

My CIDP Journey

Observations and insights

Living with chronic inflammatory demyelinating polyneuropathy (CIDP) can feel overwhelming, but you are not alone. We followed 3 people with CIDP—**Mark, Maddy, and Christina**—to better understand their CIDP experiences.

Our participants described their journey, including challenges they faced and triumphs they achieved.

It is all part of the broader educational support that you can gain from the CIDP community.

FOR ADDITIONAL INFORMATION ON CIDP, TALK TO YOUR DOCTOR.



Everyone’s experience with CIDP is different. Our participants described their journey from symptom onset through diagnosis to living every day with CIDP.



Invisible. Invalidated. Judged.
Explaining the burden of CIDP

Our participants described the frustration of having their struggles not only minimized but dismissed by friends, family, and even strangers.

How others react	How it actually feels
Resenting us for taking the better parking spot or getting extra services because we seem fine	Agonizing pain with every step
Thinking we’re slow because it takes us a minute to process information when we’re tired	Confusing and disorienting, moving from thing to thing with trouble concentrating or remembering
Questioning why we are always so tired and unable to do things	Weighted down
Judging us for not having fun or wanting to keep to ourselves	Like an internal thunderstorm with lots of lightning

This is not a comprehensive list of all possible CIDP symptoms. Be sure to talk to your doctor for more information.



On the value of accepting help

From Maddy:
“We are better at hiding how we feel, because we feel as if we already are too much for our support system by asking for help with the simple things. I had to learn how to be vulnerable, and to accept help. I had to learn to put my pride to the side.”

From Mark:
“I have an amazing support team in the form of my wife. She has always been there for me.”

From Christina:
“I have learned to be more demanding about the help I need from my family and insistent on when I need to rest. In the past, I’d pop up to help my husband find things in the fridge. Now, I tell him he needs to look harder.”



Seeking a diagnosis
Listen to your body

It can be both physically and emotionally draining to navigate the unknown, especially with symptoms that may become increasingly debilitating. Know that your experience is real and valid. Insist on transparent, open conversations with both your care teams and your caregivers.



MADDY
Age: Late 20s
Diagnosis: >10 years ago
Persistent Symptoms: Locked pinky, tremors, lack of coordination, tingling and numbness in fingers
Symptom Severity: Mild to Moderate



Maddy’s outlook:
“I say living a life with me is going into the unknown, but that stands true for every single person, healthy or not. Loving yourself—that’s what makes the unknown worth it!”



Maddy’s path:
“Every single person with CIDP has their own timeline. So, it isn’t certain whether functions, muscles, or reflexes will indeed return.”



Learning to live with CIDP

Speak up—and be honest

As you grow more familiar with CIDP, your management choices may change. Make sure that your care team clearly understands what you are experiencing, how managing your CIDP impacts your life, and what would be helpful to change. You are already resourceful. Be vocal, too.



MARK
Age: Early 60s
Diagnosis: 5 years ago
Persistent Symptoms: Tingling, leg weakness, pain and sensitivity
Symptom Severity: Mild

Mark was on a holiday when he first began experiencing tingling and weakness. He collapsed in the airport. He was misdiagnosed with Guillain-Barré syndrome twice, before receiving the correct diagnosis of CIDP.



Mark describes:

“When I was diagnosed, I knew nothing about CIDP. I was now suffering from my third attack, which was by far the worst one. As my neurologist was explaining it to me, it felt like I had finally gotten the answer.”

Mark notes:

“I have a great relationship with my neurologist. We had a connection right away from the first time I met him.”



Partner with your care team to create the right management plan for you

Your CIDP is not like anyone else's. Work with your care team to develop a management plan that considers the way CIDP affects you, your lifestyle, and your personal goals.

Discussing these questions may guide your expectations as you learn to live with and manage CIDP

- How might my symptoms change over time?
- How will CIDP impact my day-to-day life?
- What are the risks of CIDP?
- What can I expect to achieve from managing CIDP?
- Can my management plan fit into my lifestyle?
- Where can I go for physical or occupational therapy?

Visit knowingpn.com/cidp/care-team to learn more about partnering with your care team on your management plan



Ongoing CIDP management

Put self-care first

There are many ways to help yourself—both by being independent and by accepting help from others. After all, taking on too much can be stressful—and stress causes flare-ups. You are surrounded by support. Accept it. Then you can simply focus on yourself as a person, not as a person with CIDP.



ABOUT CHRISTINA

Age: Mid 50s

Diagnosis: 6 years ago

Persistent Symptoms: Balance issues, fatigue, loss of fine motor skills, tremors

Symptom Severity: Moderate

A former hospital chief operating officer, Christina first experienced tingling, sensitivity, and numbness—quickly followed by fatigue, brain fog, and dexterity issues. She was misdiagnosed with idiopathic peripheral neuropathy and Guillain-Barré syndrome, then properly diagnosed with CIDP.



Christina observes:

“Stress is my enemy, and it can be as simple as going to a new facility to get your mammogram...the tremors also get much worse.”



Christina notes:

“The support groups offer practical advice, such as shoe choices, canes, and tips for activities of daily living.”



Getting creative

Adaptive tips & techniques

Home modifications

- “Smart home” devices
- Flat, rocker-style light switches
- Keypad locks
- Easy-open containers
- Adjustable bed
- Foot tent
- Walk-in shower
- Shower chair

Personal care

- Toothbrush with grooved handle
- Electric body brush
- Pump dispensers
- Button-activated pill dispenser
- Pull-on, elasticized clothes
- Velcro-closed shoes

Helpful tools

- Zip ties as levers on zippers
- Voice-to-text software
- Steering-wheel padding
- Foam grip handle



Join our Facebook community at facebook.com/takechargeofyourcidp
Share your experiences and insights living with CIDP

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Looking ahead

No matter where you are in your CIDP journey,
you are your own best advocate.



Listen to your body.
Only you know how you really feel.



Speak up and be honest.
Partner with your care team to get a management plan that fits your needs and your life.



Put self-care first.
That includes accepting help when you need it.

Interested in inspiring others with your CIDP story?
Sign up to share your experience.