

The Benefits of Having a *Chronic Illness*

A lot of positive lessons come from having a chronic illness; they just need to be acknowledged.

By Surayyah Morris



THOSE OF US with chronic illness are in a daily battle against our bodies, making it sometimes difficult to see the good in things. But, here are a few reminders of what we can learn and how we benefit from our experiences of dealing with chronic illness.

Advocacy

If there is one thing to be learned from having a chronic condition, it's how to advocate. Having someone advocate for us is very reassuring. But, eventually, we realize that those who fight so hard for us when we're too weak or unable are actually teaching us to do the same for ourselves.

Pay close attention to what your advocate is saying to the doctor. Listen to the types of questions he or she asks. Watch how your advocate remains assertive to help the doctors provide you with what you need. Throughout your experience, you'll develop these skills, and you can begin advocating for yourself and feel confident doing it. So, tell your story. What do you feel? How are your daily activities affected? How can the issue be improved or changed? Who else can you speak to about your concerns? Let others know you are serious about being present in your care. Surround yourself with people who will stand by your side to advocate with you and support you.

Compassion

Having compassion not only forwards our kindness to make someone else feel better, but also serves us in a way that helps us to be more mindful and present in our own lives. We are more understanding of others in their situations because we've likely experienced some type of mistreatment during our journey. Being mistreated is not a good feeling for anyone, but it is especially discouraging when it comes from those who are supposed to help. Whether or not we have a chronic condition, we need people in our lives who care and show it through their words and actions.

Not everyone you encounter will go out of their way to provide good care, but when that one nurse finds a warm blanket when you forgot yours for a half-day infusion, you are beyond grateful. When the doctor listens to your concerns and responds with empathy instead of dismissing you with a psychosomatic spiel, you gain more trust and respect for that person. Appreciate these moments. Pay it forward and extend your hand to others. Even a simple smile goes a long way. Best of all, you don't lose anything!

Our experiences teach us that everyone may not be genuinely compassionate and caring, but we can be that empathetic person for someone else. In short, treat others the way you want to be treated.

Improvisation

On bad days, we develop extraordinarily convenient ways to get things done. When our bodies decide to take control, we have to take control back. No strength to cook? There's an app for that. Haven't cleaned the house in weeks? There's an app for that, too. Need to use the bathroom but can barely get out of bed? There isn't an app for that, but there is a bedside commode. Ice packs getting warm too quickly? There isn't an app for that either; however, you can freeze several ice packs and keep them in rotation or place a mini fridge/freezer where it's most convenient.

The point is that whatever you would typically struggle with, I guarantee you will find the easiest, simplest, least-taxing way to get that task accomplished. This may take some trial and error, but you'll be more than proud of yourself for having tricks up your sleeve in a variety of situations.

Having patience allows us to get what we need, accomplish tasks successfully and solve problems efficiently.

Observant

When it comes to our health, we cannot be careless. No matter how much we trust the people involved in our care, we must do our best to remain attentive. During one of my first infusions, I had my attention on the television when I broke out in hives and my throat began to swell. I was having an allergic reaction to a medication that was inappropriately administered by my nurse. From that day forward, I always ask to physically verify what I'm being administered before allowing anyone to touch me. I also make sure I'm not watching television.

Hizentra®

Immune Globulin Subcutaneous
(Human) 20% Liquid

1st and only Self-administered Ig for CIPD Maintenance

#1 Ig Prescribed for PI

**My Life,
My Way
With
Hizentra**

Hizentra is an Ig* therapy that provides proven protection for PI and CIPD with the convenience of self-administration, so you can focus on everyday living

*Ig=immunoglobulin

Important Safety Information

WARNING: Thrombosis (blood clots) can occur with immune globulin products, including Hizentra. Risk factors can include: advanced age, prolonged immobilization, a history of blood clotting or hyperviscosity (blood thickness), use of estrogens, installed vascular catheters, and cardiovascular risk factors.

If you are at high risk of blood clots, your doctor will prescribe Hizentra at the minimum dose and infusion rate practicable and will monitor for signs of clotting events and hyperviscosity. Always drink sufficient fluids before infusing Hizentra.

See your doctor for a full explanation, and the full prescribing information for complete boxed warning.

Hizentra is a prescription medicine used to treat:

- Primary immune deficiency (PI) in patients 2 years and older
- Chronic inflammatory demyelinating polyneuropathy (CIPD) in adults

Treatment with Hizentra might not be possible if your doctor determines you have hyperprolinemia (too much proline in the blood), or are

IgA-deficient with antibodies to IgA and a history of hypersensitivity. Tell your doctor if you have previously had a severe allergic reaction (including anaphylaxis) to the administration of human immune globulin. Tell your doctor right away or go to the emergency room if you have hives, trouble breathing, wheezing, dizziness, or fainting. These could be signs of a bad allergic reaction.

Inform your doctor of any medications you are taking, as well as any medical conditions you may have had, especially if you have a history of diseases related to the heart or blood vessels, or have been immobile for some time. Inform your physician if you are pregnant or nursing, or plan to become pregnant.

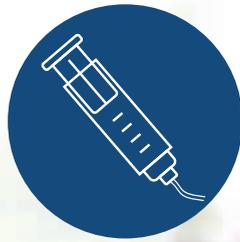
Infuse Hizentra under your skin *only*; do not inject into a blood vessel. Self-administer Hizentra only after having been taught to do so by your doctor or other healthcare professional, and having received dosing instructions for treating your condition.

Why Choose Hizentra?



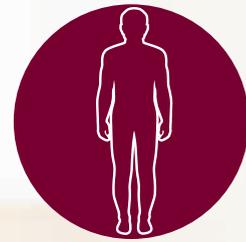
Choose where you infuse

Self-administration with Hizentra means you and your doctor can decide where you can infuse. Convenient dosing routines mean you won't have to adjust or cancel your plans due to IV infusion appointments.



No IV infusions

IV infusions can be challenging for people who have hard-to-find or damaged veins. Hizentra allows you to infuse just under the skin, not into a vein, after training from your doctor.



Proven safety

Hizentra has an established safety profile and demonstrated tolerability. In clinical trials, the most common side effects were redness, swelling, itching, and/or bruising at the infusion site; headache, chest, joint or back pain; diarrhea; tiredness; cough; rash; itching; fever, nausea, and vomiting. These are not the only side effects possible.

Discover all the benefits Hizentra has to offer at Hizentra.com

Immediately report to your physician any of the following symptoms, which could be signs of serious adverse reactions to Hizentra:

- Reduced urination, sudden weight gain, or swelling in your legs (possible signs of a kidney problem).
- Pain and/or swelling or discoloration of an arm or leg, unexplained shortness of breath, chest pain or discomfort that worsens on deep breathing, unexplained rapid pulse, or numbness/weakness on one side of the body (possible signs of a blood clot).
- Bad headache with nausea; vomiting; stiff neck; fever; and sensitivity to light (possible signs of meningitis).
- Brown or red urine; rapid heart rate; yellowing of the skin or eyes; chest pains or breathing trouble; fever over 100°F (possible symptoms of other conditions that require prompt treatment).

Hizentra is made from human blood. The risk of transmission of infectious agents, including viruses and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent and its variant (vCJD), cannot be completely eliminated.

The most common side effects in the clinical trials for Hizentra include redness, swelling, itching, and/or bruising at the infusion site; headache; chest, joint or back pain; diarrhea; tiredness; cough; rash; itching; fever, nausea, and vomiting. These are not the only side effects possible. Tell your doctor about any side effect that bothers you or does not go away.

Before receiving any vaccine, tell immunizing physician if you have had recent therapy with Hizentra, as effectiveness of the vaccine could be compromised.

Please see brief summary of full prescribing information for Hizentra on adjacent page. For full prescribing information, including boxed warning and patient product information, please visit Hizentra.com.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

IgIQ: Support Programs to Help You Get Started

Call IgIQ to find out about programs such as:



Free 1-month supply of Hizentra and free at-home nurse visits



Most patients with commercial insurance pay \$0 out-of-pocket*



Protection if you lose insurance*



Your single source for Ig solutions

1-877-355-IGIQ (4447)

*Other terms and conditions apply. Call IgIQ to learn more.

HIZENTRA®, Immune Globulin Subcutaneous (Human), 20% Liquid
Initial U.S. Approval: 2010

BRIEF SUMMARY OF PRESCRIBING INFORMATION

These highlights do not include all the information needed to use HIZENTRA safely and effectively. See full prescribing information for HIZENTRA.

WARNING: THROMBOSIS

See full prescribing information for complete boxed warning.

- **Thrombosis may occur with immune globulin products, including HIZENTRA. Risk factors may include: advanced age, prolonged immobilization, hypercoagulable conditions, history of venous or arterial thrombosis, use of estrogens, indwelling vascular catheters, hyperviscosity, and cardiovascular risk factors.**
- **For patients at risk of thrombosis, administer HIZENTRA at the minimum dose and infusion rate practicable. Ensure adequate hydration in patients before administration. Monitor for signs and symptoms of thrombosis and assess blood viscosity in patients at risk for hyperviscosity.**

INDICATIONS AND USAGE

HIZENTRA is indicated for:

*Treatment of primary immunodeficiency (PI) in adults and pediatric patients 2 years and older.

* Maintenance therapy in adults with chronic inflammatory demyelinating polyneuropathy (CIDP) to prevent relapse of neuromuscular disability and impairment.

-Limitation of Use: Maintenance therapy in CIDP has been systematically studied for 6 months and for a further 12 months in a follow-up study. Continued maintenance beyond these periods should be individualized based on patient response and need for continued therapy.

For subcutaneous infusion only.

DOSAGE FORMS AND STRENGTHS

0.2 g per mL (20%) protein solution for subcutaneous injection

CONTRAINDICATIONS

- Anaphylactic or severe systemic reaction to human immune globulin or components of HIZENTRA, such as polysorbate 80
- Hyperprolinemia (type I or II) (HIZENTRA contains the stabilizer L-proline)
- IgA-deficient patients with antibodies against IgA and a history of hypersensitivity

WARNINGS AND PRECAUTIONS

- IgA-deficient patients with anti-IgA antibodies are at greater risk of severe hypersensitivity and anaphylactic reactions.
- Thrombosis may occur following treatment with immune globulin products, including HIZENTRA.
- Aseptic meningitis syndrome has been reported with IGIV or IGSC, including HIZENTRA treatment.
- Monitor renal function, including blood urea nitrogen, serum creatinine, and urine output in patients at risk of acute renal failure.
- Monitor for clinical signs and symptoms of hemolysis.
- Monitor for pulmonary adverse reactions (transfusion-related acute lung injury [TRALI])
- HIZENTRA is made from human plasma and may contain infectious agents, e.g., viruses, the variant Creutzfeldt-Jakob disease (vCJD) agent and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent.

ADVERSE REACTIONS

The most common adverse reactions observed in ≥5% of study subjects were local infusion site reactions, headache, diarrhea, fatigue, back pain, nausea, pain in extremity, cough, upper respiratory tract infection, rash, pruritus, vomiting, abdominal pain (upper), migraine, arthralgia, pain, fall and nasopharyngitis.

To report SUSPECTED ADVERSE REACTIONS, contact CSL Behring Pharmacovigilance at 1-866-915-6958 or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

DRUG INTERACTIONS

The passive transfer of antibodies may interfere with the response to live virus vaccines, and lead to misinterpretation of the results of serological testing.

Based on March 2018 revision

Ensure all hands are properly washed and technique is clean. If the doctor comes in with multiple people, ask about the role of each individual and what purpose they serve in your care. Medical mistakes are easy to make despite having processes in place to prevent them. Be alert, oriented and fully present. Ask questions. Most importantly, though, read! The information you receive is in writing most of the time. It seems tedious, but read all the documents, and be sure you understand them. Information in black and white may not always be explained to you, even if it should be. If you do not understand something, ask for clarity. Have someone with you as a second set of ears and eyes to make sure you're safe and being treated well — to act as your your personal lookout!

Patience

Most of us with chronic illness might as well set up camp and live at the doctor's office. Sometimes, we observe a healthy person becoming impatient when experiencing long wait times or when unexpected problems arise. But for those of us with chronic conditions, our experience with multiple doctor visits with multiple doctors in multiple places and for a variety of reasons gives us a different perspective. At minimum, we deal with insurance claims, disability forms, accommodation requests and the pharmacy. Because we usually don't have a choice, at the very least, we learn to wait. Over time, waiting builds patience. Having patience allows us to get what we need, accomplish tasks successfully and solve problems efficiently.

This outlook translates into positives because in addition to having more patience with wait times, you'll also have more patience when dealing with people. Waiting for authorizations, referrals or pharmacy benefits to process can be frustrating and time-consuming, but knowing how to prepare ahead of time can also minimize stress.

Prioritization

When more than one provider is managing our health, things become overwhelming. A whirlwind of information is often provided to us with no clear direction of what to tackle first.

When the to-do list begins to grow, you will learn what's most important to accomplish based on your situation. For example, I used to think my newly diagnosed brain aneurysm was going to be the driving factor in how my life moved forward. Then, I realized my aneurysm wasn't causing me

any problems. Yes, it's very much present, but it isn't affecting my health like my other conditions. Being able to improve my health by giving priority to my primary condition as opposed to giving energy to something that isn't immediately affecting me has allowed me to be a little less stressed and lot less worried. Try to prioritize your concerns from most to least important so managing your health becomes easier overall.

Don't be scared to
show your strength.

Strength

We all have bad days, but those days come and go. Now, you may be reading this after a terrible day that seemed bad from start to finish. But remember, you are stronger than most of the people in your life, I promise. You fight a battle with your body daily, you remain mentally strong, you take care of yourself without compromising the care of others, and you wake up the next day to do it all over again. That is so difficult! But despite the pain, inconvenience and unpredictability, you are able to adapt, and that takes more strength than anyone will ever know. A stranger once told me fear means we are afraid of something we have already been through and survived. Don't be scared to show your strength.

Give Credit Where Credit Is Due

Don't let the circumstances of life trouble you. Look at all you've learned so far. Continue to learn and grow and be the person you need to be for you. The next time you find yourself down about your condition, give yourself some credit, and acknowledge how much you have learned through this journey! ■

SURAYYAH MORRIS, PharmD, is an autoimmune small fiber neuropathy patient from Central Florida. As a medication therapy management and pain management specialty pharmacist, she enjoys supporting patients with chronic pain and chronic conditions to help find balance and improve quality of life.