



**Massachusetts ME/CFS & FM**  
ASSOCIATION

EDUCATION, SUPPORT & ADVOCACY SINCE 1985

***“Your doctor is human, too!”***  
***Ruth Axelrod, PhD, MHSA***



**November 17, 2024**

# Housekeeping

- ❖ We respect your privacy
- ❖ Please stay muted
- ❖ Put questions/comments in the chat
- ❖ A recording of the main presentation and Q&A will be posted

*We cannot answer questions related to your personal or any specific, medical condition.*

*The information in this presentation is for educational purposes only. Please consult with your physician or other healthcare provider in matters pertaining to your medical care.*

*The presenters remarks are their own opinion, and do not represent the views or opinions of Massachusetts ME/CFS & FM Association.*



# Poll questions

Please enter your choices for our three questions. A pop-up should appear on your screen.

1. If you have a chronic condition, how long have you been ill?
2. How easy do you find working with your doctor?
3. Do you have a primary care provider (PCP)?





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## *Ruth Axelrod, PhD, MHSA*

Ruth earned a Master of Health Services Administration and a PhD in Management from The George Washington University.

Ruth Axelrod is a retired university professor who lives in Concord, NH.







# Your Doctor is Human, Too!

Presented by  
Ruth H. Axelrod, MHSA, PhD  
Massachusetts ME/CFS Association Sunday Conversations  
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# Working with Medical Practitioners

1. What do I hope for in this relationship?

*Do my expectations align with how my practitioner sees her job?*

2. What can I (reasonably) expect in our meeting?

*What can I do to help make that happen?*

...and, finally...

3. How did I feel afterwards?

*Am I hopeful? Do I want anything to be different next time?*



- What did I do to deserve this?
- What's going to happen in the future?
- What is my provider going to do to make my life better?
- What can I do to make my life better?

**Just Fix Me!**

**Q1. What Do I Hope For?**



1. Practitioner and patient have the same goal--to heal you, the patient.
2. Different perspectives.
3. Both must listen and show respect.
4. Work as co-detectives to arrive at a diagnosis.
5. Collaborate and share decision-making.
6. Practitioners can never promise specific outcomes.
7. "We can't find anything wrong" does NOT mean "we believe that there is nothing wrong with you."

## Q2. What Can I Reasonably Expect?

1. Tell scheduler exactly why you want appointment, e.g., medication X not working.
2. Ask for your best time of day.
3. If too ill to travel, ask for telemedicine appointment.
4. Advise if you need handicap parking, wheelchair, interpreter or other assistance.
5. Ask length of appointment; if essential, request longer session.
6. Ask if tests should be done before appointment.
7. Ask if provider has access to your other records.
8. Celebrate having made the appointment.

## Schedule an Appointment Thoughtfully



1. When scheduling, check that the practice accepts your insurance.
2. Prepare route to ensure you are on-time.
3. Check if the practice can access your relevant records. If not, bring:
  - a. Current providers, especially PCP.
  - b. All medical conditions, prior surgeries, allergies and sensitivities. Possibly, relevant family records.
  - c. Current medications, past medications.
  - d. Recent lab results and studies.

## Prepare for a New Practitioner

1. Medical buildings are stress-inducing environments.
  - a. Previous trauma—physical, mental, emotional.
  - b. Fear of contamination, needles, CT scanners, etc.
  - c. Fear of possible bad news--avoidance reaction.
2. Real risks—calmly evaluate
3. Phobias (hyper-emotionality)—consider therapy

**Keep your eyes on the prize!—  
your better health.**

**Be Aware of Emotional Predispositions**



1. “Stress makes you stupid” and forgetful, so write down what you want to say and ask.
2. Begin with a short elevator speech:
  - a. What you most need to discuss today.
  - b. Relevant updates on your condition—symptoms with context; medical visits to other specialists.
3. Pack: Lists, sweater, book or mag, fidget toy.
4. Bring a friend to provide support and take notes.

## Plan for Success

1. What brought me in today.
2. New symptoms—when began, what was happening at that time, what makes it better or worse, how bad (rate 1-10), what impact on your life.
3. Recent diagnoses from other practitioners.
4. Changes in medications, if any, incl. herbs and OTC.
5. Other relevant factors—exercise, social, family history.
6. Questions.
7. Logs to have available: medical history/diagnoses, major procedures, screenings, vaccinations.

**List It! Log It! Practice Saying It!**



# Health & Activity Log

| Date | General Notes                  | Sleep                                                    |                                          |              |                                                 | Illnesses  |            |           |        |  |        |            |            |
|------|--------------------------------|----------------------------------------------------------|------------------------------------------|--------------|-------------------------------------------------|------------|------------|-----------|--------|--|--------|------------|------------|
|      |                                | Last Night                                               | Nap                                      | Total        | Score: 0=non-existent to 5=totally debilitating |            |            |           |        |  |        |            |            |
|      |                                | Overnight<br>Sleep/Wake<br>t hours<br>in bed<br>(Fitbit) | Overnight<br>asleep<br>hours<br>(Fitbit) | Nap<br>hours | 24 Hr.<br>Sleep                                 | Depression | ME<br>pain | Dizziness | Stress |  |        | Food       | Activities |
| —    | Depressed, head/eyebrow twitch |                                                          |                                          |              | 4                                               | 1          | 0          | 4         |        |  | normal | misc       |            |
| —    | okay, aches pm                 |                                                          |                                          |              | 1                                               | 3          | 0          | 4         |        |  | normal | garden H2O |            |

# Medication List

| Diagnosis/Condition     | Medication*                           | Dosage and Notes                     | As of... | Provider |
|-------------------------|---------------------------------------|--------------------------------------|----------|----------|
| PRESCRIPTION            |                                       |                                      |          |          |
| Environmental allergies | Ipratropium Bromide 0.06% nasal spray | 2 sprays per nostril 2-3 times daily | 2021     | —, APRN  |
| Hypothyroid             | Levothyroxine 75 mcg                  | 1 tab per day in morn                | 1980s    | —, APRN  |

## Known Drug Sensitivities

- € Antibiotics: — (2020), — (2024)
- € Bronchodilator: —(2010)

# Diagnoses, Treatments, Screenings & Vaccinations

| Body System      | Diagnoses | Dates (approx) | History/Description (see separate medication list)                                                                                                                   | Location/Provider |
|------------------|-----------|----------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------|
| CFS/Fibromyalgia |           |                |                                                                                                                                                                      |                   |
|                  |           | 2004           | Sudden flu-like onset just before defending doctoral dissertation: exhaustion, inability to concentrate, lengthy sleep, etc.                                         | Washington DC     |
|                  |           | 2010-2023      | FM pain (arms, legs, joints) became significant, increasing over time. Tried various medications; currently treated with acetaminophen--only partially reduces pain. | Concord NH        |
|                  |           | 2023-present   | Entered new phase of CFS (see sleep, below). FM pain only slight, no longer daily.                                                                                   |                   |
|                  |           | 2024           | Pain worse--started __, working up to 4.5 mg daily.                                                                                                                  |                   |
|                  |           |                |                                                                                                                                                                      |                   |

| IMMUNIZATIONS |          | Updated Nov 2024                                                                                       |
|---------------|----------|--------------------------------------------------------------------------------------------------------|
|               | Due Date | Notes                                                                                                  |
| Flu           | 2024     | annual vaccination 1970-present; 11-4-24 (CVS)                                                         |
|               |          |                                                                                                        |
| COVID         | 2024     | annual vaccination and other recommended shots, 2019-present; had disease once in 2020?;;11-4-24 (CVS) |
|               |          |                                                                                                        |



- How your practitioner will have prepared:
  - Skimmed latest records in your chart.
  - If told by the scheduler why you are here, will have considered changes to care plan.
- Present your prepared story. Tell the truth. Ask for what you need.
- Keep in mind: Practitioners have “down” days, too. Show the compassion you want to receive.

**Get the Most from Your Practitioner**

- Your practitioner's analysis of what is going on.
- Her diagnosis, perhaps tentative or "to be ruled out."
- Her prognosis (what is likely to happen, at least in the short-term).
- Your choices, at least for the next step in your care, and her recommendation.
- What to do next—e.g., give blood in the lab, make an appointment for a special study, pick up the new medication, set up a sleep schedule, etc.

**Don't Leave Until You Understand**



1. Does it seem that the practitioner cares about me?
2. Did we accomplish anything together? Are we moving forward?
3. Do I trust her?
4. Am I going to do what she told me?
5. Do I want to see her again?

**Q3. How Did I Feel Afterwards?**

# Questions: A Walk in the Forest





# Medical Resources

- Online Searches: To find valid medical information using Google and most other browsers:
  - Search for phrases using quotation marks, e.g., “chronic fatigue” or “ME treatment”.
  - Limit findings to valid sources, e.g., “chronic fatigue”+(edu, org, gov). This will list only medical school, nonprofit and government sites, not commercial sites that are trying to sell you something.



## Help us advocate for your needs...

We are conducting a series of surveys on healthcare experience, needs as well as accessibility! The first one can be found in the November newsletter.

[massmecfs.org/join](https://massmecfs.org/join)

[massmecfs.org/donate](https://massmecfs.org/donate)

To join the Sunday Conversations team: [volunteer@massmecfs.org](mailto:volunteer@massmecfs.org)



# *Sunday conversations will be getting a new schedule in 2025*

|                               |     |                      |     |
|-------------------------------|-----|----------------------|-----|
| Jan<br>Community conversation | Feb | Mar<br>Guest speaker | Apr |
| May<br>Community conversation | Jun | Jul<br>Guest speaker | Aug |
| Sep<br>Community conversation | Oct | Nov<br>Guest speaker | Dec |

- Reduced frequency
- Some Sundays with guest speakers similar to the current format
- Others will be community conversation about a topic important to the community.

Please send topic suggestions to [events@massmecfs.org](mailto:events@massmecfs.org)





## How you can help this program...

We are only able to produce this speaker series through your membership and generous donations.

Thank you!

[massmecfs.org/join](https://massmecfs.org/join)

[massmecfs.org/donate](https://massmecfs.org/donate)

To join the Sunday Conversations team: [volunteer@massmecfs.org](mailto:volunteer@massmecfs.org)

