ME AND MY CIDP

UNDERSTANDING CHRONIC INFLAMMATORY DEMYELINATING POLYNEUROPATHY (CIDP)

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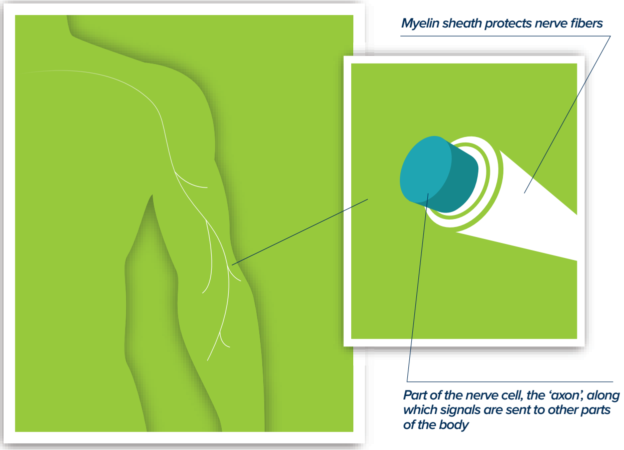
MY HEALTHCARE PROVIDER DIAGNOSED ME WITH CIDP.

How do I explain my condition to friends and family?

CIDP is an autoimmune disorder in which the body's immune system attacks healthy tissue in the peripheral nervous system. This results in impaired sensory function and weakness in the legs and arms.[1]

CIDP is caused by damage to the "myelin sheath," which is the fatty covering that protects nerve fibers.



Due to this damage, electrical impulses are slowed or lost, and messages transmitted from the brain are disrupted and may not make it to their final destination—generally, the nerve cells of the arms and legs.

The diagnosis of CIDP is generally made through a clinical examination with a neurologist. The likelihood of disease progression is high with CIDP so diagnosis and early treatment are important.

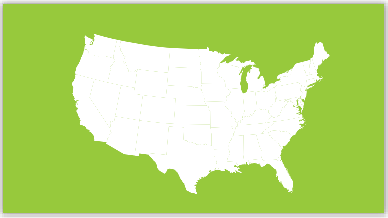
I'M TOLD CIDP IS NOT VERY COMMON.

How many people have it?

CIDP is thought to affect up to 8 out of every 100,000 people worldwide[2] and up to 40,000 people in the US.[3] The disorder can start at any age and occurs twice as often in males as in females.[3]

8 out of every 100,000 people in the world with CIDP

40,000 people in the US with CIDP



2x more men than women

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KNOWLEDGE IS POWER

What happens after diagnosis of CIDP?

You were likely diagnosed with CIDP by a neurologist. Many patients with CIDP respond well to therapy when treated early. Therapies are designed to limit the damage to peripheral nerves, help improve physical functioning, reduce symptoms and, if possible, maintain long-term "remission," when symptoms lessen or disappear.[4]

There are three commonly used treatments for CIDP[4,5]:

Immune Globulin Intravenous (IGIV): Approved by the FDA for the treatment of CIDP, IGIV contains naturally occurring antibodies obtained from healthy volunteers. IGIV is given through a vein ("intravenous") over the course of several hours per infusion.

Corticosteroids: These are similar to naturally occurring anti-inflammatory hormones made by the body. Usually taken by mouth, corticosteroids help improve strength and are inexpensive. However, side effects can limit long-term use. Examples include prednisone and prednisolone.

Plasma Exchange (PE) or Plasmapheresis (PLEX): These are processes in which some of the patient's blood is removed and the blood cells returned without the liquid plasma portion of the patient's blood. It may work by removing harmful antibodies contained in the plasma.

IGIV THERAPY

How do I prepare?

If your healthcare provider prescribes IGIV treatment for you, you will be instructed as to where your treatment will be given (most likely at an infusion suite or at your healthcare provider's office).

Here are some helpful infusion tips[6]:

- Drink plenty of water, juice and power drinks the day before your infusion. It is important that you are well hydrated. Stay away from coffee or alcohol as they can dehydrate the body

  NOTE: If you have a heart or kidney condition that prevents you from drinking large amounts of fluid, discuss a hydration plan with your healthcare provider
- Take any pre-medications your healthcare provider may have instructed you to take
- If you have a fear of needles or a history of difficult IV starts, ask your healthcare provider if using a numbing cream might be a good idea for you
- Bring something to keep you occupied—a book/magazine or watch a movie
- Notify the staff immediately if you feel pain or discomfort at any time
- Tell your nurse or healthcare provider about any adverse reactions, side effects, or sickness you experience during your infusion or have experienced since your last visit

HELPFUL CIDP RESOURCES

Where can I get more information?

The following organizations can help you and your family learn more about CIDP:

GBS | CIDP Foundation International
www.gbs-cidp.org
Information and resources on Guillain-Barré syndrome (GBS), chronic inflammatory demyelinating polyneuropathy (CIDP), and related syndromes such as multifocal motor neuropathy (MMN).

National Institutes of Health (NIH)
www.ninds.nih.gov/disorders/cidp/cidp.htm
Definitions, treatments, prognosis, clinical trials information, patient organizations, and related publications.

National Organization for Rare Disorders (NORD)
www.rarediseases.org
A non-profit organization which provides information, programs and services for thousands of rare medical conditions.

IG Living
www.igliving.com
Resources that can help to solve the acute problems of availability, affordability and safety of IG products.

FINANCIAL ASSISTANCE

Is there help available?

The following resources are available to help patients and their families access and pay for healthcare services, utilities, medications and insurance information:

The Assistance Fund
www.tafcares.org
855-845-3663
Financial support to patients who are critically or chronically ill and can't afford their medications.

Families USA
www.familiesusa.org
202-628-3030
State and national resources in finding high-quality, affordable health- and long-term care for all Americans.

HealthWell Foundation
www.healthwellfoundation.org
800-675-8416
Assists underinsured patients with chronic or life-altering diseases by reducing financial barriers.

The Medicine Program
www.themedicineprogram.com
Helps individuals and families get access to up to 2,500 prescription medications for free or nearly free of charge through Patient Assistance Programs (PAPs).

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For further information or questions about CIDP, or to discuss treatment options, contact your healthcare provider.

References: 1. Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) Information Page. National Institute of Neurological Disorders and Stroke Website. https://www.ninds.nih.gov/Disorders/All-Disorders/Chronic-Inflammatory-Demyelinating-Polyneuropathy-CIDP-Information-Page. Accessed May 12, 2021. **2.** Bright RJ, Wilkinson J, Coventry BJ. *BMC Neurol.* 2014;14:26. **3.** Steinberg JS, Koski CL. Guillain-Barré syndrome, CIDP and variants. An overview for the layperson. 10th ed. 2010. GBS | CIDP Foundation International Website. https://www.gbs-cidp.org/wp-content/uploads/2014/09/Overview-for-the-Layperson-ENGLISH.pdf. Accessed May 12, 2021. **4.** Gorson KC. *Ther Adv Neurol Disord.* 2012;5(6):359–373. **5.** Recently Diagnosed with CIDP. GBS | CIDP Foundation International Website. https://www.gbs-cidp.org/cidp/all-about-cidp/. Accessed May 12, 2021. **6.** Richlin J. IVIG Infusion Guide: Tips to Make Infusion Days Easier. IGLiving Website. http://www.igliving.com/magazine/articles/IGL_2006-10_AR_IVIG- Infusion-Guide-Tips-to-Make-Infusion-Days-Easier.pdf. Accessed May 12, 2021.

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