

# Practicing Self-Care Without Guilt

Learning to put your own needs ahead of everyone else's is a challenge for even the healthiest. When chronic illness is a factor, the hurdles are even higher.



By Trudie Mitschang

**LIVING WITH A** chronic illness can be extremely difficult. You may struggle with feelings of anxiety, loss of control of your own body, pain, anger and exhaustion. All of these feelings are normal and expected, and most individuals find this range of emotions is all part of the “new normal.” In the midst of all of this upheaval, it is also common to face feelings of guilt when it becomes necessary to prioritize your own needs over everyone else's demands. Yet, doing so is often exactly what mental health experts and healthcare practitioners advise. In fact, learning to set reasonable boundaries and practicing self-care is essential to developing much-needed coping skills.

“So many people in the chronic illness community feel guilt over all the things we can't do — guilt because we have to say no to doing things with our kids, our families, our friends. Things we used to be able to do, things we want to do. But our illness — the pain and the fatigue — means we can't,” says health and disability advocate Lene Anderson, who also believes it's important to keep guilt in perspective.

“Guilt is an appropriate feeling if you've deliberately hurt someone, or shoplifted or done something else illegal or immoral simply because it gave you a rush. Being in too much pain to go for a hike is not the same as consciously doing something wrong. Remembering that can help chip away at the guilt.”

## Learning to Say No

You can't care for yourself in the truest sense if you don't understand what it is you need — what comforts and nourishes you. Self-care is about consciously taking responsibility for your happiness. That means taking care of your physical, emotional, psychological and social needs by doing everything possible to be fulfilled in these areas. And, in many cases, it begins by simply saying “no.”

Setting boundaries is necessary when it comes to reducing stressors and maintaining self-care. You need to let friends and family know that while you would love to participate in social outings, you're not able to at the time. Saying no does

not make you a bad person, and it certainly doesn't mean you don't care. Saying no means giving yourself the space needed to heal.

It's also important to remember that saying yes just to make others happy can cause resentment. If friends, family or coworkers continue to pressure you or try to persuade you into doing activities that make you uncomfortable, you may need to put some distance between you and those individuals. There is no need to feel guilty about this; it will only help your physical and mental health in the long run.

## Wisdom From Others Who Understand the Challenge

Mary England, who blogs about mental health and self-esteem at [Uncustomary.org](http://Uncustomary.org), recently hosted an e-course in which she asked participants to share the most difficult aspects of self-care. And, she was surprised to discover more than a third of respondents referenced chronic illness in their answers.<sup>1</sup> "I was blown away by how common that answer was. I realized I had no resources like blog articles or podcasts to reference for these people. I didn't have any specific answers for them because I don't have chronic illness, but I really wanted to have those answers, so I outsourced it," she says.

England interviewed eight individuals living with various types of chronic illness and posed this question: "What's the hardest part of practicing self-care while dealing with chronic illness?" The answers were varied and insightful, including:

"I think the hardest thing about learning self-care is learning to accept that something is wrong with you, even when doctors (and others) say otherwise. It's learning to listen to your body first and foremost. Those two lessons were the hardest, and I still forget when I think one day I can just be normal, but that's not the case. I always pray for good days. It's learning to accept and work with yourself first that was the hardest." (Cody)

"Not beating myself up when I can't do the things I feel like I should be doing or when I have to cancel plans last minute because I'm in pain is an ongoing struggle for me." (Kaitlyn)

"I have very unpredictable income. Those living with chronic illness do best under the 'treat yourself' mentality for self-care because amenities make our quality of life exponentially better. I like to be able to order takeout so I don't have to cook or clean up after, but I can't always afford it even if I don't have the energy to cook." (Currie)

England's survey participants went on to provide a helpful list of self-care tips based on their own life experience.

Among the highlights:

- Drink water/take a bath. It seems simple but when you're dehydrated, it's difficult for your body to heal or even maintain your new normal. A healing bath has given respite even when my pain levels were off the charts.

- Remember that self-care is an important investment. This investment requires time, money and energy. Allow yourself to invest in self-care.

- Communicate. You have to tell your friends and family what you need or else they won't be able to help you get that time.

- Don't be afraid to spend extra money on something if it is going to make your life easier.

- Have a self-care plan. Know that self-care doesn't have to take a long time. You can do something in three minutes or you can take an hour. A self-care plan will help you look at what you can do in the time you have.

- Think of all the tremendous things your body is doing right instead of beating yourself up for the things that aren't working so well. Focusing on the positive things and expressing gratitude (even if it's just in your head) changes your entire perspective and boosts your mood.

- Accept that your illness might get better, but it might not. Working with yourself where you are is the first start.

- Make a self-care basket. This way when you really need to take a moment for yourself, everything will be in one place.

## Cultivating Coping Strategies

Chronic illness sufferers often find themselves navigating a roller coaster of emotions. You may feel accepting one day and angry the next. It may help to remind yourself that these feelings are normal and will likely ease with time. Mental health experts advise that an effective coping strategy is to practice facing your diagnosis head-on.

This strategy was evident in a study of women with breast cancer that found women who felt resigned to their fate were psychologically less well-adjusted three years later, compared to women who actively confronted their diagnosis. Another study, also of women with breast cancer, found those who sought social support and used active coping strategies — such as developing a plan of action — reported more inner peace and satisfaction with life two years later, compared to women who tended to deny or avoid their diagnosis.<sup>2</sup>

To actively face your illness, a good place to start is by writing down all of your questions and discussing them with your physician. Ask your doctor what specific steps you can take to optimize your health. Getting as much knowledge as

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#### 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 (CIDP) 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.

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

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You may also call **1-877-355-IGIQ (4447)** Monday–Friday, 8 AM to 8 PM ET

- 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](http://Hizentra.com).**

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

\*Voice2Voice advocates are not healthcare providers or medical experts. For medical questions, please contact your physician. Voice2Voice advocates are compensated by CSL Behring LLC for their time and/or expenses.



## Can IgIQ help you?

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Have you had a lapse in your insurance coverage?

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### 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](http://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.

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you can will help you feel empowered. It's also a good idea to try to manage the elements in your life that are within your control. You may not be able to control certain aspects of your disease, for example, but you can choose to eat healthy meals, take medications as prescribed and spend less time with people who aren't supportive.

Another aspect of self-care that can go a long way toward improving coping skills involves scaling back your schedule of commitments. You can significantly minimize stress by letting go of unnecessary obligations. While it may be difficult to let go of activities you once enjoyed, taking inventory of the aspects of your schedule that are draining and detrimental to your health is a necessary step. "There is so much to do in a life. Everyone I know is getting busier and wishing for a magic wand to slow down time. I looked at my to-do list for today, and it has 11 items on it, three of which will take several hours each. Not even the healthiest person would be able to do everything on my list. Setting attainable goals is a big part of managing pain and fatigue," says Anderson.

Chronic illness sufferers often find themselves navigating a roller coaster of emotions.

You also may need to humble yourself and ask for more help from family and friends. Lastly, try to build a strong support network of people you can rely on, and communicate with them regularly about how they can best support you as you manage your disease.

### Taking a Holistic View

Jennifer Mulder is a psychologist who lives with her chronic health issues and frequently writes on the topic. Mulder advises it's important to think beyond bubble baths when it comes to defining what self-care actually looks like on a day-to-day basis. According to Mulder, "Self-care can be described as all the actions you take to look after your physical, mental, emotional and social needs. It's much more than having a bubble bath after a long day. Self-care also refers to leading a healthy lifestyle, managing chronic conditions and preventing further illness or injury."<sup>3</sup>

Mulder identifies three types of self-care:

- *Basic self-care.* These are the small acts you have to do every day to tend to your basic needs: eat, drink, sleep and take care of personal hygiene. It sounds simple, but when you're chronically ill, keeping yourself and your home relatively clean can be a full-time job.

- *Specific health practices.* This type of self-care includes all the things you do to manage your health, from taking your medicines and vitamins to following therapy, joining an exercise program and avoiding stress or other triggers. The particular practices are different for everybody, depending on your illness and personal situation.

- *Indulgent self-care.* These are the activities often touted in self-care articles. Doing things you enjoy is vital for a happy and healthy life, but reading a good book and getting a manicure can only be done after you've taken care of your basic needs and health practices first.

"The irony is the moment we need self-care in all its forms the most is when it's the hardest time to do it," says Mulder. "When you're healthy, it's difficult to imagine that getting ready for the day — a quick wash, getting dressed, having breakfast — could take up so much of your energy that there's little left to do anything else. Doing the things that make living possible can take the place of actual living itself."

In addition, she says, self-care isn't just about crossing tasks off a checklist; it's more about developing a mind-set of treating yourself with kindness on a regular basis: "Self-care is not just about doing things to feel better right now, but also constructively working on your long-term well-being."

### There's No One-Size-Fits-All Method

Obviously, self-care means different things to different people; there is no one-size-fits-all method. Everyone's journey is unique, so finding the hobbies, practices and activities that make you feel refreshed, while eliminating the things that create fatigue, stress or physical pain are essential. By following these guidelines, you cannot only learn to better cope with the symptoms of chronic illness, you may also find that over time, caring for yourself becomes a guiltless pleasure. ■

TRUDIE MITSCHANG is a contributing writer for *IG Living* magazine.

### References

1. 35 Self-Care Tips For People with Chronic Illness. Accessed at [uncustomary.org/35-self-care-tips-for-people-with-chronic-illness](http://uncustomary.org/35-self-care-tips-for-people-with-chronic-illness).
2. American Psychological Association. Coping with a Diagnosis of Chronic Illness. Accessed at [www.apa.org/helpcenter/chronic-illness.aspx](http://www.apa.org/helpcenter/chronic-illness.aspx).
3. Beyond Bubble Baths: What Self-Care Means When You're Chronically Ill. Accessed at [thehealthsessions.com/self-care](http://thehealthsessions.com/self-care).