My VYVGART® Path

GUIDE TO

EMPOWERED RELATIONSHIPS

Tips and activities to help you refocus on the different relationships in your life



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EMPOWERING YOUR RELATIONSHIPS

When adjusting to life with a rare disease, like chronic inflammatory demyelinating polyneuropathy (CIDP), important relationships can change, become strained, or even fall away.

When you're ready, this guide is designed to help you **feel comfortable taking those first steps to rediscovering yourself and reconnecting with the people you love most**.



"**Relationships are healing in many different ways.** And when we've been diagnosed with a rare disease, we may feel very separate from people, but we're meant to live in community."

Jen Warner

Licensed Clinical Social Worker
and Psychotherapist

Paid contributor

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Rediscovering *yourself*

Finding joy in your day is a helpful way to reinforce your relationship with yourself. You may have different abilities now that you're living with CIDP, but you can still find ways to take part in your favorite activities. Consider the different interests below and brainstorm a way you can take part in your favorite hobbies.

WHEN FEELING GREAT, I COULD:	WHEN FEELING OKAY, I COULD:	WHEN FEELING POORLY, I COULD:
Enjoy caring for my garden	Care for a house plant	Sit in nature
Play a few holes of golf	Play mini golf with a friend	Watch golf on TV
Host a small dinner party	Cook a meal	Look up new recipes

Think about an activity you would like to do and come up with 3 different ways you could take part in it, ranging from hardest to easiest.

Acknowledging how far you've come

Brainstorm and make a list of things you have accomplished since your diagnosis. You may be surprised by how much you're still able to do every day.

Ex. I traveled out of state to visit my grandchildren.

1.

2.

3.

I read 3 books last year.

4.

5.

6.

Tip! Put this list somewhere special so you can look at it when you need a boost in confidence.

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Prioritizing your *partner*

Explore these tips to help you and your partner refocus your relationship with one another.



MAKE TIME FOR EACH OTHER:

Set aside time on the calendar each week with the intention to spend quality time together. This could mean watching a movie, playing a board game, or just enjoying a meal.



REGULARLY REASSESS CAREGIVING RESPONSIBILITIES:

You may be feeling better and can take back some of the responsibilities that your loved one has taken on. Have a conversation about what tasks you would like to take on and which ones you still need their help with.



BE OPEN-MINDED ABOUT INTIMACY:

With changes in your body and abilities, intimacy between you and your partner may be different. It's important to have open and honest conversations about what intimacy looks like to both of you.



TAKE A BREAK FROM TALKING ABOUT CIDP:

Constantly thinking about your rare disease can be overwhelming. Let your partner know that if they need a break, they can just ask for it.

Get an outside perspective

There can be some big topics that arise as you reconnect with your partner, and it's okay to get some help managing that. Consider reaching out to a mental health professional to help give you strategies for conversations. Your relationship may also benefit from couples therapy to help you both navigate this new chapter.

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Taking the pressure off *each other*

Talking about intimacy can sometimes feel scary or awkward. Take the pressure off and make it fun with these questions and activities you can do together.

Tip! For a more interactive experience, print this page out, cut along the dotted lines, and place them in a bowl. You and your partner can take turns pulling them out.

QUESTION

What does your perfect day look like?

ACTIVITY

Take a minute to write down the things about your partner that you are grateful for and then share them with each other.

QUESTION

How would you describe our relationship in one word?

ACTIVITY

Complete the sentence: I'm grateful that you've helped me realize _____ about myself.

QUESTION

What topic do you wish was easier to talk to me about?

ACTIVITY

Take a minute and write a short song that reminds you of your partner. Then perform it for each other.

QUESTION

What goal would you like us to accomplish as a couple?

ACTIVITY

Write down a memory that always makes you smile and share it with each other.

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Reconnecting to your *friends and family*

Your loved ones may be nervous about what to say to you or how they can help. Sharing what is going on with you can be **a simple way to make your loved ones realize that you're still you**.



> "If you're feeling a disconnect with a person in your life who's important to you, whether it's a family member, a friend, or a co-worker, I would encourage you to **make a plan to reach out very intentionally**."

Dr. Al Freedman, Psychologist

Paid contributor

Write a script for what you'd like others to know about how CIDP affects you. Consider how your symptoms affect your abilities or energy levels, how your treatment makes you feel, etc.

Write down ways that you would like your loved ones to respond to this news.

Ex. I'd like my loved ones to help me by checking in on me sometimes.

Write down the people who you would like to share this information with.

Connect with someone living with CIDP

Talk with an adult mentor who understands the CIDP journey.

Fill out this enrollment form or call 1-833-498-7856 to enroll over the phone.

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Practicing gratitude for your *loved ones*

Sharing your gratitude is a great way to let people you're close to know how much you care for your relationship. Write down the people you have been most grateful for throughout your CIDP journey and why. Consider reaching out to them and sharing what you wrote down.

I'M GRATEFUL FOR:

BECAUSE:

I'M GRATEFUL FOR:

BECAUSE:

I'M GRATEFUL FOR:

BECAUSE:

I'M GRATEFUL FOR:

BECAUSE:

Tip! Keep this list of people handy and look back on it to remind yourself of the people who are in your corner.



"Every time we interact with somebody who cares about us, whether it's a friend, family member, or another person in our rare disease community, **that fills up our emotional fuel tank**."

Dr. Al Freedman, Psychologist
Paid contributor

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