ CFS/ ME are thought to be similar to those among people with other chronic debilitating conditions. NB there should be no stigma attached to any form of mental or physical health problem.

See also Lochaber PVFS/ CFS/ ME Support Network's leaflet with general information and a description of symptoms: 'What is PVFS/ CFS/ ME?'

The primary aim of Lochaber PVFS/ CFS/ ME Support Network is to allow people whose lives are affected by PVFS/ CFS/ ME (both those with the illness and their carers) to support one another.

To join or find out more, e-mail
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Or leave a voice or text message on the Support Network's mobile:
07786 590 450, or find us on Facebook: Google 'Lochaber M.E.'

See our web-page: www.me-lochaber.org.uk