

WAKING TO A NEW DAWN

AONM CONFERENCE 19th November 2017

OFF THE PACE

CMIs, BPS, PACE, GUIDELINES and CONSEQUENCES

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THE BIG DIVIDE



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graph TD; A[THE BIG DIVIDE] --> B[FUNCTIONAL SOMATIC SYNDROMES ALL IN THE MIND, BSP PSYCHIATRY]; A --> C[COMPLEX CHRONIC MULTI-SYSTEM ILLNESS BIOMEDICAL BASIS SCIENCE HISTORY EXAMINATION RESEARCH];
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**FUNCTIONAL
SOMATIC
SYNDROMES
ALL IN THE
MIND, **BSP**
PSYCHIATRY**

**COMPLEX CHRONIC
MULTI-SYSTEM
ILLNESS
BIOMEDICAL
BASIS SCIENCE
HISTORY
EXAMINATION
RESEARCH**

THE BIOPSYCHOSOCIAL, BSP, MODEL

DEVELOPED BY ENGELS IN 1970S FOR MENTAL ILLNESS **ONLY**

- PATIENTS LOST ANY AUTONOMY- NO CHOICE
- FORCED DETENTION IN MENTAL HOSPITALS
- ENFORCED TREATMENT
- SOMETIMES ANTIDEPRESSANT/ANTIPSYCHOTIC DRUGS GIVEN

VERY LITTLE 'BIO' – IT HAPPENED TO LIVING BIOLOGICAL ORGANISMS/PEOPLE.

LARGELY PSYCHO –COMMONLY TALKING THERAPIES
SOCIALLY/CULTURALLY BASED.

IN UK – 'MORPHED INTO' CBT/GET UNDER CHALLENGE OF
ME and DIRECTION of "WESSELY SCHOOL"
CHANGE UNDERSTANDING OF ILLNESS: GET SOME
EXERCISE

SYNDROMES OF UNCERTAIN ORIGINS
Merck Manual 1999, 17th Edition

GULF WAR SYNDROME
GWS/I
MILITARY ME

**MULTIPLE
CHEMICAL
SENSITIVITY**

OPs

ME-CFS
FMS

MULTI-SYSTEM & ORGAN
NEUROLOGICAL- ANS, PNS, CNS
CARDIOVASCULAR
IMMUNE SYSTEM
GASTROINTESTINAL
RESPIRATORY
ENDOCRINE SYSTEM

“Considering the extent of the patients’ complaints and disability, the results of ROUTINE laboratory tests were strikingly NORMAL” S Straus

FUNCTIONAL SOMATIC SYNDROMES – ALL IN MIND CBT/GET

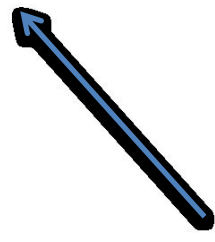
AEROTOXIC SYNDROME

Jet Engine Oils (TCPs)

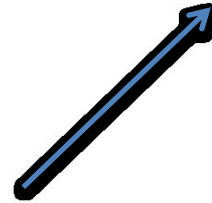
Pilots

Richard Westlake

Cabin Crews



OPs



FARMERS

Shepherds(Dips)-LAW

Live stock (Pigs/Cattle)

Grains Stores

FISH FARMS

Kathleen Sullivan

Multi System Atrophy



DEPLOYED GULF WAR VETERANS, 25-30% Chronically Sick!

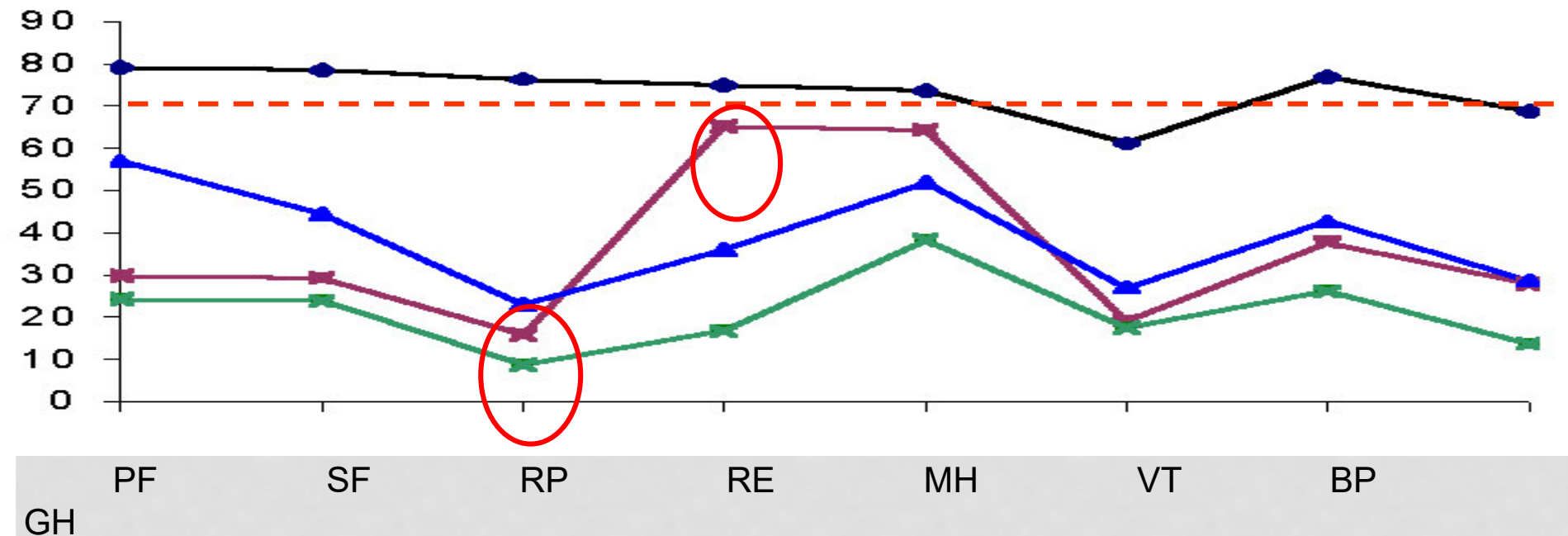
1. OP PESTICIDES (Diazinon +, Malathion. Chlorpyrifos etc.) Govt Lies
2. Pyridostigmine Bromide, NAPS,
3. Nerve agents, SARIN

Cholinergic Triple Whammy – Ian Hill Global Illness Syndrome

[VACCINES – Non - Deployed],

SF-36 SCORES MEAN OF GENERAL POPULATIONS

ME/CFS, OP & GULF WAR



PF= Physical Functioning (10); SF = Social Functioning (2); RP= Role Limitations Physical Problems (4); RE= Role Limitations Emotional Problems (3); MH=Mental Health (5); VT= Vitality/Energy (4); BP = Pain (2); GH = General Health (5)

OTHER CHRONIC ILLNESSES - SCORE < 72 HEART FAILURE, DIABETES, RECENT MI, COPD, DEPRESSION. Haley 2004 Lloyd Inquiry

WESSELY et al UNABLE TO DISTINGUISH BETWEEN SICK AND 'WELL' GWVs - JOEM 2003;45:668-675.

FUNCTIONAL SOMATIC SYNDROMES: ONE OR MANY?

Wessely et al Lancet 1999;354:936-9 **BPS MODEL**

Gastroenterology – IBS, Non-ulcer dyspepsia

Gynaecology – PMS, chronic pelvic pain

Rheumatology – Fibromyalgia

Cardiology – Atypical or non-cardiac pain

Respiratory medicine – hyperventilation

Infectious Disease – PVFS- ME-CFS

Neurology – Tension headache

Dentistry – TMJ dysfunction, Atypical facial pain

ENT – Globus syndrome

ALLERGY - MCS

CANNOT EXPLAIN BY
CONVENTIONAL
PARADIGMS

CONVENTIONAL
THERAPY INEFFECTIVE

MORE COMMON IN
WOMEN THAN MEN

SHARE NON-SPECIFIC
SYMPTOMS

SYNDROMES WILL RESPOND TO SAME THERAPIES, CBT/GET

COMPARE AND CONTRAST IN THE MIND/BPS BIOMEDICAL

UNEXPLAINED ILLNESS/

SOCIALLY DEFINED

INACTIVITY(DECONDITION)

FALSE ILLNESS BELIEFS

FEAR ABOUT SYMPTOMS

DEPRESSION – CBT/GET

EMOTIONAL STATES

MUS, PUPS, MUPS, PUS

REAL ILLNESS

VIRUSES IMPORTANT

DIFFICULT PROBLEM

USUAL TESTS NEGATIVE

RESEARCH NEEDED

**TREATMENT DEPENDS ON
INSIGHTS OF PHYSICIAN**

CO-MORBIDITIES

MYALGIC ENCEPHALOMYELITIS –WORKED EXAMPLE

–COMPLEX

- CHRONIC

- MULTI-SYSTEM ILLNESS

[MUS, PUPS, MUPS – ‘UNEXPLAINED’ - VANISH]

“Everything that cannot be understood does nevertheless not cease to exist.” Blaise Pascal (1623-1682)

“I might be criticised for presenting alarming material [about ME] but I have tried to present the truth and this in perspective” Dr John Richardson (1915-2002)

WHO - ICD 10 - G93.3 (FROM 1969) IS CLEAR
MYALGIC ENCEPHALOMYELITIS IS A NEUROLOGICAL
DISORDER

MUSCLE PAIN WITH INFLAMMATION OF THE NERVEN AND
SPINAL CORD

[THE ONLY ALLOWED ALTERNATIVE NAMES ARE
POST-VIRAL FATIGUE SYNDROME, CHRONIC FATIGUE
SYNDROME, CFS]

ME -PATHOPHYSIOLOGY - CLEAR MEANING
FOR CLINICIANS AND APPLIED SCIENTISTS

PVFS AETIOLOGY (VIRUS INDUCED) + SYMPTOM -
FATIGUE

CHRONIC FATIGUE DESCRIBES A SYMPTOM – SUBJECTIVE
– PROVIDES NO OBJECTIVE CLINICAL SIGNS - MAKES
MISCHIEF POSSIBLE

**NOT ENCEPHALOPATHY (NOT CLASSIFIED) –
ENCEPHALOMYELITIS**

Decreasing
objective
information
clinical,
diagnostic,
scientific,
aetiological.

THE DECEPTION ! MISCHIEF MAKING !

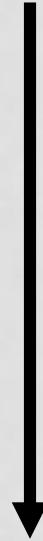
MYALGIC ENCEPHALOMYELITIS – CHRONIC FATIGUE
SYNDROME AT G93.3 [NEUROLOGICAL DISORDERS]

~~CHRONIC~~

~~SYNDROME~~

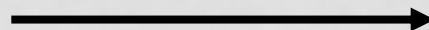
FATIGUE
SYNDROMES

CHRONIC
FATIGUE



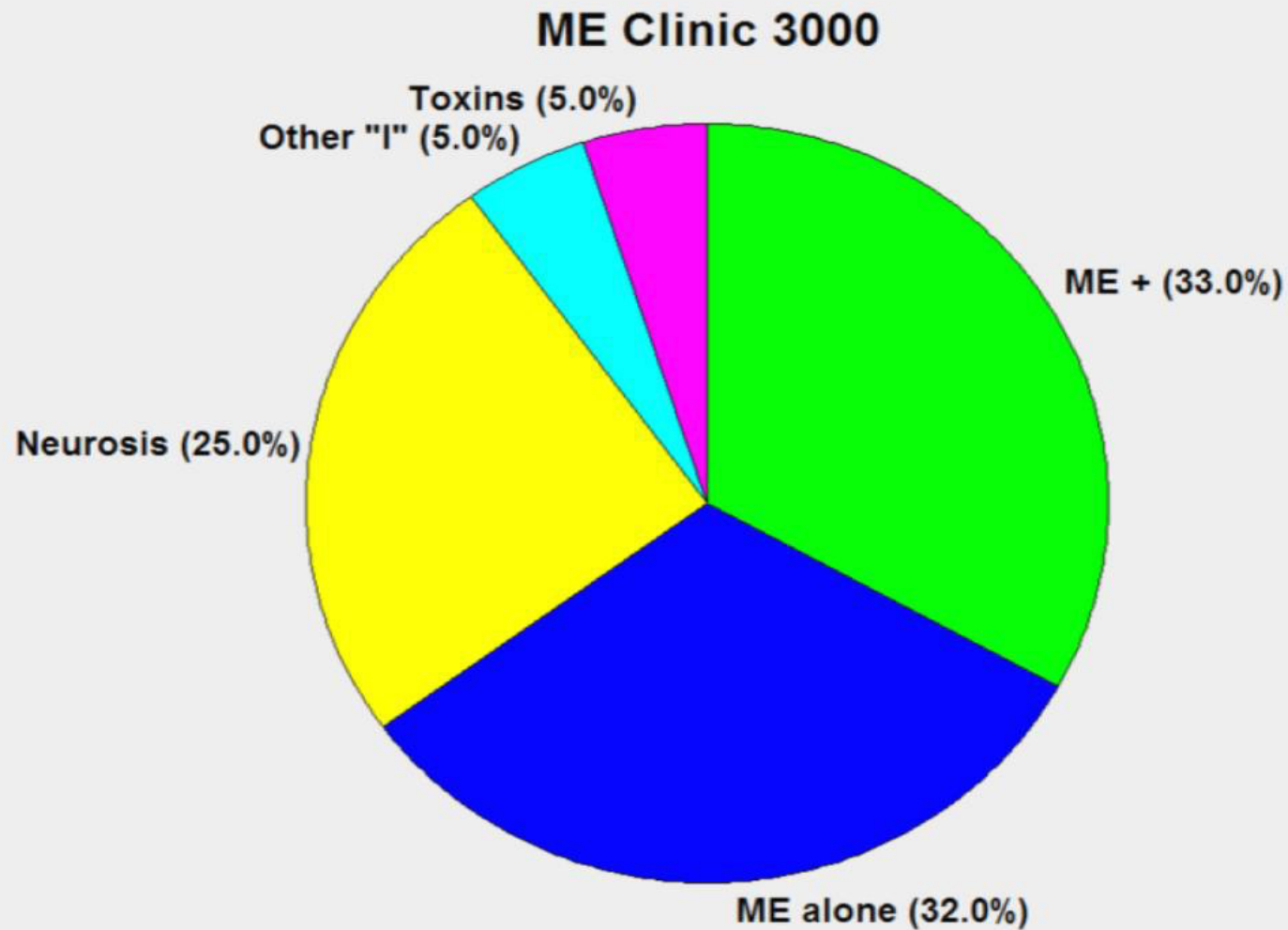
[MENTAL & BEHAVIOURAL DISORDERS –
F48.0]

NEUROLO
GY G93.3



PSYCHIATRY/PSYCHO
LOGY F48.0

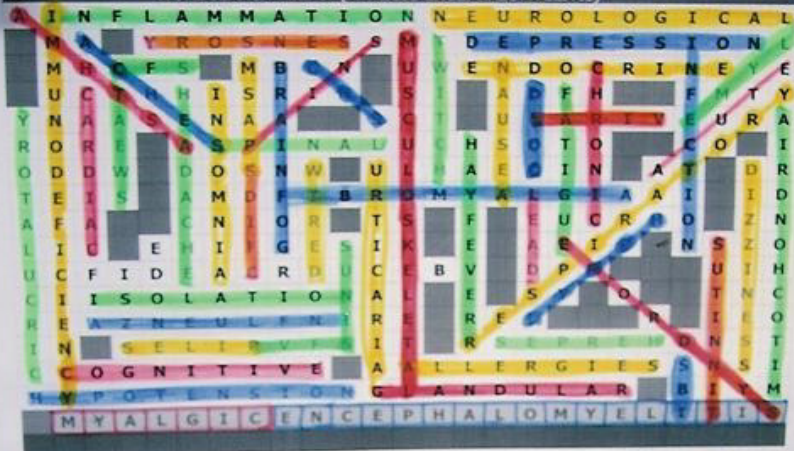
DUAL CLASSIFICATION IS **NOT** ALLOWED UNDER RUBRICS



CO-MORBIDITIES – MISSED DIAGNOSES; Diabetes, Thyroid (Cancers), Cardiovascular, GF, Autoimmune disorders

WORDSEARCH M.E.

WORDSEARCH M.E. or (MYALGIC ENCEPHALOMYELITIS)



www.jivalobo.com/invisibleME

**Making the invisible
– visible**

**LISTEN TO
PATIENT VOICES**

History Listen to
Patient and to Patient's
Parents – especially the
Mother.

John Richardson -1999

John Chia 2010



**LINDA – VERY
SEVERE ME - >20
YEARS.**

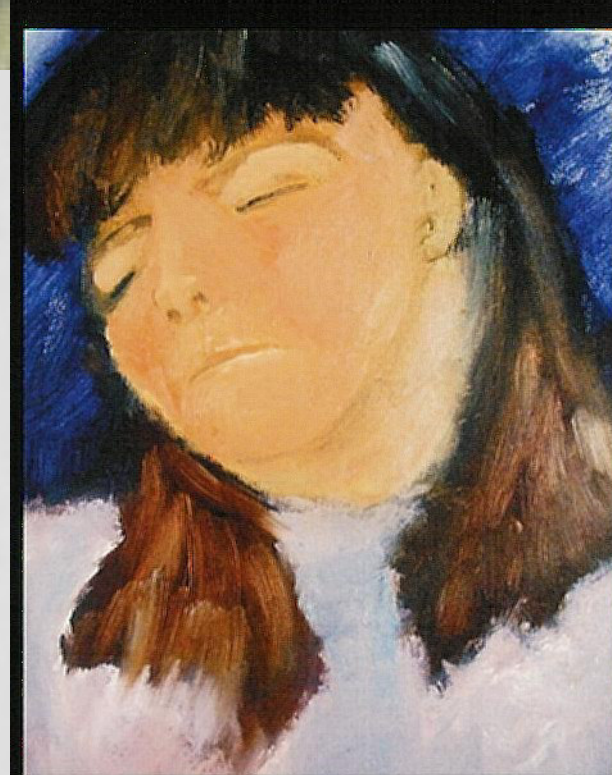
**TOUCH, LIGHT,
SOUND - ARE AGONY
PHOTO/ PAINTING BY
HUSBAND**

GREG CROWHURST

PAIN PARALYSIS

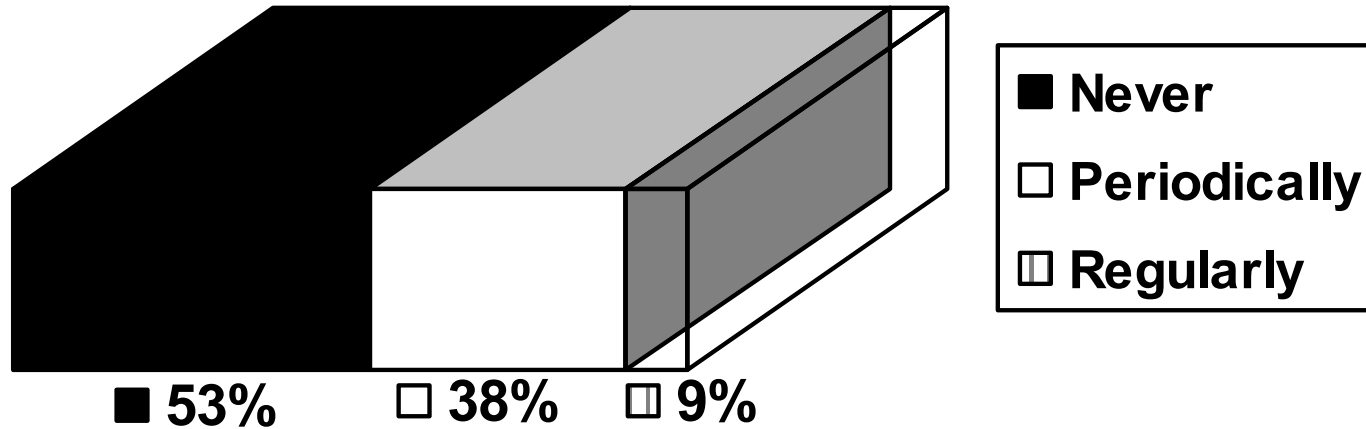


Agony - Never Ending - Pain



Paralysis

GP HOME VISITS



25% Group Survey

VISIT THE SICK – DO NO HARM –MEDICAL
NEGLIGENCE/DERELICITON OF DUTY



Tears?

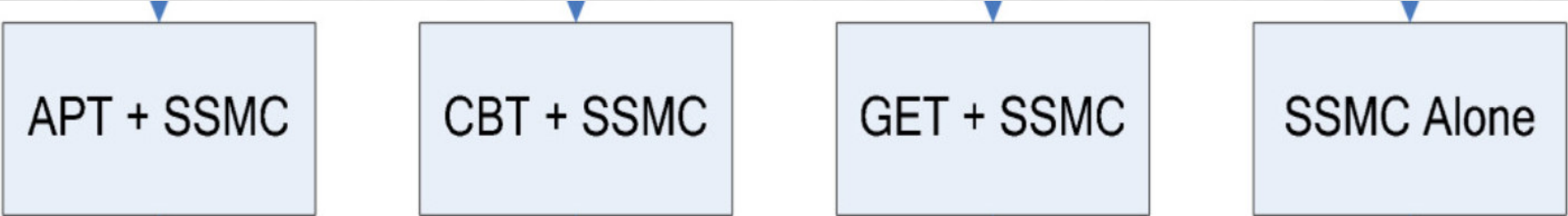
GRIEF? - FRUSTRATION- UNBELIEF- ABANDONMENT
CRUELTY- IDEOLOGICAL- APPROACH-EAN?, SOPHIA?

Voices from the Shadows – Natalie Boulton

PACE TRIAL – CFS/ME- VALIDATE CBT & GET A RANDOMISED ~~CONTROLLED TRIAL~~

NO OBJECTIVE
MEASUREMENTS

NO BLINDING – a *sine qua non* for Subjective data



APT + SSMC

CBT + SSMC

GET + SSMC

SSMC Alone

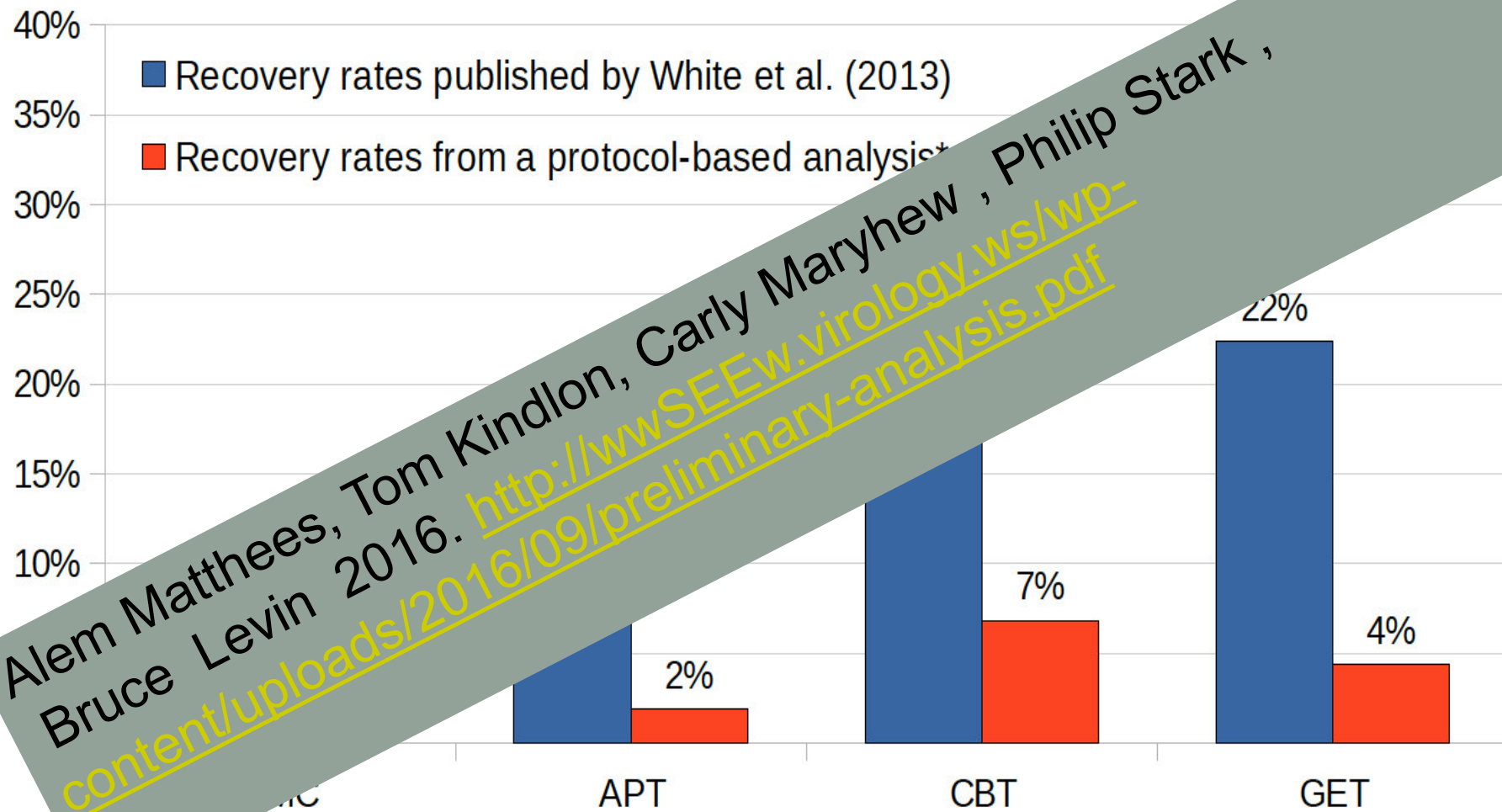
NO CONTROL GROUP Inter Group Comparisons

ORIGINAL Entry Requirements & Primary Outcomes
CHANGED AND MANIPULATED THROUGHOUT STUDY

Publicly funded research, £6 Million – data NOT released – opposed by Authors, Editor, Lancet, Publishers, QWUL who owned the data.
Needed a FOIA 5 years later - OMBUDSMAN

WHY ?

Figure 1. Post-trial changes to the PACE trial recovery criteria inflated the



Alem Matthees, Tom Kindlon, Carly Maryhew, Philip Stark, Bruce Levin 2016. <http://www.SEEw.virology.ws/wp-content/uploads/2016/09/preliminary-analysis.pdf>

None of the added therapies demonstrated a statistically significant advantage over specialist medical care alone when using the protocol-specified thresholds

MENE, MENE, TEKEL PARSIN

YOU HAVE BEEN WEIGHED IN THE BALANCE AND
FOUND WANTING

Everything is lost – chasing a 'will of the
Wisp', a mirage, investigating a NULL field

JUDGEMENT

efficacy of CBT & GET - FROM
"HORSES MOUTH" .

Why then spend £6 MILLION – FINE & PACE

£8.2 million on FATIGUE clinics ?

control

"Modestly effective"

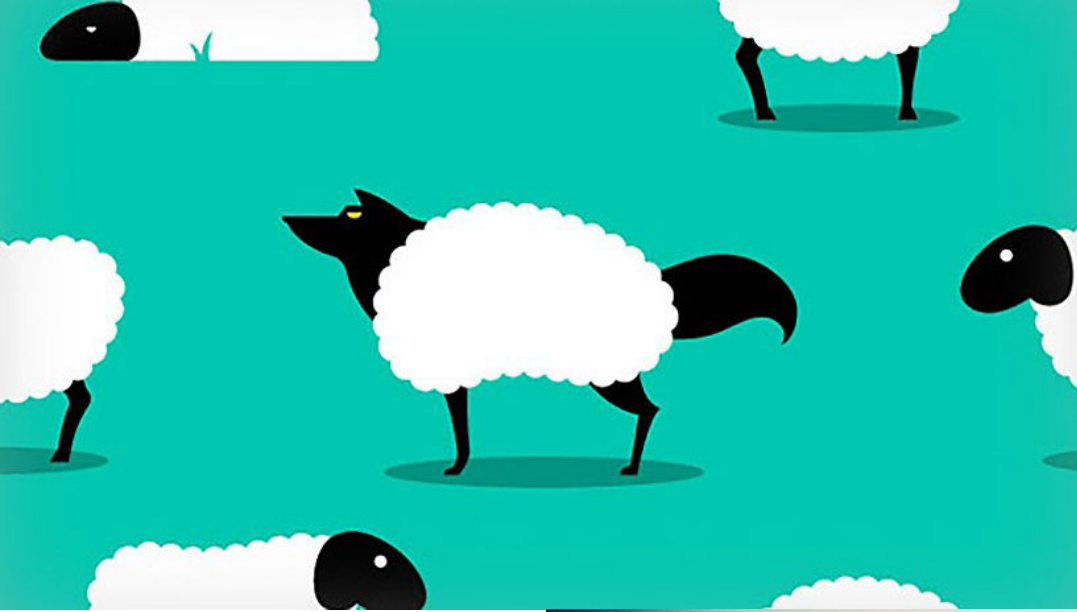
"Not remotely curative"

**"These interventions are not
the answer to CFS" .**



Professor Simon Wessely, Journal American Medical Association 286,19,2001.

Read your own papers please! Twisk & Maes 2009 make same point



CRUELTY
OBSTRUCTION/?
DATA? DENIAL

MAIMES
Public
Inquiry

S. Myhill et al



SOMATIC MEDICINE ABUSES PSYCHIATRY – AND NEGLECTS CAUSES

An almost TOTAL lack of SCIENTIFIC support

Reclassifying BODILY symptoms as MENTAL problems...where CONVENTIONAL medicine is at a loss for an explanation.

LACK OF firm KNOWLEDGE is converted into SPECULATIVE ASSERTIONS without any CRITICAL voices being heard. PD, MS, Diabetes

Causal explanation for illnesses .. go with predominantly somatic symptoms [that] lack any basic similarity to known mental disorders.

An evasive argument...with its lamentably poor record of research into causes, particularly where environmental factors are concerned.

Industrial/ Financial interests are actively influencing the course of what is ostensibly a scientific discussion.

What makes an individual human being ill cannot be determined by statistics

Lack of knowledge is a considerable handicap in the treatment of chronic diseases

Per Dalen (Psychiatrist) http://art-bin.com/art/dalen_en.html (2003)

Mercury, Lyme's disease, Al Camelford, placebo effect, toxicology, epidemiology

N McLaren THE (BIO)PSYCHOSOCIAL MODEL and FRAUD

This model is based on fraud and ignorance and a complete misunderstanding of the origins of the idea. It is a myth.

"I see psychiatry under attack from all quarters. Some people see a great future for us. I don't share that view. I believe there is a serious risk that psychiatry as we know it will no longer exist in as little as fifteen years. The reason is simply a lack of anything approximating an adequate intellectual framework for our efforts."

The myth of the biopsychosocial model.

Australian and New Zealand Journal of Psychiatry 2006; 40 (3), 277-278

<http://www.futurepsychiatry.com/> Chapters 7 and 9

This model was the basis for the rejection of the Class Action brought by GWVs and persists still- see Phil Trans Royal Soc 2006;631:689-695.

WHAT ME IS NOT!

NOT a Fatigue Syndrome/Neurasthenia. ICD-10 G.93.3 NOT F.48.0

NOT Chronic Fatigue - many causes, Amer Med Assoc 1990

NOT Burnout – cortisol responses differ Mommersteeg et al

NOT DECONDITIONING - Burnett, Newton.

NOT CFS - Spence et al, Olano et al

NOT Clinical Depression fails clinical tests –Richardson et al and many others

POLITICAL CONTROL OF HEALTH COSTS
CONCERNS OF INSURANCE INDUSTRY
FOR CHRONIC CONDITIONS
DISMISSED BY FALSE EVIDENCE AND
PATIENTS TO BE IGNORED.

POLICY-BASED EVIDENCE [PACING, CBT, GET] NO
CREDIBLE INTELLECTUAL OR CLINICAL FOUNDATION

VS

EVIDENCE-BASED POLICY
BIOMEDICAL WITH SOUND SCIENTIFIC
FOUNDATION
TARGETED HEALTH CARE & TREATMENT

MYALGIC ENCEPHALOMYELITIS

"NEVER IN THE FIELD
OF MODERN MEDICINE
HAS SO MUCH HARM
BEEN DONE TO SO
MANY BY SO FEW".

What does all this mean ?

The WHOLE of Government Policy based on BSP model now Falls DoH, NHS, NICE, MRC (Research Funding), DWP/Benefits

Payments must now be made to OP poisoned Farmers, Gulf War Veterans and Cabin Crews (AS) – Justice must be given

Insurance Companies can no longer refuse payments to the sick, ME/CFS, OPs, AI etc.

Nigel Speight, Sarah Myhill, Jean Monro and others have been VINDICATED. DRIVE HOME

THANK YOU

**Eradicating ME
Wessely S. 1992
Report of meeting
Pfizer Pharmaceuticals**

QUOTABLE QUOTES ABOUT ME/CFS

Margaret Williams, 2007