TAPANUI FLU

1983-2013

What have we learned?
Tapanui Snow
An unexplained illness in West Otago

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Trying to solve the Problem

- 1983 Round table discussion with Dunedin patients
- 1983 Support groups
- 1983 Research activity
- 1986 Mackenzie criteria
- 1989 Research studentship
- 1990 Cambridge Symposium
A Short History of CFS

- Neurasthenia/ Chronic fatigue
- Atypical poliomyelitis
- Coxsackie virus
- Epstein Barr virus
- Retrovirus
- Minor psychiatric disorder
- XMRV virus
Patient and Doctor business

Patient

• WHAT IS WRONG WITH ME?
• HOW DO I GET BETTER?

Doctor

• MAKING A DIAGNOSIS
• MAKING IT BETTER
Making a diagnosis for what?

- For Research?
- For the patient?
Measure of Scientific Interest

- In 2013 so far 160 papers in Index Medicus
- In 1983 one paper was published
• The first point that needs emphasising is that the CFS/ME syndrome is a cause of chronic illness, disability and loss of work.

S Holgate

• We do not know the cause of CFS for the same reason that we do not know the cause of many neurologic diseases: we have not yet been clever enough to figure it out.

A Komaroff
• There is no solid evidence to date that any viral or bacterial infection is associated with ME/CFS.

• Dennis Mangan

• The evidence that certain infections have the ability to trigger CFS is overwhelming. For example, there is a greater risk of developing CFS after Epstein–Barr virus than other common infections.

• Simon Wessely
To be diagnosed with chronic fatigue syndrome, a patient must satisfy two criteria:\n
1. Have self-reported persistent or relapsing fatigue for at least 6 consecutive months or longer; other medical conditions of which manifestation includes fatigue must be excluded by clinical diagnosis.

2. Concurrently have four or more of the following symptoms:
   - post-exertional malaise,
   - impaired memory or concentration,
   - unrefreshing sleep,
   - muscle pain,
   - multi-joint pain without redness or swelling,
   - tender cervical or axillary lymph nodes,
   - sore throat,
   - headache.

The symptoms must have persisted or recurred during 6 or more consecutive months of illness and must not have predated the fatigue.
The definitive prevalence study (Jason et al 1999)

Overall prevalence 420 per 100000
Females 522
Males 291
Latino 726
African American 337
White 318
A common illness

- Chronic fatigue syndrome: 420/100000
- HIV: 12/100000
- Breast cancer: 26/100000
- Lung cancer: 33/100000
- Multiple sclerosis: 70/100000
- Diabetes: 900/100000
- Blood pressure: 3000/100000
- Heart disease: 3400/100000
EXCLUSIONS

1. Active medical condition causing fatigue
2. Previous diagnosis of cancer or chronic infection
3. Past or present diagnosis of psychosis
4. Alcohol or substance abuse within 2 years of onset
5. Severe obesity  BMI>45
GP attitudes to ME/CFS (RNZCGP 1985)

- Random sample of 149 GPs
- 1-2 patients per GP, 75% female etc
- Had made a diagnosis in 43%
- Prefer postviral syndrome rather than Tapanui Flu
- Genuinely ill 88%
They can’t afford to wait

THE LAST TIME
I FELT GOOD
WAS AT
10:00 A.M.

ABOUT
NINE YEARS AGO.

POT SHOTS No 1663 ©1980 Ashleigh Brilliant
Real View of ME/CFS

• Catch a dose of flu
• Drink a lot of cheap whisky and wine
• Work hard all day
• Stay up all night
• Go to bed and set the alarm for three hours

WAKE UP AND FEEL WHAT IT IS LIKE!!
Making a diagnosis: Step 1

- Persistent fatigue
- Post exertional malaise
- Sleep disturbance
- Myalgia
Making a diagnosis: Step 2

1. Neurocognitive symptoms
   1. Impaired memory
   2. Poor concentration
   3. Hypersensitivity to light or sound
   4. Confusion

2. Autonomic
   POTS, palpitations, IBS

3. Neuroendocrine
   Heat/cold

4. Immune
   Recurrent flu, lymph nodes
Step 3: A good examination!
What is going to make me better?

- Time
- Acceptable explanations
- Acknowledgement of the illness
- Symptom control
- Improvements in health behaviours
- Relapse prevention
- Treatment of co-morbidities
IMMEDIATE CARE - ATLS

1. Treat the greatest threat to life first

2. Don’t let the lack of definitive diagnosis hold up treatment

3. A detailed history is not necessary
IMMEDIATE CARE OF OTHER EMERGENCIES

- CFS
- Down syndrome child
- Stroke in old age
- Acknowledgement of the problem
- Belief in the person
- Consistent follow on
POOR IMMEDIATE CARE

• HAND WAVING
  Have you thought of seeing someone else?

• HAND WASHING
  It’s not my fault that I can’t find out what’s wrong with you.
# Maslow’s Hierarchy of Needs

<table>
<thead>
<tr>
<th>Level</th>
<th>Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Physiological</td>
<td>Warmth, food, rest.</td>
</tr>
<tr>
<td>2. Safety</td>
<td>Protection</td>
</tr>
<tr>
<td>3. Love</td>
<td>Trust and acceptance</td>
</tr>
<tr>
<td>4. Esteem</td>
<td>Respect, self-respect</td>
</tr>
<tr>
<td>5. Cognitive</td>
<td>Knowledge</td>
</tr>
<tr>
<td>6. Aesthetic</td>
<td>Beauty, balance</td>
</tr>
<tr>
<td>7. Self-actualisation</td>
<td>Potential</td>
</tr>
<tr>
<td>Professional Help</td>
<td>N</td>
</tr>
<tr>
<td>-------------------</td>
<td>----</td>
</tr>
<tr>
<td>GP</td>
<td>96</td>
</tr>
<tr>
<td>Specialist</td>
<td>68</td>
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<tr>
<td>Psychiatrist</td>
<td>31</td>
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<tr>
<td>Naturopath</td>
<td>35</td>
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<tr>
<td>Homeopath</td>
<td>33</td>
</tr>
<tr>
<td>Chiropractor</td>
<td>15</td>
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</tbody>
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Rating of professional help
207 patients (1992)
# Rating of Treatment

(215 patients)

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Rating 1</th>
<th>Rating 2</th>
<th>Rating 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Rest</td>
<td>76%</td>
<td>91%</td>
<td>2%</td>
</tr>
<tr>
<td>Antidepressants</td>
<td>53%</td>
<td>42%</td>
<td>41%</td>
</tr>
<tr>
<td>Counselling</td>
<td>30%</td>
<td>60%</td>
<td>12%</td>
</tr>
<tr>
<td>Homeopathy</td>
<td>38%</td>
<td>61%</td>
<td>11%</td>
</tr>
<tr>
<td>Naturopathy</td>
<td>36%</td>
<td>61%</td>
<td>5%</td>
</tr>
<tr>
<td>EAV</td>
<td>30%</td>
<td>48%</td>
<td>16%</td>
</tr>
</tbody>
</table>
OUTCOME in 215 people

- Cured: 33 (15%)
- Much Better: 158 (63%)
- About the same: 33 (15%)
- A little worse: 3%
- Much worse: 2%
Specific Treatments 2013

- Cognitive behavioural therapy
- Graded exercise programmes
- Antidepressants
- Corticosteroids
- B12 injections
- Dietary supplements
TIME DISCOVERS TRUTH

• The greatest friend of truth is time
• Her greatest enemy is prejudice
• Her constant companion is humility.

• Charles Cofton