CHRONIC FATIGUE SYNDROME

Rosamund Vallings
MNZM, MB BS
Tired all the time
CFS/ME etc etc

- UNDERSTANDING OF ILLNESS
- DIAGNOSTIC CRITERIA
- EXCLUSION CRITERIA
- MANAGEMENT STRATEGIES
- TREATMENT
- FOLLOW UP
UNDERLYING PATHOLOGY

- ABNORMAL IMMUNE SYSTEM
- NEURO-INFLAMMATION
- PROBABLE AUTO-IMMUNITY
- A VERY PROLONGED POST-VIRAL ILLNESS
- A CONTINUUM OF SEVERITY
PREDISPOSING FACTORS

• GENETIC PREDISPOSITION
• MENTAL or PHYSICAL DISTRESS
• SLEEP DEFICIT
• VIRAL PRIMING
Other onset triggers

• Viral illness
• Other infection
• Bodily onslaught
  – Overexercise
  – Toxins
  – Accident
  – Surgery
  – Immunisation etc etc
Who gets CFS/FM
EPIDEMIOLOGY of CFS

- 4 per 1000
- 1 million sufferers in USA
- 18000 sufferers in NZ
- 66000 in Australia
- All age groups and ethnicity
- SEX: FEMALE 3:2
Development of CFS/ME

Stress may be physical or mental
Percentages refer to likely recovery rates after an illness such as glandular fever
CARDINAL SYMPTOMS

• FATIGUE++ (unresolved by rest)
• POST-EXERTIONAL MALAISE
• COGNITIVE PROBLEMS
• ORTHOSTATIC INTOLERANCE
• FLU-LIKE SYMPTOMS
• PAIN/FIBROMYALGIA/HEADACHE
• GASTRO-INTESTINAL DISTURBANCE
• SLEEP DISTURBANCE
FIBROMYALGIA

• Most with CFS have FM
• Most with FM have CFS

• Central sensitisation syndrome (M Butler)
• ? Genetic vulnerability
• ? early life effects (M Fitzgerald)
• Mitochondrial abnormalities (J Newton)
Making a diagnosis: CDC Criteria (Fukuda et al)

• Unexplained persistent or relapsing fatigue, of new or definite onset, not due to ongoing exertion, not relieved by rest, and results in substantial reduction in previous levels of activity

• 4 or more of defined symptoms concurrently present for 6 months or longer:
CDC Criteria – defined symptoms

1. impaired memory/concentration
2. sore throat
3. tender cervical or axillary nodes
4. muscle pain
5. multi joint pain (no redness/tenderness)
6. new headache
7. unrefreshing sleep
8. post-exertional malaise
INTERNATIONAL CRITERIA (2012)

- Include:
  - NO 6 MONTH WAIT
  - P.E.N.E (P.E.M)
  - ORTHOSTATIC INTOLERANCE
  - ALCOHOL/DRUG INTOLERANCE
  - NEUROLOGICAL SYMPTOMS
  - GASTROINTESTINAL SYMPTOMS
  - PAEDIATRIC ISSUES
LABORATORY TESTING

- Process of exclusion/differential diagnosis
- Full blood screen
- Specific symptom testing
WE NEED A BIOMARKER!

"Most of your tests are normal... it could be M.E."
• DESPITE SYMPTOMS SUGGESTIVE OF INFECTION (eg sore throat) NOTHING IN BLOOD PICTURE SUGGESTS ACTIVE INFECTION.

• ESR usually low

• ANA may be +ve ??autoimmune disease
TESTS OF LITTLE USE (Shepherd)

- HAIR ANALYSIS
- SALIVARY TESTS
- MERCURY AMALGAM
- Electro-acupuncture (Voll)
- CANDIDA
- “MUSCLE TESTING”
DIFFERENTIAL DIAGNOSES

- CHRONIC PAIN/FIBROMYALGIA
- LUPUS
- POLYMYALGIA
- POST POLIO SYNDROME
- DEPRESSION/ANXIETY
- BIPOLAR DISORDER
- LYME DISEASE
- IBS
- SLEEP DISORDERS
- HYPERVERVENTILATION
- EHLERS-DANLOS SYNDROME etc etc
PSYCH ASSESSMENT NECESSARY

• DIAGNOSIS of CFS CANNOT BE MADE IN PRESENCE OF UNTREATED DEPRESSION

• Other psychological conditions need to be treated before we can make a diagnosis eg anxiety, anorexia, bipolar
DIAGNOSIS

• A DIAGNOSIS OF EXCLUSION
• SUB-CATEGORIZATION
• ONGOING SURVEILLANCE
• 30% EVENTUAL ALTERNATIVE DIAGNOSES

• Symptoms tend to mimic initial illness
• PEM – 2 day exercise test
MANAGEMENT

- CORRECT DIAGNOSIS
- ACKNOWLEDGEMENT/SUPPORT
- EDUCATION
- LIFESTYLE
  - Stress (Friedberg, Sharpe)
  - Exercise/rest (Fulcher&White, Lapp)
  - Nutrition (Burnet)
  - Supplements
  - Sleep management
  - Pain management
PACED EXERCISE

• NONE LEADS TO POOR OUTCOME
• TOO MUCH LEADS TO RELAPSE
• NEEDS TO BE REGULAR/OUTSIDE
• START AT LOW LEVEL (?lie down)
• LITTLE and OFTEN (pacing)
• PREPARATION and REST
• BUILD SLOWLY
• AVOID CRASH and BURN
NUTRITION

• BALANCED DIET/VARIETY
• SMALL REGULAR MEALS
• MINIMISE ALCOHOL, CAFFEINE
• AVOID RICH FATTY FOODS
• PLENTIFUL FLUIDS (not excess)
• EXTRA SALT/potassium
• BEDTIME SNACK
• SUNSHINE
SUPPLEMENTS

- BETTER ABSORBED VIA FOOD
- DEFICIENCIES IN BLOOD
- DEFICIENCIES IN DIET
- TREATMENT OF CONDITION
POSSIBLE SUPPLEMENTS

- OMEGA 3/OMEGA 6 OILS (2:1) (Puri)
- B VITAMINS (B12 INJECTIONS) (Regland, Lapp)
- MAGNESIUM 300mg at night (MALIC ACID)
- COENZYME Q-10 (up to 200mg)
- D-RIBOSE (Japan)
- VITAMIN D
- AVOID VIT C EXCESS or IMMUNE BOOSTERS
MEDICATION

- SLEEP DEFICIT (Moldofsky)
- INCREASE BLOOD VOLUME (Bell)
- PAIN CONTROL
- DEPRESSION and ANXIETY
- CENTRAL ACTIVATION
- ANTIMICROBIALS
- HRT (Studd, Evengard))
- AMPLIGEN (de Meirlier)/ISOPRINOSINE (Hyde)
- AUTO-IMMUNE DRUGS
Normal sleep cycle

Awake
Stage 1
Stage 2
Stage 3
Stage 4

HOURS OF SLEEP
0  1  2  3  4  5  6  7  8

REM = rapid eye movement (dream sleep)
SLEEP MANAGEMENT

• GOOD ROUTINE/sleep hygiene/magnesium
• TRICYCLICS – FIRST CHOICE
• MELATONIN
• ANTIHISTAMINES
• MUSCLE RELAXANTS
• BENZODIAZEPINES
• QUETIAPINE
• PREGABILIN, GABAPENTIN
• ROPINAROLE (RLS)
AUTONOMIC DYSFUNCTION

- POSTURAL CHANGE
- SUPPORT HOSE
- CARE WITH SHOWERING etc
- INCREASE BLOOD VOLUME
- (salt, fludrocortisone 0.1mg)
- REGULATE PUMP (β blockers)
PAIN CONTROL

• WARMTH, MASSAGE, RELAXATION
• ACUPUNCTURE, HYPNOSIS
• SIMPLE ANALGESICS
• ANTI-INFLAMMATORY DRUGS
• STRONG ANALGESICS
• OPIOIDS
• RELAXANTS (BZDs, orphenadrine)
• ANTI-EPILEPTICS (GABAPENTIN, PREGABALIN)
• LOW DOSE NALTREXONE (1.5 - 4.5mg)
DEPRESSION/ANXIETY etc

• Counselling, CBT
• ANXIOLYTICS
• MOOD STABILISERS (eg bipolar)
• CENTRAL ACTIVATION (Ritalin/Modafinil)
• ANTIDEPRESSANTS:
  – TRICYCLICS (timing)
  – SSRIs
  – SRNIs
ANTIMICROBIALS

• ?ANTIBIOTICS (Lyme, mycoplasma)
• ANTIFUNGALS ?? (side effect!)
• ANTIPARASITICS (Tapanui)
• ANTIVIRALS: (eg persistent herpes)
  – ACICLOVIR
  – VALGANCICLOVIR
  – ?OXYMATRINE (Equilibrant) (J Chia)
OESTROGEN (Evengard)

- KEY REGULATOR of GROWTH
- REDUCED GENETIC EXPRESSION
- INCREASED BLOOD VOLUME
- INCREASED CEREBRAL BLOOD FLOW
- HIGH OESTROGEN $\rightarrow$ IMMUNE MODULATION
- RELIEF OF MUSCLE/JOINT PAIN

- ?HRT USEFUL/OCs
- PREGNANCY EFFECTS

- Risk factors
IMMUNE MODULATORS

- AMPLIGEN (Rintatotolimod)
- ISOPRINOSINE
- ANTI-VIRALS (Montoya)

IMMUNISATIONS
Latest research

• Is CFS/ME an auto-immune condition?
• Norwegian findings (B cell lymphoma)
• Treatment possibility
• B cell depletion
• Rituximab (Fluge & Mella)

• Marshall-Gradisnik et al – Goldcoast
• Gene studies – J. Kerr
ONGOING ISSUES

• AVOIDANCE OF RELAPSE
• REGULAR REVIEW
• MULTIDISCIPLINARY TEAM
• RECOVERY RATES – adults/children
LONG TERM RISKS

• LOW NK CELLS:
  – INCREASE IN CANCERS
  – INCREASE IN INFECTIONS

• INCREASE IN LYMPHOMA

• AGING OF TELOMERES
LEPTIN

• From fat cells
• Increased in stress
• Primes microglia (primary defence in CNS)
• Microglia make one “feel ill”
• Gut/brain connection
• More microglia in brain than neural cells
To reduce Leptin

Weight loss

Stress management

Diet: tumeric, reservatrol

Drugs:
  - Antihypertensives
  - Naltrexone
  - Minomycin
Likely Biomarkers

- Cytokine activity
- NK cells decreased late in disease
- NPY elevated (stress mediator)
- Leptin elevated
- VO2 max (X2) (98% reliable)

Biomarker must be specific to the disease.
All CFS patients can experience a better quality of life with compassionate care and a multidisciplinary approach.

Patient needs to feel in control of health rather than being controlled by the disease.
Rehabilitation
Physicians’ Primer

• IACFS/ME:
• www.iacfsme.org