

Caregiver compassion & connection guide



Help is here

for every kind of caregiver:

-  A parent
-  A partner
-  A friend
-  Caring for a parent

From medical management to emotional support, this guide offers a starting point for caring for a loved one with primary immunodeficiency (PI), while also taking care of yourself.

This guide contains general medical information, which cannot be applied safely to any individual case. Medical knowledge and practice can change rapidly. Therefore, this guide should not be used as a substitute for professional medical advice.

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Understanding the basics

If you are new to PI caregiving or seeking additional resources, this section provides **essential facts about PI** to help you better understand and communicate its complexities, alongside emotional validation for your caregiving journey.



What is PI?

Primary immunodeficiencies (PIs) are a group of **more than 550 rare, chronic conditions** where a part of the body's immune system is missing or does not function correctly.

All primary immunodeficiencies are different, but they all disrupt the body's immune system. They are also known as inborn errors of immunity (IEI).

PI conditions are caused by genetic variants and **can affect anyone**, regardless of age, gender, or ethnicity.

What are the signs of a primary immunodeficiency?

Frequent infections that are:

- ▶ **Recurrent** keep coming back.
- ▶ **Unusual** caused by an uncommon organism.
- ▶ **Persistent** won't completely clear up or clears very slowly.
- ▶ **Severe** requires hospitalization or intravenous antibiotics.
- ▶ **Shared by family members** others in your family have or have had a similar susceptibility to infection.

Infections can occur anywhere in the body, such as the brain or spinal cord, ears, lungs, skin, sinuses, throat, and urinary or intestinal tracts. For some types of PI, autoimmunity is the main symptom and people with these PIs typically have multiple autoimmune diseases. These types of PI can also cause a person to be at higher risk for infections, but their main symptoms are autoimmune and **may include**: Swollen spleen, liver, or lymph nodes; cancer; chronic inflammation, or allergies.

Who is a caregiver?

A caregiver provides physical or psychological care to someone who cannot fully care for themselves due to health issues, illness, injury, or medical conditions.

Caregiver responsibilities may include:

- Assisting with daily activities (e.g., toileting, bathing, dressing).
- Meal prep, housework, and financial management.
- Medication management and health monitoring.
- Providing transportation and advocating with healthcare providers.¹

**BEING
THERE**

Whether caregiving is new to you or ever evolving, these life changes offer opportunities to spend more meaningful time with your loved one. Your presence brings comfort and stability, and your care makes a lasting difference.



Navigating the unknown: Finding strength together

As a caregiver or family member of someone with PI, you're on a unique path—one that blends challenge with deep connection and growth. While there are hard days, many discover unexpected gifts: stronger bonds, resilience, and the quiet power of making a difference.

You are not alone. The Immune Deficiency Foundation's documentary, "[Compromised: Life Without Immunity](#)", shares honest stories from families like yours—highlighting both the struggles and the strength it takes to support a loved one with PI. It's a powerful reminder that your emotions are valid, and that a community walks this journey with you.

Managing mixed emotions: These feelings are normal

- ▶ Fear and uncertainty.
- ▶ Constant vigilance about your love one's health.
- ▶ Creative problem-solving under pressure.
- ▶ Feeling on edge or unable to relax.
- ▶ Gaining clarity on what truly matters.
- ▶ Physical and emotional exhaustion.
- ▶ Growing in compassion and inner strength.
- ▶ Difficulty focusing on anything else.
- ▶ New perspectives and personal growth.
- ▶ Deeper connections through shared challenges.
- ▶ Tension with a partner.
- ▶ Resilience you didn't know you had.



Holding onto hope

As a caregiver, embrace both the challenges and rewards. **You have the power to create precious memories even within limitations.** Notice positive moments, however small. Share laughter when possible. Celebrate victories of all sizes. Connect with others who understand both the difficulties and joys of caregiving. In helping someone navigate PI, you're demonstrating incredible love and strength.

You have what it takes to move through this journey with grace. Brighter days are always ahead.

Caregiving essentials



Caring for someone with PI often means **balancing caution with hope**—reducing infection risks, while still encouraging a full and joyful life. Your support can help create a sense of safety without sacrificing what makes life meaningful.

Practical tips for a safer home environment

Home modifications for safety:

- **Air quality:** Use HEPA purifiers and change HVAC filters regularly (every 1-3 months).
- **Water safety:** Follow doctor's advice on filtration, clean shower heads and aerators monthly, and set hot water to 120°F (49°C) to prevent *Legionella*.
- **Kitchen safety:** Use separate cutting boards for raw meat and produce. Replace sponges weekly, refrigerate leftovers promptly, and cook meat to safe temperatures.
- **Bathroom care:** Clean surfaces weekly, keep toothbrushes covered, and replace shower curtains or clean glass doors regularly to prevent mold.

Daily habits to reduce risk:

- **Hand hygiene:** Set up convenient handwashing stations and keep alcohol-based hand sanitizer available.
- **Shoe policy:** Use indoor-only shoes or create a designated area for outdoor footwear.
- **Regular cleaning:** Focus on high-touch surfaces and clean regularly.
- **Pet care:** Keep pets up-to-date on vet visits and parasite prevention.

Creating a socially safe environment:

- **Home entertaining:** Host small gatherings where you control the environment (e.g., a mask rule).
- **Outdoor spaces:** Set up outdoor living areas for safer socializing.
- **Virtual connections:** Use video calls during high-risk seasons to stay connected.

Hygiene and food safety when out:

- Wash hands often; carry hand sanitizer.
- Ensure meat, poultry, and seafood are cooked; avoid unpasteurized dairy.
- Wash/peel fruits and veggies.
- Use/drink bottled or boiled water if needed.
- Eat from regulated places; avoid street food.
- Carry antiseptic wipes for surfaces.
- Wearing a KN95/N95 mask when out alone or with your loved one.

Always plan for an emergency, no matter how far you're going.

When leaving home, always have:

- A copy of your loved one's insurance card.
- A list of medications and dosages.
- All contact information and emergency details for healthcare providers.
- Medications and medical supplies. Keep them in their original containers with prescription labels.
- Use a cooler bag or insulated pouch for temperature-sensitive items. For sharps, pack a sturdy container, like an empty peanut butter jar, for safe, on-the-go disposal.

Pro-tip (from experience): “Pack like you're camping an hour from the nearest pharmacy.”

– Colleen B., caregiver of children with PI



Preventative care checklist when on-the-go.

The better you prepare, the more you can relax. Packing smart with preventative care items helps **reduce the risk of infection and unexpected setbacks**—so you can focus more on enjoying your time together and less on managing last-minute needs.

- Daily prescribed medications (in labeled containers or a pill organizer).
- Pain relievers (e.g., ibuprofen, acetaminophen).
- **Antibiotics.**
- Antacids (e.g., Tums, famotidine).
- Antihistamines.
- Cough and cold remedies (e.g., throat lozenges, cough syrup).
- Anti-nausea medication (if prescribed or recommended).
- Emergency medications (e.g., epinephrine auto-injector, rescue inhaler).
- **Thermometer, masks, back-up batteries, sunscreen, hand sanitizer, etc.**

You can plan accordingly for any specific items with your loved one's healthcare team.

Traveling abroad

Before booking your travel:

- Research any health hazards at your destination.
- Discuss your travel plans with your healthcare provider(s), including the duration of your trip.

Before you leave:

- Identify medical facilities and immunologists at your destination in case of an emergency.
- Coordinate immunoglobulin infusion plans with healthcare providers, specialty pharmacies, and insurance.
- Review health insurance coverage for the trip and purchase additional travel health insurance if necessary.

If going outside the U.S.:

- Register with the State Department's Smart Traveler Enrollment Program (STEP).
- Consult your healthcare provider about recommended vaccines and whether they're necessary for your trip.
- Research vaccine requirements for your destination.
- Understand the rules for bringing medications and medical supplies into the country.
- Place medications, medical equipment, and infusion supplies in carry-on luggage, if necessary.
- Letter of medical necessity for medications and/or medical equipment from healthcare provider.



Talking PI: Advocacy & support

When advocating for your loved one, remember two things: It's your journey to share, on you and your loved one's terms, and **your experience may be someone's first insight into PI**, helping raise awareness.



As a caregiver, you play a key role in advocating for your child or loved one with PI, whether in healthcare or school.

Healthcare advocacy:

- Keep records of your loved one's diagnosis, treatments, medications, and providers.
- Prepare for medical visits with a journal and a list of questions.
- Request written instructions and discuss treatment plans at every visit.
- Request that all providers you come in contact with wear masks.

School advocacy:

If PI affects your child's education (e.g., frequent absences, medication needs, or accommodations), communicate with the school.

- Inform them about absences, medications, and necessary adjustments like rest breaks.
- Meet with staff to develop a plan, and consider identifying PI as a disability for accommodations under federal law.

Additional tips:

- Ask about additional treatments, diet, and lifestyle changes that may help.
- Keep communication open with healthcare providers, school, and insurance.
- Ask about information for more resources in the local, state, and national levels.

Finding joy in the caregiving journey

Creating meaningful moments isn't just about surviving—it's about thriving together.

- Turn routine medical tasks into **moments of connection** by incorporating conversation, games, or shared activities.
- Create meaningful rituals to **celebrate** even the smallest victories and milestones along your PI journey.
- **Preserve memories** by capturing special moments through photos, journaling, or creating a memory box to cherish.
- **Plan fun**, "normal" activities that adapt to medical needs, ensuring joy is the focus while respecting limitations.
- Use treatment time as **bonding time**—share stories, play games, or enjoy a favorite show together to make the most of the moment.
- **Embrace humor** in everyday situations—laughter can be a powerful form of healing, lifting spirits and creating memories for everyone.

With so many unknowns and demands, from medical routines to daily responsibilities, **being present allows space for you to truly connect**, prioritize what matters, and stay grounded through it all.

**HERE
FOR YOU**

We know this guide doesn't cover everything; this is just a starting point. The Immune Deficiency Foundation is here to support you every step of the way.

Self-care for caregivers



Caregiving is deeply meaningful, yet often demanding. **It's natural to experience stress or burnout at times.** Recognizing when you need a break and seeking support is crucial. Prioritizing your mental health is not only important for your well-being but also for your loved one with PI.

Recognizing caregiver burnout

Caregiver burnout is a condition of physical, emotional, and mental fatigue that can occur when you invest significant time and energy in managing the health and well-being of another person.

The signs and **symptoms of caregiver burnout** often look like those of stress or depression, and may include:

- Emotional and physical exhaustion.
- Withdrawal from friends, family, and other loved ones.
- Loss of interest in activities previously enjoyed.
- Feeling hopeless and helpless.
- Changes in appetite and/or weight and sleep patterns.
- Inability to concentrate.
- Getting sick more often.
- Irritability, frustration, or anger toward others.

If you notice signs of burnout, talk to a healthcare provider or mental health professional for support. Taking this step can help you feel better sooner and care for yourself and your loved one.²

Building your support system

It's not always easy to accept help, even when you need it most. Just as you care for your loved one, remember that **there is support available** to you when you need it.

- Delegate tasks, ask for help, and accept offers of support from others.
- Access community resources like daycare, meal programs, mental health services, and care management.
- Join a support group to connect with others, gain insights, and feel understood.³

Caring for yourself isn't selfish; it's key to sustaining the care you give.

Even when loved ones encourage self-care, caregivers often struggle with guilt. Remember: **taking care of yourself is fulfilling their wishes** and ultimately provides better care.

You **maintain your health** and well-being by:

- Accepting your feelings and being kind to yourself.
- Asking for help and talking to someone you trust.
- Setting boundaries and saying no without guilt.
- Seeking professional help when needed.
- Prioritizing sleep, healthy eating, and moving your body.
- Practicing relaxation, like deep breathing exercises or meditation.
- Staying on top of your own medical care.³



Balancing a career and caregiving

Managing both work and caregiving isn't easy, but you're far from alone. Many caregivers face this same challenge, and with the right tools, support, and planning, **it's possible** to care for your loved one while keeping up your career.

Caregiving on the clock:

- **Get organized:** Use a shared family calendar to track appointments and delegate tasks.⁴
- **Build a care network:** Coordinate help from trusted family, friends, or neighbors to cover care while you're at work.⁵
- **Set boundaries:** Try to keep caregiving tasks outside of work hours when possible.
- **Plan ahead:** Have a backup at work in case you need to leave suddenly.

Communicating needs at work:

- Be proactive: Schedule time with your manager or human resources to explain your caregiving needs and to plan.⁴
- Ask about flexibility: Explore remote work or adjusted hours.⁴
- Stay clear: Reaffirm your commitment to your role as you request adjustments or any changes.⁴
- Know your rights: Look into the Family and Medical Leave Act (FMLA) and relevant workplace policies.⁶
- Plan ahead: Early conversations help avoid future stress, ensuring care for your loved one while protecting your job.

Words of strength

No one understands caregiving like those living it every day. These reflections offer **honest insight, encouragement, and connection** from people who've walked a similar path.

On doubting decisions:

"As caregivers for those we cherish, it's vital to remember that we consistently strive to provide the best possible care. Moments of uncertainty regarding necessary decisions are natural. You may experience self-doubt about the path you've chosen, but ultimately, find strength in the profound truth that you are the designated caregiver, and every action you take is rooted in love."

On adequate self-care:

"We understand that as caregivers, dedicating time and energy to your own well-being can feel like an uphill battle. Yet, these moments of self-care are not a luxury but a necessity. By nurturing yourself, you are actively shielding your loved one from the risks associated with future caregiver burnout." – **Jenna M.**, IDF's Get Connected Groups and Peer Support Program admin.

"Being a caregiver comes naturally to most of us but we are still human. Love yourself like the human that you are and take care of yourself. We are not invincible, we do break. Give your humanity a break and don't forget to breathe." – **Chelsy N.**, from the Congenial Athmyia support group



Finding your way: Support and resources for your journey

Caregiving is a complex and often challenging role, but with the right tools and support, you can manage it with confidence. At the Immune Deficiency Foundation, we provide resources designed to guide you through the caregiving journey, offering educational materials, community connections, and professional support to help you care for your loved one while also maintaining your well-being. Our goal is to empower you with the knowledge and resources you need to **navigate the demands of caregiving with strength and resilience.**

Make meaningful connections

- ▶ Join a caring community that connects people who share similar experiences:
 - The **IDF Peer Support Program** connects you with trained volunteers who have personal experience with PI.
 - Specialized **Get Connected Groups** offering virtual support.

Ask IDF

- ▶ Got questions? We're here to help through **Ask IDF** with answers to inquiries like:
 - Information about our programs & services.
 - Assistance **finding a clinician.**
 - Details on **diagnosis, treatment, management,** or inheritance of PI.
 - Guidance on health insurance, education, or employment.
 - Connecting with others affected by PI and more!

Free educational resources

- ▶ Access our comprehensive library of IDF publications and resources for FREE like the **patient Bill of Rights** or the **IDF School Guide for Students with Primary Immunodeficiency@**. Our resources are available in multiple languages and support everyone affected by PI.

Financial assistance available

- ▶ Visit <https://primaryimmune.org/living-primary-immunodeficiency/get-support> for a list of organizations that offer financial assistance and health insurance support.



IDF is your home for hope

Since 1980, the Immune Deficiency Foundation has supported those affected by PI through resources, education, and advocacy, while partnering with clinicians and researchers to advance care and public policy. Thousands of families trust IDF for empowerment and support.

For more information, visit primaryimmune.org

References

1. MedlinePlus. (n.d.). Caregivers. U.S. National Library of Medicine.
<https://medlineplus.gov/caregivers.html>
2. Cleveland Clinic. (n.d.). Caregiver burnout. Cleveland Clinic.
<https://my.clevelandclinic.org/health/diseases/9225-caregiver-burnout>
3. Cleveland Clinic. (n.d.). Self-care for caregivers. Cleveland Clinic.
<https://health.clevelandclinic.org/self-care-for-caregivers>
4. Ashford, K. (2024, March 6). How to balance caregiving and work: 10 tips for working caregivers. WebMD. <https://www.webmd.com/healthy-aging/caregiver-balance-work>
5. Family Caregiver Alliance. (n.d.). Balancing career and caregiving.
<https://www.caregiver.org/news/balancing-career-and-caregiving/>
6. AARP. (2019, October 1). How to balance caregiving and work: 10 tips for working caregivers. <https://www.aarp.org/caregiving/life-balance/info-2019/working-caregiver-tips.html>

The Immune Deficiency Foundation, founded in 1980, improves the diagnosis, treatment, and quality of life for every person affected by primary immunodeficiency. We foster a community that is connected, engaged, and empowered through advocacy, education, and research.



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