

Testimony

H. Farnham

Preface: These are quotes from H., now age 22, who has had CFS/ME since age 14. They were transcribed over a period of several months, due to the extreme fatigue and brain fog that plagues CFS/ME people. Even so, I think you will find his incredible metaphors reveal his subtle humor and practical mind!

Transcribed from H. CFS/ME diagnosed 2010:

“It's like having an invisible chain on you that no one else can see---holding you back.”

“It's as if you have been dropped in the middle of a desert. You have a hut with food and water. You know if you leave this safe area ---you will perish.”

“I worry that if I go to an event and people forget I can't drive...I won't have the energy to find a bus or to walk home.”

“I have fuzzy limits of what I can do each day. I am never sure.”

“My energy is like a bucket with holes in it, compared to healthy people.”

“I used to have energy. Before I knew this was an energy problem, I was confused because

I couldn't run anymore. I tried to sprint (like before) but could only run a few steps.”

“Every year I can do less than the year before.”

Regarding energy and graded exercise: “Payback will happen. It's guaranteed when you exercise. It's the ultimate negative reinforcement.”

“You aren't going to feel very good about yourself when you are being (physically) punished when you do what your doctor asks you to do.”

“There could be several disease processes going on. Not knowing what's helpful or hurtful to your condition is very tough.”

“It's like being in limbo—like someone paused your life. You can't interact with the world the way you once did.”

“When you finally arrive at a destination...you can't do anything useful.”

“Whatever is causing this is not going away. People keep showing up with this.”

“Is it transmittable? My Number One request is to know if I'm safe to be around...or not. This is a basic and important piece of information that needs to be understood. This keeps me from wanting to start a relationship---for fear I would ruin someone's life. It's scary.”

“The filters (in my brain) don't seem to be working as they should. Lights, sounds...mechanical clocks are extremely irritating. Perfumes are very intense—but I can handle citrus and softer, more natural smells.”

“A good day for me is like a bad day for healthy people.”

“I don't make (many) goals. It's impossible. I don't know if I'm going to feel better or worse. I just feel sad when I don't meet the goal.”

“We shouldn't have to come to each new doctor with research studies and scientific data, just to get a conversation started. It shouldn't be left up to us to present current research, and in some cases, argue our own plight. (We're sick.)”

Addendum: After our family compiled a list of these quotes by H., we concluded that perhaps another CFS/ME patient, a young lady that prefers citrus cologne(?)---would be a good choice for a relationship with him. He laughed.

“ H.” CFS/ME patient, Oregon, USA age 22 May 2011