

EMERGENCY PREPAREDNESS: CONSIDERATIONS IN CHRONIC FATIGUE SYNDROME

**Clinician Outreach and
Communication Activity (COCA)
Conference Call
August 18, 2011**



Objectives

At the conclusion of this session, the participant will be able to accomplish the following:

- ❑ **State the 1994 International Case Definition for chronic fatigue syndrome**
- ❑ **Describe the diagnostic process and care management approaches for chronic fatigue syndrome**
- ❑ **Discuss the impact of a public health emergency on persons with chronic fatigue syndrome**
- ❑ **Identify emergency preparedness and response clinical considerations for persons with chronic fatigue syndrome**

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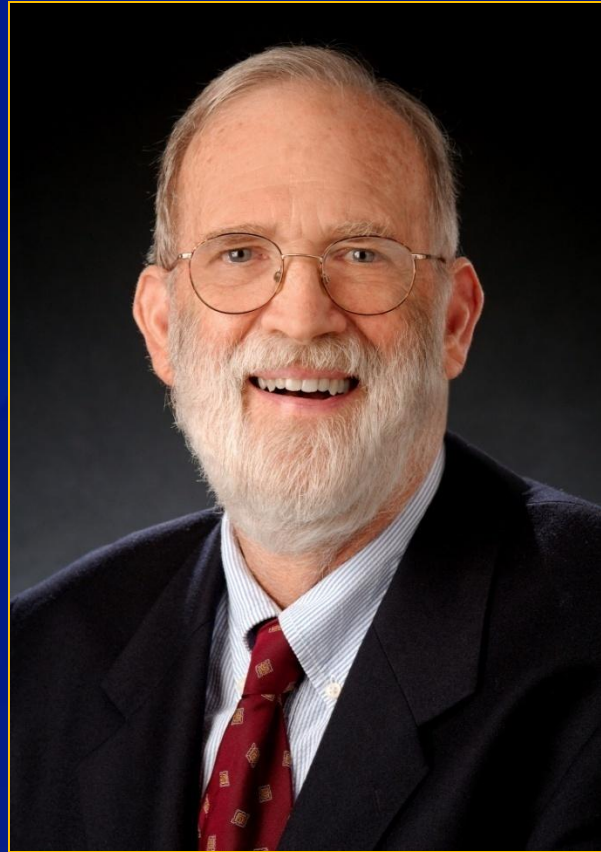


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Chronic fatigue syndrome (CFS): Background, Definition and Epidemiology

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**Clinician Outreach and Communication Activity (COCA)
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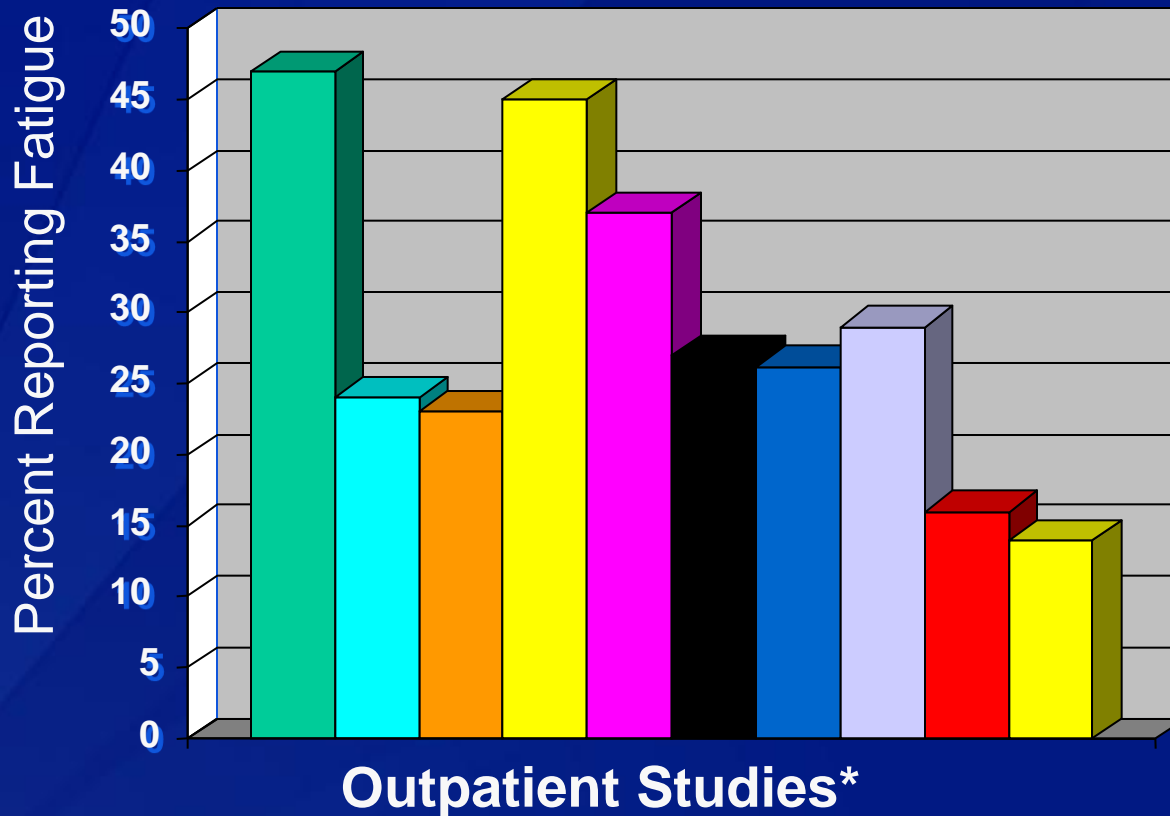
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CFS CASE DEFINITION

Chronic Fatigue Syndrome (CFS)

- ❑ CFS is a complex and serious disorder
- ❑ Characterized by chronic fatigue
 - Not improved by rest
 - Worsened by physical or mental activity
 - Hinders participation in normal activities of daily life
- ❑ Syndrome
 - Syndromes are recognized by their core symptoms
 - May have multiple causes
 - CFS patients may have multiple reasons for their symptoms

Fatigue in Clinical Practice



10 - 40% of primary care visits

*Cullen et al, 2002; Lewis et al, 1992; Kroenke et al, 1988; Morrison, 1980; Valdini et al, 1988; Bates et al, 1993; David et al, 1990

Chronic Fatigue Syndrome

1994 International Case Definition

Three Criteria in Diagnosis

1. Chronic Fatigue

- ❑ Chronic fatigue persistent for ≥ 6 months

2. Functional Impairment

- ❑ Significantly affects daily activities or work

3. Case Symptoms

- ❑ 4 of 8 case defining symptom criteria

1994 International Case Definition

1. Chronic Fatigue

- ❑ Clinically evaluated, unexplained, persistent or relapsing chronic fatigue with ≥ 6 months duration
- ❑ Not the result of ongoing exertion
- ❑ Not substantially alleviated by rest

1994 International Case Definition

2. Functional Impairment

Fatigue significantly affects previous levels of activities - occupational, educational, social and/or personal

1994 International Case Definition

3. Case Symptoms: meets 4 or more of the 8 case defining symptoms:

1. Impaired memory/concentration
2. Post-exertional malaise
3. Unrefreshing sleep
4. Muscle pain
5. Multi-joint pain without redness or swelling
6. New headaches
7. Sore throat
8. Tender cervical or axillary lymph nodes

1994 International CFS Case Definition

Other illnesses that explain fatigue – Exclusions for CFS

- ❑ Untreated hypothyroidism, sleep apnea, and narcolepsy
- ❑ Side effects of medications
- ❑ Unresolved Hepatitis B or C
- ❑ Major depressive disorders with psychotic or melancholic features, bipolar disorder, schizophrenia, dementias of any subtype
- ❑ Alcohol or other substance abuse within 2 years before fatigue onset
- ❑ Severe obesity of BMI greater than 45

Any unexplained physical or lab findings suggesting exclusionary conditions must be resolved before classification

**EPIDEMIOLOGY,
DEMOGRAPHICS, PREVALENCE**

CFS in the U.S.



- ❑ 1 to 4 million CFS
- ❑ 4 to 8 million CFS like illness
- ❑ 50% consulted physician
- ❑ 16% of CFS cases have been diagnosed
- ❑ 29% of upper middle class vs. 8% middle income
- ❑ 25% unemployed/receiving disability

CFS Prevalence

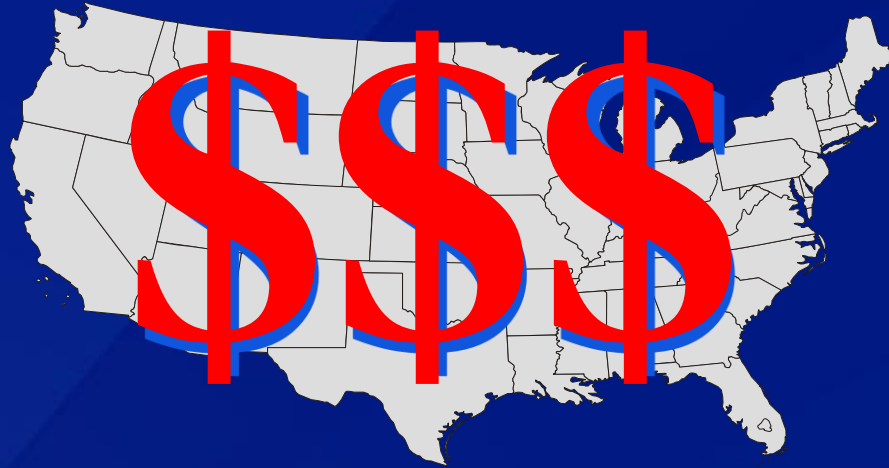
- ❑ Community and population based estimate ranges
 - ❑ 0.4% to 2.5% world wide
 - ❑ 0.006% to 2.6% United States
- ❑ 3 to 4 times more common in women
- ❑ Most common in the 40-50 year-old age group
- ❑ Highest rates may be in ethnic/racial groups
 - ❑ African Americans, Native Americans
 - ❑ Latinos > African Americans > Caucasians

CFS Epidemiology - Summary

- ❑ Fatigue is a common medical complaint but CFS is different than fatigue
- ❑ CFS is a long-lasting debilitating illness with impact similar to heart disease, multiple sclerosis, AIDS
 - Most CFS patients are ill >5yrs BUT only 50% seek medical care
 - Only 16% diagnosed and treated
- ❑ 1 to 4 million Americans suffer CFS
- ❑ CFS is 3 to 4 times more common in women
- ❑ More common in racial/ethnic minorities
- ❑ Higher rates seen in socioeconomically disadvantaged

IMPACT OF CFS

Economic Impact of CFS



Annual productivity loss \$9 billion

*Women

\$8 Billion

Men

\$1 Billion

Annual loss to each family with CFS \$20,000

CFS Impact

Patients

- ❑ Coping with symptoms can lead to stress
- ❑ Patients feel stigmatized lack of illness recognition

Family and Friends

- ❑ Chronic illnesses affect family members and caretakers
- ❑ Healthcare providers alert to family problems

Workplace and Coworkers

- ❑ Problems in workplace due to absences (i.e. stamina, problems with memory and concentration)
- ❑ “Invisible disability”

Clinical Considerations, Diagnostic Process and Management of CFS

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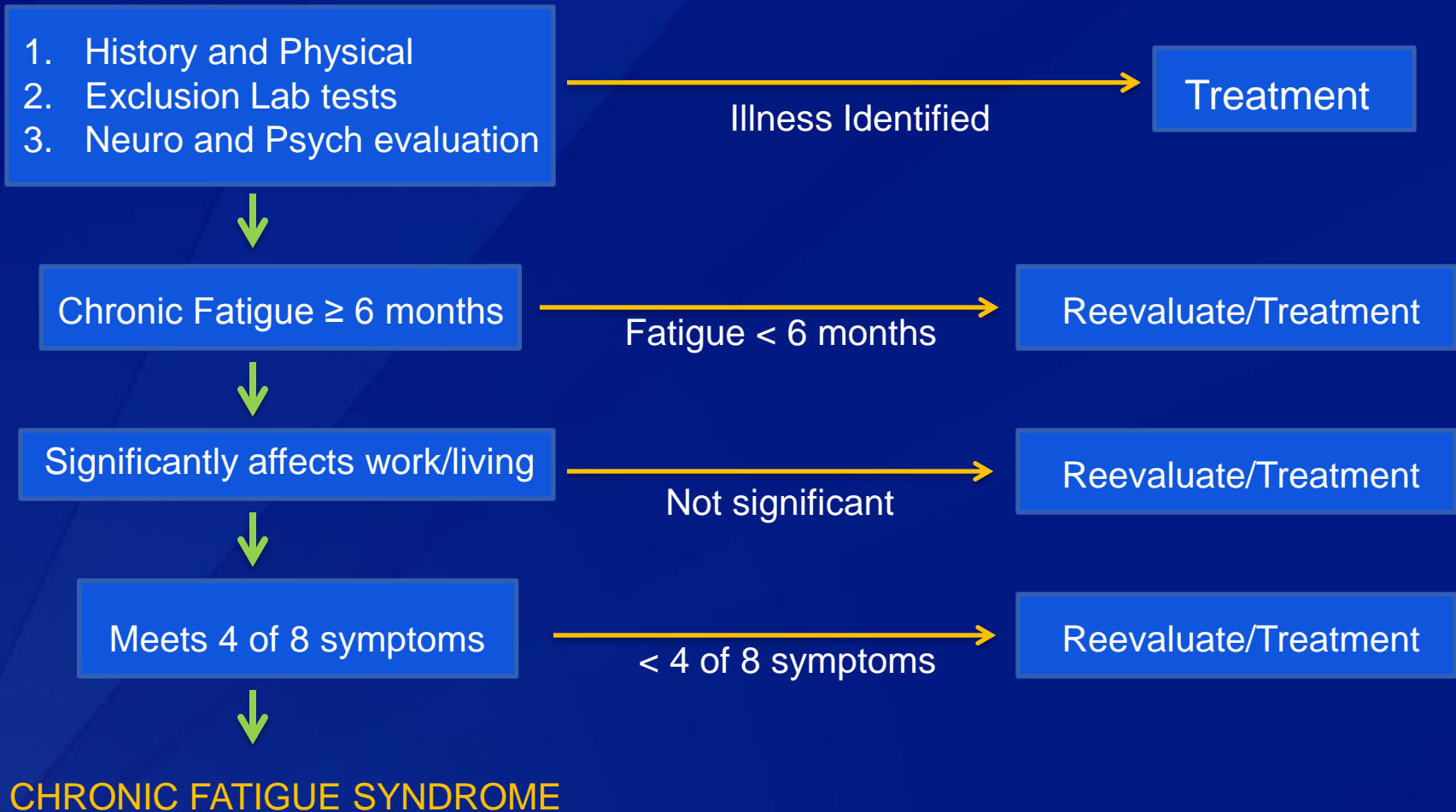
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DIAGNOSIS

Diagnosis of CFS

- ❑ Syndromes are recognized by core symptoms; patients can have multiple reasons (origins) for their symptoms
- ❑ Primary goal is to identify origin of patient's complaints
- ❑ CFS is a clinical illness to be considered after a thorough medical/psychiatric evaluation-it is a diagnosis of exclusion

Symptom Driven Evaluation



When Should a CFS Diagnosis Be Considered?

- Patient voices complaint of fatigue and additional illness complaints (only 40% identify fatigue as primary)
- Other diagnoses are not evident
- Adverse consequences of the illness
- Onset is new

Diagnostic Approach to Fatiguing Illnesses

History, history, and history:

1. Patient to describe illness in their words; a printed list to choose from does not give accurate information
2. Patient to identify primary factors that interfere with their ability to function:
 - What symptoms bother them the most?
 - What is meant by the complaint of fatigue?
 - When, where, and in what circumstances does the symptom occur?

Descriptions of Primary Complaints

Tiredness or Fatigue: what do these words mean to you?

1. Lethargy: non-restorative sleep
2. Flu-like: lack of energy with other symptoms
3. Leaden limbs: similar to post-exercise state
4. Sad and “down”
5. No energy
6. Trouble with concentration and memory

Diagnostic Process - continued

Sleep history

1. Time to bed and time to sleep?
2. Spontaneous night time and/or AM awakening time?
3. Restless or quiet sleeper?
4. Time of getting up out of bed for day?
5. Snoring?
6. Rested upon getting up?
7. Daytime sleeping?

* Tests include: polysomnogram (overnight), Multiple Sleep Latency Test (daytime)

“ I have no energy”

- ❑ Hypothyroidism
- ❑ Anemia
- ❑ Obesity
- ❑ Diabetes mellitus
- ❑ Electrolyte imbalance
- ❑ Chronic liver disease
- ❑ Poor nutrition

Laboratory Tests

- ❑ Globulin
- ❑ Glucose
- ❑ Calcium
- ❑ Phosphorus
- ❑ BUN
- ❑ Creatinine
- ❑ Electrolytes
- ❑ Total protein
- ❑ Urinalysis
- ❑ Complete blood count (CBC)
- ❑ Albumin
- ❑ Alkaline phosphatase (ALP)
- ❑ Erythrocyte sedimentation rate (ESR)
- ❑ Alanine aminotransferase (ALT) or aspartate transaminase serum level (AST)
- ❑ Blood urea nitrogen (BUN)
- ❑ Thyroid function tests (TSH and Free T4)

“Flu-like” Fatigue

- ❑ Infection: $Il-1\beta$, $IFN-\alpha$, $TNF-\alpha$, etc. are associated with symptom production
- ❑ Energy reserves spared for resolution of illness- production of new proteins, altered metabolism (including fever)
- ❑ Irritability and isolation likely protect against spread of infection and ensure rest-behavioral responses
- ❑ Changes resolve with resolution of infection, unless tissue injury occurs

Labs: UA, CBC w diff, sed rate, C-reactive protein, TSH & FT4, ANA and RF

“Legs feel like lead”

- ❑ After activity or just on standing?
- ❑ Associated with lack of stamina, nausea, headache, back pain, fast heart rate
- ❑ If light-headedness or fainting occurs, consider neurally mediated hypotension (NMH); may be considered to be postural tachycardia (POTS)
- ❑ Neither POTS or NMH are necessarily part of CFS

Tests include: Tilt table, other ANS; serum osmolality; CBC

More History

Purpose: to identify contributing factors

- ❑ Review of systems: Complete
- ❑ Past Medical History: Childhood and adult
- ❑ Medications: Type and daily regiment; OTC and prescription
- ❑ Alternative therapy

Cognitive Problems

- ❑ Cognitive deficits in persons with CFS were found primarily in the domains of attention, memory and reaction time.
- ❑ Deficits were not apparent on tests of fine motor speed, vocabulary, reasoning and global functioning.

COMORBID CONDITIONS AND PROGNOSIS

Non-exclusionary Comorbid Conditions

- ❑ Fibromyalgia
- ❑ Gulf War Illness
- ❑ Multiple chemical sensitivity
- ❑ Irritable bowel syndrome (IBS)
- ❑ Depression (not psychotic or melancholic)
- ❑ Anxiety disorders
- ❑ Somatoform disorders

Onset, Duration and Outcome

Acute or infectious onset

- ❑ associated with usual resolution within 2 years – data from clinic populations

Gradual onset

- ❑ associated with prolonged illness and/or relapsing illness – population-based studies

Prognosis and Outcome

- ❑ Younger age at onset, shorter illness duration, milder fatigue, and absence of comorbid psychiatric illness all associated with better prognosis¹
- ❑ Changes in symptoms, relapse/remitting pattern common²
- ❑ Great individual variation³
- ❑ Many people improve function over time but still have symptoms³

¹Afari and Buchwald, 2003, Joyce et al, 1997; ²Nisenbaum et al, 2003; ³Reyes et al 1997

CFS MANAGEMENT

Management for CFS and CFS-like Illnesses

- Accurate diagnosis(es)
- Education of patient, family, primary care providers, and employers re: CFS
- Appropriate behavioral changes (i.e., sleep hygiene)
- Appropriate exercise (i.e., very gentle graded)
- Revisit diagnosis with changes in clinical status
- Avoid these medications without proper diagnosis: SSRI's, Florinef, stimulants, "sleepers", anti-anxiety, narcotic analgesics and evaluate patient's "self-medication" use

Goals of Medical Care

- ❑ Initially, symptom reduction without increasing functional capability
- ❑ Patient description of needed level of function
- ❑ Determination of level of capability: formal or informal; does it match patient perception?
- ❑ Gradual increase in functional level

Immediate return to pre-illness health status is an inappropriate short term goal

Symptomatic Treatment

Cognitive Dysfunction

Cognitive training is a highly specialized form of therapy and requires referral to a trained clinician

Pain

- ❑ Simple analgesics
- ❑ Non-pharmacological modalities
- ❑ Pain management counseling
- ❑ Referral to a pain management specialist

Supportive Treatment

Diet

- ❑ Well-balanced diet
- ❑ Weight management plan
- ❑ Referral to dietitian

Coping skills

- ❑ Counseling
- ❑ Cognitive behavioral therapy (CBT)

Activity

- ❑ Highly individualized
- ❑ Paced, avoid overexertion
- ❑ Referral to occupational or physical therapist

Impact of Public Health Emergencies on CFS

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Traumatic Events and Responses

A traumatic event is an event or events that cause moderate to severe stress reactions

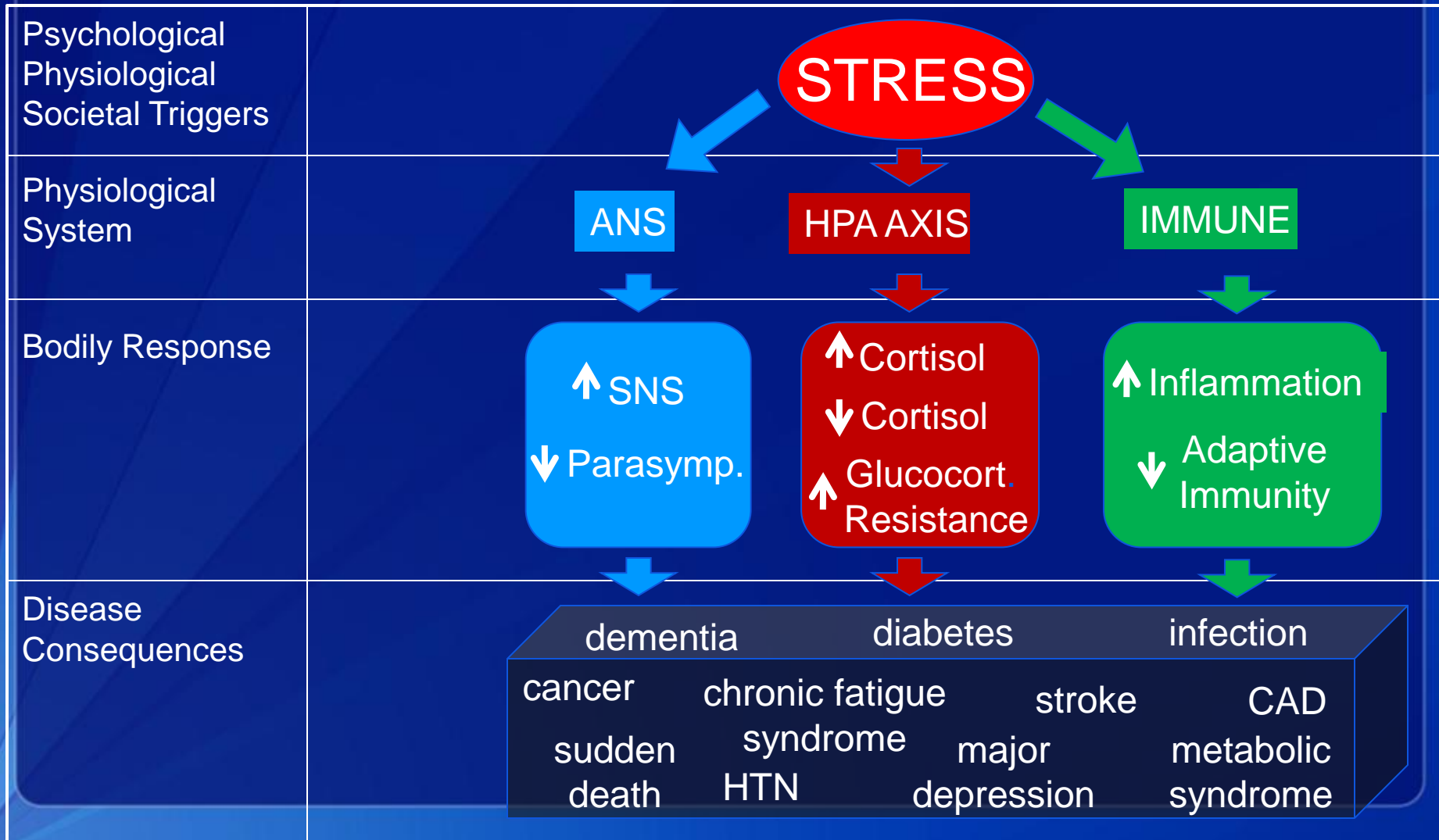
- ❑ **Cognitive** – poor concentration, memory loss, confusion, difficulty making decisions
- ❑ **Emotional** – shock, feeling abandoned, depression, numbness, uncertainty of feelings
- ❑ **Physical** – rapid heart rate, poor sleep, pain, headaches, dizziness, gastro-intestinal problems
- ❑ **Behavioral** – irritability, withdrawal, excessive silence, suspicion

Stress is a Risk Factor for, and Worsens Symptom Status for Most Diseases

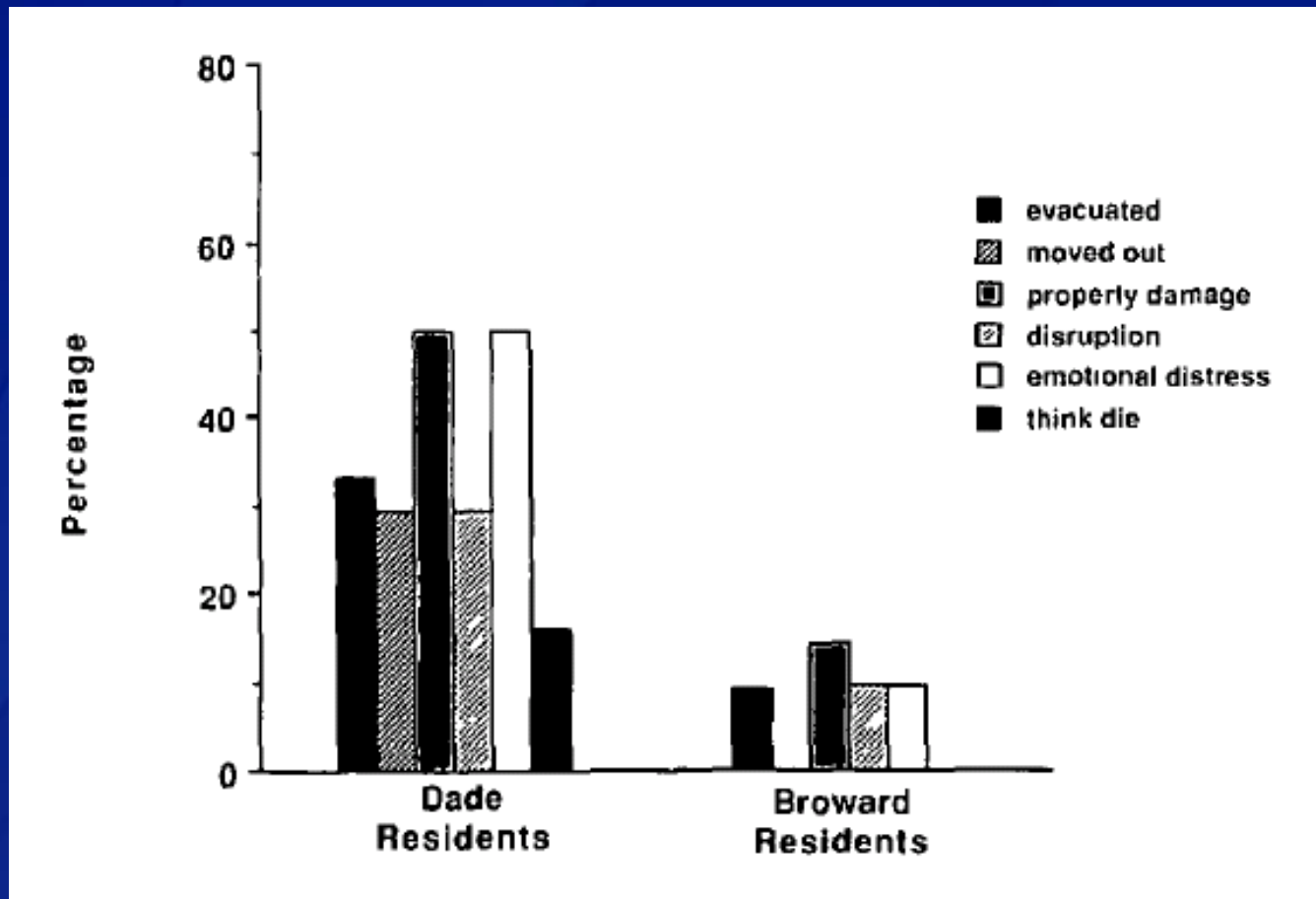
- ❑ Cardiovascular disease
- ❑ Stroke
- ❑ Diabetes
- ❑ Autoimmune Conditions
- ❑ HIV
- ❑ Cancer
- ❑ Dementia
- ❑ Depression

CHRONIC FATIGUE
SYNDROME

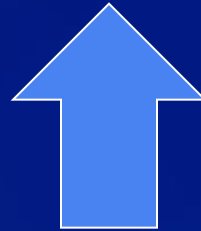
Pathways Leading from Stress to Disease



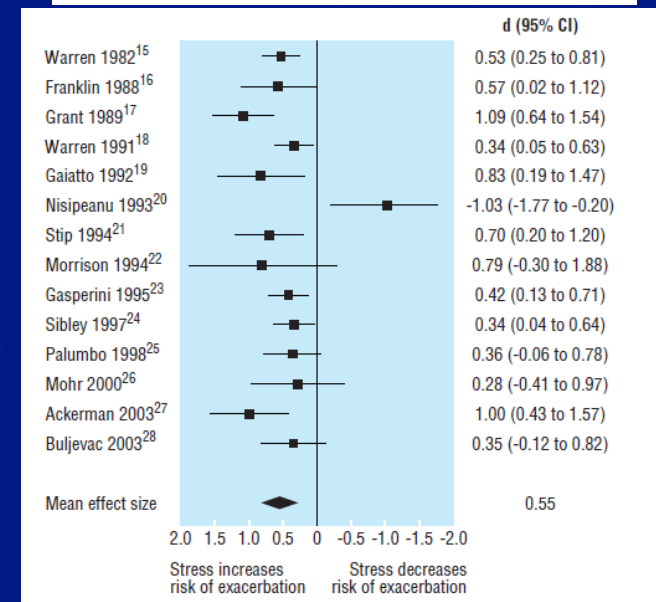
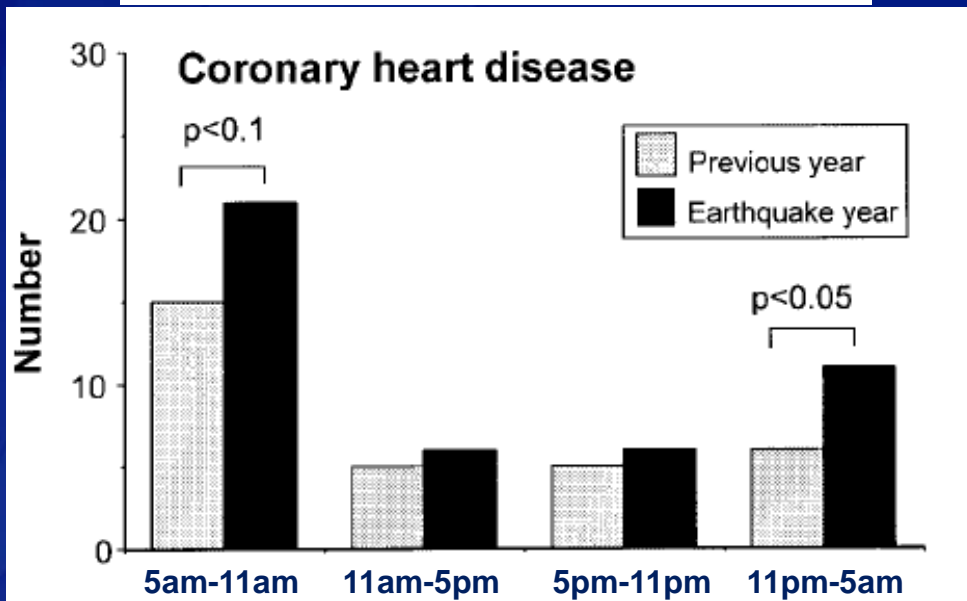
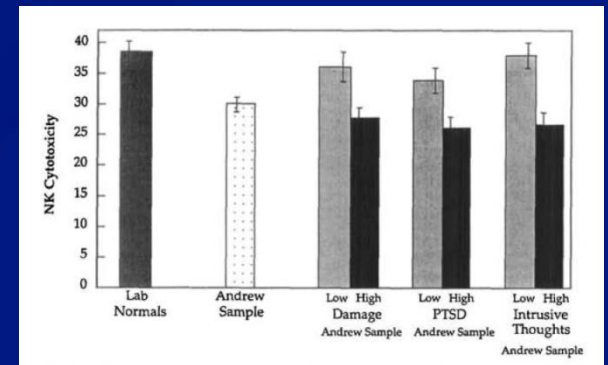
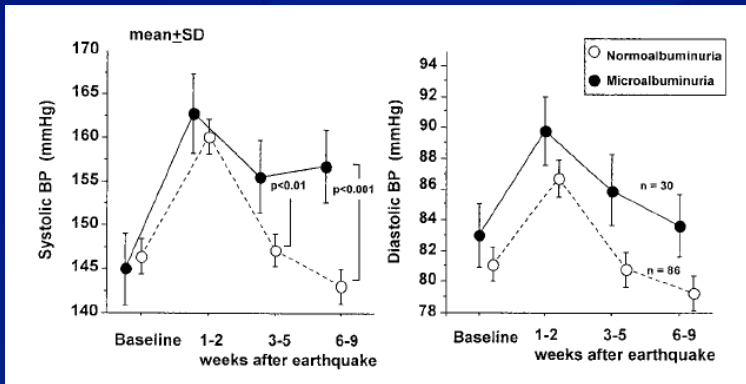
Natural Disasters Increase All Types of Stress



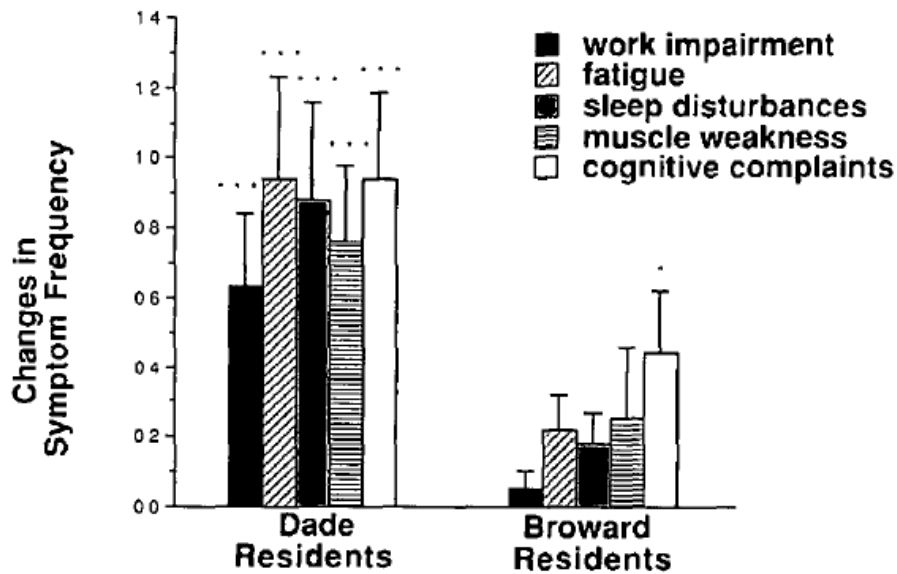
Disasters—Natural and Otherwise—Increase all Other Stressors



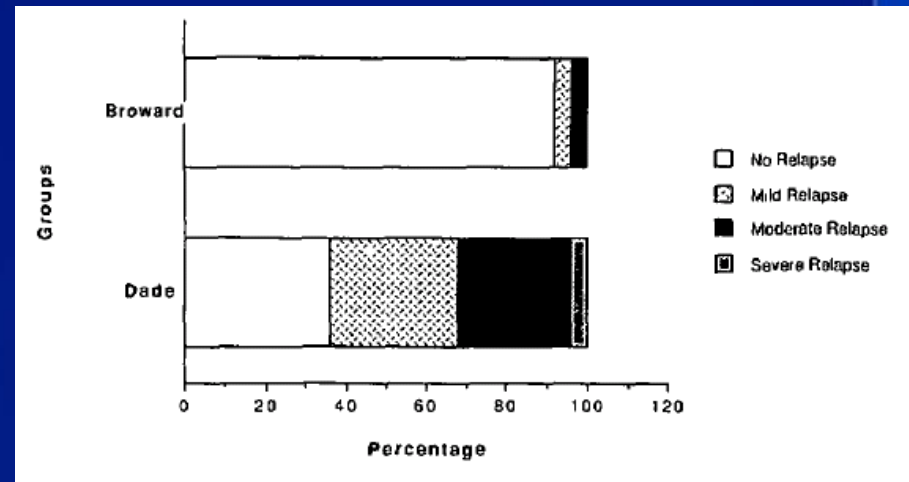
Disasters Have Documented Health Consequences



In People With CFS a Natural Disaster Worsens all CFS Symptoms

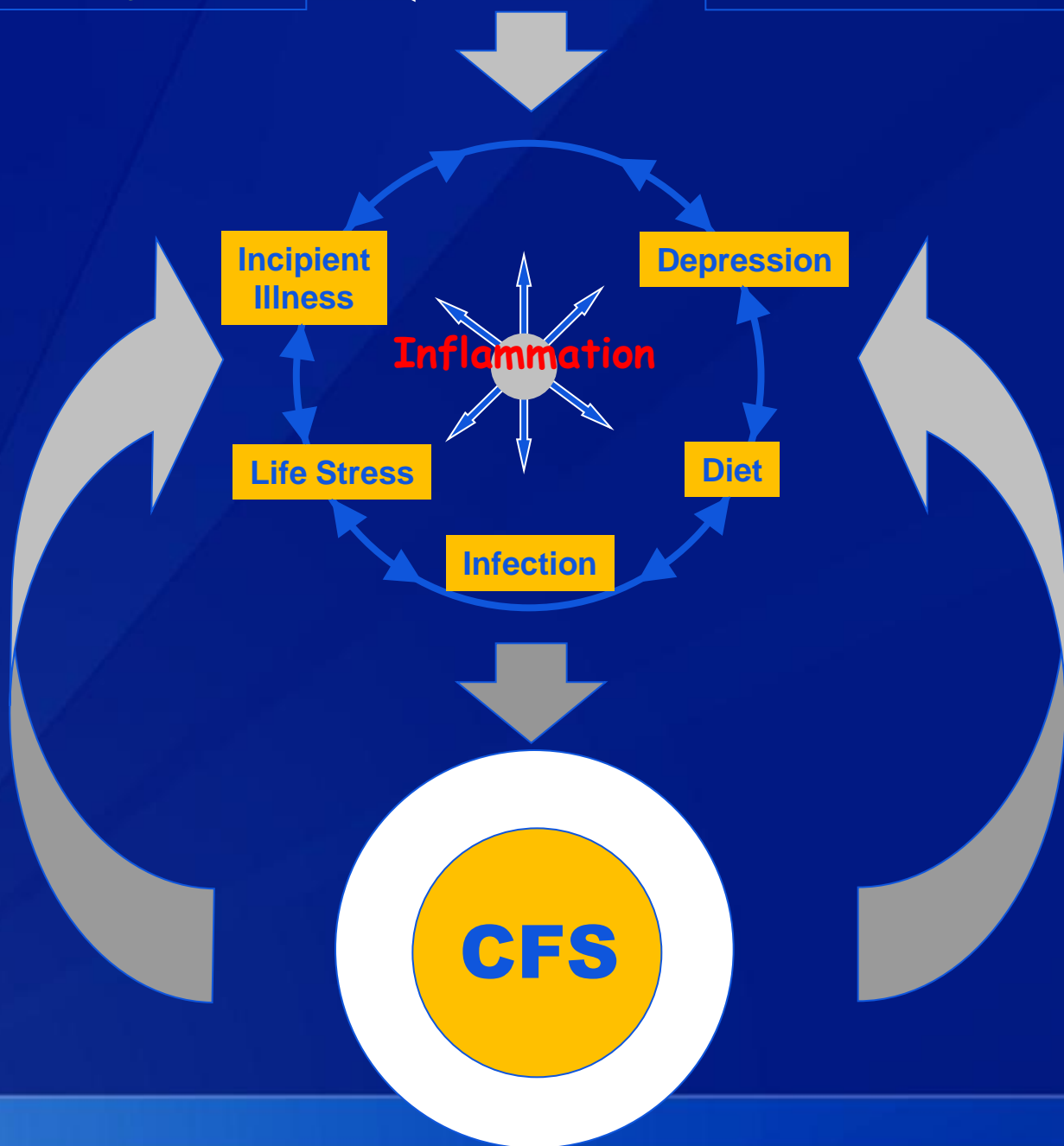


Significance of within group change: *** $p < .001$, * $p < .05$



Vulnerability Genes

Stress/Trauma/Infection



CFS

How to Prepare CFS Patients

Patients with CFS should be prepared for traumatic events in the same way as other chronic illness patients

- ❑ Prepare a written emergency and evacuation plan
- ❑ Have a contact list of friends, family, or caregivers and share with a friend
- ❑ Have a list of all medications and doctors
- ❑ Prepare an emergency kit for evacuations
- ❑ Be informed – know local emergency contacts/shelters
- ❑ Recognize that no two CFS patients are alike – will have different symptoms and needs

I. Essentials of Disaster Response for Patients with CFS

- ❑ Animal studies demonstrate that the stress response takes priority over sickness response
- ❑ In clinical terms this means that people with CFS will often perform normally in times of life-threatening emergency
- ❑ Data suggest that the big risk for CFS patients is that disasters can trigger long-term declines in functioning

II. Essentials of Disaster Response for Patients with CFS

- ❑ It is especially important that CFS patients follow all basic rules of disaster preparedness to help reduce stress of the situation and increase sense of mastery.
- ❑ Limiting trauma exposure and over-exertion may help protect against long-term functional decline
- ❑ Expect disaster related consequences to emerge over time and to require an extended period to resolve

How to Help CFS Patients After Traumatic Events

- ❑ Explain that some new symptoms may be normal after a traumatic event
- ❑ Remind patients to keep to usual routine
- ❑ Help identify ways to relax
- ❑ Identify ways to resolve day-to-day conflicts to reduce stress
- ❑ Encourage contact with support networks (i.e., friends, family, co-workers)

Conclusions

- ❑ Stress increases the risk of developing CFS and worsens symptoms in people with the disorder
- ❑ Stress induces physiological changes seen in CFS and other diseases, including increased sympathetic/decreased parasympathetic tone, glucocorticoid resistance and increased inflammation
- ❑ Disasters are major stressors in themselves that also exacerbate more chronic stressors
- ❑ Disasters may worsen long-term functioning in people with CFS
- ❑ Reducing traumatic experiences and severe over-exertion may provide long-term protection against disaster-induced worsening of CFS

The findings and conclusions in this presentation are those of the author and do not necessarily represent the views of the Centers for Disease Control and Prevention

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Thank you for joining!
Please email us questions at
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A-Z Index A B C D E F G H I J K L M N O P Q R S T U V W X Y Z #

Emergency Preparedness and Response

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Emergency Preparedness: Considerations in Chronic Fatigue Syndrome

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Presenter(s):

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Division of High-Consequence Pathogens and Pathology
National Center for Emerging and Zoonotic Infectious Diseases-CDC

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http://emergency.cdc.gov/coca/calls/2011/callinfo_081811.asp

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The screenshot shows the Facebook interface for the CDC Health Partners Outreach page. At the top, there is a navigation bar with the Facebook logo, a search bar, and login options for Email and Password. Below the navigation bar, a green 'Sign Up' button is visible. The main content area features the page header 'CDC Health Partners Outreach' with a 'Like' button and the location 'Atlanta, Georgia'. A row of profile pictures is shown below the header. The 'Wall' section contains several posts:

- A post from CDC Health Partners Outreach announcing a webinar on Crisis and Emergency Risk Communication – Radiation, scheduled for July 21 (3:00pm ET). The post includes a CDC logo and a link to the event.
- A post from CDC Health Partners Outreach announcing a booth at the AVMA Convention in St. Louis, MO, on July 16th. The post includes a CDC logo and the event details.

The left sidebar contains navigation links for Wall, Info, Photos, About, and Likes. The 'About' section provides information about the Health Partners Outreach Team and their partnership with the CDC Emergency Risk Communication team. The 'Likes' section shows 1,187 likes and a 'See All' link.

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