

OVERCOMING BARRIERS TO CARE

TIPS AND TOOLS

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October 2019



Bateman Horne Center
RESEARCH | CLINICAL CARE | EDUCATION

INDIVIDUALS WITH ME/CFS EXPERIENCE
SO MANY BARRIERS TO
COMPASSIONATE AND INFORMED CARE
THAT IT'S HARD TO KNOW WHERE TO START!

BUT NOW IS THE TIME TO PUSH BACK ON
THOSE BARRIERS, ESPECIALLY THE ONES
BASED ON IGNORANCE, BIAS, AND
INACCURATE INFORMATION.

BARRIERS TO CARE

PERSON with ME/CFS +
Comorbid Conditions and
their support teams.

PME/CC

PROVIDERS:

Primary Care Providers,
Specialist physicians
and surgeons, Ancillary
providers (physical
therapists, mental
health counselors, etc)



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BARRIERS TO CARE

“Not being believed” is a huge barrier that can result in improper treatments, medical neglect, abandonment and even malice. It can have powerful emotional and mental health consequences

- **Ignorance (being uninformed)**

- What feels like neglect and abandonment is often naïve/innocent ignorance and simply lack of exposure/knowledge....then aggravated by:

- **Nature of illness and lack of tools**

- **Financial constraints**

- **Immobility and illness severity**

BARRIER #1: IGNORANCE

Uninformed providers

- No understanding or limited understanding of the illness(s)
- Emerged from a system with little or no training in this area
- Under negative pressure from higher authority to perform

Top down and bottom up needed.

- We must educate Primary Care Providers AND Specialists.
- Bring specialists out of narrow silos for cross talk
- Develop forums and common language for intradisciplinary exchange.

INFORMING PRIMARY CARE PROVIDERS

Correct identification of multisystem illness is not easy using the information and tools they have learned (especially reliance on short history, focused exam, labs and imaging):

- Inability to function normally (physically, cognitively)
- Negative consequences of activity (worse pain, fatigue, cognition)
- Disordered sleep
- Cognitive impairment and complaints
- Orthostatic intolerance
- Widespread pain conditions
- *Nonspecific infection, immune, inflammatory sx*

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INFORMING PRIMARY CARE PROVIDERS

- PCPs need to know **what to look for** that distinguishes ME/CFS from other illnesses characterized by fatigue, pain, bodily symptoms.
- The **IOM clinical diagnostic criteria** outline the core symptoms (not all symptoms possible) that the majority of ME/CFS patients have in common, and that distinguish patients clearly from healthy controls. These criteria require all core symptoms to be present at least 50% of the time and moderate to severe in nature.
- These criteria still define a heterogeneous group.
- For example: orthostatic intolerance has a long list of causes

INFORMING PRIMARY CARE PROVIDERS

PCPs need help from specialists to continue investigation into these debilitating aspects of illness presentation, but initial screening is imperative.

Is Medical Education improving?

Yes, changes are slowly coming to Continuing Medical Education resources

CONTINUING MEDICAL EDUCATION (CME) RESOURCES

Scientific Meetings and CME conferences by subject matter. Can be \$\$\$

Many online educational resources are available

CME courses offered by local, state and national medical societies and organizations.

CONTINUING MEDICAL EDUCATION (CME) RESOURCES ONLINE

Medscape: A website owned by **WebMD** that provides free medical information and CME for clinicians

UpToDate: The UpToDate system is marketed as an evidence-based clinical resource. UpToDate is written by over 5,700 physician authors, editors and reviewers. It is available via the Internet and offline on personal computers or mobile devices. Full access to the subscription service costs **US \$519 per year** as of 2019 for a physician in the United States.

Others? Many. But these two major sources of medical information have made efforts to improve information regarding ME/CFS

CONTINUING MEDICAL EDUCATION (CME) RESOURCES

Michigan State Medical Society: msms.org → Education → On-Demand Webinars. A joint effort of MSMS, PANDORA, and BHC

Update on Chronic Fatigue Syndrome Part 1: Clinical Diagnostic Criteria for Chronic Fatigue Syndrome/CFS now called Myalgic Encephalomyelitis or ME/CFS (0.75 AMA PRA Category 1 Credits for CME)

Update on Chronic Fatigue Syndrome Part 2: Uniting Compassion, Attention and Innovation to treat ME/CFS (0.75 AMA PRA Category 1 Credits for CME)

<http://batemanhornecenter.org/medical-provider-library/>

UNINFORMED SPECIALTY PROVIDERS

- **Avoid specialists who rely on procedures alone and don't spend time listening to patients.**
- **Specialists who see complex patients, especially in academic centers, will recognize a patient with ME/CFS but may call it something else, or only describe a portion of the disease process.**
- **Specialists are loathe to label a diagnosis without objective support**
- **We need to bring specialists out of narrow “specialty silos” and develop common language for intradisciplinary exchange.**
- **We need to provide “objective” data to specialists**

SEEK SPECIALTY CONSULTATION FROM THE NICHE SPECIALISTS

- **Neurologists** who specialize in autonomic nervous system diseases, neuroinflammatory conditions, small fiber neuropathy, illnesses of craniocervical instability and spinal fluid leaks, post-concussive syndrome
- **Allergy/immunology** specialists willing to deal the common variable immunodeficiency disorders (CVID), mast cell activation syndrome
- **Rheumatologists** who specialize in Sjogrens, seronegative RA, Ehlers Danlos Syndrome and hypermobility disorders
- **Cardiologists** who specialize in autonomic nervous system and circulatory disorders.
- **Gastroenterologists** who enjoy the workup of IBS and the way systemic diseases are manifest in the GI tract (Celiac, neuroinflammatory, etc)

UNINFORMED PME/CC AND SUPPORT TEAM

- Overwhelmed and traumatized.
- You are (usually) not a doctor.
- You must educate yourself gradually and broadly relying on high quality resources. Do your homework.
- Find a PCP who will listen, communicate and learn
- Seek highly qualified niche specialists

UN-INFORMED PME/CC AND SUPPORT TEAM

Hang loose with overlapping conditions and many illness definitions. Learn about comorbid conditions.

- Fibromyalgia, pain amplification syndrome, or no dx at all unless proof of underlying cause
- CFS, post-infectious fatigue, post-viral fatigue, Lyme syndrome...
- Orthostatic intolerance, POTS, dysautonomia, neurally mediated hypotension (NMH), neurogenic orthostatic hypotension (NOH)
- Craniocervical instability (CCI), Chiari malformation, CSF leak...
- Common variable immunodeficiency, chronic inflammatory response syndrome, etc

MEDICAL EDUCATION FOR THE PUBLIC

Healthwise: a non-profit company that develops health content and patient education for health insurance companies, care management companies, hospitals, and consumer health web sites, including **WebMD**.

Working on ME/CFS updates. Yay!

WebMD: an online publisher of news and information pertaining to human health and well-being. During 2015, WebMD's network of websites reached more unique visitors each month than any other leading private or government healthcare website, making it the leading health publisher in the United States. In the fourth quarter of 2016, WebMD recorded an average of 179.5 million unique users per month, and 3.63 billion page-views per quarter. (Wikipedia).

MEDICAL EDUCATION FOR THE PUBLIC

Websites of Respected Institutions that specialize in a topic:

For example:

- Vanderbilt Autonomic Dysfunction Center
 - <https://ww2.mc.vanderbilt.edu/adc/>
- CDC and NIH website information about ME/CFS
 - <https://directorsblog.nih.gov/2017/03/21/moving-toward-answers-in-mecfs/>

Find informed and not “canned” content

Trusted blogs/websites/organizations that present leading edge information with a high degree of quality.

Societies and non-profit organizations that take on a cause and provide good information.

MEDICAL EDUCATION FOR THE PUBLIC

**Diagnosing and Treating MYALGIC ENCEPHALOMYELITIS/CHRONIC
FATIGUE SYNDROME (ME/CFS) – U.S. ME/CFS CLINICIAN COALITION –
August 2019**

- <http://batemanhornecenter.org/medical-provider-library/>
- Learn about conditions in the differential diagnosis and common co-morbid conditions
- Take this 2-page document to your doctors

BARRIER #2: NATURE OF THE ILLNESS AND LACK OF TOOLS

ME/CFS and comorbid conditions (CC) define a complex multisystem illness that are **difficult to explain (communication)** and **difficult to discern (self observation and medical evaluations)**

The lack of front-line diagnostic tests means we must rely on **clear explanations**.

Every aspect of illness (fatigue, activity intolerance, pain, sleep, cognition, emotions, weird symptoms) requires good self observation, good two-way communication, active listening.

TOOLS TO COMMUNICATE WITH PROVIDERS

Review of Systems:

- General
- Allergy/immunology
- Infections
- Pulmonary/respiratory
- Cardiovascular
- Blood and malignancies
- Musculoskeletal
- Gastrointestinal
- Urogenital
- Dermatologic
- Neurologic
- Psychiatric
- Pain

TOOLS TO COMMUNICATE WITH PROVIDERS

GENERAL SYMPTOMS

Fatigue, tiredness, lack of energy

Sleepiness or somnolence in the daytime

Weakness: What part of the body is weak?

Increased fatigue/pain/illness symptoms after activity.

Abnormal weight gain or weight loss: How much in what time period?

Poor appetite

Sweating or flushing

Cold or heat intolerance

Raynaud's syndrome (tips of fingers/toes turn white, then blue, then red and hot)

Light or sound sensitivity

TOOLS TO COMMUNICATE WITH PROVIDERS

KEY:

0 = Never had the symptom or unimportant

1 = Mild or infrequent symptom

2 = Moderate in severity or frequent symptom

3 = Severe or almost constant symptom

Communicate frequency and severity (remember the IOM criteria?)

TOOLS TO COMMUNICATE WITH PROVIDERS

SLEEP

Unrefreshing sleep/Wake up feeling unrested

Average hours of sleep a night?

Cannot go to sleep. How long does it take to fall asleep?

Restless sleep.

Cannot go back to sleep

Wake up too early

Need to take naps due to daytime sleepiness.

Restless legs (or limbs), uncomfortable sensations, leg cramps, or urge to move to relieve. Myoclonic jerks (involuntary jerking of limbs)

Snoring or altered breathing during sleep.

TOOLS TO COMMUNICATE WITH PROVIDERS

SLEEP

- 3 Unrefreshing sleep/Wake up feeling unrested
Average hours of sleep a night?
- 2 Cannot go to sleep. How long does it take to fall asleep?
- 3 Restless sleep.
 - 1 Cannot go back to sleep
 - 0 Wake up too early
 - 0 Need to take naps due to daytime sleepiness.
- 3 Restless legs (or limbs), leg cramps, involuntary jerking of limbs
- 2 Snoring or altered breathing during sleep.

TOOLS TO COMMUNICATE WITH PROVIDERS

PAIN/MUSCULOSKELETAL

- Tender points or trigger points
- Burning, tingling or numbness. Where and when?
- Achy all over. When?
- Tender when touched or squeezed
- Morning stiffness
- Joint pain. Which joints?
- Muscle pain. Which muscles?
- Neck, back or sciatic pain
- Abdominal or pelvic pain
- Chest pain
- Headaches: migraines and tension headaches. #/mo

TOOLS TO COMMUNICATE WITH PROVIDERS

INFECTION OR ALLERGY

- Low grade fevers, night sweats
- Sinus infections, sore throats
- Mouth canker sores or sore tongue
- Oral herpes (cold sores or fever blisters)
- Tooth decay, abscess, or root canals, gum disease, gingivitis
- Tender lymph nodes
- Hay fever
- Hives or rashes
- Chronic cough, asthma or bronchitis
- Itching . Where and when?
- Dry mucous membranes

TOOLS TO COMMUNICATE WITH PROVIDERS

HEART OR LUNG PROBLEMS

- Low or high blood pressure
- Irregular heartbeat, arrhythmia, fast or pounding heart rate
- Fainting or loss of consciousness
- Chest pains or chest discomfort
- Trouble breathing, wheezing
- Exercise or activity intolerance?
 - What happens during exercise or mental/physical activity?
 - What happens after exercise or mental/physical activity?
 - How long do the repercussions last (hr/day)?

TOOLS TO COMMUNICATE WITH PROVIDERS

NEUROLOGIC

- Have you ever had a concussion or whiplash accident?
- Concentration or attention impairment, memory problems
- Easily confused or overwhelmed, trouble organizing and completing tasks
- Falling down or fainting?
- **Difficulty standing in place.** Dizziness or unsteadiness
- Numbness/tingling. Where and when?
- Weakness. What part of body and when?
- Blurred or double vision
- Ringing in the ears (tinnitus), noise sensitivity and/or decreased hearing
- Loss of taste

TOOLS TO COMMUNICATE WITH PROVIDERS

MOOD

Depression, feeling sad or hopeless

Anxiety, tension, worry, nervousness, panic attacks

Bipolar or manic episodes

Suicidal thoughts or attempts

Obsessive compulsive thoughts or actions

Binging on food, purging or inducing vomiting to avoid weight gain

Restricting food excessively (anorexia) due to fear of weight gain

Treating sleep, anxiety, or depression with alcohol or drugs

TOOLS TO COMMUNICATE WITH PROVIDERS

HORMONES AND GENITAL

- Abnormal menstrual cycle
- Hot flashes
- Discharge from vagina or penis, genital herpes infections
- Poor libido or sexual dysfunction
- Breast discharge, pain, cysts, or lumps

BLADDER AND KIDNEY

- Bladder spasms or pain
- Bladder incontinence
- Urinary frequency
- Urinary infections

TOOLS TO COMMUNICATE WITH PROVIDERS

BLOOD AND VESSELS

- Anemia
- Blood clots
- Bleeding excessively
- Bruising excessively
- Varicose veins

SKIN

- Rashes
- Suspicious moles
- Other....

PROVIDE CLEAR INFO ABOUT ACTIVITY TOLERANCE

GOOD/BETTER DAYS

- Average number of good days per MONTH:
- Average **hours of UPRIGHT activity** on a GOOD day (sitting, standing, walking -- activities with FEET ON FLOOR):
- Average hours of HORIZONTAL activity on a GOOD day (reclining, elevating feet, laying in bed):

(Hours of UPRIGHT activity + Hours of Horizontal activity = 24 hours)

Give specific examples of activities/tasks you CAN do on a good day:

Give specific examples of activities/tasks you CAN NOT do even on a good day:

PROVIDE CLEAR INFO ABOUT ACTIVITY TOLERANCE

BAD/WORSE DAYS

- Average number of bad days per MONTH:
- Average **hours of UPRIGHT activity** on a BAD day (sitting, standing, walking -- activities with FEET ON FLOOR):
- Average hours of HORIZONTAL activity on a BAD day (reclining, elevating feet, laying in bed):

(Hours of UPRIGHT activity + Hours of Horizontal activity = 24 hours)

Give specific examples of activities/tasks you CAN still do on a BAD day:

Give specific examples of activities/tasks you CAN NOT do when it's a BAD day:

TYPICAL HUA*

HUA IN 24 HOURS

- Normal healthy folks: HUA 14-17
- Chronic illness/FM: HUA 10-12
- ME/CFS HUA 0- 7

*based only on BHC clinical data
and my own experience

HUA=Hours of Upright Activity

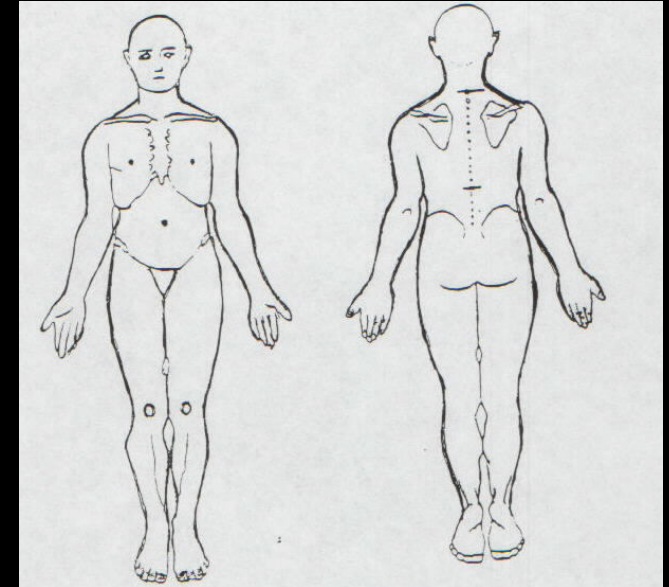
Learn to provide detailed description of each symptom:

- It's usually better to describe what it “feels like” using adjectives rather than try to use nonspecific medical terms like “inflammation” because if you don't use a term the same as the provider it can lead the provider astray.

PAIN AS AN EXAMPLE:

Draw location of pain on a body diagram.

- Describe context or typical situations the pain occurs
- Chronology (timing, frequency, duration)
- Severity (0-10 with 10 being the worst imaginable pain)
- Nature (is the pain burning, stabbing, tingling, aching)
- What makes it better?
- What makes it worse?



Give specific examples: if I do this...then this happens...

Don't overstate or understate. Be precise about when things are milder and when things are worse.

Distinguish between:

- Not feeling well enough to do something,
- Developing symptoms while doing something (impairment, debility)
- Developing symptoms after doing something (the consequence of activities, post exertional malaise/PEM/PENNE)

SELF MONITORING IS AN OBJECTIVE TOOL

Provide data to the provider through self monitoring:

- **Pulse and Blood Pressure:** Heart pounding hard but not fast? Heart rate 50, 100, 150, or 180 bpm? Relationship of HR to BP? Are values supine, seated, standing, walking, before or after meds, early or late in day?
- **Sleep:** onset? Light or frequent awakening? Trouble getting back to sleep? Length of sleep? Timing of sleep?
- **Steps per day:** Use a FitBit, Apple watch or smart phone app to understand how much you can do and can't do. Report numbers.
- **Bring photos** when helpful

BARRIER #3: FINANCIAL CONSTRAINTS

- Financial barriers that **PME/CC** face: **No easy answer. Subject for another day...**
- Financial barriers that **providers** face: understand and work within the system

PROVIDER FINANCIAL CONSTRAINTS

Providers are under tremendous pressure to be efficient and productive.

- May have pay docked, advancement blocked, or risk losing job
- Pressure from insurance, colleagues, employers, quality assurance

Know your provider's scheduling constraints and try to work within the system

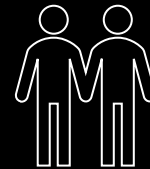


PROVIDER FINANCIAL CONSTRAINTS

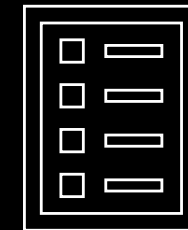
- Schedule more frequent appointments.
- Schedule longer appointments if possible.
- Prioritize and address specific aspects of illness in sequential visits



- Come to the appointment early or on time
- Be organized
- Bring someone to be your eyes, ears, scribe



- Clearly state your goal(s) of the visit up front:
- Have a list of the 3-4 things you need to cover in the visit.
- Type out concerns at home in advance when rested.



PROVIDER FINANCIAL CONSTRAINTS

Bring your medication bottles or an **up-to-date med list** with exact names, milligrams, timing and dosage. Be very specific and honest about how you take medications. Know your medications and learn the names. Keep an accurate list of medications tried in the past and the experience of taking them.

DO HOME MONITORING and BRING FitBit records, BP results, charts/graphs, etc with you to the visit

Don't produce *disability paperwork* or bring up additional medical concerns at the **end of the visit**, when there isn't enough time to do it during the appointment.

Try not to give your doctor "homework"

Draft letters. Fill in draft forms. Make fulfilling your requests as easy as possible.

Utilize staff: Physician Assistants, Nurses, Medical Assistants

BARRIER #4: IMMOBILITY AND ILLNESS SEVERITY

- Moderate to severely ill may find travel to an office visit daunting and difficult
- Severely and very severely ill may not be able to travel to the office setting without severe consequences.
- **We must develop outreach and support for the severely ill.**

IDEAS FOR IMMOBILITY AND ILLNESS SEVERITY

- Save up energy for the visit. Be rested.
- Be well hydrated, avoid hypoglycemia (bring snacks), wear compression socks
- Lie down in the car during transport
- If sensitive, wear sunglasses and noise reducing headphones
- Utilize energy saving devices (wheelchairs, walkers with seat and basket)
- Ask to lie down if needed/helpful during the office visit.
- Arrange in advance to be in a quiet, darkened room lying down until the appointment. Discuss options for lower lighting, etc, if needed.
- Arrange for 1 L of NS by IV during the visit if OI/orthostatic hypotension or POTS is present.
- Rest up after the visit for a couple of days.

IDEAS FOR IMMOBILITY AND ILLNESS SEVERITY

- Work with PCP to set up Home Nursing Services during a “crash”.
 - This requires a “skilled nursing need” and patient must be “homebound”
 - Skilled nursing needs: IV fluids or drugs, orthostatic vital signs.
- Find an MD, nurse practitioner or RN who will do home visits
- Ask PCP to do some visits by telemedicine or telephone call.
- Get a family member or friend to help gather objective information like weight, BP, heart rate, orthostatic measures, photos to communicate with PCP.
- Don't be invisible. Be seen.



BE STRONG

AND WEAR WILD SOCKS!