

Research update

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MNZM

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Where are we at?

- Our lives have been dominated by Covid-19
- Post-covid-19 syndrome = post-viral syndrome (Long-haulers)
- This will lead to greater awareness of ME/CFS (JAMA article)
- “Long-haulers stump experts!”
- But Dr M Hornig has succumbed (a leading CFS researcher)
<https://www.ama-assn.org/delivering-care/public-health/mady-hornig-md-and-patient-share-their-experiences-covid-19-long>
- Hopefully money will pour into research?

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Money

- **Nova Southeastern University Researchers Receive \$4 Million From CDC for 'COVID Long Haulers' Study**
- **Congress Approves Over a Billion Dollars to Study Long-COVID: Implications for ME/CFS**
- **\$NZ 61,000 to Prof Tate (Otago) – long haul covid study compared to ME/CFS**

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IACFS conference - August 2020

- Held on line because of covid-19 restrictions
- Here in NZ at 2.00 am !
- Attended “virtually” by Drs R Vallings and S Dalziel (funded by anzmes)
- Report available at:
<https://www.iacfsme.org/2020-conference-summaries>

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Salient points from conference:

- Whole segment on likely effects of Covid-19
- Treatment session:
 - Japanese research re-affirmed the importance of understanding underlying immunological mechanisms before treatment strategies can be established.
 - Self management group programme (USA) showed significant benefit.
 - Visits to severe housebound patients → measurable benefit
 - Low dose naltrexone – up to 4.5mg daily → symptom relief for 73%. No studies done for higher dose.
 - Oral rehydration – v important particularly if symptoms of POTS
 - Needs to contain saline and glucose – good improvement in cerebral blood flow.

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Diagnosis

- Is tilt table testing important? – NASA low lean test now used as easier.
- Dr L Bateman has guidelines for administering the test (UTAH,USA)
- Analysis of metabolic processes = changed amino acid profile = an energy starved condition (Pettersen, Norway) (159/660 metabolites different)
- Healthy muscle cells exposed to ME/CFS serum → increased mitochondrial respiration → increased lactate.

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UK/Europe Situation

Invest in ME conference May 2020 – cancelled
Rescheduled for May 2021

MEA have produced up to date brochure on current research and update on effects of Covid-19. These and other handouts available on line:

<https://tinyurl.co./y32sc7to>

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UK Summary of research

- A multisystem disease with genetic predisposition
- Comorbidities common
- Abnormalities in following systems:
 - Blood and plasma
 - Cardiac function
 - Immunological dysfunction
 - Metabolomics
 - Microbiome
 - Mitochondria
 - Neurological and neuro-endocrine

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Australian Research (large govt grant)

- Griffith University team - Transient Receptor Potential pathology:
- In ME/CFS patients' NK cells there are fewer functioning TRPM3 receptors and some are defective.
- TRPM3 receptors control movement of calcium in and out of cells.
- Damaged SNP → decreased TRPM3 receptor → changed function → decreased Calcium in cell → impaired lysis
- Affects many systems: eye, brain, gut etc
- ? Improved with LDN

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N.Z. research

- Prof Warren Tate/Eiren Sweetman (Dunedin)
(Epigenetics)
- Peripheral Blood mononuclear cells reveal mitochondrial dysfunction
- Changes in DNA Methylation profiles reflect systemic dysfunction
(clear distinction from healthy controls)

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Potential medication

- Simple symptom relief (Pain, stress, depression, sleep)
- Drug options:
 - Hormonal (oestrogen, fludrocortisone, prednisone)
 - Psychological (atomoxetine, ritalin, mirtazapine, sertraline)
 - Anti-epileptics (pregabalin, clonazepam, gabapentin)
 - Cardiac (midodrine, propranolol, nimodipine)
 - Low dose naltrexone
 - Neurological (pyridostigmine, ropinirole)
 - Sleep (melatonin, amitriptyline, promethazine)
 - Muscle relaxants (norflex, clonazepam)
 - Antivirals (?? Spironolactone)
 - Chemotherapeutics (cyclophosphamide)
 - Immune suppressants (Isoprinosine)
 - Surinam (sleeping sickness drug)

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Leptin (Fletcher, Younger)

- Promotes activity of microglia → inflammatory cytokines
 - (? activated all the time in ME/CFS → symptoms)
 - Leptin is associated with appetite and obesity, increased with stress
 - Decreasing leptin → hunger, inability to fight cancers

How to decrease leptin safely: meditation, weight loss.

Leptin is made by fat cells.

How to decrease microglial activity: possibly helped by valganciclovir, LDN

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72 years of research

- Nomenclature
- Psychological theories
- Escalation of physical awareness
- Scientific studies: blood, brain, tissues, genes etc
- Effects of exercise (PEM)
- Random treatments → symptomatic relief
- Sophisticated lab work, computer technology, scanning, gene mapping etc leading to many abnormalities defined.
- Epigenetics
- A multisystem illness – treatments more specific
- Likely sub categorised.

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Covid-19 vaccination

- Covid-19 can kill, therefore vaccination wise.
- Those with CFS/ME **may** be “self-protected” by immune activation.
- But no guarantee.
- Vaccine is not “live”, therefore risk of serious reaction less.
- Getting Covid-19 may worsen CFS/ME (serious relapse)
- Choose time for vaccine when at one’s “best”
- Allow 2-3 days before and after vaccination for rest
- Be prepared for “reaction” (paracetamol, antihistamine, prednisone)
- Stay at facility for up to an hour

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Those most at risk from Covid-19

- Those over 65
- Those with underlying illness
- Those with: high BP, asthma, heart and/or lung disease, obesity, immune deficiency

NB Vaccination may not give 100% immunity

2nd dose will be needed with several vaccines

We do not know how long vaccination will last

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Remember:

Prevention is the KEY:

Handwashing

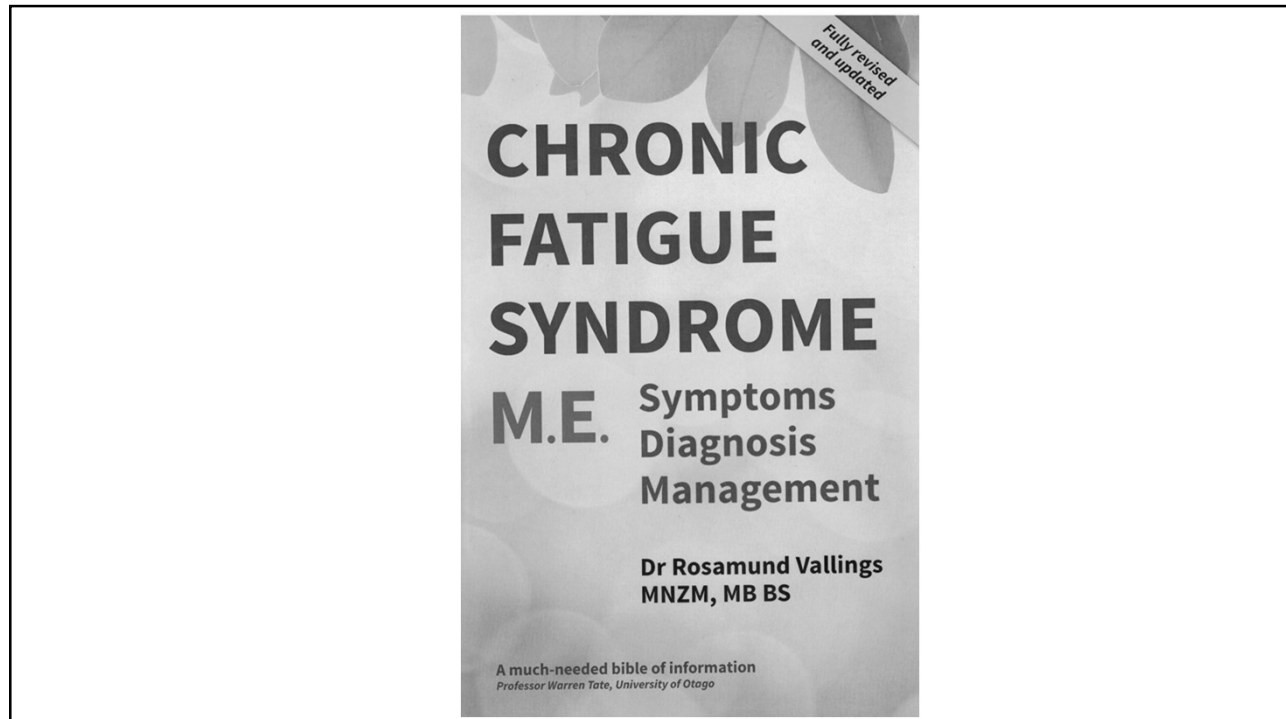
Hand sanitization

Facemasks

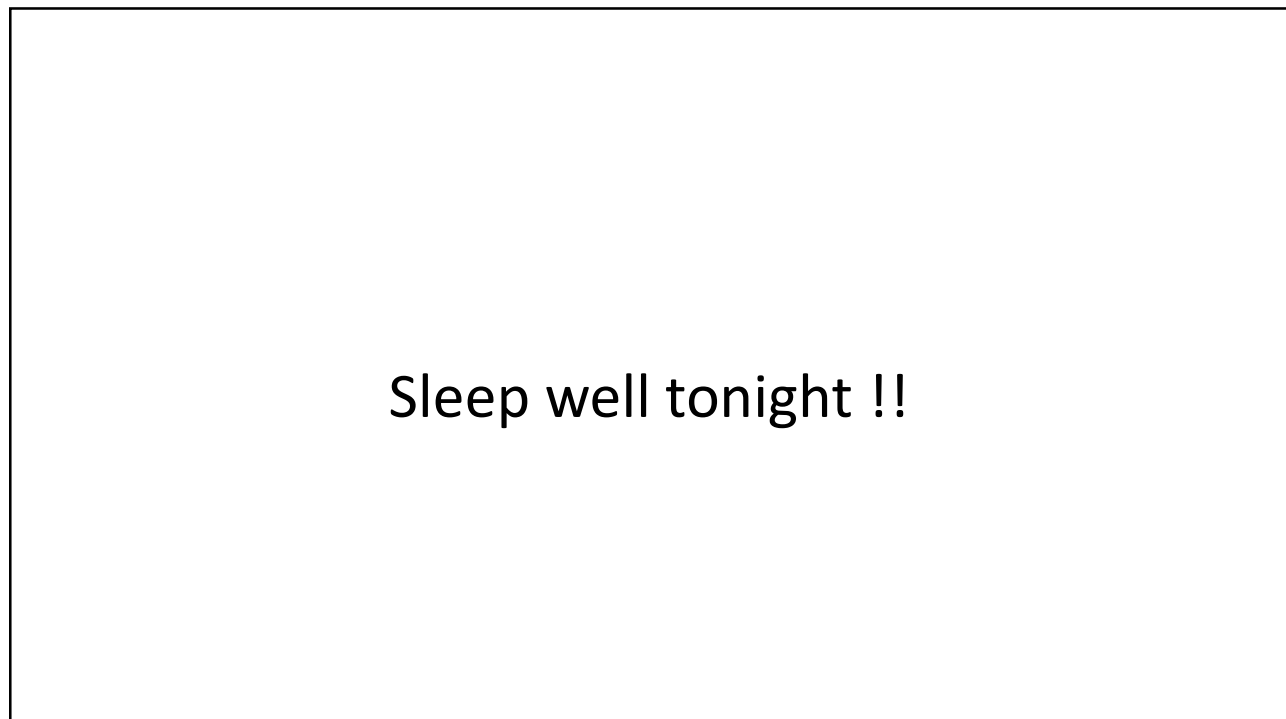
Isolation

Use of tracer App

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