

# The CFIDS Association of America

*Working to conquer chronic fatigue and immune dysfunction syndrome*

## **Top 10 Things People With CFS Want You to Know**

- 1. CFS is real.**
  - "I'm not making this up."
  - "My symptoms are very real even though you can't see them."
  - "I am sick with a real disease and I'm doing the best I can."
- 2. It is very debilitating and disabling.**
  - "CFS is as disabling as HIV, cancer and MS."
  - "Staying at home is not a 'fun vacation from reality.'"
  - "CFS is absolutely life-altering."
- 3. The fatigue is very intense.**
  - "It's more than being tired."
  - "My energy is very limited."
  - "I understand you're tired, but it's not the same as CFS."
- 4. Looks can be deceiving.**
  - "I don't look as bad as I feel inside."
  - "Even when I look good, I feel awful."
  - "Just because I look okay now, know that I'll pay for it later."
- 5. CFS is unpredictable.**
  - "I don't know from one day to the next how I'll feel."
  - "I have no control over how I feel."
  - "I need to be flexible in planning things."
- 6. It has nothing to do with being lazy.**
  - "I wish I could accomplish more each day than I can."
  - "Even simple things are often beyond my ability."
  - "I'm not trying to get out of doing something when I say I can't."
- 7. Words don't do CFS justice.**
  - "There's no way to accurately describe how bad I feel."
  - "I still hurt as badly 20 years later as I did the first day I got sick."
  - "Even when I don't talk about it, I still feel sick."
- 8. CFS is very isolating.**
  - "I am often lonely and alone."
  - "Life moves on without me."
  - "Nobody understands what I'm going through."
- 9. Your understanding is important.**
  - "I am so grateful for my family's support."
  - "I am very lucky to have their understanding. It makes life bearable."
  - "I still need quality life experiences and to be involved."

10. **CFS is not a choice.**

"I don't want to be this sick."

"I miss the person I used to be."

"It's so sad to miss out on so many things in life."

***From the CEO's Desk***

*CFIDSLink - September 2009*

<http://www.cfids.org/cfidslink/2009/090201.asp>