

Invisible* Disabilities

Chronic conditions that are rarely apparent to others, but that impede function and reduce quality of life

* 'observed' is not always visual

You have to "live inside this body" to notice the problem

Often experiential rather than functional

Chronic fatigue

Chronic pain

Many mental illnesses, brain injuries

"Somewhat Visible" Disabilities

Chronic conditions that limit opportunities and impair more of one's life than the body systems or organs that others observe to be involved

Incontinence
COPD/asthma/heart disease
Infertility
Addictions
Compromised immune system

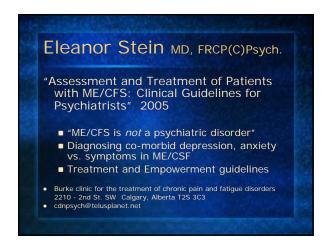
No Longer T-A-B: Fibromyalgia

Chronic myofascial pain across whole body
Prone to injury, slow to heal
Abnormal pain response
Chronic fatigue, non-restorative sleep
Depression, anxiety, "fibro-fog"
Prone to autoimmune, other comorbidities
Causes?
Neurological/CNS
Rheumatic
Immune

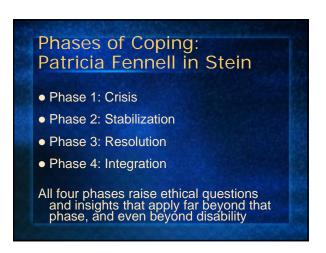




Injuring the Invisibly Disabled It isn't that bad" Can't know another's experience It might actually be that bad today (or worse) Reaction: defensive argument to persuade you it is that bad - wastes energy "Mind over matter" Only works if the material body can respond to the mind Chirpiness



"From a psychotherapeutic perspective, one can observe a change in emotional status when the patient has the moment of realization that his/her opinions are as valid as anyone else's, that s/he is not to blame for his/her disorder and that s/he has value and rights despite being ill. From that point onwards patients cope better even if their physical condition or life circumstances do not improve."



Occurs whether onset is sudden or gradual. May recur in cycles. Develops when one's values, self concept, and life goals are called into question, i.e. you are too sick to function as you used to. The action goal is to batten down the hatches, take stock of resources, adjust expenditure and try to minimize immediate pain. A tool of phase one is to begin a personal narrative. The spiritual goal of phase one is to learn to allow one's suffering.

Phase 1: Ethical Implications... • Universality: we are temporarily able bodied at best • Pain relief, therapeutic resources • Practical assistance

Phase 1: Ethical Implications • "Allow one's suffering" • Validate other's experience w/o comparison, judgment, evaluation • Support need for self-care • Support withdrawing if necessary, but never abandon another in distress • Make room for suffering, vulnerability in language, pace, expectations, images • Confront own tendencies to denial

Phase 2: Stabilization Occurs when one's physical condition has stabilized somewhat due to the lifestyle changes one has made. People in phase 2 continue to think they can function as they used to and continue to overestimate their personal resources. They have relapses as a result. The action goal is to focus on what one really needs. The tools of phase two are learning, restructuring and educating others. The spiritual goal of phase two is to learn to regard your suffering with compassion.

Phase 2: Ethical Implications... Challenge expectations How much has to be done, and what can be left undone? Fair allocation of duties among (temporarily) stronger/healthier and those less so Priority setting: where to invest available energy, concentration, etc Redirecting: take advantage of strengths, talents instead of insisting on former / "normal" activities Social, institutional norms: How do competition, lifestyle, pace, etc. cause / worsen disability? Sue Wendell, The Rejected Body

Phase 2: Ethical Implications... • Education • Patient education about resources, therapies, coping strategies, selfassessement, etc • Educating others about existence, nature, range of invisible disabilities • Education of all about ways to help, hinder management • Support for family, loved ones • Divorce common in chronic illness, pain

Phase 2: Ethical Implications... • "Regard suffering with compassion" • Observe "how much effort you have to spend to do what I do without thinking" • "It must really suck to go through this." • "I'm sorry you're struggling today" • "I'm here with you, even if I can't fully understand what you're going through"

Phase 3: Resolution Grief work, the challenge to obtain insight and develop meaning in the face of huge losses. Patients are more self reliant and self trusting with regard to health decisions. Humor, play become possible again. The action goal is to stand for oneself without apology. The spiritual goal is to meet one's suffering with respect.

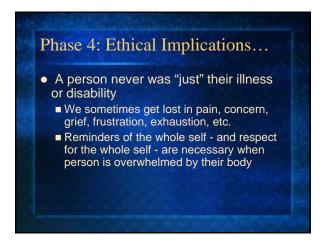
Phase 3: Ethical Implications... Grief support "It sounds like your body has disappointed you" "It just hit me how many things you've had to give up" Humor and Play Support (do not demand) >> Can laugh and cry Offer assistance, but don't coddle



Phase 3: Ethical Implications... • "Stand up for oneself without apology" ■ Assumptions of control, responsibility for health status as well as productivity, reliability, etc. ■ Feeling apologetic for how you ARE is devastating • Alternative:" Look how well I'm doing with all that I've got to deal with!" ■ Are expectations unreasonable? (above) • Should apology come from those expecting, rather than those who "failed" to meet expectations?

Phase 3: Ethical Implications... • "Meet one's suffering with respect" • 'Respect' means to embrace, accept the entire human person, not just the parts we like best • If we can meet suffering with respect, then we have hope of achieving genuine respect for each other, ourselves

Phase 4: Integration Becoming more than one's illness frees up emotional energy for other meaningful tasks and interactions. One begins to connect the personal to the world view and embrace the mystery and unknown of life. The spiritual goal of phase four is to integrate your suffering into a whole life.



Phase 4: Ethical Implications... "I'd rather be a human dissatisfied than a pig satisfied; I'd rather be Socrates dissatisfied than a fool satisfied. And if the pig or the fool think differently, it is because they only know their own side of the question." John Stuart Mill



