Seven Recurrent Themes

- ME/CFS is real: believe patients’ experiences
- Don’t confuse ME/CFS with chronic fatigue
- Post-exertional malaise ≠ post-exertional fatigue
- Getting a diagnosis is vital
- Recognize how severe the condition can be.
- Even without a cure, there are many actions clinicians can take to help patient
- Patients (pt.) can offer unique knowledge/ perspectives
1) #believeME: ME/CFS Is Real

You need to:
“find something to do with your time other than sit around and complain.”
“stop being so ambitious.”
“resolve your issues with your dad”
“get a boyfriend” “get married” “have a baby”
“go on vacation.” “drink more coffee.”
“I don’t believe in ME/CFS” “ME/CFS is made up”
“Everyone experiences fatigue”
“You’re just stressed out from work.”
“Are you sure you aren’t depressed?”

95% felt estranged
77% labelled as psychological case by at least one MD.

Clinicians add to disease burden, miss treatment opportunities and diagnoses.
2) ME/CFS ≠ chronic fatigue

- Don’t confuse disease with symptom
- ME/CFS is more than chronic fatigue
- Post-exertional malaise (PEM), problems thinking, feeling sick, etc. more disabling
- Inquire, evaluate, treat, monitor all symptoms
3) PEM ≠ Post-exertional Fatigue

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Physical/cognitive exertion N = 144 (%)</th>
<th>Emotional Distress N = 144 (%)</th>
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</thead>
<tbody>
<tr>
<td>Median # Sx.</td>
<td>7 ± 2.8</td>
<td>5 ± 3.3</td>
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<tr>
<td>Fatigue</td>
<td>135 (94%)</td>
<td>109 (76%)</td>
</tr>
<tr>
<td>Problems thinking</td>
<td>106 (74%)</td>
<td>88 (61%)</td>
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<tr>
<td>Muscle pain</td>
<td>106 (74%)</td>
<td>48 (33%)</td>
</tr>
<tr>
<td>Sleep disturbance</td>
<td>97 (67%)</td>
<td>95 (66%)</td>
</tr>
<tr>
<td>Flu-like feelings</td>
<td>88 (61%)</td>
<td>47 (33%)</td>
</tr>
<tr>
<td>Joint pain</td>
<td>77 (53%)</td>
<td>30 (21%)</td>
</tr>
<tr>
<td>Headache</td>
<td>73 (51%)</td>
<td>53 (37%)</td>
</tr>
<tr>
<td>Sore Throat</td>
<td>60 (42%)</td>
<td>28 (19%)</td>
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4) Getting A Diagnosis Is Vital

- Knowledge not the only barrier
- 70% MDs: “disabling self-fulling prophecy”; “promotes adoption of sick role”; doesn’t impact treatment
- 90% of patients: positive “turning point”
- Relieves anxiety/ fears
- Validates pt. experience: avoid “dustbin of neurotic complainer”
- Helps pt. and family cope/ strategize treatment/ explain
- Needed for supportive care
5) Recognize The Severity of ME/CFS

25% bedridden/homebound
Others must restrict/reduce/monitor activities
6X suicide risk
Influences pt. care

SF-36 Subscale scores

- Normalised - healthy
- Cancer
- Depression
- RA
- ME/CFS
6) Actions Clinicians Can Take Now!

- Assess function/ needs
- Provide supportive documentation
- Identify/ treat pain and sleep issues
- Be alert for treatable co-morbidities
- Start low, go slow with medications
- Improve pt. health, function, quality of life

Saving lives... just one piece of paperwork at a time.
7) Incorporate Patients’ Insights/Perspectives

- Patients’ lives depend on solving ME/CFS
- Listening would have prevented harm from GET/CBT
- NAM “Clinical Practice Guidelines We Can Trust”
  1. Include patients on development/reviewer panels
  2. Consider patient treatment preferences
  3. Take clinical subgroups into account
- Patients’ views have been ignored/dismissed for decades. Yet they often have real-world, time-tested knowledge/experience to contribute.


