The ABC's of CFS for DYFS

Prepared for the New Jersey Division of Youth and Family Services

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By Way of Introduction

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- Working with CFS patients for 15 years
- Author of the lead chapter of the NJ Physicians' Manual for diagnosis and treatment of CFS
- Coauthor of two clinical chapters of the NJ Physicians' Manual for diagnosis and treatment of CFS
- Former member of the CFSAC
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- Current adviser to the CFSAC
- Board member of NJCFSA
- Board member of P.A.N.D.O.R.A
- Advisor to VT CFIDS Association
- Provider of CDC's continuing nursing and medical education program for CFS.

What is CFS/CFIDS?

- CFS = Chronic Fatigue Syndrome
- CFS has been unkindly called “Yuppie Flu”
- CFS is not the same as Chronic Fatigue or Post-Viral Fatigue Syndrome
- CFS is CFIDS – Chronic Fatigue Immune Dysfunction Syndrome
- CFS is ME in England – Myalgic Encephalopathy
- CFS/ME

What is CFS/CFIDS?

- CFS is a syndrome; not a disease
- The cause of CFS is unknown
- The CDC recognizes CFS as a syndrome.
- The CDC launched a $4 million campaign to educate both the lay public and health care providers in Nov. 2006
- The 8th International Congress of the IACFS held in January 2007 brought researchers from around the world to Ft. Lauderdale to present their research findings regarding CFS.
- CFS has an “organic” cause. It is not a psycholgical/psychiatric disorder.
- CFS may be accompanied by or provoke mental health issues but it is not inherently a mental disorder.
- CFS produces pathology in many organ systems

What is CFS/CFIDS?

- A diagnosis of CFS is a diagnosis of exclusion.
- CFS is diagnosed by fulfilling the criteria of the case definition.
- There is more than one case definition.
- In the US, the usually accepted case definition is that of the CDC.
- Until recently, all case definitions were for adults with CFS.
- There is now a proposed case definition for *children and adolescents*.

Proposed Pediatric Case Definition

- Chronic fatigue lasting over *3* months which is *not* the result of ongoing exertion, *not* alleviated by rest, results in the reduction of previous levels of educational, social and personal activities.
- All three of the following symptoms must be present:
  - Post-exertional malaise – loss of mental and/or physical stamina
  - Unrefreshing sleep
  - Pain or discomfort widespread or migratory either myofascial/joint pain or abdominal/head pain

Proposed Definition continued

- Two or more neurocognitive manifestations:
  - Impaired memory
  - Difficulty focusing
  - Difficulty find the right word
  - Frequently forgetting what (s)he wanted to say
  - Absent-mindedness
  - Slowness of thought
  - Difficulty recalling information
  - Need to focus on one thing at a time
  - Trouble expressing thought
  - Difficulty comprehending information
  - Frequently lose train of thought
  - New trouble with math or other educational subjects.

Proposed Definition Continued

- At least one symptom from two of the following three categories:
- Autonomic manifestations
  - Neurally mediated hypotension, postural orthostatic tachycardia, delayed postural hypotension, disturbed balance, dizziness…
- Neuroendocrine manifestations
  - Fever, cold extremities, subnormal body temperature, sweating episodes, marked weight change, loss or abnormal appetite…..
- Immune manifestations
  - Recurrent flu-like symptoms, sore throat, repeated fevers/sweats, tender lymph nodes, new sensitivities/allergies…

Onset of CFS in Children and Adolescents (CACFS)

- CFS is difficult to detect in children younger than 8 years of age.
- Adolescent patients have signs and symptoms similar to adult CFS.
- There is a possible genetic predisposition - 15 % of CACFS have a family history of CFS

Diagnosing CACFS

- As in the adult, diagnosis is one of exclusion.
- Exclude the presence of other fatiguing illnesses common in children:
  - Cystic fibrosis
  - Inflammatory bowel disease
  - Neurological disease including seizure disorders
  - Juvenile onset diabetes
- Onset likely associated with:
  - Viral infections- Epstein Barr (Mono), HHV-6, Parvovirus B-19
  - Immune dysfunction
  - Persistent inflammatory reactions
  - Orthostatic Intolerance
  - Endocrine abnormalities
  - Adverse reactions to foods, food components, food additives, environmental factors

Prevalence of CACFS

- There is no firmly established estimate of the number of children and adolescents with CFS.
- It is estimated that the percentage of children with CFS equals the percentage of adults with CFS.
- 3 – 5 % of the American population have CFS.
- 800,000 to 1,000,000 Americans are estimated as having CFS.
- Both boys and girls may contract CFS.

Onset and Time Course of CACFS

- Infectious illness, such as EBV, can cause post-viral fatigue and CFS.
- Non-infectious causes may precipitate CFS.
- Symptoms other than fatigue may be present: tonsillitis, enlarged lymph nodes, enlarged spleen, encephalitis, carditis, dermatitis, blood abnormalities, jaundice.
- Periodic flare-ups for years. Waxing and waning of symptoms.
- Persistent fatigue for years.
- Exacerbation of CACFS by additional illness, emotional and/or physical stress.

Phases of Emotional Conflict

- Denial – I am not sick. I want to be like everyone else. I overdo on good days followed by severe relapses.
- Isolation – I cannot keep up with my peers. My peers ridicule me because some days I can and others I cannot.
- Depression/Anxiety – I will never get well. I will never do what I want to do. I will never be who I want to be.
- Resiliency – I am who/what I am. I will do what I can. My illness has taught me special things. I will be a different person than I thought.

CACFS and Psychology

- there is a high risk for depressive disorders.
- the depression of CFS can be distinguished from major depressive disorder.
- there is a high incidence of emotional disorders.
- CACFS is more disabling than other chronic illnesses.
- patients usually benefit from psychotherapy. Therapist must be experienced with CACFS.
- Families benefit form psychotherapy.
- Psychotherapy helpful in working through the phases of emotional conflict.

Mental Health Programs for CACFS

- **Educational** – information about chronic illness and its emotional impact
- **Cognitive Behavioral Therapy (CBT)** – change perceptions and beliefs about the illness, develop coping strategies
- **Patient Psychotherapy** – enhance patient's self-esteem, relieve depressive and anxious feelings
- **Family Psychotherapy** – improve communication amongst family members; improve interpersonal relationships
- **Support Groups** – relief and validation provided by hearing similar stories
- **Group Psychotherapy** – similar to support groups but led by a trained professional

CACFS and Schooling

- Up to 94% of CACFS patients suffer a decline in school performance.
- Decline may be due to physical, cognitive or both physical and cognitive performance.
- 22-44% of CACFS home-schooled because they are too ill to attend.
- Home tutorial services may need to be provided.
- An abbreviated in-school program may need to be implemented.
- CACFS patients miss social development opportunities, and school social events.
- CACFS patients may qualify for services under the Individuals with Disabilities Education Act including an Individualized Education Plan.

What the School System Can Provide for the CACFS

- Relax the attendance and tardiness policies.
- Permit extra time for exams and assignments.
- Provide copies of missed work.
- Flexibility in scheduling and deadlines.
- Access to the school elevator.
- Provide tutors and home instructors
- Extra set of textbooks for the home.
- Transportation to and from school.
- Remove/reduce physical requirements of coursework.
- Extend timeframe for graduation. Relax requirements for graduation.

CACFS vs. Mood Disorders

CACFS	Mood Disorders
Severe fatigue often with motivation	Fatigue with lack of motivation
Frequent flu-like onset	Onset unaccompanied by physical illness
Somatic symptoms include sore throats, fevers myalgias, visual symptoms	Somatic symptoms rarely include myalgias, sore throat, fever or visual symptoms
Sleep disorder in non-REM sleep	Sleep disorder in REM sleep
Depressed mood understandable based on patient's circumstances	Depressed mood inappropriate or excessive
Suicidality in response to desperation	Suicidality accompanied by thoughts of death, self-harm. Recurrent, intrusive
Self-doubt	Self-blame

CACFS vs. Mood Disorders

CACFS	Mood Disorders
Responsive to positive stimuli.	Unable to respond with pleasure to good news
Fluctuating multi-system complaints, some vague	Persistent, idiosyncratic, pervasive symptoms
Decreased concentration with specific cognitive impairments.	Globally decreased concentration; preoccupation
May benefit from low doses of antidepressants	Treatment requires full therapeutic doses
Cognition, somatic symptoms, energy not responsive to psychiatric treatment	Entire syndrome alleviated by psychiatric treatment

CACFS vs. Anxiety Disorders

CACFS	Anxiety Disorders
Panic attacks accompanied by fatigue, sleep disorder or multi-system complaints	Symptoms limited to episode of panic or fear
Panic or anxiety clearly related to understandable fear about illness	Panic seems extreme or unrealistic
Avoidance behaviors do not eliminate symptoms	Avoidance behaviors control symptoms
Anxiety symptoms are variable; coincide with fluctuation or physical symptoms	Symptoms are persistent and chronic

CACFS vs. ADHD

- The principle characteristics of ADHD are any of three characteristic behaviors: **inattention**, **hyperactivity**, and **impulsivity**.
- Symptoms of ADHD will appear over the course of many months.
- There are medications for ADHD. There are no medications for CFS. Medications used to treat symptoms only.

Causes of ADHD Differ from the Causes of CFS

- From NIMH Attention Deficit Hyperactivity Disorder (pamphlet) the causes of ADHD are:
  - A sudden change in the child's life—the death of a parent or grandparent; parents' divorce; a parent's job loss
  - Undetected seizures, such as in petit mal or temporal lobe seizures
  - A middle ear infection that causes intermittent hearing problems
  - Medical disorders that may affect brain functioning
  - Underachievement caused by learning disability
  - Anxiety or depression

CACFS and MSBP

- A diagnosis of Munchausen Syndrome by Proxy often considered when a child is doing poorly in school or has multiple medical problems.
- With MSBP the child's illness is caused and perpetuated by a parent.
- The parent gains some benefit (attention?) from the child's illness.
- The child is unnecessarily examined, treated, and/or hospitalized.
- The concern expressed by a parent of a CACFS is often mistaken for MSBP.

Summary

- CACFS is a syndrome with a physical basis.
- CACFS occurs in 3 – 5 % of the population.
- CACFS is diagnosed by using a case definition.
- CACFS has a variable, multi-organ system presentation with cognition impairment.
- There is no medication for CACFS.
- CACFS is treated symptomatically.
- The time-course for CACFS is variable.
- Symptoms of CACFS wax and wane.
- Patient and family supportive therapy is helpful.
- Supportive school services is helpful.
- CACFS can be distinguished from mood and anxiety disorders.
- CACFS can be distinguished from ADHD and MSBP.