

# Invisible Illness: Understanding and Caring for Chronically Ill Younger Adults

(handout)

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1. What is Invisible Illness?
  - There is no real "medical definition", but it is a permanent disability the person copes with on a *daily basis*.
  - Unable to "see" the disability
  - There are no "visible supports": cane, walker, etc.
  - May be "managed" by medications (Disease modifying drugs or DMD's)
  - The person is in some kind of physical or emotional pain.
  
2. Some Diseases Under This Category:
  - Fibromyalgia
    - a chronic condition and people with it often describe symptoms of hurting all over their body and feeling consistently exhausted.
    - Other symptoms include debilitating fatigue, sleep disturbance, joint stiffness, tension headaches, temporomandibular joint (TMJ) disorders, irritable bowel syndrome, anxiety and depression.
  
  - Chronic Fatigue Syndrome
    - Defined as a "complicated disorder" characterized by extreme fatigue that doesn't improve with bed rest and may worsen with physical or mental activity.
    - Symptoms of CFS include widespread muscle and joint pain,; headaches; sore throat; cognitive difficulties; chronic (often severe) mental and/or physical exhaustion, anxiety, depression, etc.

- Lupus
  - Lupus is an autoimmune disease. Lupus can affect different parts of the body; to include the heart, lungs, brain, kidneys, skin, and joints such as elbows, knees, or hips.
  - Some symptoms are: pain, rash, light sensitivity, inflammation, arthritis, hair loss, anxiety, depression, etc.
  
- Crohn's Disease
  - Crohn's Disease is an inflammatory bowel disease (IBD) which affects a person over their lifetime. Portions of the person's digestive system become swollen and present deep sores called ulcers.
  - Symptoms can include joint pain, fatigue, skin rashes, vision problems, arthritis, anemia, incontinence, anxiety, depression, etc.
  
- Multiple Sclerosis
  - an inflammatory disease in which the insulating covers of nerve cells in the brain and spinal cord are damaged, leaving scars. The immune system attacks the protective sheath (myelin) that covers the nerves.
  - Symptoms can include fatigue, pain, cognitive difficulties, visual issues, weakness, difficulty swallowing, muscle spasms, mobility issues, dizziness, incontinence, anxiety, depression, etc.
  
- Other diseases: Anxiety Disorders, HIV, Diabetes, Cancer, Colitis, Depression, Lyme Disease, Asthma, Asperger Syndrome, Narcolepsy, Rheumatoid Arthritis, etc

### 3. Symptoms

- Pain
  - Pain is a signal in your nervous system that something may be wrong. It is an unpleasant feeling, such as a prick, tingle, sting, burn, or ache. Pain may be sharp or dull. It may come and go, or it may be constant. People's threshold for pain vary.
  
- Spasticity (tightening of muscles)

- Spasticity is a condition in which certain muscles are continuously contracted. This contraction causes stiffness or tightness of the muscles and can interfere with normal movement, speech and gait. Spasticity is usually caused by damage to the portion of the brain or spinal cord that controls voluntary movement.
- Memory/Cognitive Issues
  - Attention and concentration.
  - Word-finding.
  - Speed of information processing.
  - Abstract reasoning and problem solving.
  - Visual spatial abilities.
  - Executive functions.
- Speech Changes
  - Adult speech impairments include any symptoms that cause an adult to have difficulty with vocal communication. Examples include slurred, slowed, hoarse, stuttered, or rapid speech.
- Heat or Cold Sensitivity
  - One of the most common causes of heat intolerance is medication. Allergy, blood pressure, and decongestant medications are among the most common. Allergy medications can inhibit your body's ability to cool itself by preventing sweating.
  - Examples: Temperature sensitivity in fibromyalgia, some research shows abnormal body temperatures, an inability to adapt to changes in temperature, and a lower pain threshold to both heat and cold stimuli—meaning that it takes less extreme temperatures to make you feel pain. For MS patients, An estimated 60-80% experience temporary worsening of clinical signs and neurological symptoms with heat exposure. For an arthritis sufferer, heat is better than cold. Cold causes pain and stiffness.

- Numbness/Tingling
  - Unusual prickling sensations that can happen in any part of your body.
- Vertigo/Dizziness
  - Vertigo is a sensation of spinning dizziness.
  - Dizziness is a term used to describe a range of sensations, such as feeling faint, woozy, weak or unsteady
- Fatigue
  - Fatigue is a term used to describe an overall feeling of tiredness or lack of energy. It isn't the same as simply feeling drowsy or sleepy. When you're fatigued, you have no motivation and no energy. Being sleepy may be a symptom of fatigue, but it's not the same thing.
- Vision Changes
  - Eye pain, blurry or hazy, double vision, floaters, sensitivity to light, etc.
- Sexual Issues
  - Feelings of helplessness, too fatigued, not feeling desirable.
- Brain Fog
  - Brain fog involves feelings of confusion and disorientation. Brain fog can make a person feel as if the processes of thinking, understanding, and remembering are not working as they should. It can affect their: memory, including the ability to store and recall information.
- Insomnia
  - Insomnia is a sleep disorder that is characterized by difficulty falling and/or staying asleep. People with insomnia have one or more of the following symptoms: Difficulty falling asleep. Waking up often during the night and having trouble going back to sleep. Waking up too early in the morning.
- Incontinence
  - Bladder and/or bowel

- Anger / Depression
  - Depression caused by chronic illness often makes the condition worse, especially if the illness causes pain and fatigue or it limits a person's ability to interact with others. Depression can intensify pain, as well as fatigue and sluggishness. The combination of chronic illness and depression might lead them to isolate themselves which is likely to make the depression even worse.

#### 4. Top 10 Things to NEVER say to a person with Chronic Illness

- I don't understand... You were fine yesterday!
- At least you can still walk / talk / eat / think
- It's all in your head.
- I wish I could stay home all day!
- My aunt has this and she's really bad...
- It must be nice to sleep all day.
- What do you mean you're sad?
- My sister's husband's cousin had that and she tried...
- You need to change your diet / exercise more...
- But you don't LOOK sick!

#### 5. Spoon Theory Explained

#### 6. Vision for the Future / Marketing to the younger generation

- Hotel Industry doing this. ALOFT by Marriott and TRU by Hilton
- Make it a decision based on WANT not need
- Larger living space
- Affordable
- Unbundle package deals
- Fitness Center
- Wellness Center
- Gourmet chef
- Movie Theatre
- College courses
- Travel
- Café (real latte's etc.)
- Pets