

*There are many hurdles to maneuver when navigating the healthcare system. This can be particularly challenging when you live with a chronic illness. This document will address five common hurdles experienced by patients and providers and offer tips and solutions on how to overcome them. We aim to ensure you get the most out of your time with your medical team.*

*You will also gain access to a downloadable/printable PDF, that you can fill out prior to your medical visit. This will serve as a condensed “snapshot” of your current wellness presentation and afford your medical provider a wealth of information, streamlining your visit.*

## **Healthcare Hurdles that Interfere with Productive and Satisfying Visits**

### **Five common healthcare hurdles:**

- 1) Limited number of providers experienced in diagnosis and management of ME/CFS and FM
- 2) Illness disbelief
- 3) Illness complexity
  - a. Robust and dispersed medical records
- 4) Limited duration for medical visits
- 5) Brain fog

### **Hurdle #1: Limited number of experienced ME/CFS and FM medical providers**

To this day, many medical schools do not teach students about ME/CFS and FM. As we know, much of managing complex chronic illnesses lie in the provider’s ability to identify and focus on various aspects of illness, as part of the whole, making strategic symptom management a key component to improved wellness. If you have/find a medical provider who is understanding, respectful, and treats you well, it is worth staying with this provider because they can learn alongside you.

#### **Solution:**

- You may want to bring informational material to your medical provider from respected organizations. This may help validate and guide a conversation about what you have been experiencing, and how it relates to these illnesses.
  - BHC has composed a list of helpful resources to assist you in this conversation:
    - [Healthcare Provider Letter](#): Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (available to download/print/email)
    - BHC’s expanding [Medical Provider Library](#)

### **Hurdle #2: Illness Disbelief**

The sad reality is that there are still medical providers who do not fully invest their care management practices in the belief that ME/CFS and FM are diagnosable and manageable illness. Both illnesses lack an identifying diagnostic ‘test’ which is often the key persuader for many providers. If you have heard “there is nothing wrong with you,” please don’t give up. We believe you. We know this is real. There are a few steps you can take to overcome and/or bypass this unfortunate hurdle.

**Solution:**

- Well, it is really just one step, if you do not feel believed, respected, or comfortable with your provider, and solution #1 didn't work, then it's time to find a new provider!
  - This is a difficult decision because it means starting over, exposing yourself to potential scrutiny, and sharing your medical history (yet again), but it can be well worth the effort when you find the right medical provider (and they do exist).

**Hurdle #3: Illness complexity and scattered medical records**

Due to the complexity of these illnesses, many struggle for years trying to find answers. This generates a robust trail of medical records which include provider notes, medications, diagnostic labs, imaging, procedures, etc. It can be a very daunting process to organize these records, but it is a major driver to having success with your medical providers.

Many medical providers may not know what they need out of your medical records, but arriving with a multitude of disorganized records, will not help in their diagnostic process, and may frustrate you both.

**Solution:**

- Compile your medical records to the best of your ability. Recruit the help of others and be honest with medical offices when you call. They are often more helpful when they know you are trying to make their life (and the provider's) easier in the long-run. There are also applications these days that can help you in this process. Here are a few items that you will want to include:
- Diagnostic Studies
  - Not only for your ME/CFS/FM, but also to rule-in or rule-out other illnesses
  - This includes healthcare maintenance testing
    - Examples: MRI, CT, echo, stress tests, EEG, colonoscopy, mammogram, etc.
    - Lab results from the last 2 years
      - Include labs that are not routinely ordered (even if they may be older)
        - Examples: ANA, RF, antibody studies etc.
        - Routine: Thyroid, A1C, cholesterol, etc.
- Chart notes from evaluations performed by a specialist
  - Include initial evaluation, diagnostic findings, and your most recent visit note
- Do your best to create a list of the treatments you have tried:
  - Include medications and dosage (if possible)
  - Supplements  
and
  - Alternative treatments
- What was the result of this treatment?
  - Was it effective?
  - Did it cause side effects? If so, what were the side effects?
- Add information each time you have a new study or try a new medication, etc.

Be patient with yourself! Organizing this information may take a lot of time and energy. Once you have your medical history in order, be sure to keep it updated.

**Hurdle #4: Short Medical Visits**

A large part of the frustration felt by medical providers, and patients alike, is time constraints pressed upon medical visits. It is important to acknowledge that it is not the fault of your medical provider that he/she cannot spend more time with you. Understanding this can alleviate a lot of the stress, anxiety, and frustration put on both parties; and in turn motivate you to take action in the areas you can, to ensure an efficient and productive visit occurs in the 10-15 minutes allotted to you.

**Suggestions:**

- Plan ahead!
  - Plan to address 1-2 of your most pressing issues at each visit
  - Make another appointment to address further issues
    - Chip away slowly. Yes, this can be frustrating, taxing on energy, and money-but it is worth it if you are getting your providers full attention to address each issue.
  - Download and fill out the form provided at the end of this document.
- Prepare your symptom information in advance
  - These are the things your provider will ask you to describe:
    - When did this (symptom/ailment) first start?
    - Is it getting better or worse?
    - If it is pain...
      - Where is it?
      - Describe the pain (sharp, dull etc.)
      - Is it constant or intermittent?
      - Does it radiate to another place in your body?
      - How severe is it?
        - Reference the 10-point scale; with 0 being no pain, and 10 being the worst pain imaginable
    - Any leads on what could be causing this symptom?
      - Remember you know your body, and your intuition is helpful feedback to your provider
    - What makes the symptom better? What makes it worse?
    - Have you had any diagnostic studies for this symptom?
      - If so, when, and where did you have them performed?
      - Providing a record of this study is very helpful (see tip # 3)
    - What treatments have you tried for this symptom?
      - What was the result?

**Hurdle #5: Brain Fog**

Brain fog is a common symptom in those who have ME/CFS and FM. You may have experienced the feeling of a “mental block” or that a thought has “escaped you” when trying to talk with your medical provider. This can result in prolonged discussion for one of many questions your provider may have.

**Solution:**

- Remember, your goal is to get the most out of your 10-15 minutes with your provider, so taking the time ahead of your appointment to make notes or outline key points will serve you both well.
  - Reference the attached document to help guide your conversation and reserve your energy stores.

# Effective Communication Examples

## **Example 1**

State the issue: I am having terrible back pain.

When did it start? It has been off-and-on for over 10 years but has gotten progressively worse in the last 3 weeks.

Explain what has made it worse: It got worse after I helped my brother move, and I did more lifting than I am used to.

Where is it? It is in my lower back but is now traveling down my leg.

Describe the pain: The pain is so severe it wakes me at night.

Pain scale: I would rate it at 8/10.

What alleviates the pain? I cannot seem to find a comfortable position. It does get a little better with massage, but that only lasts for a brief period.

What have you tried (medication/treatment) I have used gabapentin, 300mg at bedtime in the past, and it was mildly helpful. However, I tried it again (past few nights), and it has not been helpful.

What diagnostics have you had done? I had an MRI of my back 2 years ago and it showed a bulging disk. This was completed at St. Mark's Hospital.

## **Example 2**

State the issue: I am having problems with insomnia.

When did it start? I have had trouble for as long as I can remember, but it has gradually worsened over the course of the last several months.

Explain what has made it worse: I cannot get to sleep (it may take 2 hours) and then I tend to wake in the night, and will struggle to get back to sleep.

I think my fibromyalgia pain might be a contributor, but my mind also races with thoughts of worry at night.

What diagnostics have been completed? I had a sleep study about 5 years ago to look for sleep apnea but they said it was totally normal.

This was completed at Intermountain Sleep.

What have you tried (medication/treatment)? I have used sleep aids in the past, including Ambien and trazodone. They both helped me get to sleep but did not keep me asleep. I also did a trial of gabapentin 300mg but I felt too sleepy all the next day."

## **Example 3**

State the Issue: My fatigue is getting worse

When did it start? In the past I could be up and around 10 hours per day. Now I am lucky if I am on my feet 3 hours per day.

What has made it worse: If I try to do more 3 hours a day, than I end up flat on my back in bed, and all of my symptoms (including brain fog, body pain, sore throat, swollen glands and nausea) are all much worse.

Duration? I may stay sick like this for 2-3 days before things start to level out.

Sometimes I feel like I might have a fever, but it always comes up normal.

What alleviates it? I'm not sure what I have done to make this happen- it just seems to have gradually gotten worse. No matter how much sleep I get, I am still wiped out when I get up in the morning.

About all I can manage to do these days is get up and shower, then I must rest for the day.

What diagnostics have been completed? We did a sleep study 2 years ago, and it was normal.

As you can see, in just a few concise sentences, you provide your medical professional with a wealth of information. We have included a single page worksheet that we recommend you use each time you go in to see your provider. We hope this serves you well no matter where you are in your medical journey!

Name: \_\_\_\_\_

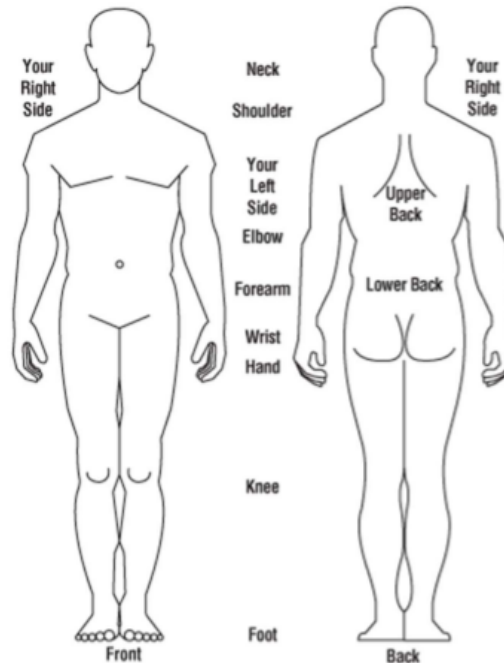
Form completion date: \_\_\_\_\_

Date of medical visit: \_\_\_\_\_

### Visit Priorities

Describe the top two points you want to work on or discuss during your upcoming visit:

- 1.
- 2.



### Pain Diagram

Please color in 'red pen' all areas of pain.

### Current Symptom Scores

Please circle below the number that best describes how you have been feeling in the last week (or how you typically feel).

SYMPTOM	Best										Worst
Fatigue	0	1	2	3	4	5	6	7	8	9	10
Depression	0	1	2	3	4	5	6	7	8	9	10
Anxiety	0	1	2	3	4	5	6	7	8	9	10
Brain Fog	0	1	2	3	4	5	6	7	8	9	10
Body Aches	0	1	2	3	4	5	6	7	8	9	10
Pain	0	1	2	3	4	5	6	7	8	9	10
Headaches	0	1	2	3	4	5	6	7	8	9	10
Sleep Problems	0	1	2	3	4	5	6	7	8	9	10

### Hours of Upright Activity

How many hours/24 hr day do you spend with feet on the floor---sitting, standing, walking?

How many hours/24 hr day do you spend with feet elevated---feet propped up, reclined, sleeping?

Note: the two answers above should add up to 24 hours

\_\_\_\_\_

\_\_\_\_\_