Back to the Basics: Improving Patient Outcomes

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Disclaimer(s)

There are no conflicts of interest to disclose or resolve.

Patient cases shared in this session are intended solely for educational purposes. Some cases represent composite scenarios that illustrate key aspects of disease presentation, rather than the experience of a specific individual.

In instances where individual patient information or video content is shared, the patients have provided full consent and authorized the use of their content and discussion of their case in this setting.

Learning Objectives

1. Illustrate the basic principles of patient care that foster mutual trust, self-efficacy, and build a long-term therapeutic relationship
2. Describe how a clinician can effectively prepare for a patient relationship
3. Outline the basic components of an effective patient encounter
4. Describe the basic components of a therapeutic relationship
5. Provide basic strategies that patients can implement in managing their condition
6. Provide tools and resources that can be implemented in the clinic

Labor & Delivery Example

Basics

If you don’t have the basics of patient care in place, then your treatments will not be as effective.

What do you consider the basics of care for someone with Long COVID or ME/CFS?


LATER
NEXT
NOW

Outcomes

- In order of priority, what outcomes matter most to your patient?
- In order of priority, what outcomes matter most to you as a provider?
- In order of priority, what outcomes matter most to your organization?

Outcomes

Patient Outcomes

- Improve quality of life
- Improve self-efficacy
- Improve accessibility
- Increase understanding of Long COVID for patient, family, caregivers
- Increase social and financial support
- Reduce number of flare ups

Clinician Outcomes

- Less frustration
- Increased impact
- Increased job satisfaction
- Improve communication and effectiveness of care
- Lower burnout

General Outcomes

- Reduce healthcare utilization (ER visits, urgent care visits, unnecessary or unhelpful healthcare appointments)
- Reduce unhelpful testing
- Reduce waste
- Save time

Simplify Care

- From start to finish, the patient experience should be taken into consideration to reduce:
  - Exertion
  - Stress
  - Anxiety
  - Confusion
  - Frustration
  - Fear
  - Reduce impact, severity, likelihood of PEM

Clinic Environment

- What is the **ideal** clinic environment for treating someone with Long COVID or ME/CFS?

- What can you **change** about the environment you practice in to improve the care for patients with Long COVID?

Appointment Setup

- What are the most **vital** aspects of an appointment?

  - ❑ Build a therapeutic relationship
  - ❑ Understand the patient's wants and needs
  - ❑ Validate the patient's experience
  - ❑ Provide hope and support
  - ❑ Decide on a plan with the patient
  - ❑ Leave the patient feeling better than you found them

Body Battery

Appointment Setup

- What can you minimize or remove from your appointments to:
  - Save the patient's energy
  - Lower their stress
  - Reduce confusion
  - Reduce inflammation

Clinic Messaging

In

Out

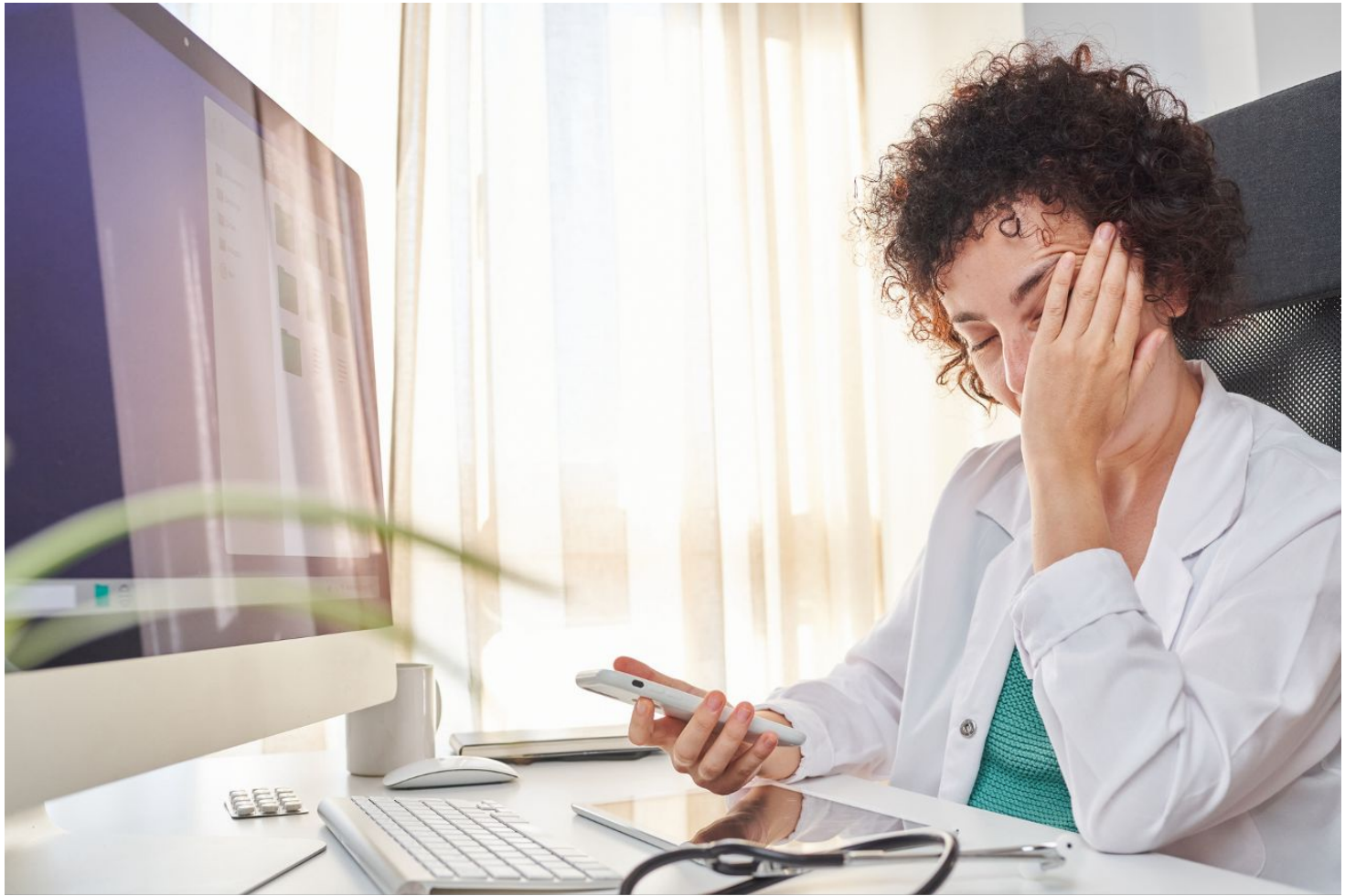
That was easy!

Go to the pharmacy

Appointment Setup Ideas

- Screen for Post-Exertional Malaise (PEM) prior to the appointment
- Send paperwork prior to the appointment
- Offer telehealth appointment option
- Provide parking that is close to the entrance
- Allow a quiet place to rest or lie down while waiting for the appointment
- Offer private room with dimmable lights and place to lie down during appointment
- Set expectations early of long-term management
- Limit paperwork, questions, movements, and testing if they have PEM
- Provide rest breaks during the appointment
- Provide educational materials in multiple formats
- Provide flexible scheduling options
- Provide assistance navigating out of the clinic (wheelchair if needed)
- Follow up after appointment to determine response to the appointment

Clinician Preparation



Clinician Preparation

- What can a clinician do to prepare themself to treat a patient?
- First recognize your own emotions and feelings
  - Are you feeling stressed, tired, frustrated, overwhelmed, threatened?
  - Do you have any biases about the patient you are going to see?

Clinician Characteristics

- What **characteristics** does a healthcare provider need to effectively treat someone with Long COVID or ME/CFS?

- What **skills** can a healthcare provider learn in order to effectively treat someone with Long COVID or ME/CFS?

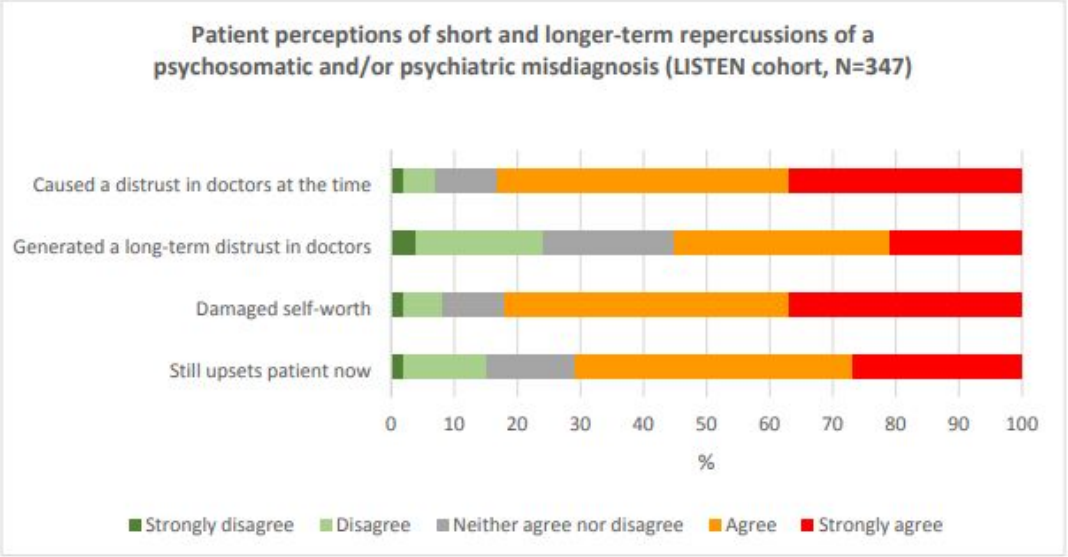
Impacts of Misdiagnosis

- Study surveyed over 3,000 participants (both patients and clinicians)
- Assessed the “persisting impacts of patient-reported psychosomatic and psychiatric misdiagnoses” in patients with systemic autoimmune rheumatic diseases
- These misdiagnoses (“in your head” diagnoses) impacted patients’ long-term physical health and diminished trust in healthcare services.

Melanie Sloan, et al. *Rheumatology*, 2025;, keaf115,
https://doi.org/10.1093/rheumatology/keaf115

Impacts of Misdiagnosis

- “Over 80% of patients reporting a psychosomatic and/or psychiatric misdiagnosis reported damaged trust in clinicians at the time of the misdiagnosis, and 55% felt it had engendered a long-term distrust in clinicians”



Melanie Sloan, et al. *Rheumatology*, 2025;, keaf115,
https://doi.org/10.1093/rheumatology/keaf115

Impacts of Misdiagnosis

- “Patients who reported that their autoimmune disease was misdiagnosed as psychosomatic or a mental health condition were more likely to experience higher levels of depression and anxiety, and lower mental wellbeing.”

- “More than 80% said it had damaged their self-worth and 72% of patients reported that the misdiagnosis still upset them, often even decades later.”

- “Misdiagnosed patients also reported lower levels of satisfaction with every aspect of medical care and were more likely to distrust doctors, downplay their symptoms, and avoid healthcare services.”

https://www.sciencedaily.com/releases/2025/03/250303141830.htm

Language Matters

"Effective communication between healthcare professionals and patients has long been recognized as essential to providing quality healthcare—the quality of the patient–clinician relationship is strongly predictive of positive patient care outcomes."

"Patients facing difficult medical situations, such as life-altering chronic medical conditions, feel especially scared, vulnerable, and out of control, which adds a level of intensity and emotional charge to these interactions. In these emotionally charged situations, practitioners may feel deskilled and revert to more authoritative language and styles of communication, which can then leave patients feeling discounted and unheard, evoking fear and distrust."

Smyth NJ, Blitshteyn S. *International Journal of Environmental Research and Public Health*. 2025; 22(2):275.

Language Matters

"People with Long COVID, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), and other complex chronic disorders consistently report having difficulty obtaining effective and compassionate medical care and being disbelieved, judged, gaslighted, and even dismissed by healthcare professionals."

"These problematic conversations between practitioners and patients often involve specific words and phrases—termed the "never-words"—can leave patients in significant emotional distress and negatively impact the clinician–patient relationship and recovery."

Smyth NJ, Blitshteyn S. *International Journal of Environmental Research and Public Health*. 2025; 22(2):275.

Table 1. Never-words, their impact, and suggested alternatives.

Never-Words	Explanation and Impact	Alternative
"You don't look sick".	Many patients may appear healthy, but feel very sick with various symptoms, including fatigue and pain.	Please refrain from commenting on their appearance.
"You need to stay positive".	Saying this to patients with debilitating symptoms with limited treatment implies that the patient did not stay positive or that the patient's attitude is to blame for feeling or staying sick.	"I know it can feel discouraging to feel so sick, and especially for so long. We will work on this together".
"At least it's not cancer".	Minimizing symptoms and disabilities is not well-received by patients who are suffering with non-terminal, but debilitating, and disabling conditions.	Comparing diseases to make a patient feel better is a strategy that is best avoided, since it usually has the opposite impact.
"Learn to live with this".	While this may be practical advice, many patients have already adjusted to living with their illness, but they want to live better and be more functional.	"I know this illness can really disrupt your life. What did you do in order to adjust to this?"
"Good news: Your tests are all normal".	This is good news for medical professionals, but patients may not care about the numbers or test results if they feel sick. This may also imply to patients that because their tests are normal, they have no reason to feel sick.	The tests we have run so far are not showing any abnormalities, and the good news is that we have excluded certain conditions based on the results of these tests.
"Many people have it worse".	Deflecting the patient's suffering can be perceived as gaslighting by the sufferer.	Please refrain from comparing patient's diseases and experiences.
"Have you tried___(lifestyle measures: yoga, going for a walk, diet, etc.?)"	Many patients have already tried various lifestyle measures without benefits and are seeking further treatment from healthcare professionals, not recommendations of the same lifestyle measures.	What are the things you have tried that have or have not helped you?
"You feel sick because you are____(psychological label: anxious, depressed, stressed)	Many patients with chronic illness do have comorbid depression, anxiety, PTSD, and other psychiatric disorders, but in many patients, it is not an explanation nor a justification for why they feel ill. Further, it is important to note that people living with a chronic complex condition experience many losses due to having that condition.	If you are suspecting significant psychological or psychiatric comorbidities, please refer your patient to a mental health professional to address these issues.

Smyth NJ, Blitshteyn S. *International Journal of Environmental Research and Public Health*. 2025; 22(2):275.

"You feel sick because you are____(hormonal status: perimenopausal, menopausal, postmenopausal, postpartum, pregnant, menstruating, ovulating)	Many patients with Long COVID, MECFS, and other chronic disorders are women who can often differentiate between hormonal symptoms and symptoms of chronic disease. Additionally, hormonal influence on symptoms is well-documented but is not an explanation or the cause of the underlying disease.	Please refrain from commenting on the patient's hormonal status. A referral to a gynecologist or endocrinologist might be appropriate if there are concerns of hormonal abnormalities or need for hormonal supplementation.
"You need to____(instruction as cures: lose/gain weight, start exercising, get fresh air, get out of the house/bed, get a job, get a hobby, start dating etc.)"	While a healthy lifestyle is important, the patient did not choose to stop it: the lifestyle changed as a result of the illness. Additionally, while lifestyle measures are important, they are unlikely to cure or effectively treat the underlying medical condition.	"When you feel better, we will work together toward a common goal of improved quality of life and a healthier lifestyle".
"You look too___(appearances: good, young, skinny, pretty)__to be sick".	Comments on appearances are inappropriate because patients with chronic illness may not look sick like patients with acute illness. Many actually hide their ill-appearing looks, especially when seeing a healthcare professional.	Please refrain from commenting on patient's appearance.
"We don't have any treatment for your illness".	While this may be true for some illnesses, given no FDA-approved therapies, symptomatic treatment is available, and the patient should not be made to feel like they are being abandoned by the medical team.	"We will talk about the available treatments we have that can make you feel better".
"You need to stop thinking about your symptoms so much".	In our experience, improved symptom control results in many patients improving their function and decreasing the negative thoughts and feelings about their symptoms. In those patients who continue to perseverate about their symptoms, psychological support, and cognitive-behavioral therapy may be appropriate.	"You have good awareness of your symptoms. I'm wondering if we can come up with a way for you to easily track them, so we that we can see the small changes when you begin to feel better".
"You have to find something productive to do with your time".	This statement assumes that patients are bored or have too much time on their hands, whereas, for most patients, having complex chronic illnesses is time- and energy-consuming and may be equivalent to having a full-time job managing disease and medical care. Additionally, many patients are not physically and/or cognitively well enough to be productive.	"Try to distract yourself with doing pleasurable and meaningful things that you can still do for short periods of time".
"Don't confuse your Google search with my medical degree".	This statement has become popular among healthcare professionals, given various online information platforms and social media groups that patients use to obtain medical information. However, we find that many patients with complex chronic illnesses had to become educated in their disorder out of necessity, given limited help from medical professionals.	"I am glad you're reading about your illness and educating yourself on possible tests and treatments. Thank you for bringing this information to me. I will look through it and let you know my thoughts".

Smyth NJ, Blitshteyn S. *International Journal of Environmental Research and Public Health*. 2025; 22(2):275.

Solutions

Possible remedy:

- “Our evidence suggests that clinicians should explicitly acknowledge previous misdiagnoses, discuss and empathise with their patients as to the potential ongoing impacts, and offer targeted support to reduce the persisting negative impacts.”

- What do you do in your practice to rebuild trust with patients who have had this experience?

Melanie Sloan, et al. *Rheumatology*, 2025;, keaf115.

Premature Death

Smoking

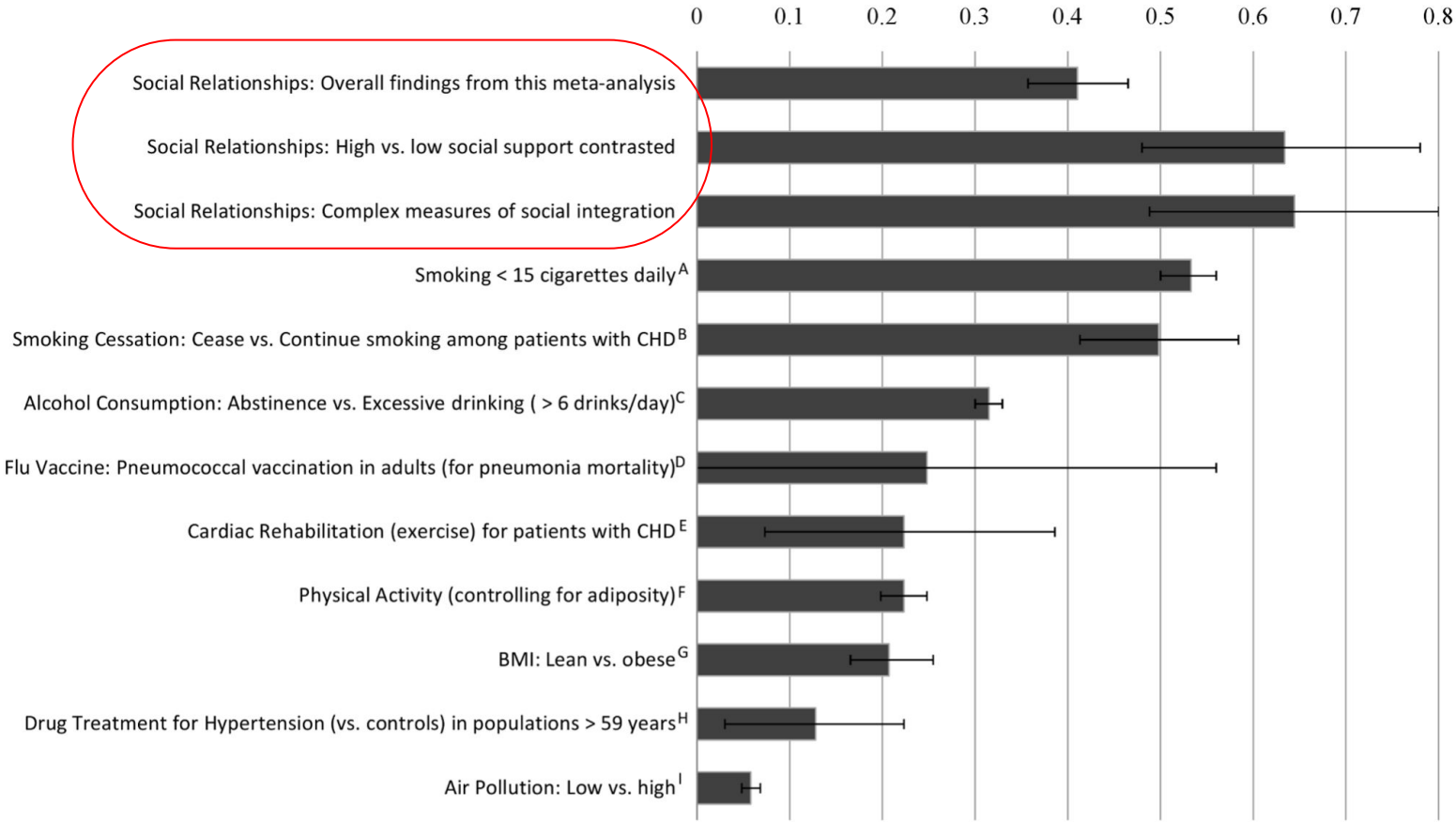
Exercise

Alcohol Consumption

Relationships

Physical Activity

BMI



Holt-Lunstad J, Smith TB, Layton JB. Social relationships and mortality risk: a meta-analytic review. *PLoS Med*. 2010;7(7):e1000316. Published 2010 Jul 27. doi:10.1371/journal.pmed.1000316

Therapeutic Relationship Basics

- Why does the therapeutic relationship matter when treating patients with Long COVID and ME/CFS?

"When a primary care physician-patient relationship is severed, patient mortality increases by 4%, emergency department visits increase by 4%, and hospital admissions increase by 3%"

Adrienne, S. *Journal of Public Economics.* 2023;225:104927.

Social Relationships

- “Among individuals with chronic pain, several cross-sectional studies have shown that social support is associated with less depression, anxiety, and pain-related distress.”

Franqueiro AR, et al. *Psychol Res Behav Manag.* 2023;16:4389-4399.

Social Relationships

- How do we help our patients with their relationships?

- How does our relationship with the patient influence outcomes?

Hall AM, et al. *Phys Ther.* 2010;90(8):1099-1110.

Therapeutic Relationship Basics

- What do you think are the most important elements of building a therapeutic relationship with patients?

"The doctor-patient relationship involves vulnerability and trust."

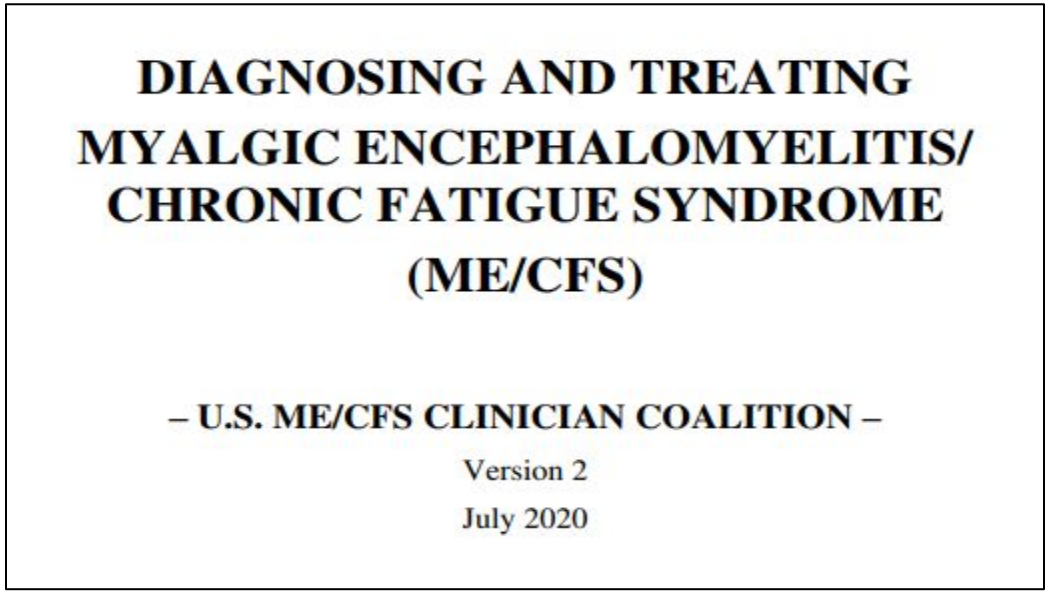
1. **"Knowledge** refers to the doctor's knowledge of the patient as well as the patient's knowledge of the doctor."
2. **"Trust** involves the patient's faith in the doctor's competence and caring, as well as the doctor's trust in the patient and his or her beliefs and report of symptoms."
3. **"Loyalty** refers to the patient's willingness to forgive a doctor for any inconvenience or mistake and the doctor's commitment not to abandon a patient."
4. **"Regard** implies that the patients feel as though the doctor likes them as individuals and is "on their side.""

Chipidza FE, et al. *Prim Care Companion CNS Disord.* 2015;17(5):10.4088/PCC.15f01840.

Therapeutic Relationship Basics

"At its core, the doctor-patient relationship represents a fiduciary relationship in which, by entering into the relationship, the physician agrees to **respect** the patient's autonomy, maintain **confidentiality**, **explain** treatment **options**, obtain **informed consent**, provide the **highest standard of care**, and commit **not to abandon** the patient without giving him or her adequate time to find a new doctor. However, such a contractual definition fails to portray the **immense and profound nature of the doctor-patient relationship**. Patients sometimes reveal secrets, worries, and fears to physicians that they have not yet disclosed to friends or family members. **Placing trust in a doctor helps them maintain or regain their health and well-being.**"

Chipidza FE, et al. *Prim Care Companion CNS Disord.* 2015;17(5):10.4088/PCC.15f01840.



1. Validate the patient experience and educate about the disease

"The most important thing that a medical provider can do is to validate the illness for the patient and the patient's family. Explain that ME/CFS is a serious medical illness and is not laziness, depression, or a psychosomatic disorder."

https://mecfscliniciancoalition.org/wp-content/uploads/2021/06/MECFS-Clinician-Coalition-Diagnosis-and-Treatment-Handout-V2.pdf

DIAGNOSING AND TREATING
MYALGIC ENCEPHALOMYELITIS/
CHRONIC FATIGUE SYNDROME
(ME/CFS)

– U.S. ME/CFS CLINICIAN COALITION –

Version 2

July 2020

2. Address impaired function and provide support as needed

“Patients with ME/CFS have significant disability. Patients may need help in obtaining accommodations for school and work or when applying for disability. They may also need parking permits, assistive devices, and/or home health aides. Because of the financial impact, some patients may need help with shelter and food.”

https://mecfscliniciancoalition.org/wp-content/uploads/2021/06/MECFS-Clinician-Coalition-Diagnosis-and-Treatment-Handout-V2.pdf

DIAGNOSING AND TREATING
MYALGIC ENCEPHALOMYELITIS/
CHRONIC FATIGUE SYNDROME
(ME/CFS)

– U.S. ME/CFS CLINICIAN COALITION –
Version 2
July 2020

3. Educate patients about pacing to prevent or minimize PEM

"An important role for the medical provider is to teach patients about PEM and how to manage it with pacing. Pacing is an individualized approach to managing physical, cognitive, and emotional energy within a patient's specific limits by carefully planning where and how to spend their available energy. It is a critical tool to prevent and/or reduce PEM…Pacing is a challenging task and some setbacks are inevitable, especially since tolerance for activity can vary from patient to patient and day to day."

https://mecfscliniciancoalition.org/wp-content/uploads/2021/06/MECFS-Clinician-Coalition-Diagnosis-and-Treatment-Handout-V2.pdf

Screen for PEM

Failure to address PEM

- "...doubled the risk of health deterioration following rehabilitation."
- "...substantially increased the probability of a decline in health and functioning following the intervention"
- "...was strongly associated with reduced perceived care quality, satisfaction, and benefit."
- "...led to ineffective, harmful healthcare

Wormgoor MEA, Rodenburg SC. *Front Neurol.* 2023;14:1247698.

Therapeutic Relationship Basics

- Screen for PEM
- Set up healing clinic environment
- First impression
- Introduction
- Expectations
- Listen and avoid interrupting
- Validate
- List plan in priority order
- End with hope

Physiological Stress Response

- “Four situational characteristics activate the hypothalamic-pituitary-adrenal axis, leading to a physiological stress response”

- STUN
  - Sense of control
  - Threat
  - Unpredictability
  - Novelty

Ghoussoub K, et al. *J Pain Res*. 2024;17:737-751.

Patient Interaction

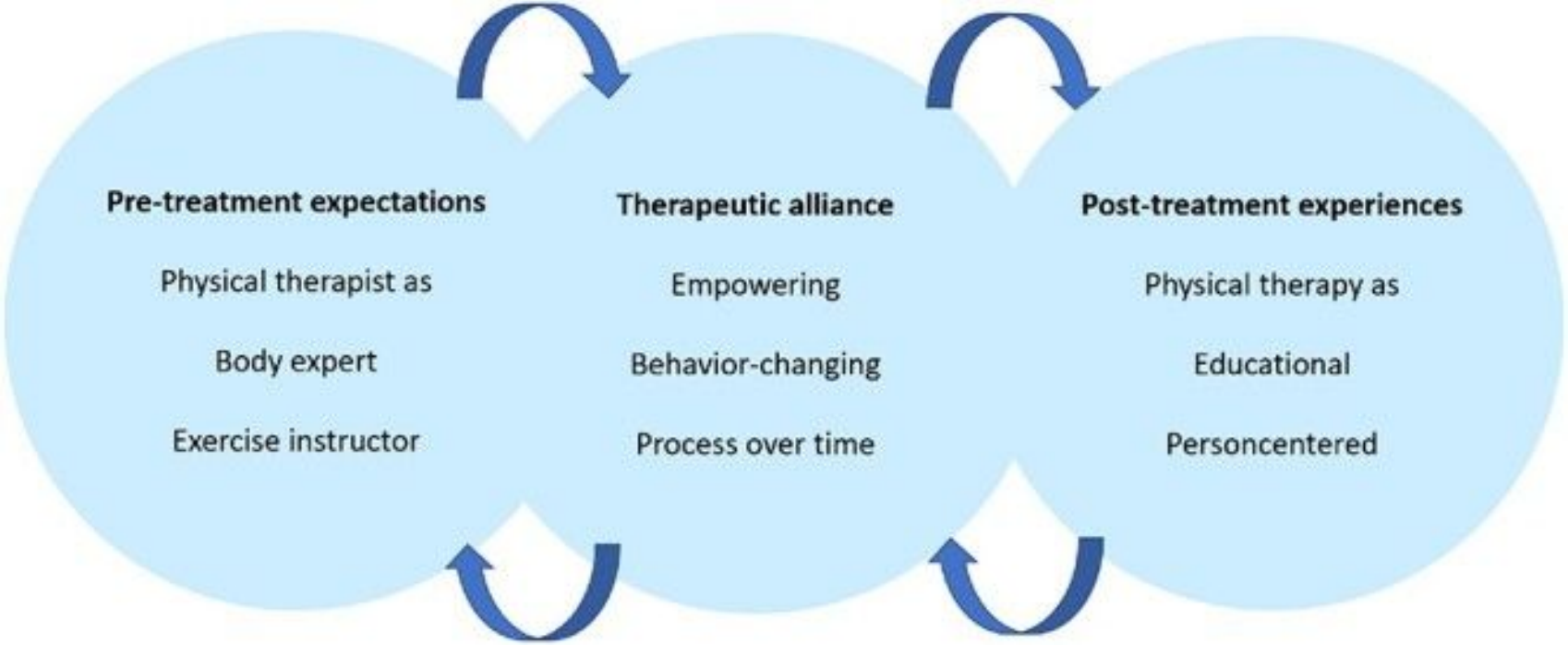
- Goal: Reduce stress and sense of threat

- Pay attention to your:
  - Tone
  - Posturing
  - Facial expressions
  - Distance from the patient

Practical Tips

- Make eye contact
- Show curiosity about the patient's symptoms
- Recognize signs of discomfort, fatigue, cognitive impairment
- Take the time to listen without interrupting
- Remember personal details
- Use clear, simple language
- Be emotionally present
- Ask for permission to share advice
- Ask for permission to touch the patient

Expectations



Unsgaard-Tøndel M, Søderstrøm S. *Phys Ther.* 2021;101(11):pzab187.

Motivational Interviewing

"Although motivational interviewing was originally developed to address abuse disorders, scientific evidence confirms that it is an increasingly used and effective approach in a wide range of therapeutic interventions."

Active Listening Principles

- Avoid judging (criticizing, labeling, expressing personal bias)
- Avoid arguments or correcting the patient
- Focus on patient concerns
- Listen with genuine interest
- Listen with appreciation without interrupting
- Provide feedback & information with permission

Non-verbal communication:

- Direct eye contact (undivided attention)
- Posture & gestures showing engagement & interest
- Facial expressions (e.g., reflect empathy)

Verbal communication:

- Discussion-based (avoid temptation to lecture)
- Clarification (accurate perception of patient concerns)
- Summarization (paraphrase what patient has described)

Kwame, A., Petrucka, P.M. *BMC Nurs* 20, 158 (2021).

Tennant K, Long A, Toney-Butler TJ. Active Listening. [Updated 2023 Sep 13]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2025 Jan.

What Matters to Patients

Systematic review of 11 research articles

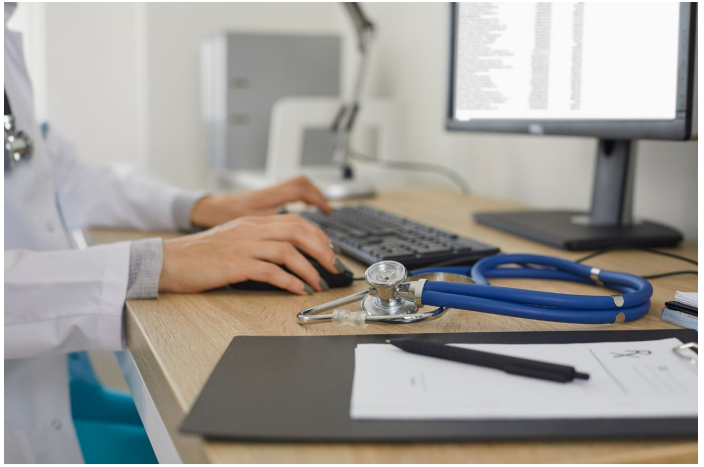
- Assessed what patients considered the characteristics of an excellent physician
- Medical expert (being an experienced physician and up-to-date)
- Professionalism (physician's attentiveness, communication, demeanour, being truthful, respecting patients preferences and being patient)
- Behaviors related to organizing care (access, follow-up, referrals, and care continuity)

Khawar A, et al. A systematic review.
BMJ Open. 2022;12(9):e065333.

Therapeutic Relationship

- Mayo Clinic study from 2018 found that physicians interrupted their patients within **11 seconds** on average.

- “Clinicians seldom elicit the patient's agenda; when they do, they interrupt patients sooner than previously reported. Physicians in specialty care elicited the patient's agenda less often compared to physicians in primary care. Failure to elicit the patient's agenda reduces the chance that clinicians will orient the priorities of a clinical encounter toward specific aspects that matter to each patient.”



Singh Ospina N, et al. *J Gen Intern Med*. 2019;34(1):36-40.

Open-ended Questions

OARS

O = Open-ended questions

- Attitudes & Beliefs: What do you think is the cause of your symptoms?
- Behaviors: What are you doing to relieve your symptoms?
- Compensation Issues: How are your symptoms affecting your financial situation?
- Diagnosis & Treatment: Are you worried that anything may have been missed in the examination of your condition?
- Emotions: What is upsetting or worrying you about your symptoms at this moment?
- Family: How does your family react to your symptoms?
- Work: How is your ability to work affected by your symptoms?
- Other:
  - What have you tried before to make a change?
  - Help me understand what you think would be good to start with.
  - How confident are you that you will be able to implement what we discussed today?
  - What may I know about you?

Affirmations

OARS

A = Affirmations

Examples:

- I want to thank you for coming in today.
- Thank you for your input.
- You are clearly a [insert compliment] person.
- That's a good suggestion.
- I've enjoyed talking with you today.
- It's normal to feel apprehensive.
- Your experience is normal.
- Your input is important.

Reflective Listening

OA**R**S

R = Reflective Listening

Examples:

- So you feel...
- It sounds like you...
- You're wondering if...
- You want…

Summaries

OAR**S**

S = Summaries

- Reinforce what has been said and show that you are listening

Examples:

- “From our discussion, it sounds like your symptoms severely impact your ability to tolerate work and care for yourself, and that you want to focus on finding ways to manage your symptoms. Is that right?”
- “Let me see if I understand so far…”
- “Here is what I’ve heard. Tell me if I missed anything.”
- “What have I left out?”

Moving Forward

- Give yourself some grace
- We are not perfect at implementing all of these strategies every time
- Despite the best efforts, some patients will still experience PEM as a result of the visit

- What changes are you going to implement to reduce stress and exertion during appointments?