

For patients with **chronic inflammatory demyelinating polyneuropathy (CIDP)** who are preparing to start intravenous immunoglobulin (IVIG) therapy

# What to Know About IVIG Therapy

This guide is designed to help you prepare for your conversations with your healthcare provider.



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# WHAT TO KNOW ABOUT STARTING IVIG THERAPY FOR CIDP

If you've been diagnosed with CIDP and your doctor has recommended IVIG therapy, this guide gives an overview of topics your healthcare provider may discuss with you. You can review this before your visit and make notes of anything you want to bring up.

## WHAT IS IVIG THERAPY?

IVIG stands for intravenous immune globulin. IG is comprised of proteins taken from purified human plasma and contains antibodies.

## WHY IS IVIG PRESCRIBED FOR CIDP?

When used for the treatment of CIDP, IVIG therapy is thought to block the immune and inflammatory processes that attack and destroy the covering of the nerves, known as the myelin sheath.\* In clinical studies, IVIG therapy has been shown to help improve the symptoms of CIDP and prevent relapse.

CIDP comes in many forms and can vary from person to person. Medical guidelines recommend IVIG, corticosteroids, or plasmapheresis as initial treatment for CIDP.

\*The way in which IVIG works in treatment of patients with CIDP is not completely understood.

## HOW IS IVIG GIVEN?

IVIG is infused through a vein, typically in the arm. It is administered by a healthcare professional and can be given at an infusion center, physician's office, or at home.

**My questions about IVIG and treatment:**

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## HOW IS IVIG DOSED?

Correct dosing of IVIG for the treatment of CIDP is important. Talk with your healthcare team to make sure you understand the dosing you will receive.

The **initial dose** (or loading dose) of IVIG is a higher dose that is often split up over several days.

**Subsequent doses** (or maintenance doses) of IVIG are lower doses that usually take a few hours. Maintenance doses are given on a set schedule.

## WHAT TO EXPECT WITH STARTING IVIG INFUSIONS

Your healthcare team will give you instructions on how to prepare for your treatment.

- Your healthcare provider may recommend that you increase your fluid intake the day before, during, and after your infusion
- Some patients may experience side effects when starting IVIG. Pre-medication or adjusting the infusion rate may help. See page 7 for a list of possible side effects
- If you receive IVIG treatment at home, a specialty pharmacy will ship the medicine and supplies to you and give instructions on storage

**My questions about starting IVIG:**

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## COST AND COVERAGE

Your healthcare team will work with your insurance plan to find out your coverage and submit documentation that may be required. Manufacturers of IVIG may offer copay assistance programs and other financial assistance programs for eligible patients. If you receive IVIG treatment at home, be sure to ask your specialty pharmacy about financial assistance that may be available.

**My insurance questions:**

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# QUESTIONS YOUR PROVIDER MAY ASK YOU

As you prepare to start IVIG therapy, your healthcare provider will work with you to ensure you're getting the most from treatment. Here are some topics your provider may discuss with you.

## WHAT ARE YOUR GOALS FOR TREATMENT?

It's important to talk with your healthcare provider to establish goals for your care. Working together helps your provider understand what's important to you and what you want from treatment. It also helps you plan for other aspects of your care, such as nutrition, physical or occupational therapy, and other support:

### Short-term:

- Feeling better
- Knowing what to expect from treatment

### Long-term:

- Improving mobility
- Increasing independence
- Better health-related quality of life

**My questions about goals:**

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## ARE YOU EXPERIENCING SIDE EFFECTS?

Side effects can occur, especially when first starting IVIG therapy or changing IVIG brands. Fortunately, most side effects are mild and of short duration. Pre-medication or adjusting the infusion rate may help. It's important to speak with your healthcare provider about any side effects.

- Headache
- Feeling tired
- Nausea
- Changes in blood pressure
- Muscle aches
- Joint stiffness
- Hives
- Itching rash
- Low-grade fever
- Chills
- Chest discomfort
- Increased heart rate



**Circle any issues you want to discuss**

## ARE YOU EXPERIENCING ANY CHALLENGES WITH YOUR IVIG THERAPY?

Sometimes you may have issues with your therapy. Talk with your provider about any difficulties you encounter or any changes that could improve your treatment plan, such as:

- Location of infusions (home, infusion clinic, or hospital)
- Scheduling for infusions (time of day or day of the week)
- Issues with your specialty pharmacy and/or infusion clinic
- Temporary changes for short-term situations (such as a medical procedure)
- Managing side effects (infusion site or systemic side effects)



**Circle any issues you want to discuss**

## HOW IS YOUR TREATMENT WORKING?

After starting IVIG, your provider will evaluate your response to treatment during follow-up visits.

Your provider may perform a neurological examination including testing your strength, balance, sensation, and reflexes. You can discuss changes in your symptoms since the last visit. This may help in assessing and guiding your treatment.

Treatment can take time to work, and every patient is different. So it's important for your provider to understand how you are improving. Keep notes each week about your sensory symptoms, strength, movement, and ability to do daily tasks.

- ☐ **Start a log to track your symptoms and how you're feeling. Share the results with your healthcare provider.**

**Other questions you may have:**

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## QUESTIONS FOR YOUR SPECIALTY PHARMACY OR INFUSION CLINIC

If you have questions for your specialty pharmacy or infusion clinic, don't hesitate to reach out to them. They are another partner in your care. You can also reach out to your healthcare provider.

### My specialty pharmacy:

Name: \_\_\_\_\_

\_\_\_\_\_

Phone: \_\_\_\_\_

### My infusion clinic:

Name: \_\_\_\_\_

\_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Phone: \_\_\_\_\_

# WHAT TO DO NEXT

Remember that your provider is your partner in care and is available to help you as you start your IVIG treatment journey. Here's what you can do:

- Keep track of your infusions, improvements, and challenges
- Share what you track with your provider at each visit
- Reach out with questions between visits to continue the conversation



There are many options available for IVIG treatment. Talk with your healthcare provider about which is best for you. Scan the code to learn more about one treatment option from Grifols.

## Additional resources and support

The advocacy organizations below can connect you to additional educational resources about CIDP.

- GBS | CIDP Foundation International. Visit [www.gbs-cidp.org/cidp](http://www.gbs-cidp.org/cidp) for more information
- Foundation for Peripheral Neuropathy. Visit [www.foundationforpn.org](http://www.foundationforpn.org) for more information

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