PERSONALIZE YOUR APPROACH TO CIDP CARE

If you've been diagnosed with **chronic inflammatory demyelinating polyneuropathy (CIDP)**, then you've likely already entered the world of specialist appointments, nerve conduction studies, medical terminology, symptom trackers, and treatment options. This information can feel overwhelming for anyone faced with the diagnosis of a rare auto-immune inflammatory disorder.

The purpose of this guide is to help you prepare for your next specialist appointment so you can become a confident self-advocate for your care and to ensure you get the information you need to help improve your quality of life.

HOW HAVE YOU BEEN FEELING RECENTLY?

The symptoms of CIDP vary widely between individuals. Symptoms can also disappear and recur over extended periods of time. These fluctuations can make it difficult to keep track of them or remember to mention them to their health care team during appointments.

Whether you're on treatment or not, it's important to inform your health care team about any recent symptoms. Use the following section to note any symptoms you've been experiencing **since the last time you saw your neurologist:**

Symptoms	How often?	When?	How long did it last?	Other notes
Fatigue				
Sensory disturbances *(e.g., numbness and tingling)*				
Pain				
Loss of balance				
Weakness in the arms or legs				
Mood changes *(e.g. feeling anxious or depressed, feelings of isolation)*				
Other? *(e.g., difficulty sensing temperature or vibration, reduced awareness of foot position)*				

HOW HAS CIDP IMPACTED YOUR LIFE RECENTLY?

It's helpful to reflect on how CIDP has been affecting your quality of life so you can give your health care team a fuller picture of your health and symptoms. With this information, they'll be better equipped to recommend the best possible approach for your care.

Reflect on the following prompts and discuss your answers with your health care team:

Are you still able to work? ☐ Yes ☐ No

Have you had to miss work recently due to CIDP-related appointments? ☐ Yes ☐ No

Have your CIDP symptoms been affecting your performance at work? ☐ Yes ☐ No

Have you recently started using any new adaptive devices? ☐ Yes ☐ No

Do your CIDP symptoms impact your ability to perform everyday tasks? ☐ Yes ☐ No

Have you experienced any changes in your mood recently? (e.g. depression, anxiety, etc.) ☐ Yes ☐ No

Have you found it difficult to manage your time when experiencing CIDP flares? ☐ Yes ☐ No

Are you satisfied with your current treatment plan? ☐ Yes ☐ No

What things do you do differently now compared with two or three years ago?

What do you avoid because it feels harder or riskier?

What would you notice first if your treatment stopped working?

What have you adapted to, rather than recovered from?

Are you experiencing any challenges related to side effects from your current treatment?

Other notes:

BECOME AN ACTIVE PARTICIPANT IN YOUR CARE

Now that you've documented your symptoms and reflected on how CIDP has affected your quality of life, you're better prepared to discuss the next steps in your care with your specialist.

Consider discussing the following questions with your specialist:

- If I'm not seeing immediate improvement in my symptoms while on treatment, should I be concerned?
- What other modifications, such as lifestyle, nutrition, or activity, do you recommend for my CIDP?
- What proactive strategies should I consider during the long-term management of CIDP?
- Is there any new research or innovation in the CIDP space that I should be aware of?
- Do you have any advice for communicating what I'm going through with my family, friends, or workplace?

Everyone's journey with CIDP is unique. That's why it's so important to take an active role in your disease management. Educate yourself about your condition and the options available to you, and have informed conversations with your health care team. A better quality of life may be possible, but it will take collaborative and meaningful action to get there.

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