

# Improving Care for Patients with Prolonged Symptoms and Concerns about Lyme Disease

## A CLINICIAN TOOLKIT



**Overview of Lyme Disease** | **Welcoming Patients** | **Evaluating Diagnoses**  
**Developing a Care Plan** | **Compiling a Team**

## **Disclaimers**

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This toolkit contains resources supplied by third-party organizations. The inclusion of these materials does not imply endorsement of these resources or of the corresponding organization.

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# Introduction

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[Lyme disease](#) is the most common vector-borne disease in the United States, and its geographic range is expanding. With more people exposed to tick habitat and tick bites, more clinicians will find themselves caring for patients with Lyme disease. Confusion regarding the chronicity and treatment of Lyme disease is common, and many patients who experience unexplained, long-lasting symptoms may be curious if Lyme disease is the cause.

## How to use this toolkit

This toolkit can help physicians and other health care professionals provide better care for patients with prolonged symptoms and concerns about Lyme disease.

### The toolkit gathers:

- Best practices and guidance from CDC, medical professional societies including American Academy of Neurology (AAN), American Academy of Physical Medicine and Rehabilitation (AAPM&R), American College of Rheumatology (ACR), Infectious Diseases Society of America (IDSA) and practicing clinicians
- Resources for patients and health care professionals
- Interviews with experts on Lyme disease epidemiology and biomedicalization
- A new CME module helping physicians improve care for patients with prolonged symptoms
- Video examples of health care professionals who care for complex patients
- Tips on how to provide comprehensive and empathetic care

## Explore these steps to learn more:

- ✓ Welcoming patients
- ✓ Evaluating diagnoses
- ✓ Compiling a team
- ✓ Developing a care plan

At the end of this document, there are several resources created specifically *for this toolkit*, to help physicians and patients navigate the complex nature of care for patients with prolonged symptoms.

[View the resources](#)

# Overview

## Epidemiology and etiology of Lyme disease

Lyme disease is caused by certain *Borrelia* bacteria that are transmitted by the bite of an infected blacklegged (*Ixodes*) tick. In the United States, over 95% of reported Lyme disease cases occur in [15 high-incidence states](#), although incidence is increasing in neighboring states and some cases occur on the West coast each year. Treatment is a [10-28-day course of antibiotics](#). With this treatment, most patients recover quickly and completely. However, some patients with a diagnosis of early or disseminated Lyme disease go on to develop prolonged symptoms, sometimes called Post-Treatment Lyme Disease Syndrome (PTLDS).



### About chronic Lyme disease

#### ***There is no established medical definition of the term***

The term *chronic Lyme disease* has no established medical definition but has been used by some clinicians and patients to give a name to long-lasting, unexplained and often debilitating symptoms that some patients experience.

No two patients with prolonged symptoms and concerns about Lyme disease are the same. Some believe strongly that they have persistent infection and may be receiving or seeking specific treatment; others are simply wondering if their symptoms might be explained by Lyme disease. Each clinic visit is an opportunity to listen as well as to educate.

#### ***Symptoms, like fatigue and brain fog, occur at a higher rate in patients with Lyme disease compared to patients without***

While it is difficult to quantify, [studies have shown that prolonged symptoms](#)—such as fatigue, cognitive impairment, and pain—are widely prevalent in the [general population](#).

In [prospective studies](#) of [patients](#) with Lyme disease, prevalence of prolonged symptoms at 6 months after treatment generally averages between 5-10% higher than general population control groups.

#### ***Many infections can lead to Infection-Associated Chronic Illness, but a common pathophysiology is not yet known***

Studies have demonstrated that PTLDS is not due to ongoing infection and that prolonged courses of antibiotics do not result in sustained improvement. Many infections can cause a post-acute infection syndrome ([PAIS](#)) or infection-associated chronic illness ([IACI](#)), most notably [Long COVID](#) or [Post Acute Sequelae of COVID](#) following SARS-CoV-2 infection.

Some patients with concerns about Lyme disease may lack clinical or laboratory evidence of prior or active *Borrelia* infection. Other potential causes for prolonged symptoms include viral infections, endocrine disorders, rheumatologic disorders, mental health disorders, medication side effects, and cancer. Whatever the cause of patients' prolonged symptoms, they are real, and clinicians can help address these patients' concerns.



## Dive Deeper

### ✓ Watch an informational webinar



[Information for clinicians](#) on the term *chronic Lyme disease*

### ✓ Listen to our conversation



Paul Auwaerter, MD, reviews the [epidemiology and classic presentations of Lyme disease](#)

### ✓ For further information on Lyme disease, explore the following external resources.

- For details on the origin and use of the toolkit, see [CDC and AMA COCA Call](#)
- Overview of [serologic testing](#)
- [Interpretation](#) of [laboratory results](#)
- [Training modules](#) with continuing medical education (CME)
- [Webinars](#)
- [Resources](#)
- [Clinical practice guidelines](#)
- [Patient information](#)
- Information about [ticks](#)
- [Tickborne diseases](#)
- Prevention of [tick bites](#)
- Lyme disease [prophylaxis after a high-risk tick bite](#)

## SECTION 1

# Welcoming patients with prolonged symptoms into your practice

*An empathetic evaluation can reframe the visit into one that ultimately offers the patient hope.*

At first, caring for patients with complex medical conditions might seem overwhelming for a busy clinician. However, an empathetic evaluation can frame the visit as one that offers the patient hope and the clinician a sense of fulfillment.

### 1 Welcoming patients

#### *Patients are suffering and looking for help*

It is important to be open and welcoming to patients experiencing prolonged symptoms. Some clinicians refuse to see patients who have prolonged symptoms and concerns about Lyme disease.<sup>1</sup> However, these patients are suffering and are looking for help from trusted experts.

#### *Patients need empathetic care and reliable information*

Providing empathetic care and a comprehensive evaluation, offering open communication about what is known and not known about the cause of their symptoms, and working with the patient to address their concerns and symptoms is the best approach.<sup>1</sup>



### 💡 Key points

- ✓ Validate the patient's experience and symptoms
- ✓ Engage in [empathetic care](#)
- ✓ Be cognizant of the limitations of [biomedicalization](#)
- ✓ Maintain diagnostic humility as there are limits to current medical knowledge

<sup>1</sup>Chen A, Felt-Lisk S. Unpublished data. August 11, 2022

### 2 Preparation

It is important to develop a relationship built on mutual trust. Even before a patient comes into the office, sending them information on [how to prepare for the appointment](#) and [what to expect](#) shows empathy. Take the time to perform a comprehensive history and physical, including asking the patient why they think they have Lyme disease, the [timeline of their symptoms](#) as well as alleviating/exacerbating factors, and their journey through the health care system.<sup>1</sup> Listening to the words that patients use can give you clues into their feelings and needs.

Obtaining prior records is also important to understand what laboratory testing has been done previously—including non-FDA-cleared [Lyme disease tests](#). This can also show you whether other diagnoses have been considered and ruled out,<sup>1</sup> any prior treatments (both pharmacologic and non-pharmacologic) and responses to that treatment. Asking patients to bring these records with them will allow for a complete review and allow for the clinician and patient to discuss them at a later visit. These records should include the patient's [own symptom diaries](#), [stress diaries](#) and [health goals](#); encourage patients to keep track of their symptoms if they do not already. A thorough understanding of any pre-existing or current medical conditions, including mental health diagnoses, is also very helpful. Each of these, and other findings, can inform next steps.<sup>1</sup>

### 3 During the visit

A thorough history can reveal key pieces of information, such as whether the patient ever lived in or visited an area endemic for Lyme disease, had a known tick bite or typical symptoms of Lyme disease (e.g., [erythema migrans](#)) and whether the patient ever received treatment for Lyme disease.<sup>1</sup>

The next section [provides other diagnoses to consider](#).

Conducting these histories with [empathy](#) is [actively listen](#), as patients experiencing prolonged symptoms have often seen many health care professionals in their journey. It is essential to actively listen to the patient's story and validate their symptoms through statements such as "I believe you."

Being aware of the limitations of [the biomedical model](#) is important, as many patients may not have a nameable diagnosis, even after a thorough medical evaluation.<sup>1</sup> While some complaints, like a sore throat being diagnosed as a *Streptococcus* infection, easily fit into the biomedical model, others, such as chronic fatigue, do not. [Biomedicalization](#) is the process by which certain human experiences have become considered the domain of medicine, increasingly through technological means, and sometimes at the expense of the patient themselves.

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<sup>1</sup>Chen A, Felt-Lisk S. Unpublished data. August 11, 2022



## SECTION 1 (continued)

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### Dive Deeper

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Visit the [AMA toolkit online](#) to hear Camille Kroll explain more about biomedicalization, how it is ingrained in clinician training and how important it is to understand where it can steer clinicians in the wrong direction. Navigate to the “Welcoming Patients” page to access these videos:



**Camille Kroll, MA, MPH, CPH**

-  **Overview of Biomedicalization**
-  **Power in Diagnosis**
-  **Understanding Clinician Bias**
-  **Overcoming Bias**

## SECTION 2

# Evaluating for other medical diagnoses

*A complete history and physical examination are essential to ensure diagnosable conditions are ruled out*

It is important to keep an open mind. A complete history and physical examination, medical record review and devising a broad differential is essential to ensure diagnosable conditions are ruled out.

### Key points

- ✓ Outline a comprehensive diagnostic work-up, as indicated. This might include:
  - Age- and risk-appropriate cancer screening
  - Two-tiered testing for Lyme disease, deciding [whether to test](#) and how to interpret test results, based on patient's [pre-test probability](#)
  - Considering autoimmune conditions with directed diagnostic testing tailored to symptomatology
  - Screening for obstructive sleep apnea (e.g., [STOP-Bang](#))
  - Cognitive [evaluations](#) (with [video instructions](#))
  - Screening for mental health diagnoses: Anxiety ([GAD-7](#)) | Depression ([PHQ-9](#))
  - Objective Activity tools like [Duke Activity Status Index](#) can help patients measure their abilities
- ✓ Acknowledge that multiple visits will be required
- ✓ Provide a thorough medical record review, which may take longer than the allotted visit time
- ✓ Consider billing for [prolonged services](#) and determine if you can use add-on codes like [G2211](#) for complex visits, which Medicare and some commercial insurance companies recognize



### Thoroughly evaluate prior testing

It is important to review prior laboratory testing and imaging results—including non-FDA-cleared tests (i.e., [laboratory-developed](#) or in-house tests). Some patients may have active Lyme disease or be experiencing prolonged symptoms after an acute episode of treated Lyme disease, called Post-Treatment Lyme Disease Syndrome. If the clinical presentation and epidemiologic risk factors suggest acute Lyme disease, clinicians should provide a course of [recommended](#) antibiotic treatment.

If a patient with evidence of prior Lyme disease has already received recommended treatment, it is important to provide counseling that additional antibiotics have not been shown to provide sustained symptom improvement and to acknowledge that for some patients, it may take months to feel better. There is some [research looking at different biomarkers](#) that might help distinguish patients with PTLDS from those with other diagnoses; however, at this time there is no commercial test available.

### Review comorbidities, including mental health diagnoses, and manage expectations

For patients with prolonged symptoms without evidence of acute Lyme disease, it is important to consider and evaluate other possible medical issues. [Research indicates](#) that more than half of patients experiencing such symptoms have a diagnosis other than Lyme disease as the cause of their prolonged symptoms.

After a thorough work up, some patients may obtain a diagnosis; some will not.<sup>1</sup> It is important to evaluate and address mental health for all patients, as depression and anxiety may be common in this population, given their long health care journey and prolonged symptoms.<sup>1</sup> There is also some [research indicating](#) that post-infection cytokine damage to part of the brain (e.g., the ventral striatum) can cause a decrease in the motivation/reward pathway, which may manifest as depressive symptoms or fatigue. In short, chemical pathways can be disrupted after an infection, leading to more fatigue and depression. Psychiatrists can recommend medications that might restore these pathways.

Obtaining a complete history and reviewing records can require long office visits, which can be difficult for health care professionals to manage financially.<sup>1</sup> Early in the initial visit, set the expectation that because patients

have been living with these symptoms for a while, it can take several visits to thoroughly evaluate their symptoms.

### Develop and systematically work through a broad differential diagnosis

It is important to do a thorough physical exam and consider possible diagnoses based on patient symptoms (e.g., [fatigue](#)). There are several cognitive assessments for clinicians to use—some examples are available on [paper](#) and some are [digital](#). Patients should have age- and risk-appropriate cancer screenings, plus a targeted workup for specific cancers if there are any concerning findings on history and physical. Clinicians should also consider ME/CFS ([evaluation](#), [diagnostic criteria](#), [using the diagnostic criteria](#), [diagnosis and management](#)),<sup>2</sup> endocrinopathies (such as diabetes, hypothyroidism) and rheumatologic diseases (such as polymyalgia rheumatica, fibromyalgia, rheumatoid arthritis and lupus) when appropriate. Screening for [sleep disorders](#) can be helpful. Multiple medical societies and the United States Preventive Services Task Force recommend routine screening for [depression](#) and [anxiety disorders](#). Primary care clinicians can use a standardized mental health screening tool such as [PHQ-9](#) and [GAD-7](#) for patients with prolonged symptoms.

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<sup>1</sup> Chen A, Felt-Lisk S. Unpublished data. August 11, 2022

<sup>2</sup> Used with permission of Mayo Foundation for Medical Education and Research, all rights reserved.

## SECTION 3

# Compiling a multi-disciplinary team

*A multi-disciplinary team can help patients get the evidence-based care they need*



Enlisting other specialists to address specific symptoms can be a way for patients to get the evidence-based care they need. However, the primary care physician remains the team leader, gathering recommendations and communicating to other specialists and to the patient.

### Key points

- ✓ Set expectations and utilize frequent visits to look at small parts of the care plan rather than trying to manage every symptom every time
- ✓ Consider referrals as appropriate to subspecialty physicians (e.g., infectious diseases, neurology, rheumatology, cardiology, psychiatry, integrative medicine)
- ✓ Patients with fatigue can benefit from physical medicine and rehabilitation consultation, rather than exercise guides
- ✓ Consider [integrating behavioral health treatment](#) in the clinic
- ✓ Discuss alternative medicine options that are typically low-risk and cost-effective by patient standards, depending on patient interest
- ✓ Recognize that insurance may not cover some therapists, mental health professionals or alternative medicine therapies
- ✓ [Communicate expectations](#) and goals clearly to other health care professionals
- ✓ Collect and assemble recommendations from care partners, acting as the main point of contact for the patient

### Appropriate referrals can help shape a full care plan

A multi-disciplinary team can help patients with prolonged symptoms by using evidence-based medicine for specific symptoms, validating a patient's concern in the setting of a specialist's office and providing the primary care physician with guidance on further management. It is important to temper patients' expectations that the specialist will "find the answer," as many patients will continue to need ongoing management of prolonged symptoms.

When [referring to specialists](#), being clear about the purpose of the consultation and asking them to focus on one particular symptom, such as joint pain or fatigue, might help the patient and specialist concentrate their efforts. Once again, be sure to set expectations with the patient prior to subspecialty referral.

Similarly, non-physician professionals, such as physical or occupational therapists, can provide useful insight and support. Referrals to alternative medicine providers, such as massage therapists or acupuncturists, may be helpful for some patients.<sup>1</sup> Psychiatrists can evaluate patients to individualize pharmacologic treatments to [restore optimal mental health](#). Referrals to mental health professionals can also provide patients with ways to discuss past traumas and alternate methods of coping.

### Resources can help you do more

Transportation and inability to get to appointments because of fatigue and pain can be an issue. Adding more clinicians to the patient's list may be overwhelming. Many insurance carriers are reimbursing telehealth video visits, which can keep fatigued patients connected to their clinicians. In these cases, the primary care physician may be the only clinician that the patient has the energy to visit—even virtually.

Multiple medical societies and the United States Preventive Services Task Force recommend routine screening for [depression](#) and [anxiety disorders](#). Primary care clinicians can use a standardized mental health screening tool such as PHQ-9 and GAD-7 for patients with prolonged symptoms. There are resources for patients to assess and work through [complex emotions](#) that relate to prolonged symptoms. Similarly, there are resources for clinicians to learn how to manage [post-infection fatigue](#), when PM&R referrals are not available. Some symptoms can overlap with ME/CFS, so [resources](#) on managing that condition might be helpful for other [IACI](#) patients.

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<sup>1</sup> Chen A, Felt-Lisk S. Unpublished data. August 11, 2022

## SECTION 4

# Developing a Care Plan

*Building trust will help align patient and clinician care plan goals*



The basis for every successful patient-clinician relationship is trust. Trust grows when both parties listen to each other and are honest about expectations. The internet and social media can easily spread misinformation, and it can be tempting to dismiss patients who have firmly held beliefs that are not evidence-based. Empathy is essential in all patient interactions, but particularly those with prolonged symptoms and chronic diseases.<sup>1</sup>

### Key points

- ✓ Validate the patient's symptoms and their health experience
- ✓ Build trust to help align patient and clinician goals
- ✓ Recognize the limitations of the [biomedical model](#)
- ✓ Explain the need for multiple visits and allow for longer visit times in the future
- ✓ Use [motivational interviewing](#) to help patients move away from [potentially harmful treatments](#) (e.g., prolonged antibiotics) and towards a symptom-based approach
- ✓ Focus on improving individualized quality of life, not just on finding a "cure"
- ✓ Encourage use of patient symptom trackers (paper or digital app)
- ✓ Educate patients on where to find [reliable information](#)
- ✓ Recognize support groups may provide helpful emotional support but they may not be beneficial for all patients
- ✓ Make a follow-up visit to see the patient back in your clinic
- ✓ When possible, allow more time for [visits](#)

<sup>1</sup> Chen A, Felt-Lisk S. Unpublished data. August 11, 2022

## SECTION 4 (continued)

### Use motivational interviewing to connect with patients

[Motivational interviewing](#) involves 5 steps that clinicians can use to connect with patients. It centers on [open-ended questions](#) and allowing patients to talk about their health decisions. For example, if a patient does not want to try a specific medication, ask “What is it about this medication that concerns you?” to give the patient an opportunity to describe their fears or concerns.



- 1 Express empathy:** acceptance of the situation can help facilitate change.
- 2 Develop discrepancy:** make connections to consequences by asking, "What is good (or not) about this?"
- 3 Avoid argument:** confrontation does not motivate people; ask for clarification if an argument is brewing.
- 4 Roll with resistance:** emphasize that choice and control are with the patient; invite reflection by saying, "This sounds important to you."
- 5 Support self-efficacy:** motivation occurs when patients believe change is possible; empower the patient to choose an action plan.

### Focus on quality of life

History notes Hippocrates as stating, "It is more important to know what sort of person has a disease than to know what sort of disease a person has." Knowing the patient can help the clinician shift from a recovery narrative to one that is more focused on optimizing quality of life and achieving specific health goals. This can help patients and clinicians recognize small improvements and setbacks. Rather than focusing exclusively on a diagnosis and a cure, clinicians can ask patients [what is most important](#) to them and try to manage those symptoms. Referring back

to their goals, through multiple frequent visits, validates their experience and makes them an active player in their care plan.

Some clinicians recommend focusing on symptom management with tailored pharmacologic or nonpharmacologic support as appropriate. Keeping a [symptom diary](#), talking about risks and benefits and side effects of medications, and being willing to change course if a medication or other therapy is not working<sup>1</sup> were found to be helpful to [being willing to change](#).

<sup>1</sup> Chen A, Felt-Lisk S. Unpublished data. August 11, 2022

# RESOURCES AND ADDITIONAL INFORMATION



## Access the Toolkit Online

[ama-assn.org/Improve-Care-for-Prolonged-Symptoms-Toolkit](https://ama-assn.org/Improve-Care-for-Prolonged-Symptoms-Toolkit)



## Supplements

### 1 Section 1: Welcoming patients

- 1.1 Healthcare Appointment Checklist
- 1.2 Infection-Associated Chronic Illness (IACI): What to expect from your visit
- 1.3 Symptom and medical history timeline
- 1.4 Symptom diary
- 1.5 Stress diary
- 1.6 Health goals

### 2 Section 2: Evaluating diagnosis

- 2.1 Finding reliable clinical laboratories

### 3 Section 3: Compiling a team

- 3.1 Referral letter: Sample letter template

### 4 Section 4: Developing a care plan

- 4.1 Managing differences of opinion
- 4.2 Finding reliable health information online
- 4.3 Motivational interviewing: Sample script
- 4.4 Goal tracker

## Interactive Tools & Resources

5 **Access the CME module:** [Caring for Patients With Prolonged Symptoms and Concerns About Lyme Disease](#)

6 **Watch the CDC and AMA COCA Call:** [New Clinical Tools and Resources to Support Patients with Prolonged Symptoms and Concerns about Lyme Disease](#)



# HEALTHCARE APPOINTMENT CHECKLIST FOR LONG COVID | COVID-19 |

Accessible link: [Healthcare Appointment Checklist for Post-COVID Conditions \(cdc.gov\)](https://www.cdc.gov/long-covid/healthcare-appointment-checklist)

This checklist is designed to help patients and caregivers get the most out of appointments with healthcare providers for Long COVID.

## Before the Appointment



- List your healthcare providers**  
If visiting a new healthcare provider, ask the new provider's office if they need paperwork signed so your medical records can be sent to them directly.
- Write down your health history**  
Prepare a journal or list describing all of your past or current symptoms, how they have affected your daily activities, and anything that made them feel better or worse.
- List your current medications**  
Make a list of medications and supplements you are currently taking.
- Write down questions for your healthcare provider**  
Think about and make a list of questions to ask your healthcare provider. Identify which questions are a priority for you (in case time is limited).
- Talk to a family member or friend**  
Consider discussing your appointment with a family member or friend to assist with transportation or help remember your conversation with your healthcare provider.
- What to expect**  
Your provider could be a doctor or other type of healthcare professional and may ask questions and run or order tests to determine a diagnosis and plan for treatment. It may take more than one appointment to evaluate and diagnose your Long COVID symptoms.

## During the Appointment



- Bring/share your health history**  
Be sure to talk to your healthcare provider about how your symptoms have changed over time and how they have affected your daily activities.
- Bring/share your list of medications and supplements**  
Be ready to discuss whether any of your medications or supplements have helped you feel better.
- Bring/share your list of questions**  
Bring your list of prepared questions to your healthcare provider. Ask your most important questions first (in case time is limited).
- Know your next steps**  
Carefully listen to and answer all of your provider's questions. Make sure you understand the next steps, such as tests, follow-up, referrals, and future appointments.
- Ask for a summary**  
Ask for an appointment summary. If needed, ask your provider to write down, print out, or email any instructions, medication names, or diagnoses.

## After the Appointment



- Track your appointments**  
Make appointments for follow-ups with your provider, referred specialists, or diagnostic testing facilities. Record the appointments and tests in both your calendar and your caregivers' calendar.
- Work with your healthcare provider and seek support**  
Contact your provider's office with any additional questions or clarifications and follow your provider's instructions to the best of your ability. Reach out to recommended support groups.
- Document your experiences**  
Continue to record and update your symptoms, conditions, and medication list, so you can refer to updates or changes during your next appointment.



For more information on Long COVID, visit:

<https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/index.html>



# Healthcare Appointment Checklist for Post-COVID Conditions | COVID-19 |

Accessible link: <https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/post-COVID-appointment/index.html>

This checklist is designed to help patients and caregivers get the most out of appointments with healthcare providers for post-COVID conditions.

## Before the Appointment

- Ask the new provider's office if they need **paperwork** signed so your medical records can be sent to them directly.
- Keep a **journal or a list** for a week or two to document your activities, symptoms, their severity, and anything that made you feel better or worse.
- Prepare a brief **report** that summarizes your experience and symptoms and describes your best and worst days.
- Make a list of your **current medications/supplements**.
- Make a list of **questions to ask your healthcare provider**. Identify which ones are a priority for you (in case time is limited).
- Make a **plan for remembering** your conversation with your healthcare provider — e.g., taking notes or bringing a friend.
- If needed, arrange **transportation** to your appointment.

## During the Appointment

- Tell your provider the most important **symptoms or issues** you'd like to discuss.
- Answer the **provider's questions**.
- Share your **medication/supplement list**.
- Discuss your **level of activity**.
- Ask your own questions**, starting with your priorities and issues.
- Make sure you understand the **next steps**, such as tests, follow-up, referrals, and future appointments.
- Ask for an **appointment summary**. If needed, ask the provider to write down or print out any instructions, medication names, or diagnoses.

## After the Appointment

- Make appointments** for follow up.
- Record future appointments**, including tests, in your calendar. If others will go with you or drive you to future appointments, make sure the appointments are on their calendars too.
- Follow your **provider's instructions** to the best of your ability.
- Contact your provider's office with any **questions or clarifications**.
- Continue to record symptoms and keep your **journal**, so you can refer to updates or changes during your next appointment.
- Update and keep track of **medications and supplements**.



For more information on post-COVID conditions, please visit <https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects.html>.

# Infection-Associated Chronic Illness (IACI)

## What to Expect from Your Visit

1



### Complete History and Physical Exam

It is important to share with your clinician when symptoms started and what makes them better or worse. Tell them about any medical problems in family members and personal things like your job and hobbies and where you live.

2



### Review Old Records

If you have old medical records—lab work or imaging reports—**bring them to your appointment**. Your clinician may need time to review them all, but it is important they know what has been done already.

3



### Evaluate Results

Your clinician will talk about ruling in or out other medical conditions. While some people with **Infection-Associated Chronic Illness (IACI)** will not have another medical diagnosis, sometimes **your clinician can uncover another medical condition** that requires treatment.

4



### Make a Follow-up Appointment

**IACI is a complex condition that will require regular, ongoing care.** Your clinician will look for ways to manage symptoms **and help improve your quality of life.**

5



### Individualize Your Treatment Plan

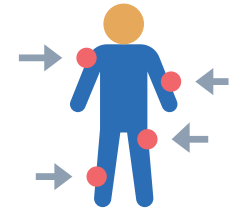
**Patients with IACI have similar symptoms, but the treatment plan should be individualized.** Your clinician may refer you to other specialists or therapists to focus on specific symptoms or concerns.





# Symptom and Medical History Timeline

Sharing a timeline of when your symptoms started, how they have changed over time, and how they have responded to treatment can be very helpful for your health care professional. Use this timeline to fill in when symptoms started, what clinicians you have seen, and what treatments you have taken. You can add in your opinions, too, such as if a particular clinician was helpful or if a medication worked but had side effects that you did not like. Below is an example, with the second page blank for you to fill in and share with your health care professional.



**Symptom and Medical History Timeline**

**Patient Name:** \_\_\_\_\_ **Date:** \_\_\_\_\_

<b>2004</b>	Had mono in college, took 6 months to feel mostly better.
<b>2013</b>	Had first child, no problems.
<b>2015</b>	Had second child, some postpartum depression that improved.
<b>2016</b>	Vacation to Minnesota, multiple tick bites.
<b>2018</b>	Fatigue, brain fog.
<b>2019</b>	Saw PCP, CT head done and negative. Work-up for lupus negative.
<b>2021</b>	Got COVID vaccine, mild fevers.
<b>2022</b>	Got COVID, some fevers, fatigue. Fatigue was worse than before and didn't go away.
<b>2023</b>	Telehealth with doctor, started antibiotics for 30 days for Lyme, mild improvement. Tried another 30 days, no improvement. Got IV vitamin infusions for 3 months, no improvement.
<b>2024</b>	Doctor recommended more infusions, too expensive.


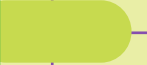



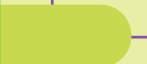
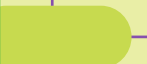






# Symptom and Medical History Timeline

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**Patient Name:** \_\_\_\_\_ **Date:** \_\_\_\_\_

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	_____
	_____






# Symptom Diary

**It is important to track your symptoms and how they vary from day to day.** Writing your symptoms down and sharing them with your physician and others on your care team can help determine triggers to your symptoms and how you are responding to interventions.

**There are many mobile apps for smart phones and tablets that you might find convenient, as well as paper journals and books.** Make sure that the apps will keep your data secure and that they are easy for you to use and review with your clinician.

**Getting Started:** You can use this document to start and then look for a version that fits your needs. In this diary, you can use shorthand for your symptoms (e.g., use “F” rather than writing out “fatigue” each day) and then give it a numerical value. Out of a maximum scale of 10, perhaps your fatigue one day was a 7 out of 10 (7/10) but on another day it improved to a 3 out of 10 (3/10).

**Example Symptom Diary:** You can see the example chart below. A line is at the top to list your **goal(s)** for the week, to keep them top of mind. There is also a spot for reflection at the bottom of the page. The second page is blank for you to try.

**Symptom Diary**


**Patient Name:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Symptom List:**    Fatigue (F)        Chronic Pain (P)        Headache (H)

<b>★ Goal:</b>	<b>Keep fatigue at &lt;6 and walk to the corner 3 days per week.</b>
Sunday	Walked to the corner and back, extreme fatigue at 6p (F 9/10)
Monday	Couldn't get out of bed all day (F 10/10)
Tuesday	Able to do some laundry, napped at 2p (F 6/10)
Wednesday	Friend brought lunch over, sat outside for a few hours (F 5/10)
Thursday	Headache, tried new med with no relief (H 8/10)
Friday	Headache, tried meditation and ibuprofen with 50% improvement (H 4/10)

**Thoughts/Reflection:**  
The combination of meditation and ibuprofen was very helpful. Will try again next time. Small naps helped manage fatigue, but still went to bed early that night. Lots of fun playing cards with neighbors.





# Symptom Diary



**Patient Name:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Symptom List:** \_\_\_\_\_

 <b>Goal:</b>	
Sunday	
Monday	
Tuesday	
Wednesday	
Thursday	
Friday	
Saturday	

**Thoughts/Reflection:** \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_





# Stress Diary

Physical and emotional stress affect our bodies and our minds. You might find that your symptoms change when you encounter different stressors. It can be helpful to keep track of them in a diary or journal. You might also find that different meditative activities help lower your stress level and associated symptoms. For example, 4-7-8 Breathing (breathing in for 4 seconds, holding for 7 seconds and exhaling for 8 seconds) has been shown to lower anxiety levels.

Visit: <https://www.webmd.com/balance/what-to-know-4-7-8-breathing> to learn more or scan the QR code.



## Example of a “Stress Diary”

Activity	Symptom	Change
Credit card declined at store	Shortness of breath Headache	2→5 4→6
No wheelchair at clinic, walked upstairs	Fatigue	5→9
4-7-8 Breathing for 3 minutes	Headache	5→2

- **Activity Column:** List what triggered a stress response. You can also use it to track how your symptoms improve after implementing a deep breathing exercise, a meditation session or other stress-reducing exercise you find helpful.
- **Symptom Column:** Describe how your body reacted to the stress-reducing activity.
- **Change Column:** Track how your baseline symptoms changed with that stressful incident. For example, if your credit card was declined at a store, perhaps your headache increased slightly from a 4 to a 6.

The second page is blank, for you to see if it is helpful in tracking how your mind and body interact with stress and stress-reducing activities.







# Stress Diary

---

**Patient Name:** \_\_\_\_\_ **Date:** \_\_\_\_\_

Activity	Symptom	Change





# Health Goals

---

Everyone has a different notion of quality of life. For some, having a pain-free day is the goal. For others, running brings joy. What comes to mind when you think about your “quality of life”—as it is now and as you want it to be? Here are some questions for you to answer. If you feel comfortable, share them with your clinician, so that they can get to know you and your values.

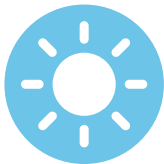
**Patient Name:** \_\_\_\_\_

**Date:** \_\_\_\_\_



**1. What brings you joy?**

\_\_\_\_\_



**2. Describe your perfect day.**

\_\_\_\_\_



**3. What does it mean to you to “feel better”?**

\_\_\_\_\_



**4. What does a successful treatment plan look like to you?**

\_\_\_\_\_



**5. What does a successful relationship with your health care team look like?**

\_\_\_\_\_





# Finding Reliable Clinical Laboratories

In order to process human samples (like blood), **laboratories must be certified** to do so. *The Clinical Laboratory Improvement Amendments* of 1988 (CLIA) regulations include federal standards applicable to all U.S. facilities or sites that test human specimens to diagnose, prevent, or treat disease. The use of **FDA-cleared antibody tests** at a **CLIA-certified laboratory** is recommended for the diagnosis of Lyme disease.

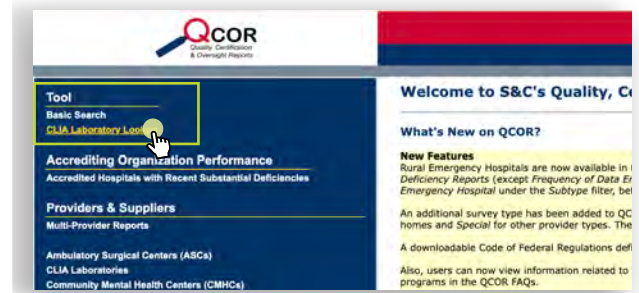
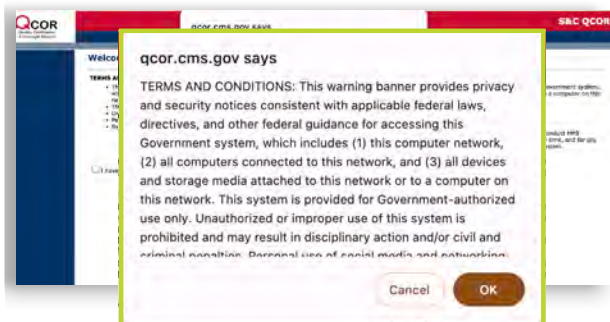
## Finding a Certified Laboratory

To look for a certified laboratory visit <https://qcor.cms.gov/main.jsp> or scan the QR code.



### Follow these steps:

1. First, agree to the **terms on the site.**
2. Click the upper left-hand corner where it says **“CLIA Laboratory Lookup.”**



3. Enter a laboratory name, city, zip code, etc.
4. You will then see a **list of certified laboratories.**



## Finding Information on Tests

If there is a particular laboratory test you have heard about and want more information on, **ask your clinician.** They can help determine whether that test is right for you.



## Sample Letter Template

Use or adapt this template to refer patients who have been identified with prolonged symptoms and concerns about Lyme disease.

---

<<YOUR LETTERHEAD>>

<<ADDRESS>>

<<PHONE NUMBER>>

<<DATE>>

<<REFERRING CLINICIAN NAME>>

<<CLINICIAN ADDRESS>>

Dear <<REFERRING CLINICIAN NAME>>,

I have a patient I am referring to you for [prolonged fatigue].

The patient is a [46-year-old woman (G2P2) with well-controlled asthma who is seeing me for fatigue lasting over 8 years without a clear diagnosis].

Relevant past medical history includes [Lyme disease, asthma and depression. The diagnosis of Lyme disease was based on a laboratory-developed test that has not been cleared by the FDA].

The social history includes [working part-time as a school aide 3 days a week but finds she is taking naps when she is home and often sleeping over 11 hours at night without feeling rested when she wakes].

The work up so far includes [negative CT scans of the chest, abdomen and pelvis in 2019, an equivocal ANA with negative reflex testing in 2022. Hgb A1c, TSH, CBC and CMP are normal]. At this point, our goal is to focus on symptom management and improving the patient's quality of life, rather than pursuing further work-up or treatments for Lyme disease.

Symptoms are affecting their life in the following ways: [She is having difficulty getting through her workday and she is missing out on family functions in the evenings due to fatigue].

I'm referring them to you to see if there are any other diagnoses or work-up that we should consider. The patient's main goal is [to improve her exercise tolerance and reduce her fatigue. I've given her a symptom diary to fill out related to the fatigue that she will bring with her].

Please send me your consultation note, as I would like to know what your treatment plans are. I see this patient every [4 weeks], so I will talk through your thoughts and recommendations with the patient. Thank you for your insight and help with their care.

Sincerely,

Dr. <<YOUR LAST NAME>>



# Managing Differences of Opinion

Differences of opinion between patients and clinicians happen. These types of interactions can help foster a positive relationship or can lead to a rift between the parties, eroding the trust and confidence that both require. Learning how to manage some of the more common areas of disagreement can help de-escalate or even avoid high tension in the office and allow you to *provide better patient care.*

## Patients who want to be tested for a particular disease:



**Patient:** "I want you to test me for [disease X]." **or** "Can you order [test X]?"



**Clinician:** "What makes you concerned about [disease X]?" **or** "How do you think [test X] would be helpful?"

## Patients who want antibiotics when they are not medically indicated:



**Patient:** "The antibiotics are the only things that work. I need to continue taking them or I'll find another doctor."



**Clinician:** "In what way do the antibiotics help? What improvements have you seen?"

Then, "What if we try [x] for the next 2 weeks instead of the antibiotics? You can use a symptom diary to document your days, and then come back and talk about how you've been feeling. Do you think that's enough time?"

## Helping patients manage expectations:



**Clinician:** "We've ruled out [list conditions that have been tested for], so that's reassuring."

I appreciate you bringing back the symptom diary, and I see you've had some good and bad days. I know there will continue to be some bad days, but what do you think is the next step to try and get more good days?"

"I know you've tried a lot of different medications for your brain fog. We've had some success, but I hear you that you're still suffering. How do you feel about seeing a neurologist, to see if there's anything we've missed or a treatment that I don't know about?"

"I want you to be aware that even specialists can struggle to find the right combination of therapies, so try not to be disappointed if they don't have answers right away."

Our knowledge about Infection-Associated Chronic Illness (IACI) is incomplete. It is important to remind patients that research is ongoing, and we may need to adjust our care plans as we learn more.





# Finding Reliable Health Information Online

Finding reliable information on the internet is not as easy as it seems. While we can search for any word or phrase, the search results we get are **biased by algorithms and advertisements**.

Here are some tips to help you navigate health information on the internet.

## Educate yourself

Trusted websites that give tips on internet searches:

**National Library of Medicine Tutorial**

<https://medlineplus.gov/webeval/webeval.html>



**Public Library Association**

Short videos on web searches:

<https://www.digitallearn.org/courses/basic-search>



**National Institute on Aging**

<https://www.nia.nih.gov/health/healthy-aging/how-find-reliable-health-information-online>



**Tulsa Community College Library**

Offers a guide on how to limit your Google search to only reliable domains:

<https://askus.library.tulsacc.edu/faq/220078>



Domain names can identify safe sites:

**Government Websites**

Websites ending in **“.gov”** are from U.S. federal, state, or local government agencies and **are safe to click on**.

**Educational Websites**

Websites ending in **“.edu”** relate to educational centers, like universities and **are safe to click on**.





## Never share personal information

No website should ask for personal information. Never share any medical information, bank account numbers or Social Security numbers, for example.

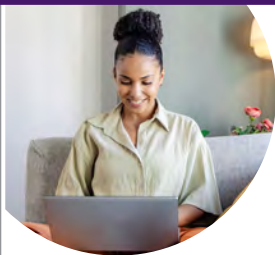
It is also important to be cautious when you read testimonials or posts on discussion boards or social media. Personal stories may or may not be true. Even if some people did find benefit from a certain medication or treatment, **everyone experiences health problems and solutions differently**. If you are interested in health information you read about online, **bring the information to your health care professional and ask if it might work for you**.

## Look for paid advertisement

Search engines, like **Bing** or **Google**, rely on advertisers to make money. However, many people do not realize that companies can pay to have their link listed at the top. Some search engines label these as "Sponsored" or "Ad." These labels can be small and easily missed. Here is a checklist to help you search more cautiously online. Visit: <https://medlineplus.gov/webeval/webevalchecklist.html> or scan the QR code.



## List of reliable sites



As you search and use reliable sources, you will become more confident in recognizing sites that might be trying to take advantage of you. While the internet can open doors to great information, it is always a good idea to be cautious until you know the source. Here is a list of reliable websites to get you started. Visit:

<https://www.luriechildrens.org/en/patients-visitors/visiting-lurie-childrens/tour-the-hospital/family-community-destinations/pedersen-family-learning-center/reliable-websites-for-health-information/>

or scan the QR code.





# Motivational Interviewing

## SAMPLE SCRIPT

It can be challenging to navigate conversations when there is a difference of opinion. For patients with prolonged symptoms who desire long-term antibiotics or other interventions that may be harmful, it can be hard to know how best to explain why they are not recommended while maintaining a positive clinician-patient relationship. Here are some examples of what you might say when a patient is seeking a treatment that is not medically indicated.



### **Validate their feelings.**

“I can understand why you feel that way.”



### **Encourage discussion about harmful outcomes.**

“What side effects have you experienced in the past? What problems do you think more antibiotics might cause?”



### **Concisely state your stance on the treatment in question, in clear terms the patient can understand.**

“Multiple studies have shown there is not a benefit to taking antibiotics for a long time. Many people have experienced real harms, like blood stream infections from IV lines. I don’t want you or any of my patients to experience something like that.”



### **Open the door for alternative therapies.**

“Besides antibiotics, what has worked for you? What else are you interested in trying?” or “I think antibiotics are too risky, but I do want to help you feel better. What other options do you think might help?”





**MOTIVATIONAL INTERVIEWING SAMPLE SCRIPT**



**Help the patient navigate some options, looking at pros and cons.**

“This option might cause [x], but there are some reasons why it might work for you.”



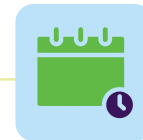
**Acknowledge the patient’s control of the situation.**

“I think these are good options, but which one do you think you’d like to start with? It’s up to you.”



**Encourage a structured way to measure treatment failure or success.**

“How do you like to document your response to medication?”



**Agree upon a time frame to try the new treatment before returning.**

“Generally, it takes some time to see if a medication is going to work for you. I’m thinking of having you come back with your symptom diary for a follow up in about 4 weeks. Do you think that’s enough time?”



**The most important thing is to use open-ended questions, let the patient lead wherever possible, and work together as a team on a treatment plan.**

While documentation is important, keeping good eye contact and not being distracted by electronic medical records helps in all clinician-patient interactions. Keep in mind that you will have multiple visits and conversations with patients. It can be helpful to let the topic sit until the next visit after everyone has had time to consider the other side.




# Goal Tracker

It can be helpful to write down your health goals and list steps you can take to achieve those goals. **Ask yourself:** What do I think will **improve my days**? When have I **overcome** these **challenges** in the past—and **how**? If this worksheet does not meet your needs, create your own and share it with your clinician.

Below is an example.

## Goal Tracker



**Patient Name** \_\_\_\_\_ **Date** \_\_\_\_\_

**Health Goal**  
Walk for 20 minutes every day

**Action Steps**

1. Put walking shoes by the door
2. Have a walking buddy to call
3. Start a walking journal

<p><b>Anticipated Benefits</b></p> <ol style="list-style-type: none"><li>1. More energy</li><li>2. Less shortness of breath</li><li>3. Sleep better at night</li></ol>	<p><b>Anticipated Challenges</b></p> <ol style="list-style-type: none"><li>1. Bad weather</li><li>2. Lack of motivation</li><li>3. Too busy</li></ol>
--	---

**Lessons Learned**

1. Schedule this on my phone so I keep the time open; set a timer
2. Plan to go with a friend
3. Bring music if I walk by myself
4. I like being outside, head feels clearer





# Goal Tracker

---

It can be helpful to write down your health goals and list steps you can take to achieve those goals. If this worksheet does not meet your needs, **create your own** and **share it with your clinician**.

**Patient Name** \_\_\_\_\_ **Date** \_\_\_\_\_

**Health Goal** \_\_\_\_\_

**Action Steps**

_____	_____
_____	_____

**Anticipated Benefits**

**Anticipated Challenges**

_____	_____
_____	_____
_____	_____

**Lessons Learned**

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

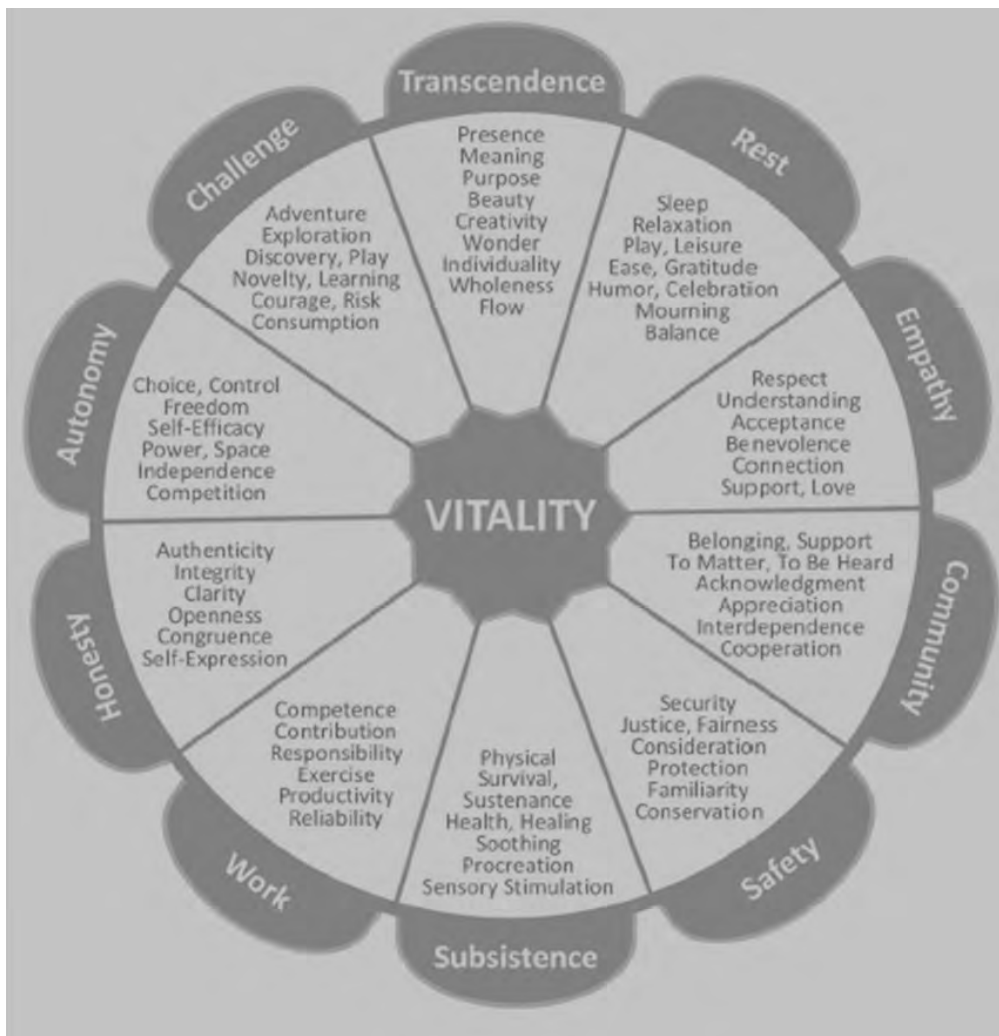


## Identifying Underlying Needs

This tool will help you gain a deeper understanding of the underlying needs we all have but may not openly or knowingly express. Needs make no reference to any specific person doing any specific thing. Needs can also be referred to as values, desires, or aspirations.

The Wheel of Universal Human Needs is a visual representation of a person's overarching needs (outer ring of petals in dark gray) with words commonly used to describe them listed in the center. You may notice a patient use these words when you are listening with empathy, or you may intuit these needs from what they are saying. Page 2 of this handout is designed to help you check your understanding of what's important to the patient.

### The Wheel of Universal Human Needs



Inspired by the work of Manske J, Manske J. 2005. <http://radicalcompassion.com>. Accessed May 16, 2016.

Rosenberg M. Center for Nonviolent Communication. 2005. <http://www.cnvc.org>. Accessed May 16, 2016.

Max-Neef M, Ekins P, eds. *Real-life Economics: Understanding Wealth Creation*. London, UK: Routledge; 1992.

Adapted with the permission of the creator:

Jeff Brown, Certified Trainer with the Center for Nonviolent Communication ([www.evolutionaryorganizations.org](http://www.evolutionaryorganizations.org))

## Expressing needs in conversational language

The following list gives examples of how needs may be expressed in conversational language. As written, these questions might be used to check your understanding of a patient’s needs. They can also be used as a springboard to further discussion. Think about a patient who starts asking questions about a mammogram in an angry voice. The clinician guesses that what’s important to her is autonomy. He might ask, “Would it help to know that you really have a choice in whether to undergo this test?” In this example, the clinician translates the word “autonomy” into the word “choice” and then uses it in conversation.

AFFECTION	Do you want to be close?
APPRECIATION	Do you want to know that what you did is important?
AUTHENTICITY	Do you want to say what’s really in your heart?
AUTONOMY	Would you like to choose what to do?
CELEBRATION	Would you like to show how happy you feel?
COMPANIONSHIP	Would you like some company?
COMPASSION	Do you want to be heard about how special or hard this is for you?
COMPETENCE	Do you want to really know, or show me, that you can do it?
CONSISTENCY	Do you want to be able to count on this happening the same way each time?
CONTRIBUTION	Would you like to be able to help or share?
COOPERATION	Do you want everyone to work together as a team?
CREATIVITY	Do you want to explore what you can create?
EFFECTIVENESS	Do you want to be able to make things change?
EQUALITY	Do you want the same for everyone?
FREEDOM	Do you want to decide, by yourself, what is good for you?
HONESTY	Do you want to trust that what is said is true?
IDENTITY	Do you want to find out what you like? Do you want to try different things and have the freedom to decide in another way if you didn’t feel comfortable with it?
INCLUSION	Would you like to be a part of what’s happening?
MOURNING	Do you want to show how sad you feel?
MUTUALITY	Do you want to share the same ideas or beliefs?
ORDER	Do you want to find things easily? Do you want to know what’s going on around you?
PARTICIPATION	Do you want to have a say in what we do?
PEACE	Do you want quiet? ...or calm? ...or an easy time?
PURPOSE	Would you like something important to do?
RECREATION	Do you want to have any time without a schedule?
SECURITY	Do you want to know that you’re going to be ok?
STIMULATION	Are you looking for fun, or for something new to do?

Adapted with the permission of the creator:

Jeff Brown, Certified Trainer with the Center for Nonviolent Communication ([www.evolutionaryorganizations.org](http://www.evolutionaryorganizations.org))

(Originally created and conceived by Marshall Rosenberg)

[The Center for Nonviolent Communication](http://www.ccnv.org)

With contributions from:

Tom Carlisi, Compassionate/Nonviolent Communication Coach & Trainer ([www.carlisiandassociates.com](http://www.carlisiandassociates.com))

[Compassionate Communication Center of Ohio](http://www.compassionatecommunication.org)

Source: AMA. *Practice transformation series: listening with empathy*. 2016.

# Pretest Probability of Lyme Disease

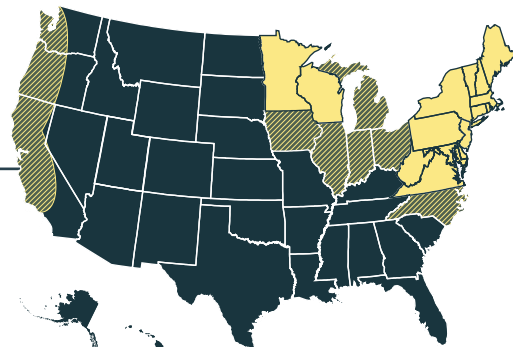
Pretest probability can help inform when testing for Lyme disease is most helpful.



## Clinical Questions to Determine Pretest Probability

### 1 Has the patient been in an area where Lyme disease is common?

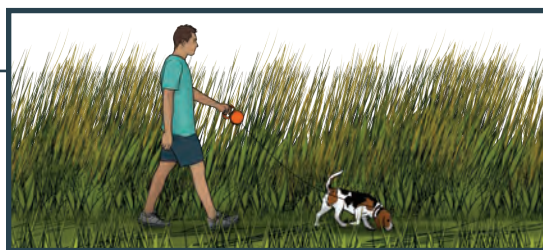
Areas where Lyme disease is common include the Northeast, the Mid-Atlantic, and the Upper Midwest (especially Minnesota and Wisconsin). Some states that neighbor these areas have emerging Lyme disease, with increasing numbers in recent years. Some local transmission of Lyme disease also occurs in areas of the Pacific coast, like northern California and some parts of western Washington and Oregon.



Yellow: Areas with HIGH INCIDENCE of Lyme disease  
Hatched: Some local transmission of Lyme disease

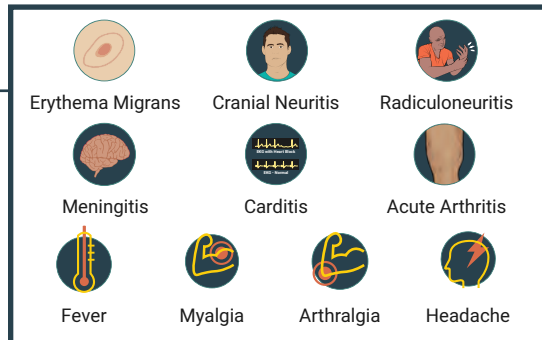
### 2 Was the patient likely exposed to ticks?

Exposure to ticks might occur during outdoor activities in places where ticks live, or through exposure to pets that spend time outdoors. It's important to remember that up to half of all people bitten by a tick do not recall the bite. Patients who are active outdoors have a higher probability of exposure.



### 3 Does the patient have symptoms characteristic of Lyme disease?

Manifestations of Lyme disease can include erythema migrans, cranial neuritis, radiculoneuritis, meningitis, carditis, and acute arthritis. Lyme disease can also present like an acute flu-like syndrome with fever, myalgia, arthralgia, and headache.



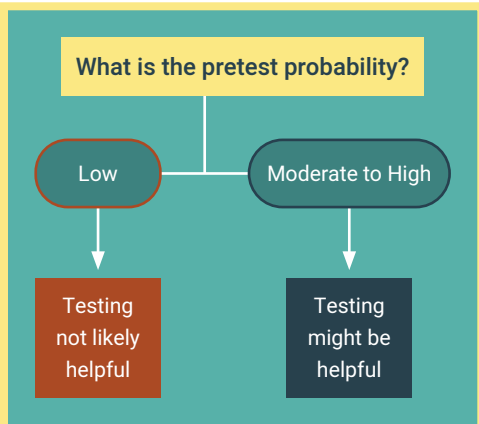
Answers to these questions help a healthcare provider determine the pretest probability that a patient has Lyme disease.

Pretest probability for Lyme disease is **moderate to high** when the following conditions are met:

- The patient has been in an area where Lyme disease is common. **AND**
- The patient had possible exposure to ticks. **AND**
- The patient has symptoms characteristic of Lyme disease.

Pretest probability for Lyme disease is **lower** when **ANY** of these conditions are met:

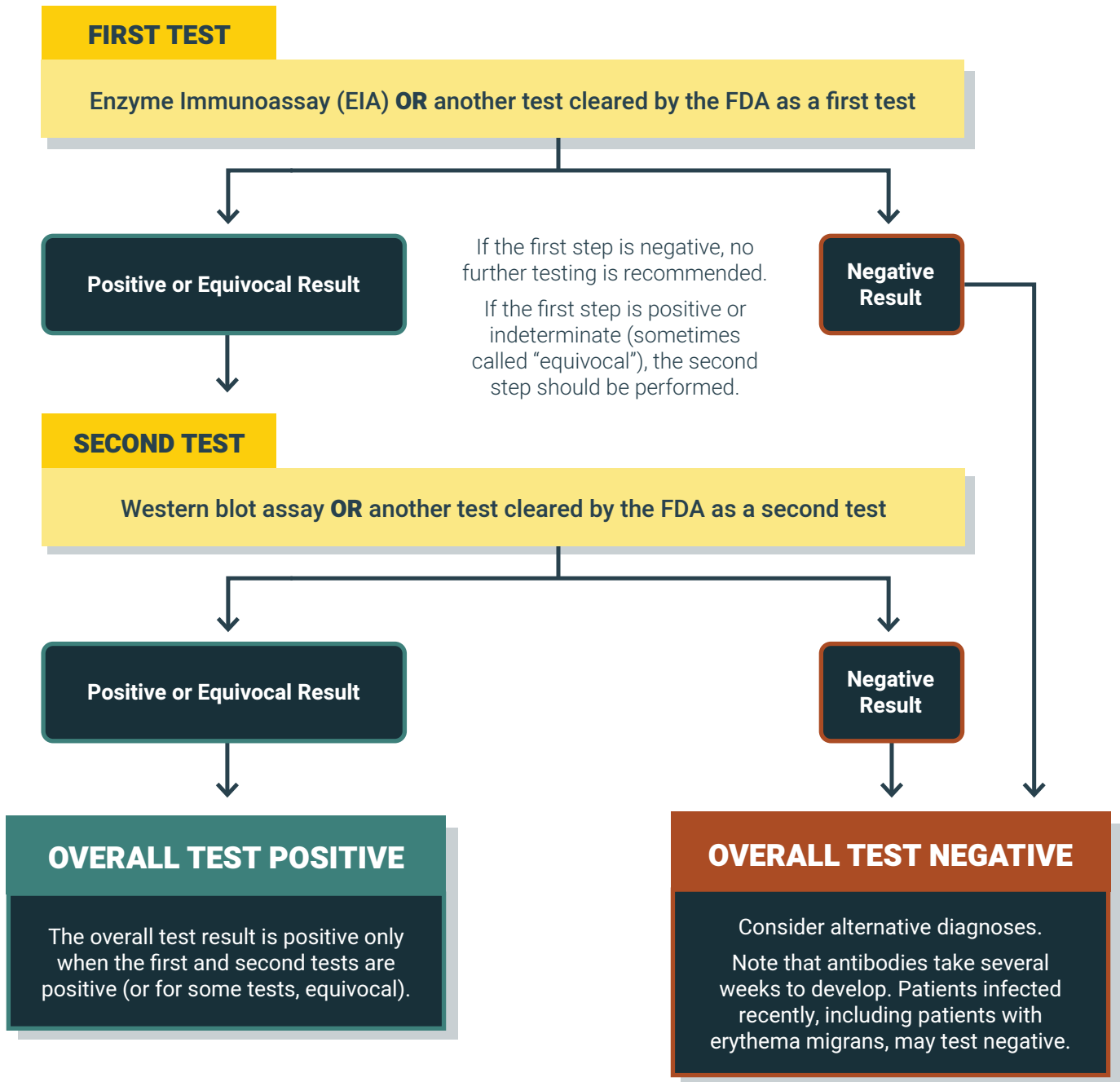
1. The patient has not been in an area where Lyme disease is common. **OR**
2. The patient had no possible exposure to ticks. **OR**
3. The patient is asymptomatic or has nonspecific symptoms that are not characteristic of Lyme disease.





# Lyme Disease Serologic Testing

CDC recommends a two-step process using Food and Drug Administration (FDA)-cleared serologic tests for Lyme disease. Both steps are required and can be performed on the same blood sample.



CDC recommends using only FDA-cleared assays performed in CLIA-certified laboratories. Some laboratories, including some with CLIA-certification, offer laboratory-developed tests that are not FDA-cleared. CDC recommends against using these tests as there is less assurance regarding their clinical accuracy.

Lyme disease serologic testing is recommended only for patients with moderate to high pretest probability (i.e., patients with symptoms characteristic of Lyme disease and with possible exposure to ticks in areas where Lyme disease is common). Patients with low pretest probability for Lyme disease have a higher risk of a false positive test result.

