



# Talking to Patients About Long COVID:

## GUIDANCE ON SHARED DECISION MAKING

Long COVID is a complex and variable chronic condition that can persist for weeks, months or longer after the acute phase of COVID-19 infection.<sup>1</sup> Symptoms range from mild to debilitating and often fluctuate over time. Family physicians are critical in helping patients manage and coordinate the care for this condition through shared decision making with patients and other specialists by encouraging open dialogue and aligning treatment options with patients' values and goals.<sup>2</sup>

The guidance in this document uses the [Agency for Healthcare Research and Quality's SHARE approach \(Seek, Help, Assess, Reach and Evaluate\)](#) to facilitate effective communication and decision making with patients experiencing long COVID.<sup>3</sup>

### The SHARE Approach

#### STEP 1: SEEK PATIENT PARTICIPATION

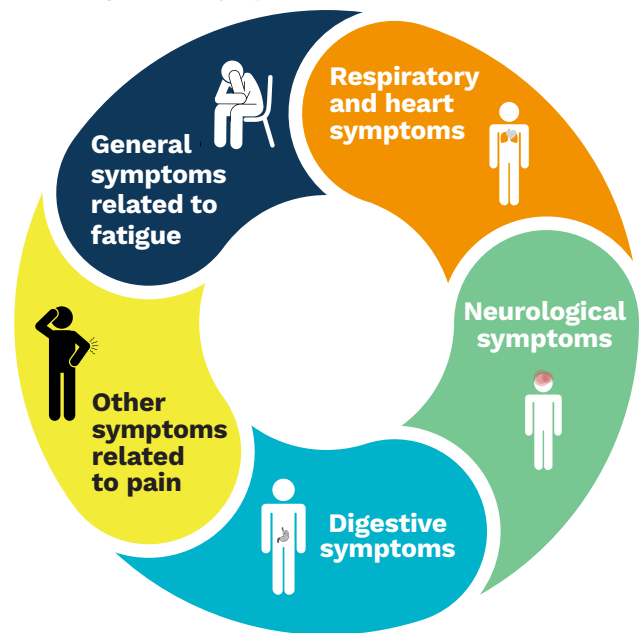
- **Establish Rapport:** Begin by creating a comfortable environment for open discussion. Ask patients about their primary symptoms and how these impact their quality of life.
- **Discuss the Complexity of Long COVID:** Explain that long COVID affects everyone differently, with symptoms ranging from fatigue to cognitive dysfunction. Variability and fluctuation of symptoms over time are common.
- **Acknowledge the Patient's Experience:** Ask patients about their health history (i.e., COVID severity, previous treatments, recovery milestones) and how their symptoms impact their daily life, work and relationships.

Conversation starters and/or questions to ask patients:

- "Which symptoms bother you most, and how have they changed over time?"
- "What are your biggest concerns about managing long COVID?"
- "How do you feel about your ability to perform daily activities right now?"

Multiple organ systems can be affected by long COVID and cause various symptoms in different body parts, as illustrated in Figure 1. Managing and coordinating the care of patients with long COVID is a skill that family physicians are trained to provide.

Figure 1. Long COVID Symptoms<sup>4</sup>



Created from information from Centers for Disease Control and Prevention, Signs and Symptoms of Long COVID, [www.cdc.gov/covid/long-term-effects/long-covid-signs-symptoms.html](https://www.cdc.gov/covid/long-term-effects/long-covid-signs-symptoms.html).

#### STEP 2: HELP PATIENTS EXPLORE AND COMPARE TREATMENT OPTIONS

- **Discuss Symptom Management:**
  - Breathing exercises and the [4 P's \(Prioritize, Plan, Pace and Position\) of energy conservation](#) are common ways to manage symptoms, including fatigue and post-exertional malaise.<sup>5</sup>
  - Explore treatment options for specific symptoms (e.g., cognitive rehabilitation for brain fog, physical therapy for muscle weakness, medications for pain or sleep disturbances).<sup>6</sup>

- Highlight the importance of tracking symptoms using diaries/journals<sup>7</sup> or symptom tracking apps, such as Visible: Pacing for illness.<sup>8</sup>

- **Discuss Multidisciplinary Care Needs:**

- Explain the potential need for referrals to other specialists (e.g., pulmonologists, neurologists, cardiologists, psychologists).<sup>9</sup>
- Family physicians are integral in the initial evaluation and ongoing care management. Let patients know you'll be there to help them by coordinating and consulting with other specialists.

- **Mental Health:**

- Highlight the psychosocial impact associated with long COVID, including the high prevalence of anxiety, depression and brain fog.<sup>2</sup>
- Discuss options for psychological support and available treatments (e.g., therapy, medications), if indicated.

- **Telehealth Options:**

- Telehealth offers a convenient care option for patients with mobility issues or who reside in medically underserved areas.<sup>10</sup> Explore opportunities for the patient to meet virtually with other specialists and ensure they understand the technology requirements and resources available to them.

- **Disability Accommodations:**

- Under guidance from the U.S. Department of Health and Human Services, long COVID may qualify as a disability under the Americans with Disabilities Act.<sup>11</sup>
- Discuss the potential need for school or workplace accommodations (e.g., reduced hours, remote work) or applying for disability benefits if long COVID affects daily functioning.

Conversation starters and/or questions to ask patients:

- "I understand what you're experiencing can be overwhelming. Let's talk about your specific symptoms and how we can work together to manage them."
- "Would you like to explore options for mental health support, including therapy or medication?"
- "How do you feel about telehealth appointments for ongoing management or specialist consultations?"

### STEP 3: ASSESS PATIENT VALUES AND PREFERENCES

- **Empower Patients to Share Their Priorities:** Long COVID can have diverse impacts, so it's important to understand what matters most to patients regarding their health and treatment.

- **Tailor Options to Patient Goals:**

- Emphasize individualized care plans that align with the patient's values, goals and preferences.
- Consider symptom-specific pathways, including for:
  - > Physical symptoms: discuss activity limitations and the importance of pacing to avoid exacerbations.<sup>12,13</sup>
  - > Cognitive symptoms: assess how the patient feels about cognitive rehabilitation and the role of medications.<sup>6</sup>

Conversation starters and/or questions to ask patients:

- "Every person is different, and treatment can be different for different people. Let's explore some of your treatment options."
- "What are your most important goals for managing your long-COVID symptoms?"

### STEP 4: REACH A DECISION WITH THE PATIENT

- **Collaborate on a Care Plan:** Work with the patient to create a personalized care plan that includes symptom management strategies, referrals, follow-up visits and mental health support.
- **Set Goals Together:** Create clear, SMART (Specific, Measurable, Achievable, Realistic and Time-bound) goals with the patient. Ensure these goals reflect their priorities and can be adjusted as symptoms change.

Conversation starters and/or questions to ask patients:

- "Let's talk about making a gradual return-to-activity plan for your fatigue."
- "Let's schedule a follow-up appointment in a month to see how things are progressing and adjust the plan, if needed."

**STEP 5: EVALUATE THE PATIENT'S DECISION**

- **Monitor Progress:** Emphasize the importance of regular follow-up visits to adjust the plan based on symptom progression or new challenges.
- **Adapt the Plan:** The relapsing and remitting nature of long COVID means that treatment plans may need to be adjusted periodically.
- **Empower the Patient:** Celebrate progress and provide encouragement for continued efforts.

Conversation starters and/or questions to ask patients:

- “How have you been feeling since we started your care plan?”
- “Are there any new symptoms or challenges you’d like to discuss?”
- “Let’s check in at your next appointment to see if any adjustments are needed.”

**Additional Long COVID Resources**

American Academy of Family Physicians – [Long COVID](#)

Centers for Disease Control and Prevention – [Long COVID Basics](#)

U.S. Department of Health and Human Services – [Long COVID](#)

National Institutes of Health – [RECOVER: Researching COVID to Enhance Recovery](#)

**References**

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