

Mobility Tips From the CIDP Community A collection of over 50 tips aimed to help people living with CIDP.

ShiningThroughCIDP.com

CIDP=chronic inflammatory demyelinating polyneuropathy.

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Helping You Feel Empowered While On the Move With CIDP



When it comes to navigating mobility in daily life with CIDP, who better to get tips from than members of the community themselves. That's why Shining Through CIDP reached out to CIDP healthcare experts and people living with CIDP, like you!

Through this collaboration, we created this eBook featuring practical mobility tips from the CIDP community, for the CIDP community. Because CIDP affects everyone differently, this collection includes diverse insights and perspectives to help you find tips that resonate with your lifestyle.

We hope these tips help you get around and feel more empowered in your day-to-day life—whether it's when running errands, finishing work assignments, or simply navigating around your home.

Just remember, the tips provided in this eBook are not professional advice, nor are they a substitute for treatment or professional medical care. Please ensure that you talk with your healthcare team about which tips might be right for you.

Meet the Contributors

Shining Through CIDP partnered with CIDP community members, Shine Makers, and healthcare experts to compile this collection of mobility tips exclusively for you.

Shining Through CIDP Shine Makers



Wayne



Lynn



Rick



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Crystal



Amanda

CIDP Healthcare Experts



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This information is provided as educational information for patients. It does not replace a doctor's clinical judgment. Patients should speak with their doctor about their medical condition and any specific symptoms that they may be experiencing. Persons featured are paid contributors to Shining Through CIDP.

Moving About the Home

Your home should feel like a safe haven—where you feel most comfortable and capable. Adding some accessories or making modifications may help with your mobility and improve your sense of confidence as you go about your day.



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Making small adjustments can go a long way in making your space easier to navigate, and more importantly, give you the confidence to move around your home, promoting greater independence.

-Crystal, living with CIDP

-Dr. Kerri Waegelein, Physical Therapist

Created by the CIDP community with input from healthcare experts, these tips are designed to help make day-to-day activities more achievable and comfortable. It's important to consult with your healthcare team before making changes to your routine. Check with your doctor to make sure any activities you want to try are safe and suitable based on your physical condition, as well as where you are in your CIDP journey.

Little adjustments around the home

Making small modifications, like rearranging furniture or removing throw rugs, may reduce the risk of tripping and can make a difference for improving movement throughout your home. Ask a friend or family member if you need help making adjustments to your home.



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I rearranged my furniture in my house, making sure I have something to hold onto as I navigate through my daily routine."

-Shining Through CIDP Community



Consider a lift chair

It can be challenging to get up and down stairs in a multistory home, so a lift chair can offer easy access to other levels.



Renovating your home to accommodate your current abilities can be stressful. There are many programs and grants that can help, if you qualify. Check out this resource for more.

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Try grip-assist doorknob covers

These can enable better grip and control when going in and out of rooms.

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Put rubber covers on all round doorknobs to make gripping easier. They're affordable and you can buy them online."

-Shining Through CIDP Community







Using a mobility scooter around your neighborhood or outside your home may be a helpful way to move around with more ease. If you're considering using a scooter, your doctor may be able to help you work with your health insurance to obtain coverage.

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Try a chair-height toilet or raised toilet seat

The elevated height of a chairheight toilet, also called a comfort toilet, provides accessibility and may help if you have difficulty when sitting down or standing up. Look into options to see what works best for you.







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Our luxurious bath towels and washcloths became too heavy for me. A friend suggested shopping at a dollar-type store for lightweight and smaller towel sets. Now, it is much easier to shower."

-Shining Through CIDP Community

Switch to lightweight towels

If you have difficulty gripping heavy towels, some stores have lightweight towels or smaller towel sets that could be easier to use in the bath.



Wayne's Tip

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I have thin bath mats in the bathroom, and I buy the rubber grips to keep them from sliding."

-*Wayne*, living with CIDP

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Consider these for your shower or bath:



Shower hose

Using a shower hose allows you to shower while seated, so you don't lose your balance, and it makes it easier for your caregiver to help you, if needed.

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shower."

Grab bars

If you find it difficult to keep your balance when showering or getting up from a shower chair, grab bars may offer additional support.

Shower chair

Standing in the shower can get tiring, and it may become challenging to keep your balance, so try using a shower chair to reduce exertion.



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I use grab bars in my shower and near the toilet. They are useful if my balance is not good or if I need to use extra strength to push up or sit down."

-Shining Through CIDP Community

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A shower hose reduces the

-Rick, living with CIDP

amount of turns during a

Cooking in the Kitchen

Whether you're finding it challenging to cook a meal or organize cabinet space for better accessibility, there are ways to improve your mobility in the kitchen with tools or simple modifications. That way, you can spend time savoring moments—and your favorite dishes—with loved ones.



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Consider these items when cooking:

<text>



Bonus Tip

Manual food choppers typically allow you to chop or mince food. If you do a lot of cooking at home, you may want to try an electric food chopper that has additional features such as mixing, puréeing, whipping, and emulsifying.

Automatic can or jar opener

With reduced dexterity, it can be difficult opening cans. Automatic can or jar openers may be an alternative that work with your symptoms.

Prep with pre-chopped produce

Buying pre-chopped produce can help you avoid injury and may save you time and energy.

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I usually get the veggies pre-chopped to avoid having to chop them myself. I also buy smaller grocery items, so I can open them and lift them, even if they cost more."

-*Lisa*, living with CIDP



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Try needle-nose pliers

With CIDP, it can be difficult to grip or open smaller objects in the kitchen due to numbness or weakness in your hands. Using needle-nose pliers can help with tasks such as opening a small bag or peeling a hard-to-open food package.



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I have lost strength in my hands, especially my thumbs. I use mini needle-nose pliers to grab/hold items, such as opening a ziplocked bag, pulling a tab, etc."

-Shining Through CIDP Community

Organize your cabinets for easier access

Sometimes trying to get items in and out of cabinets can be strenuous. Try rearranging your kitchen cabinets so heavier items are on the lower shelves and lighter items are on the higher shelves.



66 The dishes (

The dishes I use most are in easily-reached spaces."

Lisa's Tip







Morning Coffee:

Place your coffee pot next to the sink so that you can draw water and clean the pot without moving.

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Getting Dressed With Finesse

Start your day from a place of confidence. If you have a hard time getting dressed due to symptoms limiting your mobility, there are tips that may help you move with more ease when it comes to your morning routine.

-Michele, living with CIDP



Dr. Kerri's Tip

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Dressing can take up significant energy (especially after bathing). You can conserve energy by laying out clothes the night before and sitting down while dressing.

-Dr. Kerri Waegelein, Physical Therapist

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Consider adaptive clothing:



Gripper socks

Gripper socks are durable and have anti-slip support, which may help getting around the house without shoes a bit easier.

Shoes with straps

If you have difficulty with hand function, shoes with Velcro[®] straps may be a better option compared to shoes with laces.

Wheelchair pants

Wheelchair pants are specifically designed for your comfort and functionality, making it easier for you to put them on or take them off from a seated position. Some include convenient fasteners and openings to make it easier for you to use the bathroom.



I always wear shoes with a back because they provide me with better stability."

-Shining Through CIDP Community

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Try magnetic-clasp jewelry

Magnetic-clasp jewelry offers a simpler way to secure your favorite necklaces, bracelets, etc.





I have fine motor skill issues, so magnetic jewelry makes looking fashionable easier."

-Crystal, living with CIDP

Use a shoehorn

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Having difficulty bending down to put your shoes on? Try using a long-handled shoehorn to help make the task a bit easier.



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Getting the Job Done Workplace Tips

Wherever you may work, certain daily work tasks can be difficult to achieve with CIDP symptoms. Consider these tips that may help you move with ease when you're in your workflow.



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Focusing on making your activities of daily living easier allows you to focus more of your energy on the activities you would like to do each day.

-Dr. Jon Durrani, Neurologist

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-Scott, living with CIDP

Optimize your office setup:

Ergonomic chair

The type of office chair you have makes a difference. Ergonomic chairs are designed with your comfort in mind, which may help alleviate pain and allow you to be mobile in your office space.

Talk-to-text software

Talk-to-text software can provide a hands-free typing solution for people who have reduced dexterity in their hands. A dictation tool feature may already be installed on your computer or device.

Adjustable-height desk

Having an adjustable-height desk may allow you to find the position that works best for you. Changing positions throughout the day may help with chronic back pain from sitting for long periods of time.



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Need a break at work? Try these tips:



Squeeze the stress away

Using a stress ball or putty may help promote stress relief.



Fidget gadgets or finger stretchers

These engaging devices may help with attention and concentration.



Therapeutic massage devices

Massage devices can help relieve muscle tension from standing or sitting for long periods of time.



Make use of heating pads

If you experience peripheral neuropathy symptoms when sitting for long hours while working, heating pads may help relieve the pain. **66** I use large-grip pens when writing."

Bonus Tip

-Shining Through CIDP Community





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Setting an alarm every for 30 minutes or an hour for a "mini-movement" break is a great help. Whether it's a lap around your office, standing up, stretching your neck, or moving your arms overhead, take 1-3 minutes to move in opposition to the sitting posture.

-Dr. Kerri Waegelein, Physical Therapist

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On the Go Around Town

Want to meet up with friends, take care of errands, or explore town, but you're concerned your CIDP symptoms may get in the way? Consider using modifications and accessories that may help you move outside your home with more confidence.



When I go grocery shopping in the city, I use my own cart to help me transport my items to and from my house."

-Amanda, living with CIDP

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Get a car door assist handle

The looped striker plate protruding out of your car doorframe may be able to hold a car door assist handle. These often help provide grip and stability when getting in and out of the car. Make sure to follow product instructions.



Bonus Tip

Look up videos online for step-by-step instructions on how car door assist handles work.



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Use a portable step stool

A portable step stool may help make it easier for your caregiver to help you get in and out of taller vehicles and avoid falls.

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When getting in and out of a car... Grab that overhead handle and then swing your legs in one by one. On the way out, always remember to put both feet square on the ground to avoid falling."

-Shining Through CIDP Community



Consider applying for a disability parking permit

If you're able to drive or if your caregiver drives with you, this permit allows you to park closer to your destination to limit the amount of walking. The forms and criteria for disability parking permits differ by state. Look for more information on your state's DMV (Department of Motor Vehicles) website and talk to your doctor to help with the process.



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Whenever I go out, I use a cane. If I'm going to a supermarket, I'll park in the handicap zone and look for a shopping cart. I would rather take a shopping cart into the supermarket because it is easier to walk around."

-Shining Through CIDP Community

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Ready, Set, Go Essential Travel Tips

Want to take a trip, but not sure about the logistics because of your symptoms? Planning ahead and making some key adjustments can make your travel routine feel more comfortable.



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Traveling can be exhausting! Be mindful of your activities before and after a day of travel, and refer to the tips in this book to help conserve energy while on the move.

-Dr. Kerri Waegelein, Physical Therapist

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-*Martha*, ^{'I} living with CIDP



Book an aisle seat

When traveling by plane, bus, or train, try to book an aisle seat ahead of time. That way, you'll have easier access to the restrooms or exits nearby. Plus, you may have more legroom to stretch or get up to move around with more ease.

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Wear compression socks

If you're traveling for a long time, consider using compression socks, which may help reduce the risk of swelling during your journey.



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Getting an aisle seat is key, so I am not climbing over people. Compression socks keep my feet from swelling."





Too hot or too cold? Temperatures can fluctuate while traveling, so be prepared to travel with layers so you can add or remove them without needing to access your luggage. <u>Check out more travel tips from the</u> <u>GBS | CIDP Foundation International</u>.



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Request accommodations:

Wheelchair

Even if you don't typically use one, a wheelchair can make getting around a busy airport easier if you have difficulty walking. Look into requesting one in advance so it's ready to go when you arrive.

Electric cart

In addition to wheelchairs, some airports may offer electric carts or golf carts to help you get around. Upon arrival, contact the airport or airline personnel to request assistance.

Priority boarding

Avoid crowded lines and give yourself the time and space you need to settle into your seat without feeling rushed. This is especially helpful if you use a wheelchair or a cane, or need extra time when walking. Just ask the gate agent about medical pre-boarding or other necessary accommodations you may need!





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I always give myself extra time to get to the gate. I also carry a walking stick which demonstrates I may need assistance."





Bring on the beach

If your symptoms make a visit to the beach challenging, you and your caregiver may be able to rent a beach wheelchair. These are specialized chairs designed with larger wheels that can roll across the sand without sinking. Contact the beach or state park directly, and ask if they have beach wheelchairs available.

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Mindfulness in Motion Wellness & Self-Care Tips

There are many exercises and activities that can help you take care of your physical and mental well-being. Although you may have symptoms that impact your mobility, there are ways to navigate and modify your activities so that moving around may be easier for you. Remember to give yourself grace when it comes to any physical exercises, your mental well-being, or trying new things.



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Approach wellness activities, whether old or new, with a beginner's mindset. This keeps things fun, light-hearted, and allows for grace as you continue your journey.

-Dr. Kerri Waegelein, Physical Therapist

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Try chair yoga

Yoga may help with muscular strength and flexibility, and can help improve balance. Look into chair yoga or other yoga modification options that may be better suited for your specific CIDP symptoms.



Watch this guided video from the <u>GBS | CIDP Foundation International</u> for gentle chair yoga and mindfulness techniques.

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I do strengthening exercises for my legs with a yoga strap while lying down or in a recliner-and also upper body stretches."

-Shining Through CIDP Community

Consider physical exercise

If you would like to incorporate more activity into your routine, work with your healthcare team or a physical therapist to determine what kind of exercise is suitable for you.

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I have lost a lot of muscle in my right leg. What I have found to be helpful is doing leg exercises and climbing the stairs at my apartment complex."

-Shining Through CIDP Community

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Practice meditation

Get in tune with your body. Meditation may help with pain, anxiety, and general well-being. Speak to your doctor if you are considering meditation.



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For me, meditation is key in keeping my pain manageable."

-Dana, living with CIDP

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Use a walker for stability

If you have a walker that locks into place, you can use it to help you keep your balance during strength exercises. Regular lower body exercises seem to help me. I use a walker when I do leg exercises."

-Shining Through CIDP Community

Brush up on your art skills

For some, art can be an activity that may help with chronic pain. Plus, it may reduce stress by providing an outlet for creative expression.



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I draw and paint. It relaxes me and allows my creative side to shine through. It's therapy without it feeling like it."

-Shining Through CIDP Community

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Assistive Devices

There are many options when it comes to assistive devices that are designed to help with your day-to-day mobility. Consider these tips when discussing assistive devices with your healthcare team to find what may work for you.

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Assistive devices have made a world of difference for my patients, and we are always on the lookout for new and interesting devices that could help improve their quality of life."

-Dr. Jon Durrani, Neurologist

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CIDP

Use AFO (ankle or foot orthoses) braces

These devices help control the position and motion of your ankle or foot by providing support to your lower leg muscles, which may help with balance and foot drop.



Consider a medical alert bracelet

Wearing a medical alert bracelet can help you get the proper care you need in an emergency situation. It informs the medical professionals of your condition and any other critical medical information.

Types of walkers:

There are many options when it comes to which walker may work best for you.



Standard walkers

This type of walker provides the most stability; however, you have to lift it with every step.



2-wheel walkers

These have 2 wheels on the front, so you can move the device forward without lifting it.



Rollator walkers

Rollators typically have 4 wheels, with 2 swivel wheels on the front, making them easier to turn. Many have a cushioned seat with additional storage underneath.

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A lightweight rollator that I keep in the back of the car and another that I keep at home are the essential tools that keep me mobile without the risk of falling."

-Shining Through CIDP Community



Consider these features when researching a walker:

- Handle height and adjustability
- Collapsibility and portability
- Wheel size
- Seat size (if applicable)
- Weight of walker

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Types of canes:

Take a look to help you determine which type of cane may work for you.



Folding canes

If you're on the go, a folding cane is an option that's compact and convenient.



These walking canes have orthopedic handles that may help reduce strain on the hand and wrist.



Quad cane

A quad cane has 4 small feet that extend from a broad base to help with support.



┢ Bonus Tip

Walking sticks are another alternative that may help people with CIDP walk more confidently by providing stability and support.

Trekking poles, which are commonly used for hiking, come as a pair. They provide balance on uneven surfaces.

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I have recently started using walking sticks (with cane tips on them) for short walks and walking over uneven areas. I have found this helps with my balance and endurance."

-Shining Through CIDP Community

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Manual wheelchairs

These are typically lightweight transport wheelchairs that have hand brakes and can fold into a compact size for easy storage.

Types of electric wheelchairs:

See 3 options that could work for your lifestyle.





Full-size electric wheelchairs

These offer more comfort and larger seats.



Heavy-duty electric wheelchairs

These have reinforced frames and heavy-duty motors.

Bonus Tip

I use a grabber. It's very helpful when I'm in my wheelchair."-Shining Through CIDP Community



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Martha





Paula





From the Community For the Community

Shining Through CIDP was created by argenx to help those living with CIDP by providing resources, helpful articles, and relatable stories from real people who have CIDP.

A big thank you to our Shining Through CIDP Community and the experts who collaborated on this eBook.

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