

Navigating Your Vasculitis Journey

An Interactive Guidebook



VASCULITIS
FOUNDATION®



Stacey Ivits, MSW, RSW
Counselling Services

ABOUT THE AUTHOR

I was diagnosed with EGPA Vasculitis in 2001 while in 12th grade of high school, after five years of mystery symptoms and serious health complications. As I struggled with my health during my adolescence, I often doubted my own experiences of fatigue, pain, and illness. It was hard to navigate the transition from pediatric care to adult care while balancing the demands of my health, education, finances, and social expectations. The internet was still in its early stages, so it was difficult to connect with others living with vasculitis or chronic illness in the same life stage. I often felt like I had to forge my own path to living life fully while chronically ill.

However, I was able to complete high school and my BA degree alongside my peers, thanks to my wonderful team of specialists at Sick Kids and Mount Sinai in Toronto and my amazing parents. I was then fortunate to experience a period of sustained remission in early adulthood and decided to pursue a Master of Social Work degree in the hopes of one day advocating for the importance of mental health support alongside physical health treatment for individuals experiencing chronic illness.

My career began in Toronto, Ontario at wonderful research and teaching hospitals. I also met and married my wonderful husband and had two delightful children. We now live in the small city of Guelph, Ontario, about one hour northwest of Toronto. After parental leave, I returned to work part-time at a community mental health agency specializing in the treatment of eating disorders. In 2018, I started my own psychotherapy practice supporting individuals with trauma, eating disorders, or chronic physical and mental health concerns.

Not everything health-related has been smooth sailing since entering remission in my twenties. I experienced health challenges during both pregnancies related to my vasculitis and experienced a major flare in 2017. I had to adjust to medication side effects and changes in my abilities. I was also diagnosed with PTSD during this difficult time. Thanks to the support of my medical team and my psychotherapist, I was able to heal and thrive.

I began writing this guidebook in 2020 during the COVID-19 lockdowns while homeschooling two young kids, working virtually with my clients, and staying strong and healthy. With the input of others who have vasculitis and support from the Vasculitis Foundation, *Navigating Your Vasculitis Journey* became this resource. I share it with humility. Not every chapter, activity, or resource will work for each person because everyone's journey with vasculitis is unique.

4 TIPS TO REMEMBER

1

Consider this an invitation

to begin a journey with your health based on body respect and radical self-love.

2

Take YOUR time

You could take one day or one year (or more) to work through the guidebook. Do what works for you.

3

Make it YOURS

There's no right way to complete this guidebook. Do what helps you; no one's marking it.

4

Look for the icon

Throughout the guidebook, you'll see this icon



This indicates that you can find more information and links to helpful resources by visiting the Navigating Your Vasculitis Journey resource page on the Vasculitis Foundation website.



Scan to view the online resource page.

<https://vasculitisfoundation.org/wellbeing-resources/>

A person is shown in silhouette, performing a yoga pose (Tree Pose) on a rocky beach. Their arms are raised with hands pressed together in a prayer position above their head. The background is a bright, hazy sunset over the ocean, with the sun low on the horizon. The person is wearing a patterned sports bra and dark shorts.

WELCOME TO NAVIGATING YOUR VASCULITIS JOURNEY

Navigating Your Vasculitis Journey is an interactive guidebook for people to develop skills to manage life with this complex illness. It's not a treatment plan. It makes no promises of a cure or remedy. It's self-directed and self-paced. The guidebook has information for you to work through independently to tune in and reflect on specific aspects of your own journey.

This is a living document you can add to and edit as needed. You can use it as a template to create your own documents or journal that's unique to you, your specific diagnosis, and treatment. Use the parts that help you. You're encouraged to use this with your healthcare providers. Nothing in this is personalized medical or psychological advice. Consult with your medical team before beginning any medication, supplement, diet, or exercise regime.



NAVIGATING

UNDERSTAND, PREPARE,
PLAN, AND TAKE CARE

MAIN OBJECTIVE

Identify key areas of self-care that support you in navigating your journey with self-compassion. By doing so, you'll be better equipped to explore and find your own way to live and love with vasculitis.

LEARNING OUTCOMES

- Introduction to mindful self-compassion.
- Able to prioritize your physiological needs for rest/sleep, nourishment, and movement so you can better manage your health and well-being.
- Learn how mindful awareness and reflection practices support you in making practical and sustainable behavior changes.
- Introductory understanding of nervous system regulation and its role in managing emotions, thoughts, and behaviors.
- Identify behavioral goals for your Journey.

TOPICS COVERED

- The role of self-compassion
- Physiological awareness and meeting your needs
 - Sleep/rest
 - Nourishment
 - Movement
- Window of tolerance and nervous system regulation strategies
- Boundaries with self and others
- Behavior change science

WHAT DO YOU NEED

Equipping

The key aspects of self-care

- Everyone has basic physiological needs. People with vasculitis must pay more attention to meeting these needs to effectively manage demands on their time and energy.
- Assess these key aspects of self-care to see how to better meet these common human needs.
- Understand the role of the window of tolerance and how you can return to a place of thoughtful decision-making after encountering distress.

Planning

Knowing and doing are different

- Use the provided worksheets to reflect on these key areas and create self-care routines to meet your physiological and psychological needs effectively.
- Use strategies from mindful self-compassion to practice awareness and self-kindness when suffering.
- Create plans to manage the multiple aspects of life with vasculitis that are guided by your values.

WHO CAN HELP

Reflecting

Who can support you professionally and personally

- Identify different care providers and how they can support you with compassion.
- Create routines that support your needs and bring awareness to your daily experience.
- Use self-reflection tools to pace your day and refine your plans based on needs, preferences, values, and capacity.

Sharing

Providing information with intention

- Create plans that communicate your self-care needs so your loved ones better understand what you do and how they can support you.
- Determine who, how, and what you share with others based on relationships and boundaries.

SETTING GOALS

Tracking

Use the tools provided to set and track goals

- Prioritize your self-care needs, track, and reflect.
- Notice areas that need additional support.
- Consider how meeting the needs of the body and nervous system help you manage emotional and psychological distress more effectively.

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USING THIS GUIDEBOOK EFFECTIVELY

Previous users recommend having a journal, pen, highlighters, and sticky notes to use while reading and completing activities. Do what works for you.

Each chapter has pages labeled Orienting, Organizing, Observing, and Optimizing.

Orienting = Description of a concept that may be helpful for you.

Organizing = Understand how the concept connects to your journey.

Observing = Reflect on your experience of using the concepts and apply them to your path.

Optimizing = Apply the information from the chapter to take action.

Part 1: Understanding Your Compass

Chapter 1: Mindful Self-Compassion



SELF-COMPASSION DEFINED

Self-compassion acknowledges the experience of suffering without judging and responds with kindness. It sounds simple, but it takes practice. Self-compassion requires consistently working with our thoughts, emotions, behaviors, and relationships with kindness.

With self-compassion, you can:

- ***Change internal self-talk to be gentle and validating of personal experiences.***
- ***Hold space for all emotions (especially tough ones), and use language to describe them and acknowledge their impact.***
- ***Set realistic expectations for behavior based on available resources (time, energy, current ability, money, prior experiences, and skills).***
- ***Meet the body's needs.***
- ***Interact with others with accountability and kindness.***
- ***Maintain interpersonal boundaries.***
- ***Acknowledge and accommodate personal preferences.***
- ***Make choices that align with your values.***
- ***Ask for help when needed.***
- ***Advocate for your care needs with professionals.***

Mindfulness is a skill that helps you act with more self-compassion. For people living with vasculitis, mindful self-compassion brings nonjudgmental awareness to our thoughts about having this illness, the related emotions, the sensations (including pain), and the lifestyle changes required to live with it. Mindful self-compassion helps us approach these aspects of daily life with the intention of relieving our suffering.

It's important to emphasize the two complementary aspects of mindful self-compassion: Tender and fierce. Tender self-compassion is soothing, such as gentle self-talk. Fierce self-compassion is taking accountability, such as prioritizing rest and movement daily. Both work together to promote well-being.

To learn more about mindful self-compassion, please visit www.self-compassion.org.

“Mindfulness and self-compassion both allow us to live with less resistance toward ourselves and our lives. If we can fully accept that things are painful, and be kind to ourselves because they're painful, we can be with the pain with greater ease.”

**—Kristin Neff and Christopher Germer,
The Transformative Effects of Mindful Self-Compassion, 2019**

Basics of Mindful Awareness



Mindful awareness is incorporated into many psychotherapeutic approaches and religious practices. Reflection practices, like mindful meditation and journaling, benefit mental health independently of other interventions. Often associated with Buddhist traditions, it's a secular reflective practice. If you'd like to practice mindful awareness in a way that fits your beliefs, connect with a faith mentor in your community.

Throughout the guidebook, there are different opportunities to practice mindful self-compassion along with reflection. Mindful self-compassion is in the first chapter because mindful awareness is an anchor that can be used whenever you feel overwhelmed. When living with vasculitis, it helps to stop and notice our needs – physical, emotional, relational, or spiritual. Self-compassion is like a compass orienting you to health-promoting activities that relieve suffering.



In pop culture, seated meditation represents mindful awareness practices. Though this works for some, guided meditation or active practices can be more helpful when you begin. The skills of moment-by-moment, nonjudgmental awareness are commonly practiced in movement activities like yoga and tai chi, and they can also be practiced in dance, gardening, household chores, or creative expression.

At first, try 5-10 minutes of guided meditation or active practice (like yoga) daily. Build this activity into your daily routine where it fits best. When it's a regular part of your day, try to increase the time you spend on it or use an unguided practice. Numerous resources are available online or at your library to learn more.

Apps that offer guided meditation or gentle yoga exercises can be a great place to start. Apps are tools and not required. Before starting a mindfulness exercise, ensure that your location is safe and free from distractions so you can engage with the present moment and your chosen activity with full attention. Don't practice any type of meditation while driving.

Key Points to Cultivate Self-Compassion

Mindfulness: Moment-to-moment awareness of internal and external experiences. Notice, name, and allow experiences to exist and change.

Self-kindness: Reliably meet the needs of the body, brain, and nervous system. Gentle self-talk, soothing strategies, and boundaries are ways to promote well-being.

Common humanity: Honors the interconnectedness of people and the world, with both joy and suffering (because painful experiences are part of being human).

Nonjudgement: Carefully assess situations. Many things are nuanced (including both “good and bad” qualities), others are neutral. *Neutral example: Boiled rice*

Non-attachment: Allow the natural ebbs and flows in internal and external experiences such as events, thoughts, emotions, sensations, and behaviors.

Tender self-compassion: Attend to your experiences with kind self-talk as a soothing strategy.

Fierce self-compassion: Enact internal and external boundaries around time, energy, relationships, and resources.

MYTHS OR FACTS

ABOUT SELF-COMPASSION

Self-compassion is selfish.



Failing to meet your own needs results in more work for others (family, care providers, community). We all need support at times! Try to prioritize meeting your own needs first. ("Put your own oxygen mask on before assisting others.")

Self-compassion is weak.



Research shows that people who practice self-compassion are better able to cope with challenging circumstances and are more resilient in the long-term. It's protective.

Self-compassion is lazy.



Self-compassion is not self-indulgent or passively accepting difficult circumstances. It asks us to act to prevent and ease suffering.

Self-compassion is pity.



A core component of self-compassion is recognition of common humanity, acknowledging that every being experiences pain and suffering in life. It asks for perspective taking and balance.

PRACTICE: PAUSE AND SCAN

Mindful Awareness is an anchor to be used at various times and is especially helpful whenever you feel overwhelmed. When living with vasculitis, it helps to stop and notice our needs: Physical, emotional, relational, or spiritual. One practical application of mindful awareness that we build on in the guidebook is called the ***Pause and Scan***.

Notice and name these three aspects of awareness using short, descriptive statements.

1. **Thoughts:** Start at the top with your head and consider your current thoughts.
2. **Emotions:** Next, shift down to your heart and the feelings you experience.
3. **Behavior:** Then shift your awareness to your hands and feet and describe your actions.

Examples

Pause and scan while reading:

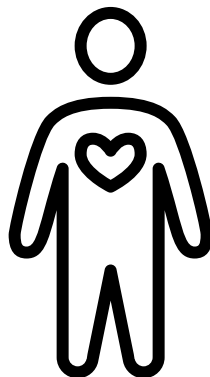
"In this moment I notice myself asking questions about how useful this information will be for me. I feel skeptical and curious. Right now, I'm reading and reflecting."

Pause and scan when walking the dog:

"In this moment, I'm thinking about our upcoming plans. I feel anxious because there's a lot to do. I'm walking quickly."

The head represents thoughts:

The heart represents emotions:



Hands and feet represent behavior:

SELF-COMPASSION INVITATIONS

EXPLORE COMMON BLOCKS

Watch a video of Dr. Kristen Neff talking about the issue that stops folks from being kind to themselves.

LEARN ABOUT YOU

Take a self-compassion assessment. Remember that the information you learn about yourself is one way of acknowledging the present moment with kindness.



TRY A HAND-ON-HEART EXERCISE

- Take three deep breaths. Place your hand on your chest, over your heart. If it's comfortable, close your eyes.
- Notice the sensation of your hand on your chest. The feeling of the breath; the rise and the fall of your chest.
- Take five gentle breaths and repeat a kind mantra aloud or in your head, such as:

***"Everyone is worthy of kindness,
including me."***

- Continue the practice as long as you wish.
- Conclude your practice by opening your eyes, wiggling your toes, and noticing your surroundings.



SELF-COMPASSION IN ACTION

LIST WAYS TO ATTEND TO YOUR VASCULITIS JOURNEY WITH MORE SELF-COMPASSION

EMOTIONALLY

Example: Instead of pushing away feelings of loss, I take time to cry and process the grief.

BEHAVIORALLY

Example: I maintain a consistent bedtime to prioritize my rest so that I have less pain.

RELATIONALLY

Example: I state my needs and opt out of busy weekend plans so that I can pace my energy levels.

TRANSFORMING CRITICAL SELF-TALK INTO SELF-COMPASSION

CRITICAL THINGS I SAY TO MYSELF

Example: I'm so weak! I can't even vacuum my house anymore.

COMPASSIONATE THINGS I COULD SAY

Example: I'm doing the best I can, and everyone needs help sometimes.

FIRST THOUGHTS ON SELF-COMPASSION

Part 2: Packing Your Bag

Chapter 2: Identifying Needs of the Body

Chapter 3: Nervous System and Window of Tolerance

Chapter 4: Psychological Needs, Preferences, and Values

Chapter 5: Your Health Story and Care Plan



Make the Packing List

What do you bring on your journey?



Survival
needs
must be
reliably
met for
you to
thrive.

Part 2 of the guidebook explores how to equip yourself to navigate your journey more effectively. Remember, everyone is on a different path. The next few chapters will help you understand your specific physiological and psychological needs, preferences, and values. Use this understanding to work with your healthcare team to design a vasculitis care plan to fit your situation.

Physiological needs include sleep, food, water, shelter/safety, movement, and tending to wounds/illness. All living beings need these.

Psychological needs include sense of safety, feeling of autonomy (able to choose), social connection, ability to make sense of oneself and environment, and opportunity for self-expression.

Vasculitis and its treatments can impact your vulnerability in every aspect of self-care.

It's assumed that guidebook users have a safe living environment. If you're underhoused or living with the threat of violence, please seek resources to meet these essential survival needs.

Needs, Preferences, and Values

Self-compassion has two complementary aspects: Tender and fierce. Tender self-compassion focuses on acknowledging and validating experiences. Fierce self-compassion focuses on protecting, providing, and motivating oneself.

To develop self-compassion, you must KNOW your needs, preferences, and values and how they change over time, especially with vasculitis. For example, some people on high-dose prednisone have trouble sleeping and must adjust how they meet the need for rest. As the dose changes, other priorities may change, like rebuilding muscle or increasing fitness.

Common Human Needs

Physiological Needs

- Safety (shelter, warmth, free from threat)
- Nourishment (oxygenation, hydration, nutrition, medication)
- Rest (sleep and relaxation)
- Movement

Psychological Needs

- Safety (sense of ease and bodily autonomy)
- Connection
- Creativity and expression
- Meaning and purpose

When living with chronic pain, illness, and uncertainty, meeting our social-emotional and sensory needs can help ease suffering by reminding us to connect with the people and activities that are meaningful to us. In this way, mindful self-compassion provides a framework for prioritizing both physiological and psychological self-care.

Preferences are the likes and dislikes unique to each person. They're often connected to sensory experiences. Understanding our sensory experiences and preferences can be a grounding tool when we're overwhelmed. Values connect individuals to their sense of meaning and purpose. They're unique to each person.

Example of Prioritizing Specific Needs When Living with Vasculitis

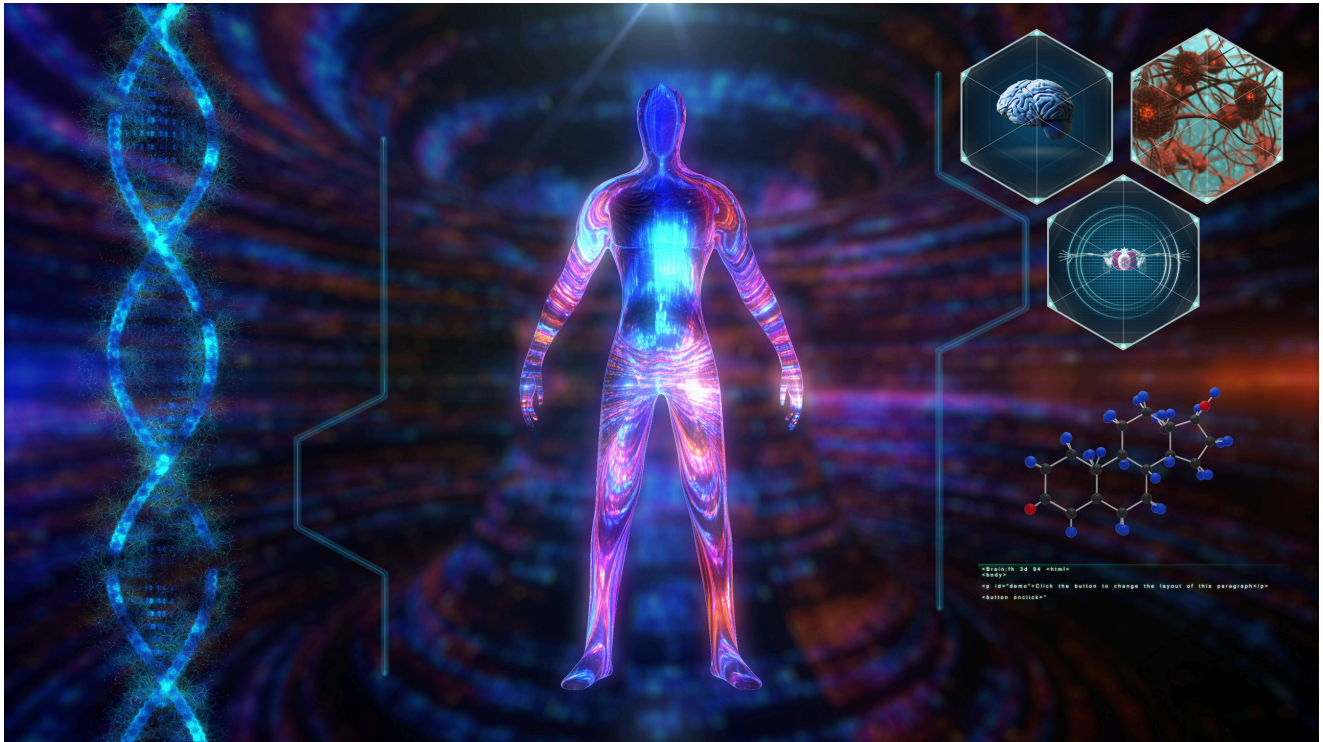
Physiological:

- Attend infusion appointments on schedule.
- Have an afternoon nap every day.
- Drink more water.
- Go to physiotherapy (physical therapy) every week to rebuild strength and protect bones.

Psychological:

- Keep a gratitude journal.
- Attend a vasculitis support group every week.
- Practice yoga daily.
- Plan early family dinners to connect with the people who matter most to you while alert.

CHAPTER 2: IDENTIFYING AND MEETING THE NEEDS OF THE BODY



This chapter provides information about meeting the physical needs for rest, nourishment, and movement that all people share. With or without vasculitis, everyone must effectively meet these needs. Vasculitis or its treatments makes it harder to meet these needs at times. Though they're presented in this chapter as part of physical wellness, they're also deeply connected to mental well-being, as explained later in the guide.

Sleep

Vasculitis and its treatments impact your sleep and energy levels. You can adjust some aspects of your environment and routine to improve your sleep. However, some concerns require more specialized advice from your care provider.

Daily routine can significantly impact sleep at night. Moving your body and getting outside in daylight, appropriate amounts of food and water, and avoiding stimulants (such as caffeine) can help. Keeping an irregular schedule, chronic stress, and screen time just before bed can disrupt sleep. Being diagnosed with vasculitis may be a stressor and impact your sleep, so it's useful to learn ways to manage stress, such as relaxation techniques.

There are also environmental shifts you can make to help you to sleep better, which are covered in the next few pages. Some seem so simple, but they can transform your relationship with sleep.

If you had trouble sleeping before your diagnosis and notice the effects more deeply now, it's vital to address your sleep difficulties alongside your other health concerns. There are medications and interventions to help both physical and psychological conditions that affect sleep. For ongoing sleep troubles connected to symptoms of anxiety or depression, connect with a registered mental health clinician in your area. The most effective intervention for insomnia is a type of therapy called cognitive behavioral therapy for insomnia (CBT-i) that can be delivered by a trained psychologist or psychotherapist. For trauma symptoms, a recognized trauma therapy like cognitive processing therapy (CPT) or eye movement desensitization and reprocessing (EMDR) may help.

If you don't have access to counseling or therapy, try these: Pay attention to your daily routine, create an environment that supports sleep, consider journaling regularly, and use relaxation exercises before bed.

"Sleep is the single most effective thing we can do to reset our brain and body health each day."

- Dr Matthew Walker PhD, Neuroscientist
and Founder-Director of the Center for
Human Sleep Science at the University of
California, Berkeley.

Your Components of Restful Sleep

ENVIRONMENT

Cool, quiet, comfortable, and safe

How is your space?

DAILY ROUTINE

Regular wake-up and bedtime,
movement, nourishment

Do you set yourself up to sleep well?

PHYSICAL AND MENTAL HEALTH

Medication, pain management, stress, or worry

How do you manage these important factors?



Components of Restful Sleep You Can Adjust

ENVIRONMENT

Temperature: Can you optimize the heating and cooling system in your home? Fans or extra blankets may help.

Darkness: Wear an eye mask or install blackout curtains. Reduce any electronic lights in the space. Avoid sleeping with the TV on.

Sound: Some find white noise or nature sounds soothing. Others use earplugs to cancel out any noise from traffic or a partner.

Comfort: What's your bed like? Bumpy and lumpy? If a new mattress isn't possible, consider a mattress topper or extra padding.

Co-Sleeping: Though you may be used to sleeping with a loved one, does it work right now? If sharing a bed adds stress to your sleep and you have space in your living arrangement, consider sleeping separately while you manage any impacts of vasculitis on your sleep. You can cozy up together again when you feel better.

DAILY ROUTINE

Movement: Moving your body during the day helps you sleep better, even if you stand once per hour, do arm circles and leg lifts while seated, or go for a short walk. Avoid intense exercise in the evening, though a gentle walk or stretch can promote relaxation.

Consistent Wake-Up Time: Try to wake up every day at the same time, even if you need to rest or nap later in the day. Avoid naps in the late afternoon or evening.

Nourishment: Paradoxically, difficulty sleeping can be a side effect of not eating enough to meet your energy needs, so be sure to eat regularly.

Play: However you define it, attempt to engage your brain enjoyably during the day so that you avoid bedtime procrastination, which can seriously impact your sleep routine. Consider a device curfew approximately one hour before you hope to sleep. Don't scroll into the wee hours.

Sleep Reflection

How's your sleep? Can you prioritize rest with small changes to your environment, routine, or self-care practices to improve the quality of your sleep? Would it help to discuss your sleep with your care team to see if there are supports available?

Assess: From 0-10, how would you rate your average night's sleep? Why?

Act: Are there any aspects you could adjust in your daily routine or sleep environment to improve your sleep?

Pain and symptom management: Are there any specific concerns that you could discuss with your care provider?

Prepare for Better Sleep

3 things that could help you sleep better

30-90 minutes before bedtime

1- **Device curfew:** Put the phone, tablet, or remote control down earlier than usual and choose a new habit to unwind.

60-90 minutes before bedtime

2- **Worry journal:** Does your mind whirl with things to remember for the next day or different anxieties? Schedule some time before you go to bed to jot things down. Don't try to figure them out now just a note to prompt you the next day.

20-30 minutes before bedtime

3- **Relaxation exercise:** Guided body scans, progressive muscle relaxations, or visualizations can help you relax and fall asleep. You'll find links to try later in the guidebook. There are numerous apps and offerings.



What small change could you make to improve your sleep?

NOURISHING THE BODY

FUELING RECOVERY AND MAINTAINING REGULATION



Every food group has important elements that support the body in recovery and regulation.

Numerous diet trends and fads attribute specific health benefits to foods that are championed while villainizing other foods. Based on current evidence, there's only one "evidence-based diet" proven to support health for many: the Mediterranean diet. This diet includes every food group and even sweets in moderation. It promotes fresh foods and lean proteins from both plant and animal sources. Other approaches may claim benefits, but don't have rigorous evidence to back them up.

If you have specific health concerns such as kidney disease, diabetes, inflammatory bowel disease, high blood pressure, and/or you're recovering from an eating disorder, please follow the specific dietary recommendations from your care provider. For clarity, connect with a registered dietician/nutritionist in your area.

Two other evidence-based approaches that don't list specific "good vs bad foods" or endorse a specific diet are mindful eating and intuitive eating. They aren't diets and don't promote weight loss. These approaches deepen awareness of food from production to post-consumption, encourage you to express gratitude, and help you hear your body's hunger and satiety (feeling of fullness) cues. They make space for dietary needs, preferences, and religious requirements, and you don't need to buy an app or sign up for a program. There are books to learn more about these ways of nourishing the body.

Importantly, these ways of meeting the body's nutritional needs don't increase risks for disordered eating, eating disorders, OCD, or food anxiety. They don't encourage fixation on body shape or size, but on how nourishing the body attentively improves function and well-being. Fad diets carry both physical and psychological risks, and don't help overall well-being.

FUELING RECOVERY AND MAINTAINING REGULATION

Regular nourishment with a variety of foods is essential to widen the window of tolerance and promote nervous system regulation. When the body can depend on regular nourishment, there's less physiological stress and it can move through environmental and emotional distress more capably. When you live with vasculitis, especially with medication side effects that change the size and shape of the body, it's tempting to follow fad diets in an effort to regain a sense of control and to "fit in" to societal expectations for bodies. This is understandable, but the risks of following fad diets are often amplified for folks dealing with chronic health concerns. And it adds another stressor for your body and brain to cope with effectively, along with the other priorities.

Alternatively, "giving up" or the "whatever" approaches to food and movement are equally unhelpful for people living with vasculitis. These amplify the negative side effects of medications (like prednisone) and can cause further long-term damage of steroid-induced diabetes, osteoporosis, and kidney or liver problems. It increases the risk of meal skipping and then over-eating that's taxing and uncomfortable.

Instead, follow a regular pattern of eating that includes all food groups in moderation over 2-4 set mealtimes and 1-3 snacks every day. Work with a registered dietician (RD) or registered nutritionist in your area if you're uncertain what this looks like for you. No body is the same, so no single plan for eating will be right for every person. Use personalized advice along with self-awareness to nourish your body reliably.

Start to notice hunger cues, which aren't always a grumbly tummy and can include difficulty concentrating and fatigue or other discomforts. Respond to hunger cues compassionately with nutrient-dense snacks like veggies and hummus or cheese and whole-grain crackers between meals. Similarly, respond to satiety cues by paying attention to how your body responds during the meal. Stop eating when you've had enough or take a few extra bites of nutrient-dense options like protein and vegetables if still hungry.

If you notice regular post-meal discomfort, try food tracking and discuss with your care provider. Folks with vasculitis often have digestive difficulties. Some can be addressed by identifying the offending food and choosing to skip it. Other problems need more investigation and treatment. Working with your PCP and an RD can help you live more comfortably, because every body needs nourishment.

Follow a regular pattern of eating every day, focus on including more nutrient-dense foods, and listen to your hunger and satiety cues: These are some of the most self-compassionate acts you can do. Nourishing your body promotes physical healing and supports mental health.

Foods to Keep on Hand

PROTEIN AND DAIRY

- yogurt (dairy or nondairy)
- nut butter
- cheese
- frozen meatballs
- tofu
- canned beans
- canned fish or meat
- eggs
-
-
-

VEGETABLES AND FRUITS

- frozen broccoli or spinach
- frozen mixed berries or fruits
- apple sauce
- dried fruit
- tomato sauce
- frozen mixed vegetables
- preserved fruits (i.e., peaches)
- root vegetables like potatoes/carrots
- canned vegetables
- preserved vegetables (i.e., pickles)
-

COMPLEX CARBOHYDRATES

- oatmeal
- brown rice
- whole grain pasta
- freezer waffles
- whole grain pancake mix
- cereal
- granola bars
- wraps
-
-
-

EASY AND FUN FOODS

- canned soup/stew/baked beans
- frozen entrees
- chocolate
- jam
- jello
- pudding
- chips
- cookies
-
-
-

Relationship with Food

People struggle with their relationship with food for many different reasons. Feeling conflicted or confused about what to eat or how to feed yourself is common. Reflect on where you are in your relationship with food and nourishing your body regularly. If you notice more to it, reach out to your PCP or a mental health provider for support.

What's your current eating pattern?

What are your hunger cues?

What are your satiety or fullness cues?

3 STEPS TO Nourishment

1

Throw out arbitrary food rules (based on fad diets, counting calories or carbs, good vs. bad foods, etc.). Listen to your body (hunger/fullness cues) and how it responds to different foods.



2

Keep fresh, quick, easy, and tasty foods on hand for times when pain, fatigue, or illness overwhelms, and nourishing your body feels like a chore. Then you can feed your body regularly and more easily. It's especially important during these times to nourish your recovery.



3

Develop a weight-neutral and respectful approach to nourishment every day with regular meals and a flexible attitude, no matter your body size or activity level.

Flare-Up Menu

Develop a one-week meal plan including easy, fresh, and tasty options for you and your loved ones. Focus on things you keep on hand and don't require much effort for when your symptoms flare. Include variety. Try to balance protein, fruit/vegetables, and complex carbohydrates.

Easy Fresh Tasty

Things to keep on hand

Monday

Tuesday

Wednesday

Thursday

Friday

Saturday

Sunday



Movement

Regular physical activity is important for EVERY body. However, it can be a huge challenge to get moving after a vasculitis diagnose, flare-up, or setback. Check out the Victory Over Vasculitis Physical Wellness and Movement resources, designed by patients with vasculitis who also have professional expertise in exercise. As they write, **“When we choose movement that is both appropriate to our fitness level and respects where we are in our vasculitis journey, our bodies thank us.”**

Restoring physical capacity is an investment in your future ability, endurance, strength, bone health, and resilience. Exercise can reduce inflammation and improve mental health. There are two main types of physical exercise, and both are important: Aerobic exercise (cardio) and muscle strengthening (strength training). Check with your healthcare provider before beginning any new exercise plan. A trained movement professional in your area can also create a plan based on your current capacity and movement goals.

Sometimes people have a mental barrier getting in the way of regular physical activity because exercise is associated with pain, competition, or discomfort. For those who previously enjoyed exercise, their illness may have changed their relationship with their body. Re-engaging with movement can bring up feelings of frustration and grief. This is understandable. Remember to practice self-kindness by respecting your body’s cues to stop or rest. Consider working with a regulated mental health professional trained in grief, body image, and/or trauma.

Engage in movement that’s gentle, accessible, and fun!



Gentle Movement Activities

There's a narrow definition of exercise that's about going to a gym and sweating for an hour or more. Consider other ways to move your body at home or in your community, independently or socially. Depending on your current health and activity level, start with five minutes at a time and check in with yourself regularly. If you feel up to it and want to do more, increase by five-minute increments.



Walking



Yoga/Pilates



Tai Chi



Dancing



Bowling



Swimming



Cycling



Gardening



House or Yard Work

Movement Reflection

Vasculitis often impacts how people move. Your body's functioning and endurance could be drastically different than before you were sick. You could have been extremely active or relatively sedentary prior to your vasculitis diagnosis. Regardless, including regular exercise now is an important factor in your well-being. Use the following questions to determine your current movement baseline.

Describe your current level of activity and stamina:

**Are there movement activities you enjoyed prior to your diagnosis that you miss?
If so, what are the barriers to engaging in them?**

What do you envision as joyful movement?

Start Wherever You Are

It's difficult to get moving after illness. It's important to both acknowledge the struggle and to act with fierce self-compassion.

With vasculitis, this might look like: *I notice that I struggle to walk far, and it sucks! But I can walk to the mailbox and rest on the bench, then walk home. I'll do that daily until it becomes easier.*

Please don't let perfect be the enemy of the good enough when taking care of your movement needs. There are exercises and movement activities available for every body, even those who require special support.

Progressive Muscle Relaxation engages your body using micro-movements and can be done while sitting or lying down.

Soma Yoga with Molly: Molly is a certified Soma Yoga therapist and trainer who has vasculitis. She's provided virtual and in-person workshops for the Vasculitis Foundation.

Seated Strength: In this short video, Brandon Hudgins, who has a Master's degree in Kinesiology and Exercise Science and is also a former long-distance runner with vasculitis, take you through a series of strength exercises that can be done while seated.

Daily Movement Practice: If you're able, incorporate a short morning stretch or walk (15 mins of movement) into your daily routine. If you can be more active, develop a daily movement practice that incorporates both aerobic and strength-building exercises. Movement is an essential component for your vasculitis journey.



Scan to view the online resource page.

<https://vasculitisfoundation.org/wellbeing-resources/>



Check out the next activity which uses goal-setting strategies from later chapters.

Movement Goals

Use the following prompts to set movement goals. Use mindful self-compassion when choosing something gentle and enjoyable to you. Check in with yourself before, during, and after.

SPECIFIC: DEFINE WHEN,
WHERE, AND HOW OFTEN.

MEASURABLE: HOW WILL YOU
KEEP TRACK?

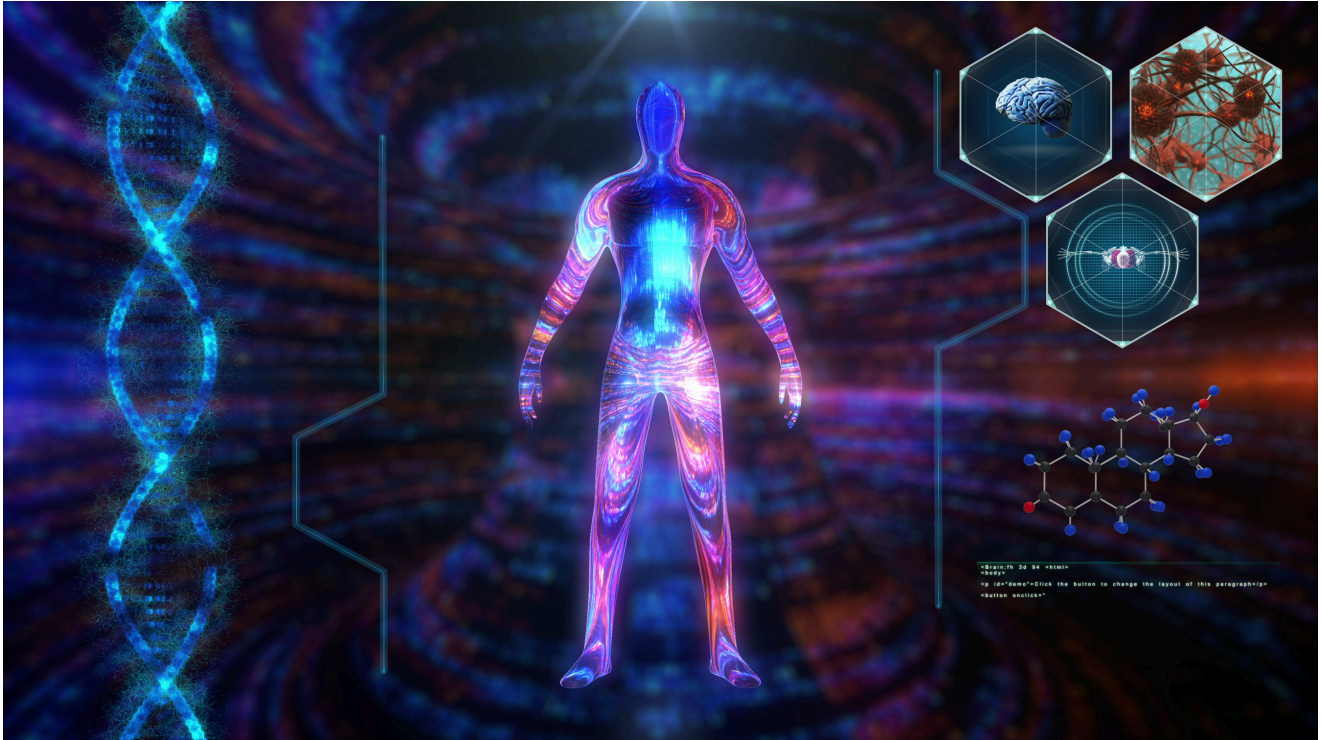
ATTAINABLE: BASED ON
CURRENT HEALTH STATUS.

REASONABLE: BASED ON YOUR TIME AND RESOURCES. DO
YOU NEED ANYTHING (SPORT SHOES OR A YOGA MAT)?
HOW CAN YOU MODIFY YOUR GOAL IF NEEDED?

TIMELY: FOR THIS SPECIFIC GOAL, CONSIDER CHOOSING
SOMETHING YOU CAN DO MOST DAYS FOR 2-4 WEEKS.

CHAPTER 3: THE NERVOUS SYSTEM

A BRIDGE BETWEEN YOUR PHYSIOLOGICAL AND PSYCHOLOGICAL WELL-BEING



Understanding nervous system regulation is helpful for people living with vasculitis. Your nervous system is your body's threat detector. Sometimes the alarm is set off. While that's important and helps with survival, sometimes it stays on too long. This is chronic stress and can cause more physical and mental health problems. Meeting your physical, psychological, and nervous system needs reliably can turn off that alarm. Then you'll feel more relaxed, which can help you experience a calmer, connected, and enjoyable life.

THE NERVOUS SYSTEM

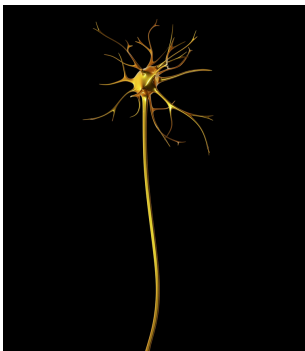
A BRIDGE BETWEEN YOUR PHYSIOLOGICAL AND PSYCHOLOGICAL WELL-BEING

The human nervous system connects all parts of the body with the brain. It's an amazing internal communication system! It works faster than human language and independently of conscious awareness.

Sympathetic Nervous System: Responsible for autonomic (a.k.a. automatic) functions like heart rate and blood pressure. Known for its role in the fight/flight response.

Parasympathetic Nervous System: Also responsible for autonomic functions as the recovery part of the stress response. Known for its role in the freeze/fawn response.

The parasympathetic system is also part of the relaxation response (rest and digest) which can be confusing. To learn more, check out resources such as *Polyvagal Practices: Anchoring the Self in Safety* by Deb Dana LCSW.



Helpful Vocabulary for Understanding Nervous System Regulation

Vagus Nerve: Primary nerve for the parasympathetic nervous system with an important role in digestive function, heart rate, immune system, and mood. Its branches connect through much of the torso.

Instinct: Reactions that occur without conscious decision-making and based on survival.

Conditioned Response: Something learned, often early in life, then practiced in response to the same events, so that when we do it now, it feels automatic.

Scripts: Similar to a conditioned response, scripts are beliefs, thoughts, and behaviors that feel automatic. Unlike instincts, scripts can be challenged and rewritten when they're unhelpful.

Routines: Like conditioned responses and scripts, these are behaviors that can become automatic. At first, they're intentional and designed to support a desired outcome.

*Instincts, conditioned responses, scripts and routines are different processes—
but can feel the same when we go through the motions of life
and they occur outside of awareness.*

NERVOUS SYSTEM REGULATION: THE WINDOW OF TOLERANCE

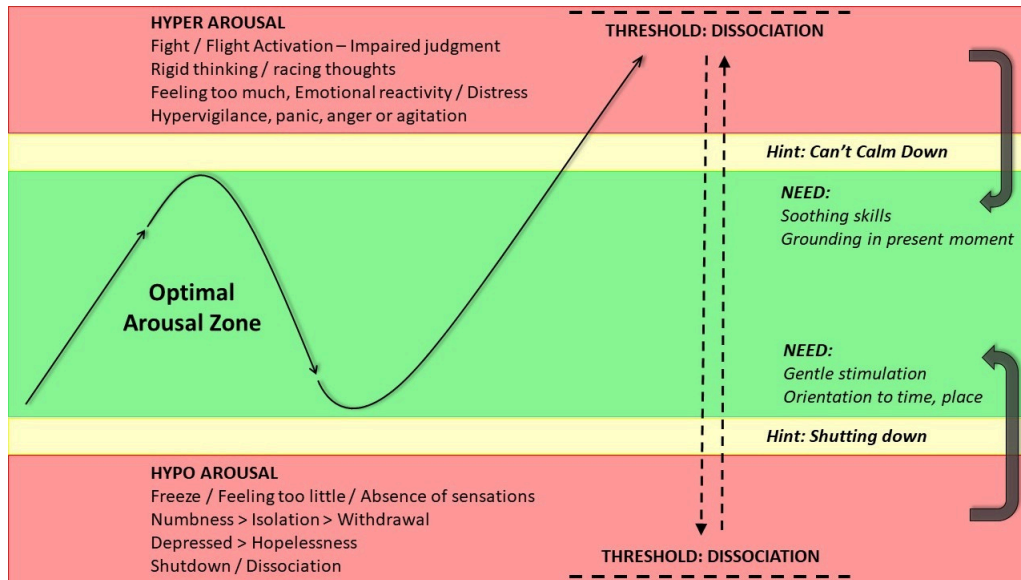


Image from: <https://mi-psych.com.au/understanding-your-window-of-tolerance/>

- Optimal Arousal Zone: Calm and Connected Thriving Mode**
- Hyperarousal: Fight/Flight Survival Response Mode**
- Hypoarousal: Freeze/Fawn Survival Response Mode**

The window of tolerance is a model of the nervous system responses first used by psychiatrist Dr. Dan Siegel. This model has three distinct states:

1. **Optimal Arousal:** You feel alert, engaged, and motivated.
2. **Hyperarousal (Survival Mode):** Occurs when the nervous system perceives a threat and assesses that we can get away (flight) or protect ourselves (fight). You may feel:
 - Panicky
 - Hypervigilant
 - Restless
 - Startle easily
 - Racing thoughts
 - Unable to relax

3. Hypoarousal (Survival Mode): If you feel stuck, trapped, and helpless due to your diagnosis, its treatments, or ongoing pain, then the hypoarousal system may activate, causing people to withdraw further from people and activities, even ones they may still have the physical ability to do. This can lead to further physical deconditioning and more social isolation. When thinking about making changes, people stuck in freeze mode say, “I can’t...” or “I wish I could but...” or “I don’t know what I like anymore...”

Hypoarousal prompts the body to respond in one of two ways.

- a. Go into shutdown mode to hide, wait out the threat, or go numb (freeze).
- b. The fawn response activates when people try to befriend or please the threat in an attempt to receive mercy.

The freeze state occurs after an extended period of fight/flight energy or ongoing stress without any recovery. It's the brain and body trying to conserve energy to escape later. It was a wise response years ago when humans faced large predators or natural disasters, with few options to solve the problem except to wait. However, this response is much less helpful when living with a chronic illness.

In the hypoarousal freeze state, a disconnection occurs across multiple aspects of life. You feel lethargic. It's a push to leave the house or answer a text. The apathy is debilitating. Shifting out of freeze or shutdown mode requires action, one step at a time, that's new and different to tell the body that it's not stuck. Slowly, you reconnect with your self, your people and the activities that are meaningful to you.

These survival responses developed to help humans adapt to a variety of circumstances. However, continuously interacting with the world from any of the survival modes can lead to a sense of dissatisfaction, fatigue, and dis-ease.



NERVOUS SYSTEM REGULATION: THE WINDOW OF TOLERANCE

The optimal arousal zone of the window of tolerance is also known as a state of flow or Zen in some traditions. It's nicknamed the rest-and-digest state. This state includes all emotions and even stress; it's not ongoing happiness or a lack of distress. The key difference between being in this regulated state while experiencing heightened stress or unpleasant emotion is a sense of safety, the ability to use language, an appropriate orientation to time and space, and the ability to think critically and problem-solve. It allows for perspective-taking: the ability to narrow focus and notice granular distinctions and also to zoom out and see patterns or innovate. This state allows genuine connection with other people, animals, and even ideas. It's a true feeling of integrated presence.

When in the optimal arousal zone (within the window), unpleasant emotions can be felt without overwhelming the entire body and brain. Or if overwhelm occurs, it can be noticed and calmed. Deadlines for work or school can be experienced as an exciting challenge (or frustration). However, they don't lead to hopelessness or helplessness. There's proactive energy to complete the tasks at hand. The saying "this too shall pass" reflects this state of momentary discomfort while in the window of tolerance and experiencing distress.

By becoming familiar with your own signs of safety and dysregulation, you can work with the nervous system's arousal. Returning to your window of tolerance allows you to make choices that align with your goals and values because you can access problem-solving and meaning-making capabilities that require mindful awareness and executive functioning (complex decision-making).

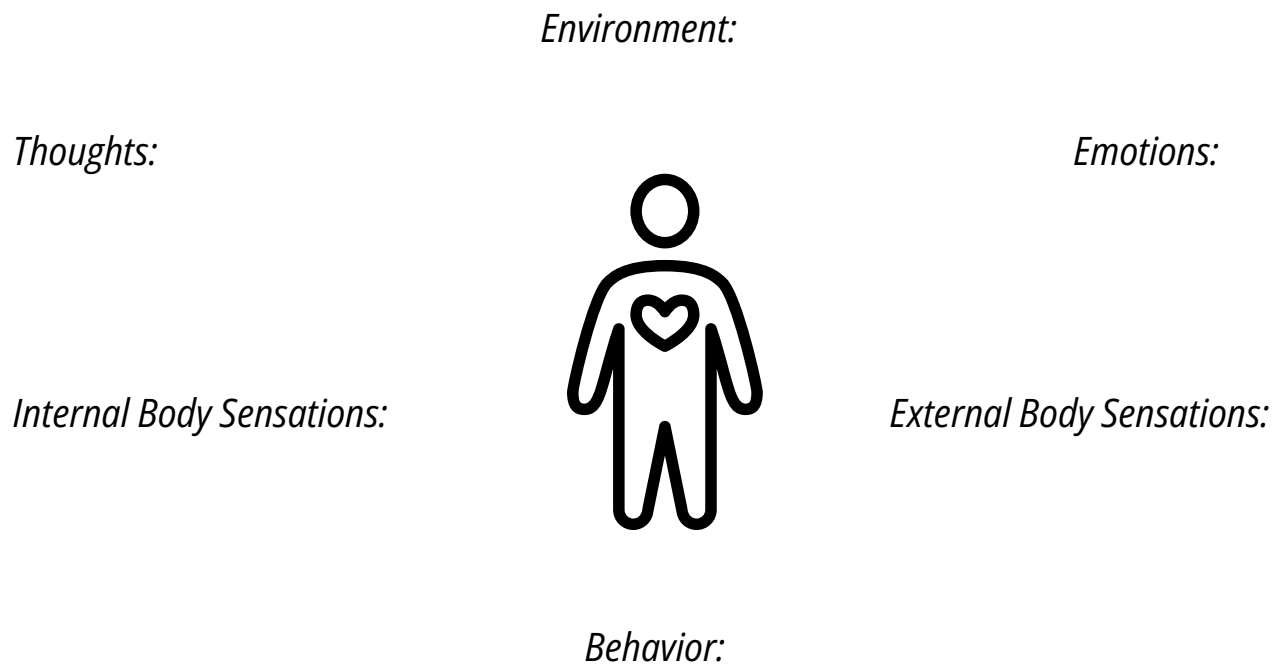
Signs of Safety or Comfort

- Environment: Tidiness and order, temperature (not too hot or cold), comfort items like blankets, etc.
- Thoughts: Orientation to time and place, can describe experiences, ability to play logic games like Sudoku
- Emotions: Able to observe and name emotions and choose how to express them safely
- Sensation: Pleasant, enjoyable, calming, or soothing
- Behavior: Understandable and connected to routines or goals

On the next page, use the pause and scan image to note your personal signs of safety and nervous system regulation.

NERVOUS SYSTEM REGULATION: THE WINDOW OF TOLERANCE

Pause and Scan: Signs of Safety, Comfort, and Regulation



Questions to Ponder as You Check in with Yourself

Environment: What do I notice around me? Is it orderly? Is there space for me?

Emotions: Do I feel at ease? Do I notice contentment or satisfaction?

Body Sensations: Are my muscles relaxing? Is my heart rate even?

Behavior: What activities soothe me? What am I doing when I feel safe?

Thoughts: Am I curious and flexible in my thinking? Can I view things from different perspectives?

THE NERVOUS SYSTEM AS THE BRIDGE BETWEEN BODY AND BRAIN

The Survive State: Your nervous system senses danger in the environment, your body, or interpersonally without you being fully aware. When your brain flips the switch into the survive state, you may feel alert, a surge of energy that asks to move (fight or flight), heightened pressure to please or perform, the urge to distract/detach, a sense of numbness, or the desire for proximity to another person for safety (not the same as connection).

There are times when survival modes are 100% the most appropriate responses to situations. However, sometimes there's a glitch in the system. Like smoke detectors, the threat detection system can go off just for burnt toast. Burnt toast doesn't need a fire truck or even a fire extinguisher. Similarly, there are many burnt toast situations for people, especially if you live with a chronic illness that has threatened and changed your life. This means the survival modes for many people with vasculitis can be over-responsive and easily activated when there's no imminent threat. This is understandable and manageable (if you know what's happening). Sometimes, the treatments for vasculitis (looking at you, Prednisone) contribute to dysregulation.

Dysregulation (both hyperarousal and hypoarousal) hijack your thoughtful decision-making processes with the goal of survival. This is important and innate; you aren't doing anything wrong when this occurs. However, you can learn how to recognize when this switch from thrive to survive happens through mindful awareness. Sometimes, you might "flip your lid" despite being a typically grounded and competent human, especially when on high-dose steroids. Getting quickly and safely back within your window of tolerance when this occurs is beneficial, and mindful awareness can help with that.

Self-compassionate strategy: RAIN

- R**ecognize dysregulation is occurring
- A**llow the sensation
- I**nquire (get curious in the moment)
- N**urture your system

Movement helps communicate with the body and resolve dysregulations. For example, pushing against a wall, running, jumping jacks, boxing or other intense movements can be cathartic for fight energy. If you can't do intense movement, consider progressive muscle relaxation.

NERVOUS SYSTEM REGULATION: MAPPING YOUR DYSREGULATION

Using this diagram, note your experience of hyperarousal (fight/flight energy that activates under threat).

Environment:

Thoughts:



Emotions:

Internal Body Sensations:

External Body Sensations:

Behavior:

NERVOUS SYSTEM REGULATION: MAPPING YOUR DYSREGULATION

Using this diagram, note your experience of hypoarousal (freeze/fawn energy that activates under threat).

Environment:

Thoughts:

Emotions:



Internal Body Sensations:

External Body Sensations:

Behavior:

UNDERSTANDING REGULATION AND DYSREGULATION

Widening the Window of Tolerance: This refers to improving your capacity to manage intense emotions and sensations before triggering the survival responses. This can occur in multiple ways. An important and often overlooked aspect of widening the window of tolerance is attending to common human needs, both physiological and psychological.

The body's physiological needs are met when you eat and sleep on a regular schedule, take medications as prescribed, avoid non-prescribed psychoactive substances, move the body, practice relaxation, and tend to physical injury or illness in a timely way. This supports nervous system regulation, and people access the thrive state more reliably. Failing to meet the needs of the body causes added stress and can narrow the window.

Attend to your psychological needs for sense of safety, meaningful connection to other people, creative expression, exploration, and meaning-making. These are NEEDS that are deeply connected to human well-being. Failing to meet these psychological needs causes added stress and makes it harder to cope.

For more information about nervous system regulation, look for reputable sources such as Dr. Dan Siegel MD PhD, Dr. Stephen Porges PhD, Deb Dana, Dr. Peter Levine PhD, and Dr. Janina Fisher PhD. To work with symptoms of traumatic injury, connect with a helping professional who's comprehensively trauma trained and ensure they're certified to practice in your area.

The Thrive State: Calm, curious, and compassionate. It's integral for learning, growth, and healing.

Why does this matter for navigating the vasculitis journey?

In the thrive state, you can hold multiple perspectives, maintain awareness of emotions and sensations, remember past events in detail, and plan for the future including multiple-step processes. In the thrive state, you can solve complex problems and learn new information. You can attend to your own needs, preferences, and values with care and connect meaningfully with the people around you.

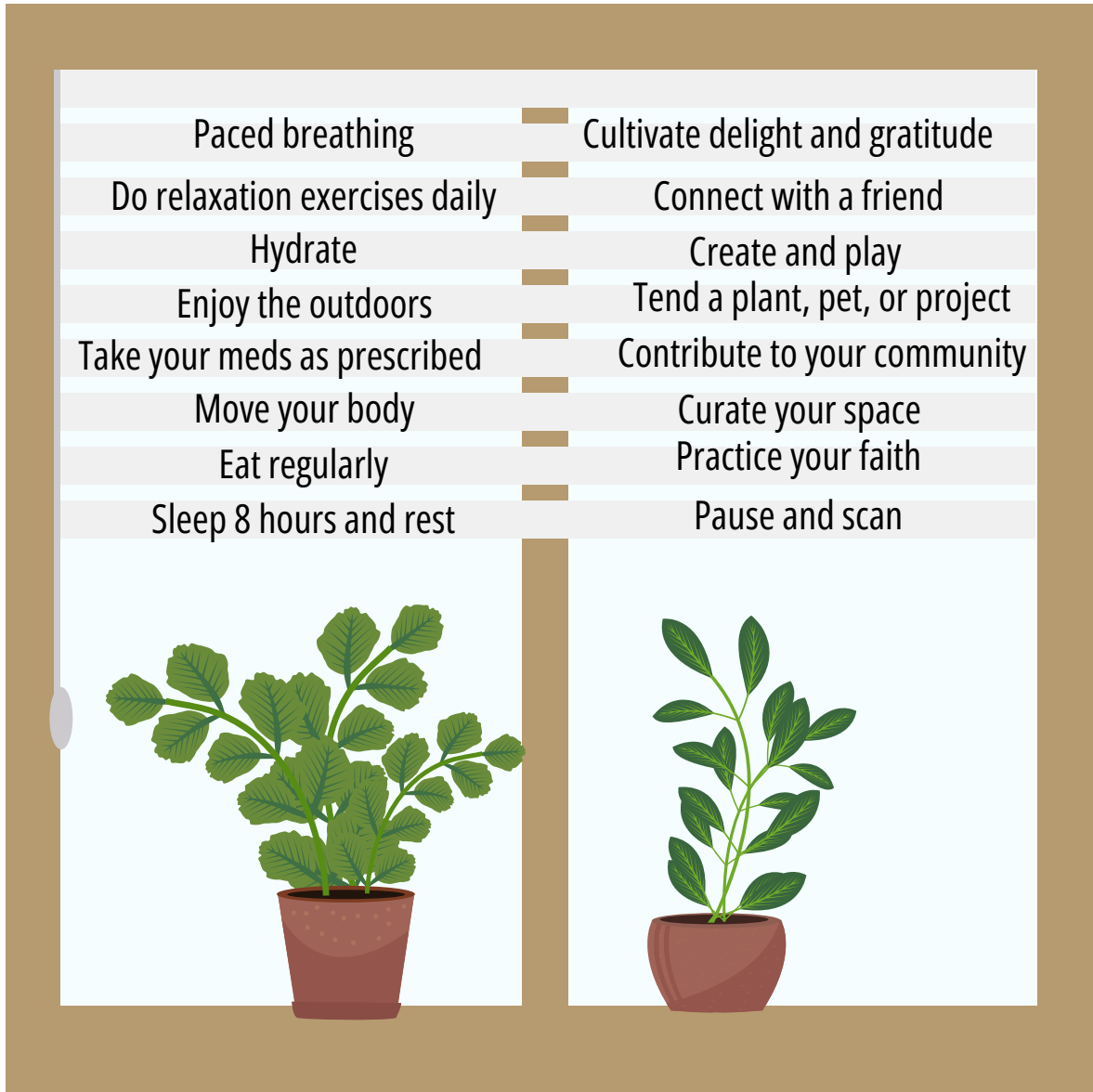
When you thrive, you can cope with daily demands and respond effectively to new, challenging situations.

Survive State: Hyperarousal of sympathetic nervous system or hypoarousal of parasympathetic nervous system in response to perceived threats.

Thrive State: Sense of safety that allows for connection, problem-solving, and meaning-making. A regulated nervous system.

Both states are vital and important to human experience. They work together to keep us alive.

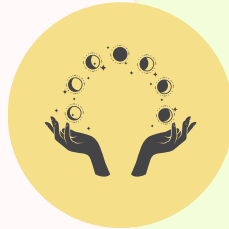
STRATEGIES TO WIDEN YOUR WINDOW OF TOLERANCE



MYTHS **OR** FACTS

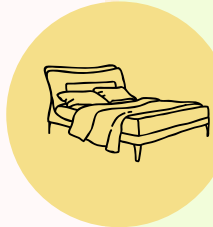
ABOUT FATIGUE

It's always caused by doing too much.



Fatigue can be a symptom of hypoarousal, not an indicator of energy use. Learn more about your nervous system and regulation to understand the difference between exhaustion, lethargy, and drowsiness.

There is nothing to do about it except sleep more.



When fatigue is from nervous system dysregulation, sleep isn't always the best way to manage it. In fact, gently moving the body and engaging the senses helps regulate the nervous system and could decrease fatigue.

It's all in my head, so I just need to push through.



Though "pushing through" may work for some, nervous system dysregulation is a systemic issue and not just "in your head." A holistic approach including regular sleep, nourishment, and stress management practices can help.

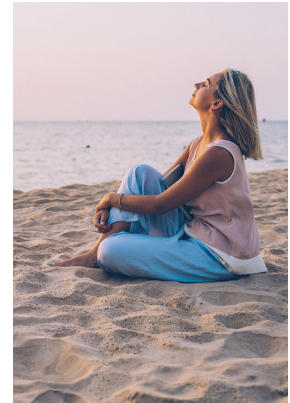
No one understands how tired I really am.



Feeling misunderstood by loved ones, employers/teachers, and care providers when you change plans is frustrating. Don't explain why you have specific limits. Focus on clear boundaries for what you can and can't do when your needs change. People don't have to understand it to respect and support you.

EXERCISES TO NURTURE THE NERVOUS SYSTEM

Self-soothing strategies help regulate the nervous system and help you recharge, and rest.



MINDFULNESS & MEDITATION

- Listen to a guided meditation
 - *Loving Kindness* meditation by Kristen Neff, PhD
 - *Relaxation* meditation by Rick Hansen, PhD
 - *Gathering & Arriving In Presence* a 4-minute meditation by Tara Brach, PhD
 - *Body Scan* meditation
- Try progressive muscle relaxation
- Experiment with box-breathing

SOUND & MUSIC

- Consider connecting with a music therapist and sound healing
- Learn about and use Bilateral Music
- Listen to a comforting playlist in your favourite streaming app
- Play an instrument
- Sing or hum a familiar song
- Use nature sounds or ambient noise in the background while you rest
- Dance with a loved one

VISUALIZATION

- Guided visualization from an App
- *Safe Place* guided visualization
- *A Sleep Story* from an App
- The *Container Exercise* from EMDR Therapy
- Imagine yourself performing an activity that brings you joy
- Remember in full detail a moment of delight from the recent past (a hike or laughing with a loved one)

CREATE

- Write creatively or journal
- Craft: knit, sew, mold with clay, scrapbook, collage, bead jewelry, carve wood, or whatever craft you enjoy can all be engaged with mindfully to regulate the nervous system
- use mindful coloring, drawing, or create mandalas to focus, relax, and quiet your worries

CONNECT

- Play cards or a board game with loved ones
- take a walk with a loved one or a pet
- Gentle touch: have a loved one or massage therapist provide a relaxing massage
- Dance in the kitchen with a loved one
- Consensual intimacy with a trusted partner
- Cuddle with a loved one and watch a favorite movie together



Visit the resource page to find links for these and other activities that nurture your nervous system.
vasculitisfoundation.org/wellbeing-resources/

NERVOUS SYSTEM REGULATION

CALM AND PEACEFUL STATE REFLECTION

What are your signs of safety? How does your body feel when you're content? Do you have a special place where you feel most at home? Use the following prompts to focus on those internal and external signals that everything is okay for now. Cultivating this calm and content state by remembering the feelings and sensations when you're safe and secure can be a tool to turn to when overwhelmed, anxious, or worried.

DESCRIBE WHERE YOU FEEL
COZIEST AND AT HOME.

NAME THE PEOPLE YOU FEEL
MOST AT EASE AROUND.

DESCRIBE AN ACTIVITY YOU
FIND RELAXING.

DESCRIBE HOW YOUR BODY FEELS WHEN
YOU ARE SAFE, AT EASE, AND RELAXED.

IS THERE AN IMAGE OR METAPHOR THAT
GOES WITH THIS SENSE OF CONTENTMENT?



MINDFUL ACTIVITY TRACKER

Practicing mindfulness daily helps regulate your nervous system and widen your window of tolerance. It helps you notice dysregulation, then respond more effectively. Use this calendar to track the days when you do an intentional mindfulness practice, something from the page of soothing activities in this guidebook (p.48) or a guided meditation from an app. Choose a short practice (5-15 minutes) that you find interesting or enjoyable.

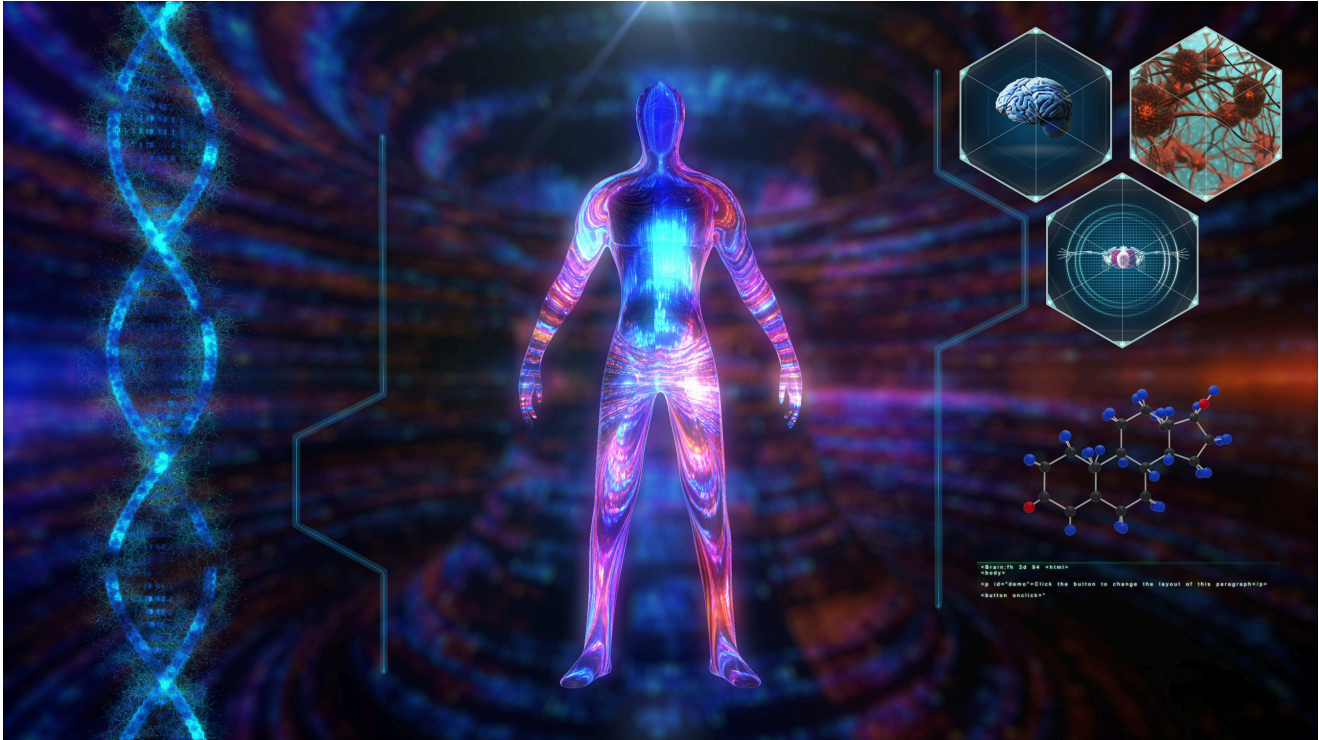
SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

After 6 weeks of practicing, reflect on what it was like to have a mindfulness practice.

Which activities did you enjoy the most?

If you didn't like any of the activities you tried, are there other ways you check in with yourself?

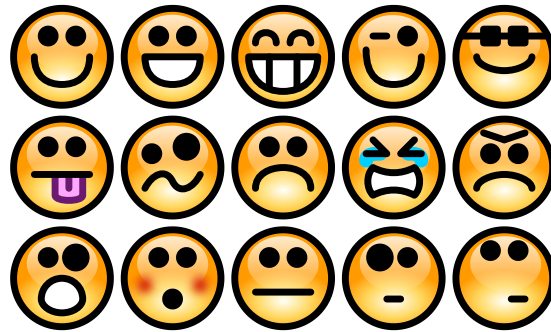
CHAPTER 4: EMOTIONAL AWARENESS, PREFERENCES, AND VALUES



Humans don't come with operating manuals. But developing emotional awareness is like reading the operating manual for you. In previous chapters, physiological and psychological needs have been discussed. In this chapter, strategies for tuning into and understanding emotional experiences are shared. Noticing the experiences and activities that are pleasurable and meaningful is another step in navigating your journey with more self-compassion. Both preferences and values can be anchors during times of difficulty (life transitions, illness flares, relationship troubles), directing people to what matters most so they can make decisions that will work best for them.

EMOTIONS AS UNIQUE DATA

DEVELOPING EMOTIONAL AWARENESS AND AGILITY



Every emotion provides information about a need, preference, or value

Harvard Medical School psychologist Susan David writes in her book, *Emotional Agility*, that emotions are data points, not directives. Emotions provide information about your unique needs, preferences, and values without indicating WHAT you should do. She discusses how disconnecting from emotions by ignoring, minimizing, bottling, or brewing impairs effective decision-making. Also, feeling a certain way doesn't provide an excuse for behaviors that hurt you or others. Noticing the emotion, naming it, and working to understand the information is building emotional agility. Simply knowing emotional states is not enough; processing and responding effectively is key.

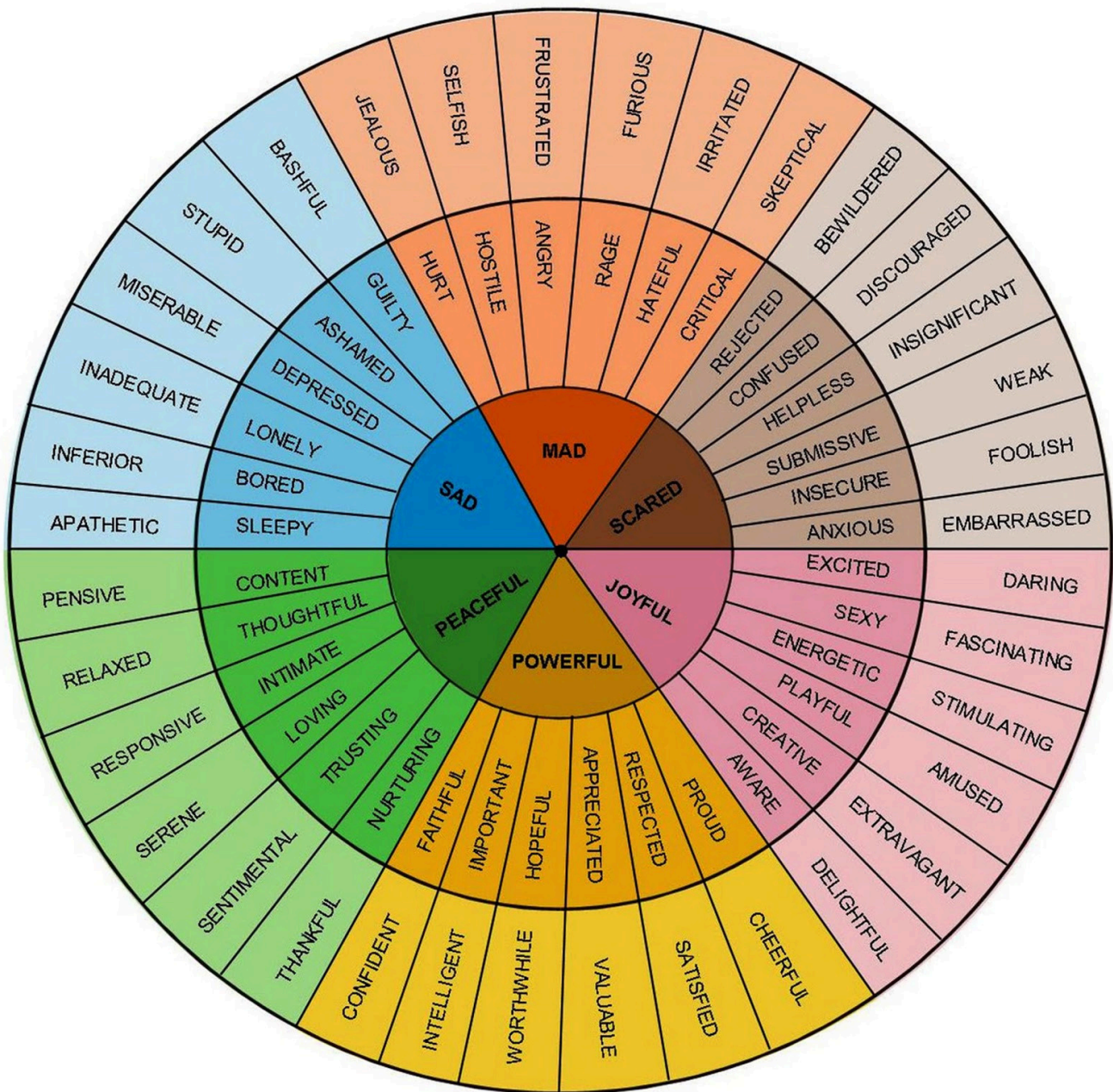
Emotional agility skills can help you manage the impact of vasculitis diagnosis and treatment on the aspects of life that matters most. Emotions give clues on how to build a self-care plan that works for your needs, preferences, and values.

To notice, name, and respond to emotion cues, it's vital to understand emotions in general and how they show up for you in your thoughts, behaviors, and body sensations. On the next page is an emotion wheel. Like many concepts, this attempts to represent a complex human experience in words and pictures. If your first language is not English, you may have additional words that are important to you. Add them so that it's most useful to you. The emotion wheel is just one tool for learning and understanding more about emotions.

In the animated movie *Inside Out*, the characters Joy, Sadness, Fear, Disgust, and Anger represent core human emotions. Watching this movie is a fun way to learn about emotions.

EMOTIONS AS UNIQUE DATA

DEVELOPING EMOTIONAL AWARENESS AND AGILITY



Source: Feeling Wheel from Willcox, Gloria (1982): "The Feeling Wheel: A Tool for Expanding Awareness of Emotions and Increasing Spontaneity and Intimacy"

EMOTIONS AS UNIQUE DATA

DEVELOPING EMOTIONAL AWARENESS AND AGILITY

Self-validation is a skill from dialectic behavior therapy (DBT). It's the part of mindful self-compassion that encourages understanding the context when uncomfortable emotions occur. It requires non-judgmental awareness and avoids classifying emotions as good or bad. Self-validation separates the emotional experience from the urges or behaviors that occur alongside them. This distinction is important for developing emotional agility, the ability to change how you respond to circumstances.

Step 1: Acknowledge Notice and name the emotion(s) without judging them

Step 2: Allow Let yourself feel the emotion even if uncomfortable. Describe the events and environment occurring alongside the emotion using neutral language (just facts) in 1-3 sentences.

Step 3: Understand Use "because statements" to connect events and situations that contribute to the emotion.

Example: "I feel frustrated because I'm exhausted from a day of medical tests. I need to rest. I asked for quiet, but my family plays loud music which makes it hard to nap. I notice anger rising, and have an urge to shout at them. I feel unheard and disrespected."

This example connects the emotion frustration to environmental circumstances that impact the ability to meet a physiological need. It's also connected to psychological safety.

Note: Self-validation doesn't suggest a specific response to the emotion. By taking time to pause, avoid judgment, and understand yourself in the moment, you respond with self-kindness.

EMOTIONS AS UNIQUE DATA

RESPONDING TO EMOTION: SOOTHE THEN CHOOSE

In DBT, self-validation is followed by soothing and then choosing. Many different strategies promote emotion regulation (some described below). If this interests you, work with a mental health clinician trained in DBT.

Step 4: Soothe: Engaging in an activity that calms the nervous system (see p. 48 for a list) helps with overwhelming emotions.

Step 5: Choose: In DBT and mindful self-compassion, you use emotions as data points to go beyond naming the emotion and use that data to learn about what you need, prefer, or value. Then, you make decisions based on this information. Some DBT techniques include:

- **Build Mastery:** When dealing with ongoing discomfort, like when your ability changes due to a diagnosis of vasculitis, find new ways to engage in the world that respects your current capacity and interests so you can find enjoyment again.
- **Problem Solve:** Consider where you have choice points and brainstorm ways of creating a change cascade that's within your control (see next chapters).
- **Cope Ahead:** Note distressing situations and consider how to handle them in the future. Make a plan and practice new strategies in advance.

In the example of family members not respecting the request for quiet to rest, a solution might be to use earplugs to block the noise. Cope ahead might look like having a heart-to-heart conversation with the family about the importance of respecting rest and planning quiet activities they can do instead of playing loud music when you need rest.

Emotional awareness and agility skills also help you notice things that delight you. Responding effectively means prioritizing these enjoyable experiences in your daily life (where possible).

COPE AHEAD

USE EMOTIONAL REGULATION SKILLS TO IMPROVE TOUGH MOMENTS

Is there a tough moment you regularly experience? How can you improve it with self-knowledge? Self-knowledge includes your understanding of nervous system regulation, emotions, behaviors, and preferences. When we travel, there are items we bring for comfort, not just for necessity. These can vastly improve our experiences. Consider this specific tough moment, plan and practice a coping strategy that could make it more comfortable.



Preferences

“Let your joy be in your journey,
not in some distant goal.”

- Tim Cook (CEO Apple)

Preferences are the personal interpretation of information taken in by the senses. They're impacted by sensory sensitivity and cultural contexts. These are the things you LIKE and DISLIKE. Preferences are usually connected to feelings of pleasure and delight and are unique to each person. To notice delight, individuals must develop emotional and sensory self-awareness. Preferences don't impact basic survival, so they're negotiable with others. There's no hierarchy of preferences or aesthetic (despite what marketing agencies would have you believe), and people can share some preferences while disagreeing on others. For example, I like roller coasters; the faster and higher, the better! My partner does not. Neither of us are right or wrong in these preferences (though my kids say I'm cooler). This is a preference based on sensory interpretation.

Acknowledging and acting on preferences is connected to individual autonomy and agency. This is especially important to individuals facing pain, disability, and disruption to daily life due to vasculitis. Notice your preferences so you can prioritize daily experiences you enjoy and express your individuality. Preferences can be used to anchor you in times of distress.

Everyone is unique. What comforts one may be intolerable to another. Communicating these preferences effectively with loved ones and care providers is vital. Getting to know your preferences allows you to actively choose what to include (and exclude) when you pack your vasculitis journey bags. This helps in daily life and even more when you encounter a flare. By preparing ahead of time, you can tell loved ones about the practical supports that would help you or make a hospital stay more comfortable.

Noticing the Senses

Mindful awareness helps us notice the pleasant aspects of an experience. Rate the following qualities with either a 1 (dislike), 2 (neutral), or 3 (love) to better understand your preferences. Use what you learn to seek out things you enjoy more often.

Taste

- Spicy flavors
- Sweet flavors
- Bitter flavors
- Tart/sour flavors

Smell

- Citrusy
- Floral
- Woodsy
- Tropical

Sound

- Energetic music with words
- Soft instrumental music
- Nature sounds
- Quiet

Texture

- Soft
- Squishy
- Bumpy
- Smooth

Sight

- Vivid
- Neutral
- Pastel
- High-contrast

Self-Scientist Skills

Using mindful self-awareness, choose a daily activity you often enjoy and engage with it intentionally. This expands on the pause and scan strategy. Notice the sensory information (see, hear, touch, smell, taste, texture); emotions (anger, sadness, joy, surprise, disgust); and thoughts (questions, assumptions, beliefs, patterns) you experience. Some possible activities: Dance to your favorite song, color a picture, take a walk around the block, have a shower, drink a cup of tea. Describe it below.

Sensory Information

Emotions

Thoughts

Superpower Kit

Tapping into your preferences helps you transform your experiences. Brainstorm items to include in a superpowered senses kit you can use to improve a moment. Make it portable to take with you to medical appointments to provide distraction, soothing, or enjoyment through sight, sound, smell, taste, and proprioception (sense of movement through space, like rocking a baby). These items can be used to pass time, provide comfort, decrease sensory activation, or feel grounded (connected to your body in the moment). They can also be items that simply bring you delight.



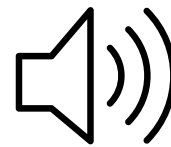
Visual

- A beautiful image
- A maze or mandala
- Eye mask
- _____
- _____
- _____



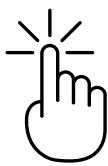
Proprioception: Sense of Movement

- A fidget to play with
- A resistance band
- Balance disc
- _____
- _____
- _____



Sound

- Earplugs
- Headphones
- Playlist of songs
- _____
- _____
- _____



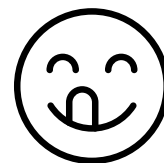
Touch

- A shawl or wrap
- Hand cream
- Touchstone
- _____
- _____
- _____



Scent

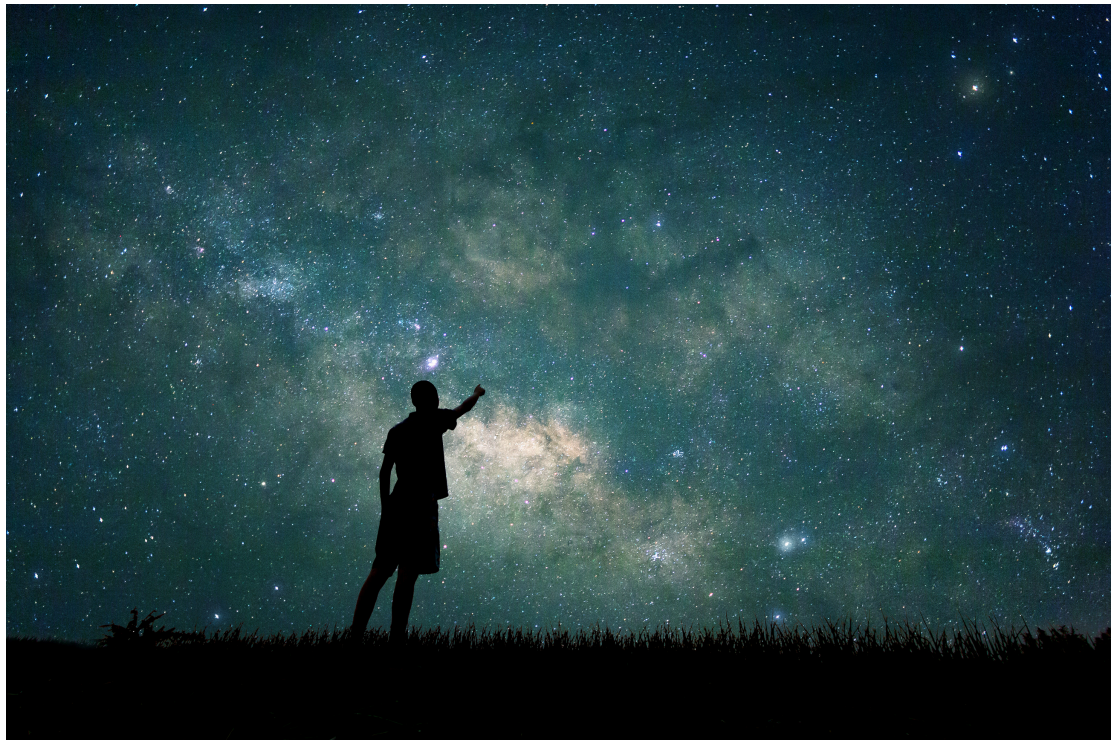
- A candle
- Essential oil roller
- Dryer sheet
- _____
- _____
- _____



Taste

- Tea
- Snack
- Gum
- _____
- _____
- _____

Values



Mariners used the stars and constellations to guide them across oceans they'd never sailed to explore lands they'd never visited. Similarly, your values constellation can guide you to new, meaningful, and fulfilling ways of living with vasculitis. Your values may not protect you from adversity, just as reading the stars didn't protect sailors from storms, but they can help you get back on track to living well.

Personal values are connected to an individual's culture, the family they were raised in, and their own interests and preferences. A values constellation is as unique as a fingerprint. Despite each and every person having values that guide their decisions, values are rarely stated explicitly, and it can be hard to find the language to name them. It helps to think of your personal values constellation as your own mission statement. (You'll be asked to state one at the end of Part 2.)

Like preferences, there is not a hierarchy of values - no specific set to hold that will get you the "right answer" or "win the game." The key is to understand yourself, and then use that information to choose what's next for you.

IDENTIFYING YOUR VALUES

Values are formed based on individual characteristics, history, and community. Identifying your specific constellation of values (your why) is important for navigation. Sometimes it's difficult for people to identify their specific values, but they can completely understand NOT THAT or NOT FOR ME. It's a place to start. Reflection activities, such as meditation, journaling, talking to a counselor or faith mentor, can help.

The following prompts are designed to help you clarify your values.

QUALITIES I ADMIRE IN MENTORS

ACTIVITIES AND INTERESTS THAT
BRING ME JOY

ISSUES THAT ARE IMPORTANT TO
ME

THE PEOPLE WHO ARE MOST IMPORTANT
TO ME CAN BE DESCRIBED AS

Try using a gratitude journal to track things you appreciate daily. A gratitude journal template is provided on the next page. Use it to note the parts of your day that bring you joy, connection, or satisfaction. Use it for at least one week to better understand your values. You can make copies of the template or write your responses in a notebook.

GRATITUDE JOURNAL

DATE

S M T W T F S

TAKE A MOMENT EACH DAY TO REFLECT
ON THE THINGS YOU'RE THANKFUL FOR

TODAY I'M GRATEFUL FOR

THINGS THAT MADE ME SMILE TODAY

SOMETHING THAT
INSPIRED ME TODAY

PEOPLE I'M GRATEFUL
TO HAVE IN MY LIFE

UNDERSTANDING VALUES



OPERATIONALIZING VALUES

Dr. Brene Brown discusses Living Into Values on her podcast Unlocking Us.

<https://brenebrown.com/podcast/living-into-our-values/>

LEARN ABOUT YOU

Complete a values card sort, a tool from motivational interviewing (form of counseling that can be helpful for making meaningful changes in life).

<https://meetingpointcounseling.com/tools/MI-card-sort/>

FEELING INTO YOUR VALUES

Self-Compassion for Dummies author Dr. Steve Hickman provides a guided meditation to help you connect with your felt values.

<https://www.mindful.org/savor-your-values-finding-strength-in-compassion/>

Within this meditation he states,

“Consider that whatever difficult, strong emotion is present for you just now, something you may be struggling with, the reason it’s arising is because there’s something underneath that is deeply held and valued by you.”

Remember: What you learn about yourself is a way of acknowledging the present moment with self-compassion. Values can change as you learn more about yourself and the world.



ALIGNING WITH YOUR VALUES

Identifying your personal values constellation is important and satisfying. These are included in this guidebook so you can use them to select goals to promote your well-being. Changes tied to your values (intrinsic motivations) are more likely to succeed.

Your primary (core) values are the most important qualities when making life decisions. They inform and underpin who we are and what we do. Very rarely does someone’s primary values change. For example, if someone has a primary value of generosity, they’ll choose options daily that allow them to give kindness, share resources, and provide support to others. When deciding how to spend time and energy, a person with vasculitis who wants to align with generosity will prioritize activities that give to their community over activities that don’t contribute meaningfully.

Secondary values are important but may change over time or are things you’re willing to compromise. While it’s rare for primary values to change, secondary values may be influenced by your environment, interactions with others, or societal changes.

Primary Values	Secondary Values

Prioritizing my health is tied to my personal values because:

I can prioritize my health every day by:

My Personal Mission Statement

CHAPTER 5: YOUR VASCULITIS CARE PLAN



Understanding your diagnosis, treatment, and care providers are important to navigating life with vasculitis. Since each form of vasculitis is rare, and every person is unique, it helps to have your medical history and contact information for your vasculitis specialist on hand when you meet new care providers or follow up with an existing provider after diagnosis. This aids you in self-advocating effectively. In this chapter, the activities help you organize your health information in a way that you can look back on and share with treatment providers (if you choose).

This information also helps you understand your vasculitis journey so far and how it impacts you. Grief is part of the process of adapting to diagnosis. Adaptation doesn't mean surrender. It means changing to flourish in a new environment.

YOUR HEALTH STORY

Before deciding where to go, consider where you've been and where you are right now. This reflection allows you to adapt to the events, emotions, thoughts, beliefs, and people that are important in your journey. One way to do this is through compiling your health story. Like any story, this has both a long and a short version.

There are many ways to organize it. You can write a long-form narrative; writing prompts are provided on the next page. You can make bullet points (point form notes). You can voice record. You can draw a cartoon or create a photo collage. The important thing is to reflect and consider how your health story impacts you on the path of your life.

Activity 1: Major Health Events List

Use your long-form recollection or the medical documents to compile the list of major health events connected to your vasculitis diagnosis and treatment. Include hospitalizations, surgeries, flares, and symptoms. Note dates (if known) and places tests or treatments occurred, and if possible, name the care provider. Make a note of any complications or side effects of treatments. This list is designed to be shared with current or future care providers.

Activity 2: Your Health Story

Using a word processor (or paper and pen) write your health story using the prompts on the next page. You can share this writing, but there's no obligation to share it with anyone. Capture what you remember thinking, feeling, and experiencing.

You don't have to understand all the medical or psych jargon to accurately tell your experience of the events that have occurred in your life, though you can use labels or diagnoses if that's helpful.

If the writing process overwhelms at any point, give yourself time and space to recharge. When you finish, put it away for the day. Emotionally and physically writing your story may have been a big step. You may want or need to connect with a friend, family member, counselor, or faith mentor for support. Some will find this process cathartic and energizing. If you're energized and want to move on to the next part, go for it! If you need a break, take it.

MAJOR HEALTH EVENTS

Use bullet lists to complete the chart or make your own. Include hospitalizations, surgeries, flares, when and how symptoms started. Provide the date(s) it occurred and duration, care provider, location, and treatment provided and any complications.

NAME	
DIAGNOSES	
ONGOING TREATMENT	

DATE AND HEALTH EVENT	TREATMENT PROVIDED (TYPE, BY WHO, WHERE)	OUTCOME (RECOVERY, COMPLICATIONS, CURRENT IMPACT)

DATE AND HEALTH EVENT	TREATMENT PROVIDED (TYPE, BY WHO, WHERE)	OUTCOME (RECOVERY, COMPLICATIONS, CURRENT IMPACT)

DATE AND HEALTH EVENT	TREATMENT PROVIDED (TYPE, BY WHO, WHERE)	OUTCOME (RECOVERY, COMPLICATIONS, CURRENT IMPACT)

OWN YOUR STORY

Use these prompts and questions to help you write your health story.

WHO

Describe yourself and your relationships.

Reflect on if/how your sense of self changed when your health changed.

Did any of your relationships change when your health changed?

WHAT

Describe your vasculitis diagnosis in as much detail as you choose.

Describe the various symptoms.

Try using a consistent scale (for example, 0-10) to rate the impact on your daily life.

WHEN

State the date (as close as possible) each symptom first started, when you sought and received diagnosis and treatment.

WHERE

Describe your health right now.

What things are going well?

What is most difficult for you living with vasculitis?

HOW

Describe the ways your vasculitis diagnosis shows up in your daily life right now.

Include how it impacts different things like family, work, school, relationships, and recreation.

WHY

Describe why you engage with the guidebook.

Think about the strengths that have helped on your journey is so far.

What other skills could help you ?

PRACTICE REGULATION SKILLS: EMOTION TENDING

Documenting your health story can be an emotional process. For many, it brings up a sense of tenderness that's uncomfortable. Rather than pushing away this emotional discomfort, distracting yourself from them, or sinking into them in a ruminative cycle, try an emotional regulation skill, such as emotion tending.

Emotion tending is a practice that brings together concepts from emotional agility, mindful self-compassion, and DBT (reviewed in the previous chapter). This tool is another way to build on the pause and scan strategy introduced in Chapter 1. It overlaps with the RAIN strategy from Chapter 2 and Emotion Validation + Soothe Then Choose from Chapter 4.

Steps to Emotion Tending

- 1. Notice that you feel tender in this moment.**
- 2. Name the emotions you experience.**
- 3. Self-validate the impact of the experiences leading to this moment (the reasons you feel tender).**
- 4. Radically accept the emotion and discomfort of this moment, just as they are, without judgment or blame.**
- 5. Respond to yourself kindly by taking a moment to soothe, distract, connect, or rest based on your needs.**

An example of how this could sound (in your head or aloud):

"I feel sad after writing my health story because I experienced a lot of suffering in my vasculitis journey. These events interrupted my life, and I miss my healthy life. That makes sense. May I be kind to myself as I work through this guidebook as these feelings come up. I'm going to take a few minutes now to walk around the block."

CONNECTING WITH CARE PARTNERS

Next Steps on Your Vasculitis Journey

Stories are meant to be shared; you are not alone

1. Share your Major Health Events List with new AND current care providers and a trusted family member or friend.
2. Share what it was like to recall your health story and major health events with someone you trust. Tell them about working with this guidebook and how it will support you in your journey.
3. Consider joining a Vasculitis Foundation support group to feel seen, heard, and understood in this journey.
4. Share your unique story with the vasculitis community when opportunities arise.
5. Connect with a mental health clinician in your area to learn more about managing your emotions and meeting your psychosocial needs.



KNOW YOUR CARE TEAM

Vasculitis is a complex and chronic illness. You may have numerous clinicians involved in your care. Understanding each person's role in your treatment can help. It also helps your care team to know who else provides care and what's being recommended. This activity is designed to help you communicate more effectively with your care team, so everyone is on the same page.

Use the provided template to record this information quickly and easily, then make copies to share with all your care providers. Ask if they're willing and able to collaborate with each other. It's especially important that all your prescribers know about each medication, supplement, and substance that's prescribed to and used by you.

Consider if it would help you if the professionals involved in your care communicate and collaborate with your primary medical specialists.

Your **Vasculitis Specialist**: The expert physician who looks after all aspects of your vasculitis diagnosis. It may be a rheumatologist, immunologist, respirologist/pulmonologist, or nephrologist. They monitor the symptoms and treatments and work with your primary care provider and other specialists to provide you with the best care possible to live with vasculitis.

Your **Primary Care Provider (PCP)**: The physician or nurse practitioner who attends to your typical health care needs (regular checkups and routine exams). You'd connect with them first for any new symptoms and ongoing care.

Other Medical Specialists: Depending on the type of vasculitis you have, there may be multiple organs and body systems involved that must be monitored and treated. These specialists monitor each specific part of you and work with your vasculitis specialist and/or PCP for your care and treatment planning. The involvement of these specialists may change over time depending on disease activity or life stage.

Allied Health Professionals: The regulated professionals who work with your medical care team, often in hospitals or medical settings, to support other aspects of your health care. These may include physiotherapists who specialize in the movement of the body; dieticians who are experts in nutrition; or social workers who help you adapt psychologically and socially to the changes that a vasculitis diagnosis brings. There are many other allied health professionals who may be involved.

Mental Health Clinicians: These professionals (psychiatrist, psychologist, or psychotherapist) support your mental health and wellness through a combination of medications, behavioral, emotional, and psychological interventions.

Holistic Treatment Providers: These professionals (chiropractors, massage therapists, and naturopathic doctors) use complementary protocols and therapies to support their patients.

YOUR TREATMENTS

Use the provided worksheets on the next page to record all current medications, supplements, treatments, and therapies that were prescribed, and that you currently use.

How well do you follow your treatment plan? Many people take meds as prescribed while others struggle for various reasons. What about any physiotherapy/physical therapy exercises? Attending appointments with your care providers is important. But many treatment plans have activities you must complete independently between sessions. How does that work for you? The next page has a treatment tracker to note your adherence and your daily functioning. Consider whether this would be helpful for you to track for two weeks (make copies for longer).

Many people seek additional treatments and/or work with multiple allied and complementary treatment providers, hoping that someone has the magic wand to make everything better. Wanting to improve your daily functioning is understandable and important. But before seeking out more intensive or expensive options, consider how you can optimize your current treatment plan (take your medication regularly, do assigned home exercises, or engage in lifestyle modifications like prioritizing sleep, getting more movement, nourishing your body adequately, taking up a new hobby, or reconnecting to your social circle). Each care provider tends to one piece of the puzzle. As the person with vasculitis, it's your job to put them together in a way that works for you.

Always communicate with every care provider about the treatments, therapies, supplements, or protocols prescribed or recommended by other clinicians.

Care Team Contact Info

PERSONAL CONTACT INFORMATION

EMERGENCY CONTACT INFORMATION

DIAGNOSES

PRIMARY CARE PROVIDER

ADDITIONAL CARE PROVIDERS

NAME AND LOCATION	ROLE	CONTACT
<hr/>	<hr/>	<hr/>
<hr/>	<hr/>	<hr/>
<hr/>	<hr/>	<hr/>
<hr/>	<hr/>	<hr/>
<hr/>	<hr/>	<hr/>
<hr/>	<hr/>	<hr/>
<hr/>	<hr/>	<hr/>
<hr/>	<hr/>	<hr/>

PRESCRIBED TREATMENTS/THERAPIES

- INCLUDE MEDICAL SPECIALISTS
- INCLUDE ALLIED HEALTH PROFESSIONALS
- INCLUDE MENTAL HEALTH CLINICIANS
- INCLUDE HOLISTIC TREATMENT PROVIDERS

Currently Prescribed Medications/Therapies

MEDICATION	DOSE/FREQUENCY	DATE STARTED

Additional Supplements and Therapies

CURRENT TREATMENTS AND FUNCTIONING TRACKER

Use this chart to track adherence to prescribed treatments and your level of functioning for two weeks. To track adherence, note each dose of medication, supplement, or daily therapy using a scale of 1-5. A five on adherence means you adhered to all prescribed treatments. A five on functioning means you completed your planned activities with no pain, fatigue, or health-related difficulty.

Do you see a relationship between adherence and function?

	Adherence	Functioning
Monday		
Tuesday		
Wednesday		
Thursday		
Friday		
Saturday		
Sunday		
Week 1 Overall		
	Adherence	Functioning
Monday		
Tuesday		
Wednesday		
Thursday		
Friday		
Saturday		
Sunday		
Week 2 Overall		

REFLECTIONS ON YOUR CARE PLAN

WHAT PATTERNS, THOUGHTS, OR FEELINGS DO YOU NOTICE AS YOU LOOK AT YOUR ADHERENCE TRACKER?

Based on the work you've done so far, consider where you are now in your vasculitis journey. List adjustments you could make to your current lifestyle or treatment plan (after talking with your doctor) to better support your health needs. You can also sketch how you're making sense of the process.



Part 2: Packing Your Bags

Your Packing List

List what you've found helpful for each physiological and psychological aspect of your journey. Remember, these can change over time. It helps to check in regularly and adjust based on current circumstances. Don't forget the comfort items that can help you soothe intense emotions or cope with pain or sensory overwhelm. Noticing and meeting your needs, preferences, and values helps you become better equipped to navigate your ongoing vasculitis journey.

Adherence to Vasculitis Treatment	Therapies	Emotion Regulation Skills
Sleep	Nourishment	Sensory Superpowers
Movement	Relaxation Exercises	Mission Statement

Part 3: Planning Your Itinerary

Chapter 6: Time and Resources

Chapter 7: Relationships and Roles

Chapter 8: Pacing and Assessing



Chart Your Course

Use mindful self-compassion principles to assess your resources and invest wisely.



Being aware of your resources helps you make informed choices about where to go next.

Part 3 of the guidebook is about the resources you have and how you use them. Time, energy, finances, relationships and responsibilities are interconnected and dynamic. Understanding them helps you navigate your journey more purposefully and ensures you spend your precious time and energy on the people and activities that matter most to you!

Chapter 6: Time and Resources helps you account for these variables to meet the needs, preferences, and values you identified in Part 2.

Chapter 7: Relationships and Responsibilities discusses how roles often change after a vasculitis diagnosis. This can lead to disconnection from activities and people important to you, which contributes to loneliness and dissatisfaction. Developing new ways to connect with your people and passions can be key to navigate your journey more meaningfully.

Chapter 8: Energy and Pacing discusses how mindful self-compassion helps you choose how to invest your precious resources wisely based on what you have available in the moment while planning for where you go next.

It's important to remember that these reflections are about the current moment, just one snapshot in time. You can use these skills in the future to realign with your values and invest your resources as the seasons of life change.

CHAPTER 6: TIME AND RESOURCES



At first glance, taking time to assess seems boring or unnecessary. But it's essential to understand how your time, energy, and resources impact your journey. Understanding these parameters means using your resources more wisely. Planning effectively allows you to reconnect to the meaningful and enjoyable parts of life.

When you have vasculitis, you have more to do and less energy and resources to do them. That doesn't have to stop you from experiencing a full life; it just takes some adjustments, creativity, and prioritizing so you can take care of your health and do what you love!

Resources



Besides time and energy, consider the financial and material resources you can access to support you. People reading this guidebook live in various regions with vastly different medical and social security systems. Below are questions to consider regarding financial planning with vasculitis:

- How are my medical expenses covered?
- Can I access any additional programs to cover my medical expenses? How do I do that?
- Have I claimed all eligible expenses through my insurance providers?
- Are there support programs nearby to help with the financial burden of illness? How do I connect to those?
- Is there a case manager or social worker at my vasculitis center or linked to my primary care team who can help me?
- Do I have a financial planner who could assist me? If not, can I hire one?
- How does vasculitis impact my ability to earn income now?
- How does vasculitis impact my job security, future earnings, or savings?

Talking about money can be really uncomfortable. But it's vital to have these hard conversations with loved ones and care providers so you can meet your current needs and plan for your future.

UNDERSTAND YOUR TIME

One overwhelming and elusive aspect of living with vasculitis is time. Attending to your health takes time and energy—precious commodities. Not only is it harder to do regular daily tasks with vasculitis, but now there are also appointments, tests, or treatments to fit into your life. An activity that helps capture vasculitis' impact on your life is time accounting.

Everyone has 10,080 minutes in a week. About 3,500 minutes are for sleep (ideally). If you work full time (5 days/week for 8 hours/day), that's 2,400 minutes at work, leaving 4,180 minutes for everything else. How does that add up for you?

This doesn't account for basics of daily life (food preparation and eating, hygiene, movement/exercise, commuting). It also doesn't include connecting with loved ones, tending a garden, or watching tv. How much time do you really have to tend to your complex chronic health needs?

Time accounting seems dull. However, it validates the sense of never having enough time to do it all.

Time accounting provides perspective so you can choose how to spend your time on the most important things. If you have a severe time deficit, how does that contribute to your well-being, especially mental health? Chronic stress and burnout impact many people, and this impact is amplified for people with vasculitis.

Time accounting works with energy awareness. Christine Miserandino, who lives with chronic illness, uses a spoon analogy to describe the changing energy reserves affected by pain, fatigue, and symptoms. How do your time commitments and changing energy impact your daily life with vasculitis? Using the spoon analogy can help explain your limits to others.



TIME ACCOUNTING PART 1

Add up all the time spent taking care of your health and wellness. Include activities directly related to your treatment, AND include all other health maintenance activities such as tending to your body, nervous system regulation, and psychological well-being as reviewed in Part 2.

The bottom shows the total time you spend on health management.

	MORNING	AFTERNOON	EVENING	TOTALS
<i>MONDAY</i>				Morning: Afternoon: Evening: Total Minutes:
<i>TUESDAY</i>				Morning: Afternoon: Evening: Total Minutes:
<i>WEDNESDAY</i>				Morning: Afternoon: Evening: Total Minutes:
<i>THURSDAY</i>				Morning: Afternoon: Evening: Total Minutes:
<i>FRIDAY</i>				Morning: Afternoon: Evening: Total Minutes:
<i>WEEKENDS</i>				Morning: Afternoon: Evening: Total Minutes:
	TOTAL WEEKLY MINUTES			<input style="width: 100px; height: 20px;" type="text"/>

TIME ACCOUNTING PART 2

In this chart, account for all other commitments and interests (work, childcare, household management, sport, creativity, leisure, community engagement, faith activities, time with family and friends).

These are things you need to do to provide for yourself and activities you enjoy.

The bottom shows the total time you spend on personal commitments.

	MORNING	AFTERNOON	EVENING	TOTALS
<i>MONDAY</i>				Morning: Afternoon: Evening: Total Minutes:
<i>TUESDAY</i>				Morning: Afternoon: Evening: Total Minutes:
<i>WEDNESDAY</i>				Morning: Afternoon: Evening: Total Minutes:
<i>THURSDAY</i>				Morning: Afternoon: Evening: Total Minutes:
<i>FRIDAY</i>				Morning: Afternoon: Evening: Total Minutes:
<i>WEEKENDS</i>				Morning: Afternoon: Evening: Total Minutes:
	TOTAL WEEKLY MINUTES			

REFLECT ON YOUR TIME

What do you notice about your 10,080 minutes each week? Does anything surprise you? Do you feel satisfied with how you spend your time? Use the chart below to understand your time accounting data and consider what's next for you.

HOW I SPEND MY TIME

HEALTH MANAGEMENT TIME

LIFE COMMITMENTS TIME

TIME AVAILABLE

PROS AND CONS OF HOW I SPEND MY TIME

BENEFITS OF HOW I SPEND MY TIME NOW

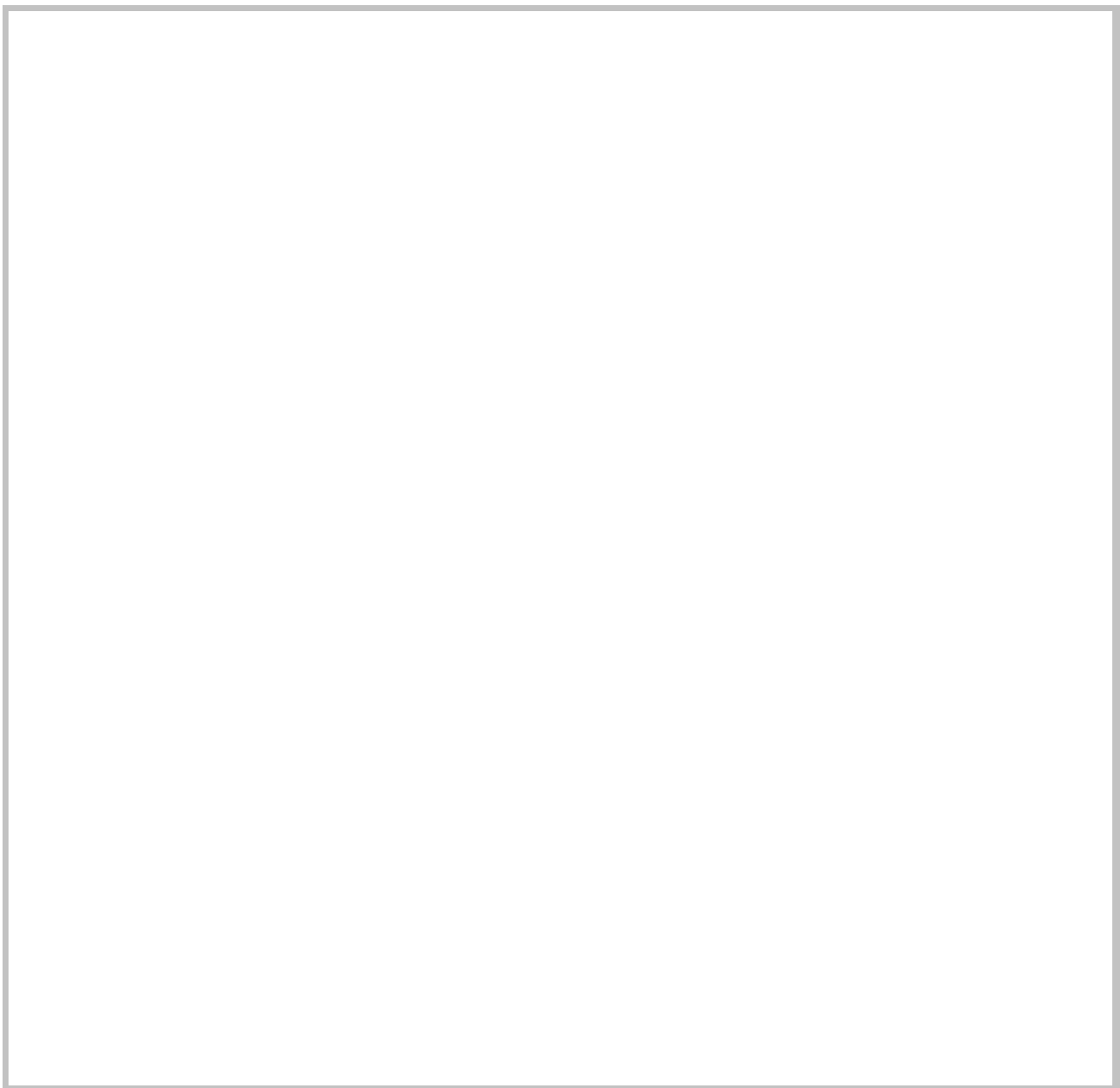
COSTS OF HOW I SPEND MY TIME NOW

DO I HAVE TIME FOR MY MOST IMPORTANT THINGS?

TIME: HOW DOES IT LOOK

USE THIS PAGE TO DOODLE OR DRAW

Based on the work you've done so far, doodle or draw how you make sense of your relationship with time and energy. Does this activity provide new insights? Does it help you determine where you want to go next? Remember that all activities in this guidebook are invitations, so if this doesn't resonate, feel free to skip it.



Daily Routines

TASKS FOR TODAY

TODAY I LOOK FORWARD TO

HOW CAN I SET MYSELF UP FOR SUCCESS TODAY?

MORNING

BEDTIME

I AM GRATEFUL FOR

I WAS SUCCESSFUL WHEN

THE MOST WONDERFUL THING THAT HAPPENED TODAY WAS

CHAPTER 7: RELATIONSHIPS AND ROLES



Everyone with vasculitis has a network of people (family, friends, peers and/or colleagues, neighbors, faith community, and social groups). The impact of vasculitis ripples through those communities. Understanding how vasculitis affects you requires thinking about your roles in these networks, especially in your closest relationships (as children and/or parents, partners, and dear friends). It can be vulnerable to acknowledge how abilities change due to illness or disability and the impact this has on the people we love or the work we do. Ignoring the shifts doesn't make it easier on anyone. How you acknowledge these changes in your social network differs depending on the closeness of the relationship, level of trust you share, current care needs, and your preferences and values.

VALUING HEALTHY RELATIONSHIPS

Healthy relationships nourish and sustain the people in them, especially for those with vasculitis. However, the importance of these relationships to health and healing can be overlooked within the medical system. It's also assumed that the people who come with a patient to a medical appointment have a strong relationship with them. Consider the strength and health of the relationships in your life as you manage your diagnosis. Some will be important allies whom you can confide in confidently. Others are available for practical support or are important emotional support.

Healthy relationships thrive on three components: Mutual respect, reciprocity, and trust.

Mutual Respect involves valuing the other person's perspective, especially when it differs from your own. People can have a variety of preferences and hold vastly different opinions on important topics as long as they maintain mutual respect.

Reciprocity is the willingness to show up authentically with each other. It means both asking for and accepting help.

Trust is harder to define. In her work on leadership, Brene Brown, PhD breaks it down into seven elements: BRAVING.

BRAVING Formula for Trust in Relationships

B- Boundaries: What's okay, not okay, and why

R- Reliability: Following through with what you say you'll do

A- Accountability: Acknowledge mistakes, apologize, and take steps to do better in the future

V- Vault: Keep private information safe (not gossiping)

I- Integrity: Authenticity across contexts which means upholding your values even when it's tough

N- Non-judgment: Create space to share emotions and experiences vulnerably

G- Generosity: Assume the kindest interpretation of intentions, words, and actions

Each relationship has different levels of mutual respect, reciprocity, and trust. Not every person in your life will be all things in all moments, and that's okay. Be clear with yourself about your expectations for a relationship, communicate that with the other person, and elicit their expectations. Work together to find common ground where everyone feels respected. Within relationships, individuals have unique thoughts, emotions, preferences, needs, and values. Healthy relationships value communication that's kind, clear, and direct and upholds the dignity of self and others when stating what feels okay and what doesn't work.

DETRIMENTAL RELATIONSHIP DYNAMICS

Unfortunately, healthy relationship dynamics aren't taught explicitly today. Parents, educators, and community leaders do the best they can with the tools they have to help young people interact safely and nurture supportive relationships. Many of the skills adults use are the basic ones taught in kindergarten, while more mature interpersonal skills aren't explicitly nurtured. Many families and communities pass down unhelpful patterns through generations. It's difficult to teach what we haven't learned ourselves.

Some patterns are annoying but harmless. In caring, trusting relationships, using skills from assertive communication and boundary setting can help. Other patterns are deeply hurtful and can perpetuate abusive dynamics.

Some examples of detrimental relationship patterns are:

Relational hierarchy based on arbitrary factors (class, race, sex, etc): Some relationships are built on uneven ground, where one person has more power or authority than the other (or thinks and acts like they do). Even where power is unevenly distributed, like in a parent-child relationship, mutual respect and consent are vital to healthy relationships.

Pleasing Patterns: Some folks feel uncertain of their worthiness (sometimes due to temperament or prior experience) so they defer to others' opinions and preferences to avoid stating their own or making decisions.

Oppositional Patterns: Sometimes, people are inclined to disagree with others no matter what, even if it causes them to miss out on something that they'd enjoy.

Passive-Aggressive Communication or Aggressive Communication Styles: In these patterns, boundaries are set as an extreme reaction to discomfort or to intimidate or guilt-trip another person. They're often a last-ditch effort to get one's needs met by emotionally controlling other people. This is disrespectful to the autonomy and agency of the other person and often leads to less connection and intimacy in the relationship because it erodes trust.

Detrimental patterns impact many different social relationships, even between trustworthy people. These patterns can be resolved with communication, support, and respectful intentions. To improve social connection, learn more about assertive communication and boundary setting.

CHANGING RELATIONSHIP DYNAMICS

Prior unhealthy relationship experiences make it difficult to trust people, especially when you feel vulnerable (e.g., during a flare). It makes it harder to use assertive communication skills that center your health needs. The next pages provide tools for kind communication and boundary setting.

All relationships follow a pattern and flow, like a dance. When you choose to do something differently in your life, like prioritize your health, it interrupts the previous flow in the relationship. In healthy, trusting relationships, there will be a period of adjustment, and then flow is restored. But keep the following in mind when setting interpersonal boundaries:

Safety first Assertive communication and boundary setting skills rely on safety. If you live in an unsafe relationship, please know that no one deserves to be disrespected or abused, and it's not your fault. You are not alone. For more information and support, contact the National Domestic Violence Hotline (thehotline.org). Choose the communication style that keeps you the safest, especially when vulnerable.

Clear is kind Directly state your own needs, preferences, and boundaries while respecting the other person's humanity.

Concise is helpful Communicate in as few words as possible.

Pause before responding If someone questions your boundary or asks why you can't do something, you don't owe them an explanation. Choose what you share based on the trust and level of closeness in the relationship and/or your current capacity. You can say - "I'm exhausted, but I'll explain later."

You can't control others' responses or emotions And you don't want to. Regulating your own nervous system and emotions is enough work. Others are allowed to dislike your boundary, experience uncomfortable emotions, and express them. You're allowed to express care without changing your stance.

Value the circle back Take a break if the interaction becomes heated, soothe your nervous system, and take perspective. When you're back in your window of tolerance, return to the conversation with an assertive boundary that prioritizes what you NEED in the situation and makes space for the other person's experience too.

VALUING HEALTHY RELATIONSHIPS

The Role of Boundaries in Strong Relationships

One of the keys to trust and respect within relationships is boundary setting. Folks in a healthy relationship have space for hard truths, including setting or changing boundaries.

Boundaries are the rules for the relationship. It outlines expectations for everyone involved. Some boundaries are cultural, others family-based or generational. Unfortunately, the idea of stating rules, expectations, or boundaries has gotten an undeserved negative reputation. Boundaries are quite simply what is and isn't okay. They can be stated kindly, and they don't privilege one person over another. They're for the benefit of the relationship itself.

For example, in some relationships, jokes and teasing are part of the dynamic, especially among peers, but in other relationships it's hurtful, usually when there's unequal power between individuals in a relationship (like between a teacher and student). That's due to the context of the relationship. No two relationships, even among family members, will look or feel exactly the same or have the same boundaries. Boundaries can also change over time. Communication is key.

In healthy relationships, boundary changes are welcomed, even if they create changes in the dynamic. It's uncomfortable to state needs or preferences, especially if it changes the relationship. Relationships require time to adjust after major life changes, like a vasculitis diagnosis or flare, in order to return to a comfortable flow. Everyone impacted by the change has valuable insight into what the new boundaries could look like to adjust to the current circumstances. When folks with vasculitis set limits on their resources (time, energy, or money) so they can manage better, it feels really vulnerable to ask others to accommodate their needs.

You can't predict another's response to your boundary (i.e.: emotions or actions). In healthy relationships, each person takes responsibility for managing their own responses and behavior. A loved one expressing disappointment regarding a boundary is not disrespecting it unless they're attempting to elicit guilt. Expressing sadness, grief, or disappointment at a change in the dynamic isn't a reflection of detrimental relationship patterns. Disagreement and expressing emotions safely are two signs of healthy relationship dynamics, even when uncomfortable. A caring person can validate a loved one's feelings about the boundary without backtracking on it or compromising their needs. Remember that negotiation is a healthy part of assertive communication and boundary setting when you're open to alternative solutions to meet the need or you're discussing preferences and the mutual enjoyment of a shared experience.

Boundary Setting Guide:

- 1-Determine the need that's impacted by a role or relationship
- 2-Choose how you will self-compassionately meet that need and how that impacts your relationships
- 3-Inform the impacted people about your need, your plan to meet it more consistently (the boundary), and how this impacts them and your relationship
- 4-Explain how you will protect this boundary (consequences for boundary violations)
- 5-Assert and protect the boundary
- 6-Continue to assess. Needs change so boundaries may change

SETTING BOUNDARIES

Setting boundaries is an ongoing process necessary to all relationships. It's common to be unfamiliar with the boundary-setting process. There are many resources to help you learn more. Check out Nedra Tawaab on Instagram or her book *Set Boundaries, Find Peace* if more info would help you. Below is a boundary-setting strategy from DBT called DEARMAN. Use this formula to practice setting a boundary that's important to navigating your vasculitis journey more effectively.

D(escribe) The facts of the event

E(xpress) How you feel about it

A(ssert) What you need/prefer/value

R(einforce) What you will/won't do if needs/preferences are not respected by others

M(indfully) State to yourself or the other person the reason you're setting the limit (need, preference, value)

A(ppear) Refers to how you communicate the boundary (The words and nonverbal cues — focus on volume, tone, and clarity. Keep it simple.)

N(egotiate) Alternative solutions or how you are willing to compromise if the boundary is related to a preference

MAPPING YOUR CONNECTIONS

People have different relationships and levels of connection based on many factors. How frequently you see someone doesn't always indicate the level of trust or safety in the relationship. There can be some individuals in the outer rings of the diagram whom you trust, but don't see socially (boss, doctor, psychotherapist). In contrast, there could be people in your middle circles who you see frequently and rely on for material support or camaraderie, but who you don't trust to share your personal thoughts, feelings, and opinions. In the two rings closest to the center, include only those whom you trust. It helps to visualize your social connections. You may not have space to list everyone; note 1-5 individuals for each ring.

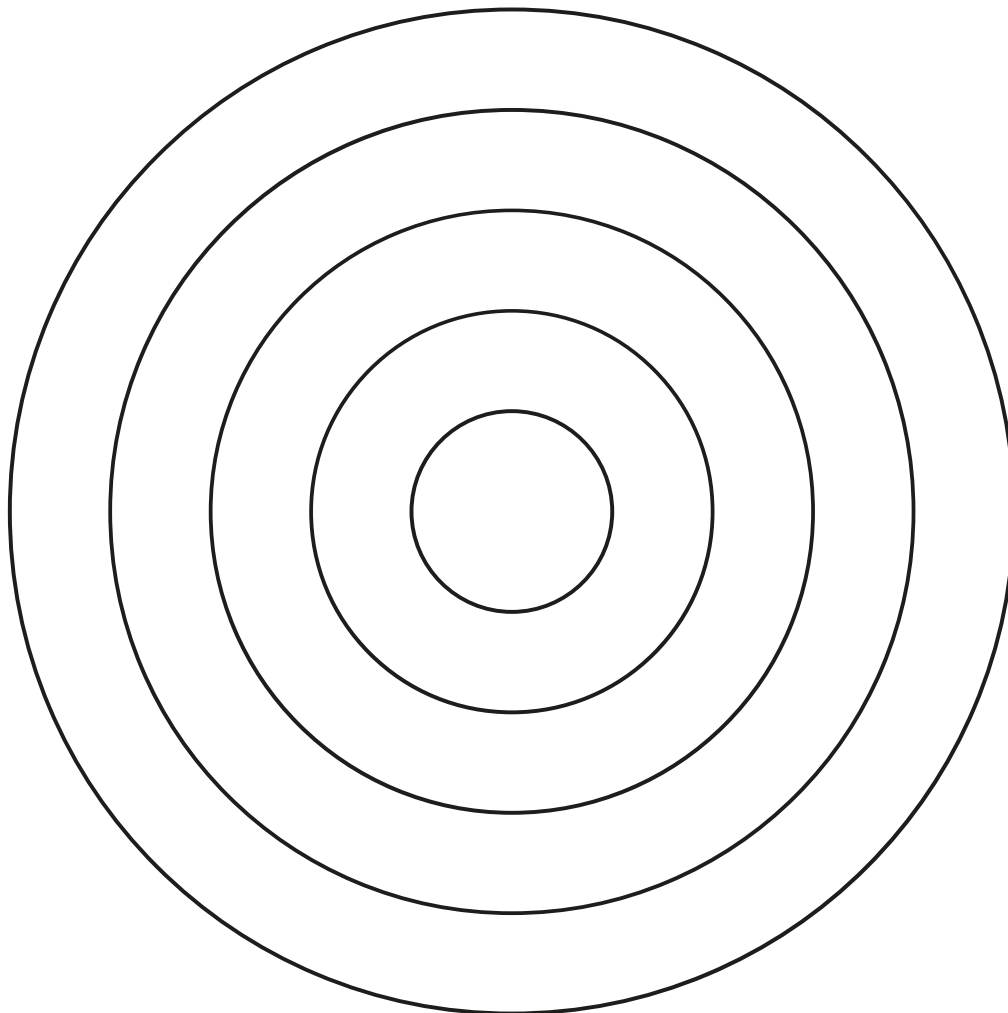
The inner circle Highly trusted people with whom you share a deep reciprocal relationship (3-5 people generally).

Ring 2 Extended family members and your closest or most enduring friendships.

Ring 3 People you often see at work, participating in hobbies, or in the neighborhood. Acquaintances.

Ring 4 People who you recently met or with whom you share a common interest, or someone with whom you had a deeper level but you don't see as often or there's been a relationship rupture.

Ring 5 People you may see often but whom you do not rely upon OR people you know/trust in a specific professional capacity.



CONNECTION REFLECTION

Due to changes in energy and ability, vasculitis can be isolating and often takes a significant toll on mental health. What was it like to map your current social connections? Did you notice any patterns?

In the boxes below, note the most important relationship in each category. Notice how it relates to the rings in the previous activity. What would you enjoy doing with these people to reconnect or strengthen the relationship? Maybe it's a phone chat to catch-up. Or if you met playing a sport, suggest watching a game together. Is there another way to engage that respects your current level of ability and energy?

THE INNER CIRCLE

CLOSE FAMILY MEMBER (PARENT, CHILD, SIBLING)

FRIEND

NEIGHBOR

COLLEAGUE/ACTIVITY PARTNER

OTHER

YOUR CIRCLE OF CARE

A circle of care includes treatment providers and professional support, but it also includes your trusted loved ones and extended community network. Each person's relationship with you is different and influenced by their role in your care. The circle is a helpful visual because it's not a hierarchy, and responsibilities are distributed.

Your partner, parent, adult child, or dear friend may have a pivotal role in supporting you during flares or times of increased illness/disability. This can change how you relate when you feel better. It helps if this "point person" learns about vasculitis, your treatment plan, and the roles of various treatment providers. It could help to share the previous chapters with them. Your point person may benefit from mindful self-compassion skills and support.

Sometimes, it's beneficial to have a logistics point person to manage the details of your care and a separate emotional point person to discuss your inner experiences with. Trust is an essential component for all.

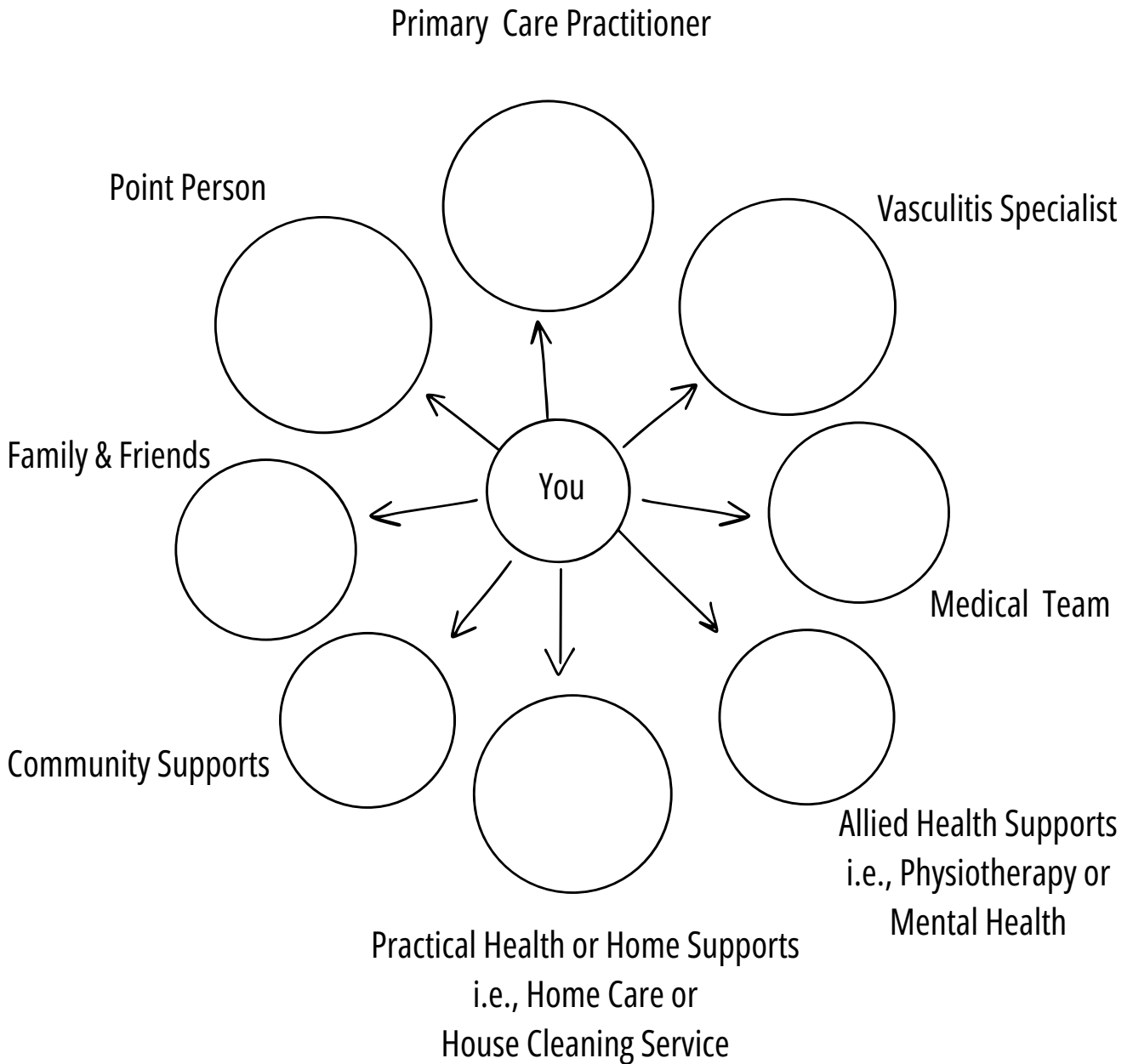
In addition to your point person, other members of your community can provide necessary assistance. Nearby folks could help with practical tasks like mowing the lawn or bringing a dinner on tough days. Trustworthy others who are at distance may be a source of comfort, creativity, or connection. Some folks can relieve your point person so they can take time to nurture themselves. Clear communication is an essential part of building and maintaining your circle of care.

For many with vasculitis, feeling like a burden happens, especially during flares when you need more help. It helps to notice and name that worry with loved ones. Also remind yourself that you're worthy of care and practicing self-compassion. Foster a culture of responsible self-care within your circle so your loved ones are also encouraged to tend to their needs regularly. That helps maintain relationships.

It's tempting to avoid voicing your needs, preferences, or limits with your people. Remember that clear is kind!

YOUR CIRCLE OF CARE

Take a minute to fill in the chart below with your circle of care. How does each person support you on your Journey?



FLYING SOLO

You may navigate your vasculitis journey solo, without that key point person by your side for logistic and emotional support. Creating a safety net of professional and volunteer services can help you get through it.

Looking back in the guidebook can help you enhance your circle of care while flying solo. A point person doesn't need to be a parent, partner, or adult child. They must be a trusted associate like a colleague, neighbor, or friend whom you invite into this role. Clear communication outlining what you want from this person, especially when it isn't a traditional point person, is essential so they understand the role and your expectations. You may invite someone who can't take on the full responsibility, so consider if there are a few people who can take on parts of the role together.

For people who genuinely prefer to fly solo and do things on their own, with efficient organization and specific hired help, you can navigate your vasculitis journey independently. Using a digital planner and reminders are important. Take notes or voice memos during medical appointments. Also, plan for future aspects of care and contact the professional or volunteer networks you could enlist to help if your capabilities to care for your home or your body are impacted.

In Chapter 2, physiological needs were reviewed. When you think about your home, consider what logistic supports you require now or later. For example, household management tasks that help you maintain a safe and comfortable living space can be physically demanding. At times, handling these may overtax you physically or mentally. Depending on where you live, different home care services may be available. This is one subject where the available resources can vastly differ based on where you live. Ask your primary care provider or local social services agency for the most accurate information for your situation.

If you can afford a professional care navigator, they're a valuable support to connect you with resources in your region. Other professionals can also help, such as psychotherapists or counselors, clinical or registered social workers, or nurse case managers. Having a variety of allied health professionals to check in with periodically also provides social connection. For example, physiotherapists/physical therapists, massage therapists, and chiropractors/podiatrists can provide both allied health care and an ongoing professional relationship.

There may be volunteer networks in your community that can help with meal delivery or transportation to medical appointments. As a patient flying solo, you may need to make multiple calls to find a service group with the resources that will help you get through these times. Connecting with a recreational activity, a community center, or faith group in your area can help you develop social connections that, in time, grow into friendships.

REFLECTIONS ON YOUR CIRCLE OF CARE

WHAT DO YOU FEEL AS YOU MAP OUT YOUR SOCIAL CONNECTIONS AND CIRCLE OF CARE?

You can feel conflicting emotions as you reflect on your relationships. You may experience nostalgia mixed with guilt or gratitude + frustration . . . or the entire emotion wheel at once. Practice making space for the paradox. As reviewed earlier: Acknowledge, name, self-validate, soothe dysregulation, and then choose what to do next based on your goals and values.



(RE)CONNECTING WITH YOUR POINT PERSON

Just as vasculitis contributes to disconnection in your overall social network, it can also disrupt your closest relationships. It may seem that everything revolves around managing the illness and its treatments or maintaining work/family commitments. This leaves little time or energy for fun and non-vasculitis-related discussions with your loved ones. Valuing your healthy relationships includes nurturing them — especially with your point person — whether that's your partner, parent, adult child, or trusted neighbor.

Step 1: Intentionally and collaboratively **protect time to connect**.

Step 2: **Express gratitude** for their role in your life before diagnosis and the extra care they give you as your point person. If you haven't used that specific term with them before, see if it fits for them and your relationship.

Step 3: **Inquire**: What do they need right now? How can you support them in meeting that need? What would they find fun or enjoyable?

Step 4: **Plan to connect** regularly (outside of providing care or household management) and build enjoyable activities into your routine together.

For some people, this connection time may look like an afternoon walk where the V word is not allowed. For others, it may be having takeout together on the couch while watching funny movies.

Some find it more practical to express vulnerable emotions with a card or gift. If that's your style, go for it. If you notice that your point person needs a break, ask another person in your community to support you so they can take care of themselves. If you can, consider gifting them a spa day, museum trip, round of golf, etc., whatever they like. But remember, gifts are not required to express appreciation!

Part 4: Taking Steps

Chapter 8: The Change Process

Chapter 9: Pacing, Reflecting, and
Celebrating

Chapter 10: Evolving



The Science of Change

Connect the process of change with principles of mindful self-compassion to take the next important steps on your vasculitis journey



Bringing all the practices together to traverse the next phase of your vasculitis journey

In this last part of the guidebook, we'll explore exercises to help you embrace health promoting-behaviors in your daily life. These can help you make effective changes that support living with vasculitis.

Often, people are excited and hopeful at the beginning of a journey. However, somewhere along the way, despite research, planning, and preparation a storm rolls in. In chapters 9 and 10, we'll learn how to manage the storms. Important factors to keep in mind are curiosity, compassion, and consistency. When things don't go exactly to plan the first time (because life happens) bring curiosity to the table. Consider how to adapt your plan. Gently acknowledge the difficulty of making changes in your life, even seemingly simple or tiny changes, and recognize your efforts with compassion. When making changes, pick small things that you can do even on your worst days. This helps you build consistency, and consistency builds momentum.

CHAPTER 8: THE CHANGE PROCESS



Making changes sustainable over time requires a skill set. Fortunately, like many other skills, behavior change can be taught and practiced. A commonly used strategy for teaching these skills is the SMART Goal acronym. SMART Goals are those that are Specific, Measurable, Attainable, Realistic, and Timely. The missing piece of the equation when using this strategy is RELEVANCE — the goal must be meaningful to you. The following activities can help connect your preferences and values to any goal and set you up for success!

Remember that this resource is not individualized medical or psychological advice. No specific change is being advocated or encouraged. Please consult with your medical team before making any treatment changes. One of the most important steps for wellness is to adhere to your prescribed treatment plan.

THE SCIENCE OF CHANGE

Doing something differently can be intimidating, making it overwhelming before you even begin. This doesn't mean you're stuck; embrace the choice points outlined below and see if the change cascade can transform how you live and love with vasculitis.

In a systemic illness, one shift can flow into multiple spheres. This is amazing for building momentum! This is why it's incredibly important to communicate with your care team.

A change cascade begins by focusing on one relevant goal and breaking it down into manageable steps. By connecting each practical step to your individual preferences, abilities, and resources, you can feel excited and more prepared. This can increase confidence and help you to take those first steps.

The change cascade approach can help you adhere to your currently prescribed treatments and therapies or try an adjunctive treatment. Focusing on increasing fierce self-compassion by prioritizing sleep, nourishment, or movement is an accessible way to practice these skills. Ultimately, self-compassion helps you protect your limited time and energy for the people and activities that matter most.

Pace yourself. Choose one overall goal, break it down into small steps, then take the first one. As that step is integrated into your daily life, take the next step that gets you closer to the goal. Continue the process until the goal is integrated and a typical part of your life.

These activities are invitations to build your personal care plan based on your values and priorities. There is no right way to use these activities; do what works for you.

CHOICE POINTS MENU

Looking for small changes you can make to support your health? Everyone using this guidebook will have different priorities based on their needs, preferences, and values. This isn't a complete list of changes, but a small sample based on previous chapters. Consider which topics were most interesting to you or seemed most impactful. This isn't medical or psychological advice. Communicate with your care team.



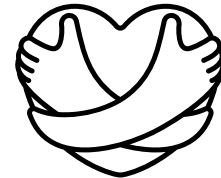
Mindful Self-Compassion

- Practice mindful awareness daily
- Keep a gratitude journal
- Work with a mental health provider
- -----
- -----
- -----



Fierce Self-Compassion

- Focus on healthy sleep and rest
- Practice mindful eating
- Add daily movement
- -----
- -----
- -----



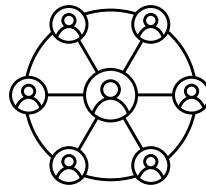
Gentle Self-Compassion

- Respond to distress with kind self-talk
- Understand and embrace preferences
- Practice daily relaxation exercises
- -----
- -----
- -----



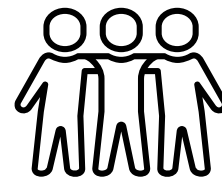
Adherence

- Track your medication and symptoms
- Do home activities from allied therapies
- Attend scheduled lab tests/appointments
- -----
- -----
- -----



Tend Your Resources

- Budget your money, time, and energy
- Prioritize your self-care and schedule effectively
- Cultivate your circle of care and communicate needs
- -----
- -----
- -----



Nurture Relationships

- Develop assertive communication skills and boundaries
- Connect with a support group
- Reconnect with your point person
- -----
- -----
- -----

SELECT A FOCUS

Remember the Aligning with Your Values activity from Part 2 (p. 64)?

Use that information to reflect on any changes you may make to better manage your health. Is there one specific area of life you're most interested in changing?

How does this change connect to your personal mission statement? Describe how focusing on this area of change will help you.

ALIGNING WITH YOUR VALUES

Identifying your personal values constellation is important and satisfying in its own right. However, the reason these activities are included in the Navigating Your Vascularis Journey Guidebook is so you can use them to select shifts and changes that promote your well-being. When changes are tied to your values (intrinsic motivations) they're more likely to succeed.

Primary Values	Secondary Values

Prioritizing my health is tied to my personal values because:

I can prioritize my health every day by:

My Personal Mission Statement

TAKE THE FIRST STEP

Since making changes can be overwhelming, break the goal into smaller, actionable steps. Build simple health-promoting habits into each day to reach your main goals in any of the areas discussed. How? By making the first step EASY.

EASY steps build a realistic path toward achieving your goal. The key thing is to create a step you can complete daily in as little as 5 minutes, taking no more than 30 minutes. You can build it beyond those parameters eventually, if that makes sense after considering all of your needs, preferences, values, available resources (money and energy), and your other time demands. The EASY step process asks you to consider how the change you are making impacts the flow of your life and your relationships. The changes are sustainable because the process acknowledges that everything is interconnected, and the process encourages pacing and reflecting before taking another step toward your goal.

EASY steps

Every day

EASY steps are about building a path toward your goal into your daily life.

Every day The step is small enough to manage on hard days.

Anchored in Values

Anchored in Values The steps and the goal are meaningful to you.

Simple

Simple Each step is as uncomplicated as possible to minimize barriers.

Yours

Yours Forget the shoulds; by enjoying the step, you are likely to sustain it.

Goal

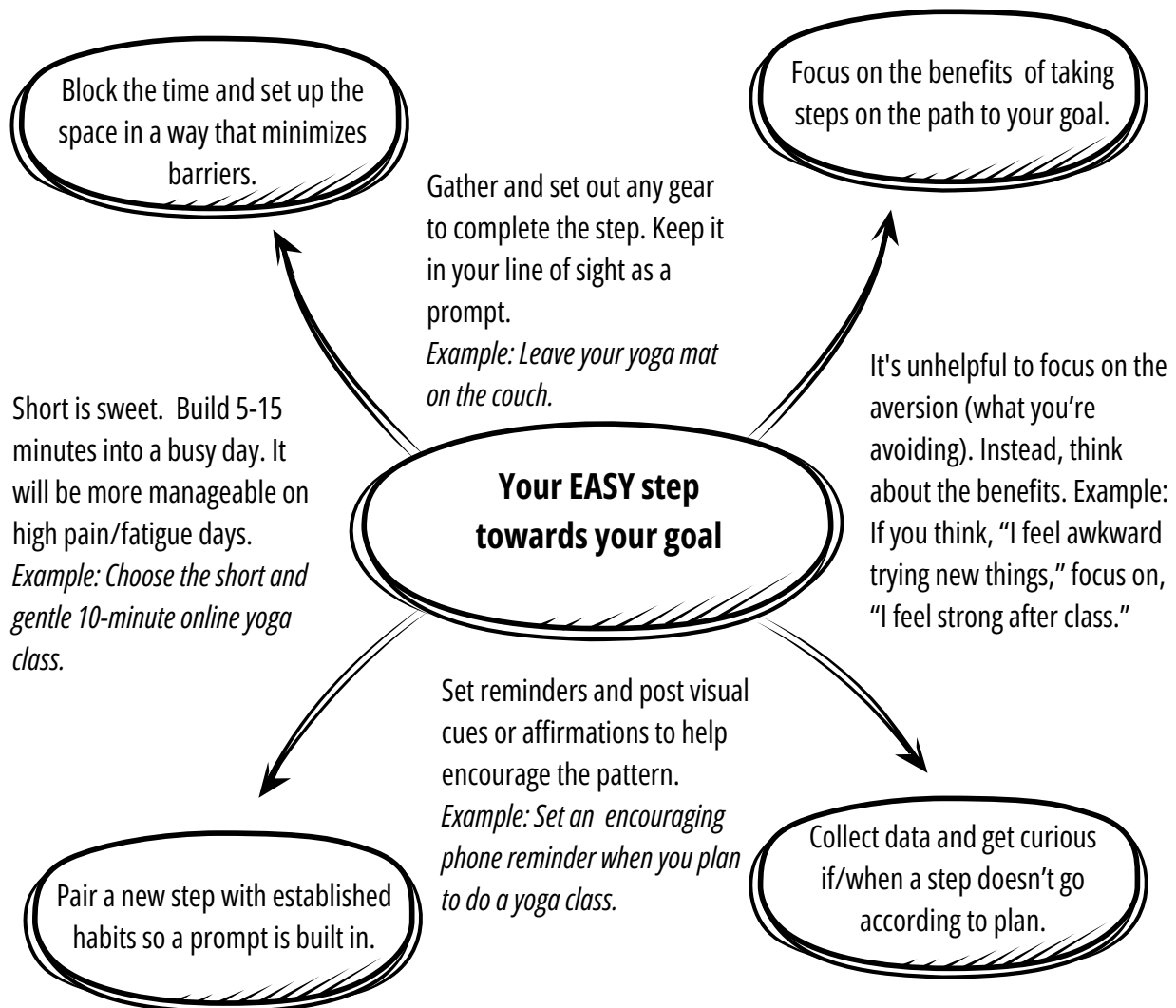
EASY step

When, what, and how long

What do you like about it

HOW TO SIMPLIFY THE STEP

Scaffolding is a tool to help you take your first steps toward your goal. Scaffolding includes: Gathering materials needed to take the step, scheduling time to complete it, thinking about what you do before and after you take the step, and asking a friend to go with you or check in after you try the new thing.



USING SMART(R) GOAL SETTING

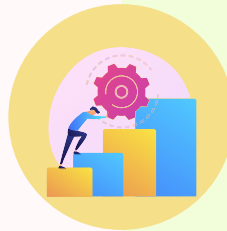
SMART(R) goals are those that are Specific, Measurable, Attainable, Realistic, Timely and Relevant to you. Often people attempt a change because they think they should based on external pressures. It's key that the goals you set in your journey are ones you want and are connected to your values.

SPECIFIC	<ul style="list-style-type: none"> • What is your goal? • Tie in your WHY? • What are the EASY steps that build to your goal? 	
MEASURABLE	<ul style="list-style-type: none"> • How do you know you're working on it? • Are you tracking? • How will you know you achieve it? 	
ATTAINABLE	<ul style="list-style-type: none"> • How are you prepared? • What materials do you need? • Do you need social support? Who? 	
REASONABLE	<ul style="list-style-type: none"> • Do you have the time, capacity, and resources to meet your goal? • Do you need to consult a professional? 	
TIMELY	<ul style="list-style-type: none"> • When will you begin? • When will you reflect and adapt if needed? • When will you celebrate success? 	

MYTHS OR FACTS

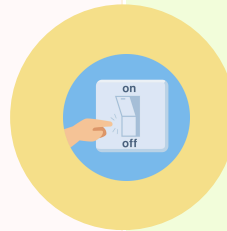
ABOUT MOTIVATION

You're either the type of person who has motivation or you aren't.



Motivation isn't a personality trait. It's impacted by the context, the support available, and the individual's interests and confidence. Research shows that people are more motivated when there's less judgment, they feel more prepared, and they're connected to the community.

Motivation is like a switch, on or off.



Motivation is complex. You can increase it by building skills related to achieving the specific goal and developing growth mindset, which helps to mediate struggles and challenges. People also feel more motivated with social connection and mentorship.

Praise increases motivation.



Praise has been shown to decrease motivation, leading people to avoid challenging tasks. Celebrating creativity, effort, and perseverance – (qualities of growth mindset) are shown to increase motivation to persist when challenged.

If something really matters, all you need is motivation.



Motivation is only one aspect of behavior change science. Building skills and strategies, having the resources and support, and creating an inquisitive and safe environment are all essential for sustainable behavior changes.

UNDERSTANDING MOTIVATION

Motivation is made up of multiple factors. Connection to the goal is key, whether from external sources (rewards and/or punishment) or internal alignment (it's enjoyable and/or meaningful). In addition, you must have capacity — the resources, time, and energy to take the steps needed to reach your goal. Finally, it's important to have the skills and strategies to take the steps and follow the plan. These can be the specific skills connected to your goal, like how to belay in rock climbing or understanding shutter speed in photography. Most importantly, achieving goals requires executive functioning skills like the ability to learn new information, problem-solve, and persist when challenged. These skills are also referred to as having a growth mindset.

My Motivation Recipe

Importance to Me

My Capacity

Equipment I need

A Coach, Teacher or Mentor

A Supportive Community

Confidence in the Plan

MOTIVATION MEASURE

Use these scales to see if the goal you set for yourself aligns with your values, is reasonable given your time and ability, and appropriate based on where you are right now in life and your vasculitis journey.

Importance of the change to me based on my values

1 2 3 4 5

Confidence in my preparation for change

1 2 3 4 5

How ready I feel to get started

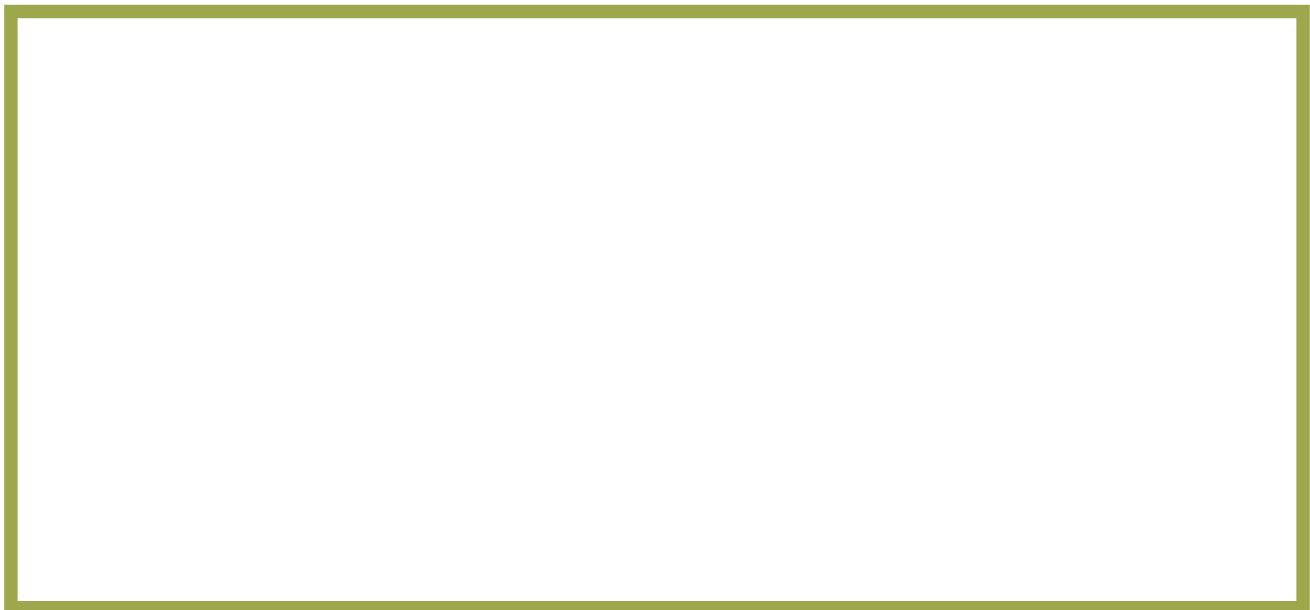
1 2 3 4 5

Reflect on your scores. What would it take to score higher on each measure?

PICTURING THE BENEFITS

Visualization can be a powerful part of planning for the future. Athletes use visualization to rehearse technical aspects of their sport and prepare for competition. In your vasculitis journey, it can help to rehearse the next step in your healing. In this exercise, imagine a moment in the near future when you have incorporated an EASY step toward your goal into your routine. What happens before, during, and immediately after this behavior shift? How do you feel? What are the body sensations? Using a multi-sensory approach helps to prepare the body.

In the space below, write out the process, step by step, like a script if that helps. Or use a flow chart, diagram, or illustration if you prefer. Then review the process and imagine doing it tapping into all your senses.



CHAPTER 9: PACE, REFLECT, AND CELEBRATE



We invest a lot of energy in preparing for change (it's important) and give a lot of attention to successfully completing the goal. Gold star! But most of us don't plan a big adventure, spend a bunch of money, and then celebrate by arriving home to unload the suitcase and do the laundry thinking, "What a success! This is why I travel." So why do we do that with our goals?

The joy of travel is in the process: Exploring somewhere new, learning, basking in our sensory experience (like yummy food and warm sunshine), and having fun with our people! Similarly, the most important aspect of change occurs in the middle of it. In travel, this middle section IS the journey.

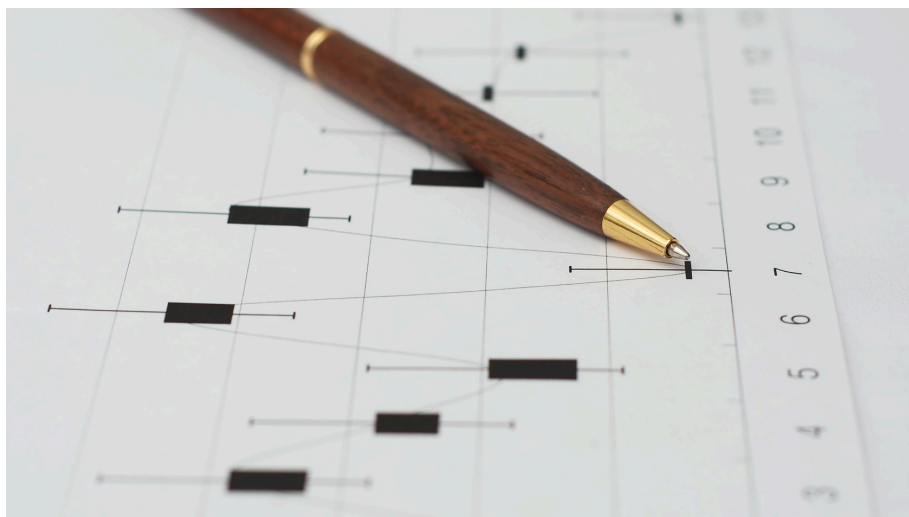
The three most important factors in the midst of the journey are pacing, reflecting, and celebrating each step on the path toward your goal.

THE VALUE OF PACING AND PAUSING

Timing is essential in any journey. There are seasons, tides, lunar phases, daylight and darkness, circadian rhythms, and healing cycles that affect each of us differently. When you navigate your vasculitis journey, consider pacing and pausing. These two factors are easily overlooked. They both allow us to more mindfully experience the journey so we notice when we experience joy, satisfaction, and pleasure. They help us stay attuned to our needs, which is essential to prevent overwhelm and burnout.

Think about taking a flight. So many things can impact whether or not the plane takes off and lands on schedule. If the next part of your trip hinges on your arrival in one destination before proceeding to the next, you can plan buffer time in between to account for any delays or complications with your flight. This is pacing. It's similar to your vasculitis journey. You never know when an appointment will run late or a nap is needed. Slow down and stay connected to the present moment to decrease pressure and prevent overwhelm. It also helps you check in with yourself regarding your preferences and values.

It's important to ask yourself along the way: *Do these steps still serve my goal? Is my goal still relevant and important? Am I on the path that works best for me?*



NOTICE AND REFLECT

Chapter 1 introduced mindful awareness as an essential component of using your self-compassion compass. Mindful awareness practices are highlighted throughout the guidebook to help you understand your needs, preferences, and values.

As you move toward your goal, reflection skills continue to be important. They orient you to what works and what you want to tweak.

Effective Reflection Practices:

- Set intentions, which provide focus.
- Use descriptive words, which avoid judgment.
- Observe through the five senses and notice emotions, which allows thorough consideration.
- Language: Write or talk through observations so meaningful connections are made.
- Let yourself have more than one perspective.
(Example: On one hand, taking a walk in the morning is enjoyable and helps me move more. On the other hand, I feel more rushed to get out the door on time in the morning.)

Reflection allows you to make adjustments during the change process. It connects you to the present moment which helps you enjoy the process more. Just as taking photos during travel highlights moments during the journey, reflective journaling captures these key moments during the change process.

Reflection gets an unfair reputation as being the opposite of taking action. In fact, it facilitates decision making.

Some unhelpful thinking patterns can be mistaken for reflection. These include making assumptions about situations you haven't experienced or making harsh judgments about yourself or others. These thinking shortcuts disconnect you from present moment awareness, curiosity, and discernment. Rumination (thought spiraling) can also be mistaken for reflection. In rumination, people replay certain events from the past over and over or obsess over a future concern. They feel stuck in a loop. Often there's a sense of dread and disgust.

Differentiate Between Thinking Traps and Reflection Practices

- **Write or talk it out (get it out of your head)**
 - **Notice how you feel when you reflect**
 - Curious
 - Calm
 - Connected to the present moment (not stuck in the past or the future)
 - **Set a timer (15-45 minutes)**
 - **Avoid either/or thinking or other traps like catastrophizing or fortune-telling**
 - **Plan an activity afterwards**
 - Take a walk
 - Do a puzzle
 - Phone a friend
 - **Choose prompts that elicit helpful data for decision-making**
-

REFLECT ON YOUR CURRENT STEP

Use any of these prompts (or create your own prompts) and your choice of journal to reflect regularly. Choose 2-3 prompts, and set a timer when you take time to reflect.

SPECIFIC

Describe the current step in your process.

Using mindful awareness, note the thoughts, feelings, and sensations that you experience.

Is it fun or satisfying?

ATTAINABLE

If you struggle to complete this step, how can you make it less intensive?

Are there any supports or mentors to connect with to help?

Is there a different step to try that's connected to your goal?

TIMELY

How does this step fit in your schedule?

Does it take more or less time to complete the step each day than you thought? Can you modify the duration?

Do you struggle with the frequency?

MEASURABLE

Use a rating scale (like 0-5) to measure how this step is going for you. Try to use the same scale consistently if you use this prompt often.

Do you foresee increasing the time, frequency, or intensity of the step to reach your goal?

REASONABLE

Describe your health right now.

What things are going well?

Is this step manageable given your current capacity (finances, time, energy, abilities, other life demands)?

RELEVANT

Describe your reasons for engaging with this step toward your goal.

Think about the strengths that helped you on your journey so far.

Do you still feel connected to this goal based on your preferences and values?

ACKNOWLEDGE PROGRESS

Setting SMART(R) Goals means knowing how and when to measure progress. Regular reflection helps you understand how the change process is going. There are some thresholds that can be used to measure progress. Keep in mind that these are estimates because everyone is unique.

As a guideline, assess how things are going every three days, every three weeks, and every three months. A single day or even a week can be a fluke, whereas three weeks of data gives you something to work with effectively.

Notice what improvement feels like for you. It can be feeling calmer, having more connection, increased creativity, or greater capacity to work, depending on what matters to you. A 1% shift is meaningful! It changes your trajectory when you maintain the shift over time. Taking more EASY Steps toward your goal creates a change cascade.

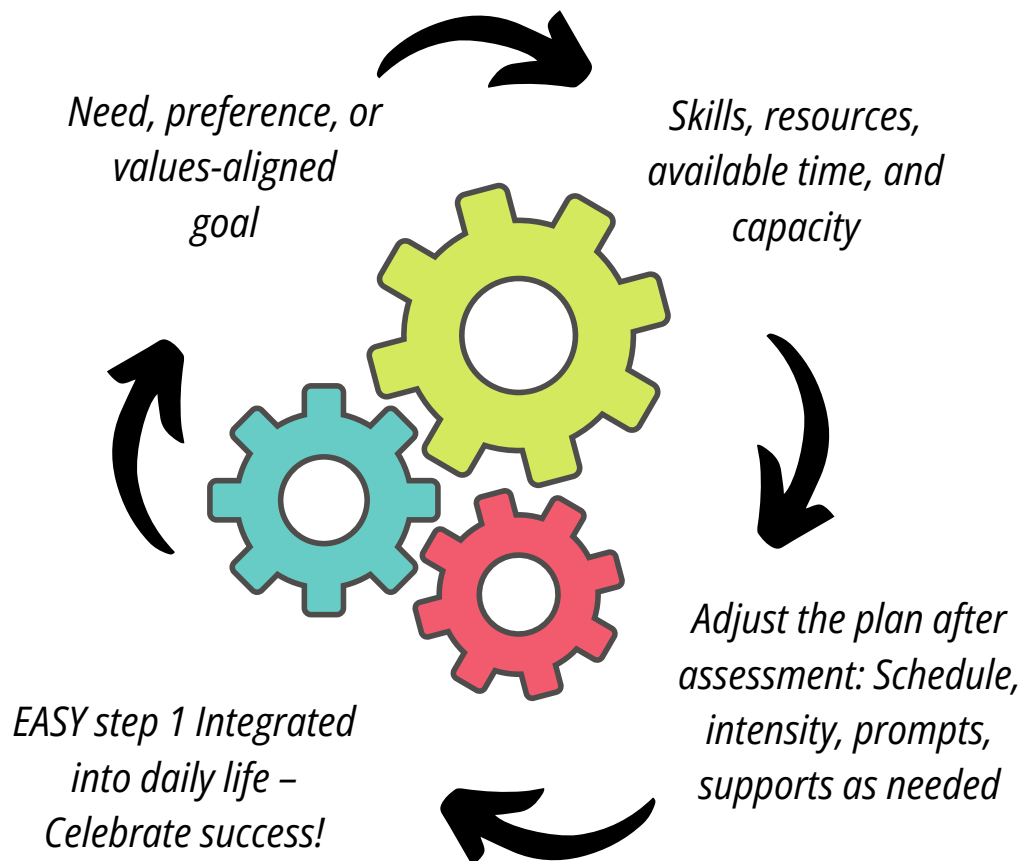
Even if you do *the thing*, if you don't enjoy yourself, no amount of discipline will help you succeed. The goal and the steps to reach it must be attractive to you, which is why understanding your nervous system, emotions, and preferences is vital. And also why there's no specific regiment for navigating your vasculitis journey. It's a process so you can discover what works best for you.

Assess Progress

Focusing on Improvement + Enjoyment



REFINE AND ALIGN



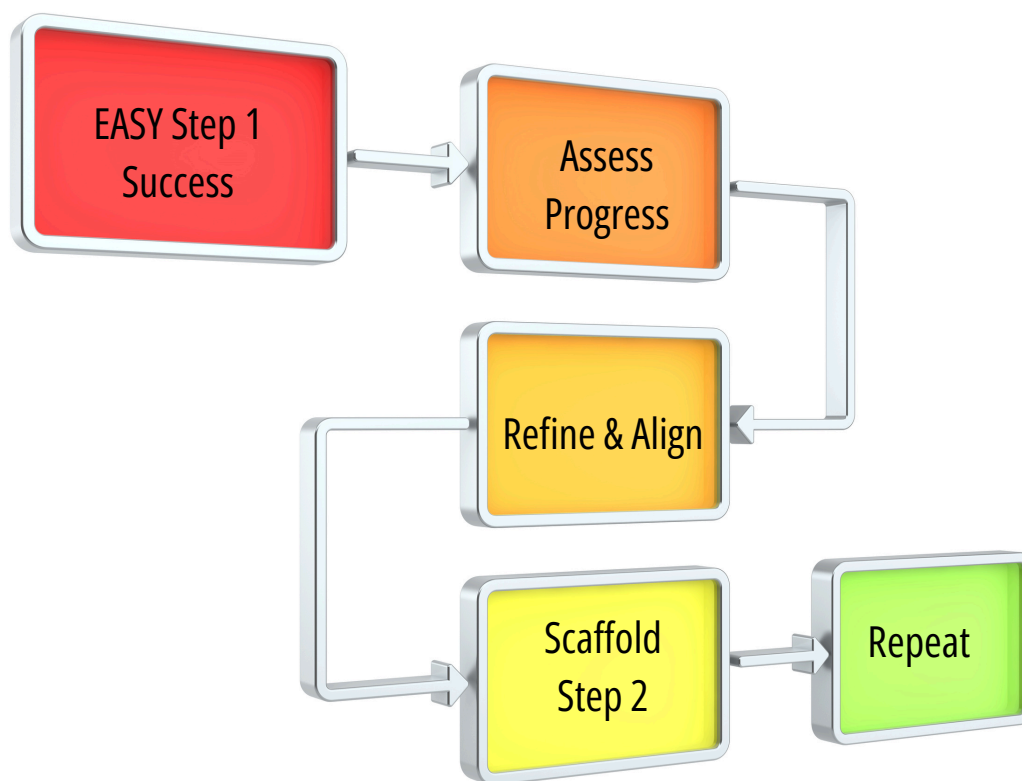
Making adjustments to your EASY step is an important part of the change process. It's normal to notice things that need to be refined. Consider how the step fits into your schedule, if the intensity is too much to begin or not challenging enough (making it boring). Notice if you need social or practical supports or would like professional advice. Many of these aspects can be tweaked to make the activity more achievable and enjoyable.

Discomfort when starting something new is common. Are the challenges because you're getting used to it and are in the awkward learning phase? If so, do you want to stick with it a little longer before choosing whether or not to adopt it? If you decide that this specific step isn't for you, but the overall goal remains, brainstorm alternative first steps.

Stop Signs: Increased pain, exhaustion that impedes completing your other daily demands, deeply disliking the activity after becoming familiar with it (for any reason).

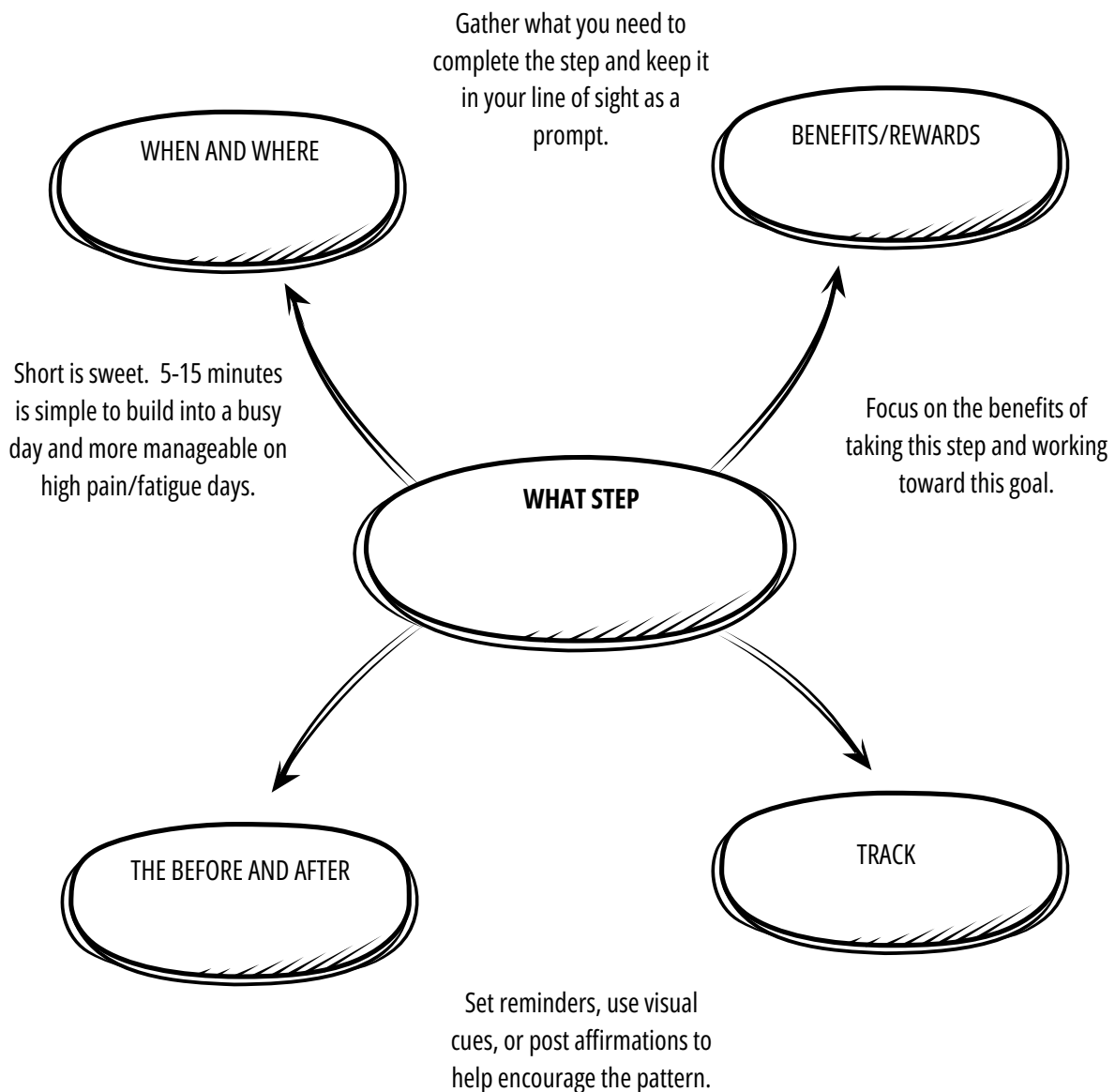
TAKE THE NEXT STEP TOWARD YOUR GOAL

EASY Steps are all about breaking your overall goal for your journey into manageable parts that build onto each other over time. As you incorporate a step into your life and make the necessary tweaks, so it works with your resources and demands, it becomes a habit. When you notice that a step takes less effort and feels like a normal part of your day, then it's time to celebrate! Acknowledge your progress and consider how to proceed. You can choose to stick with the step you've made (maintenance) OR you can plan to take another step toward your goal (new action). When taking the next step, take time to prepare and plan as reviewed in Chapter 8.



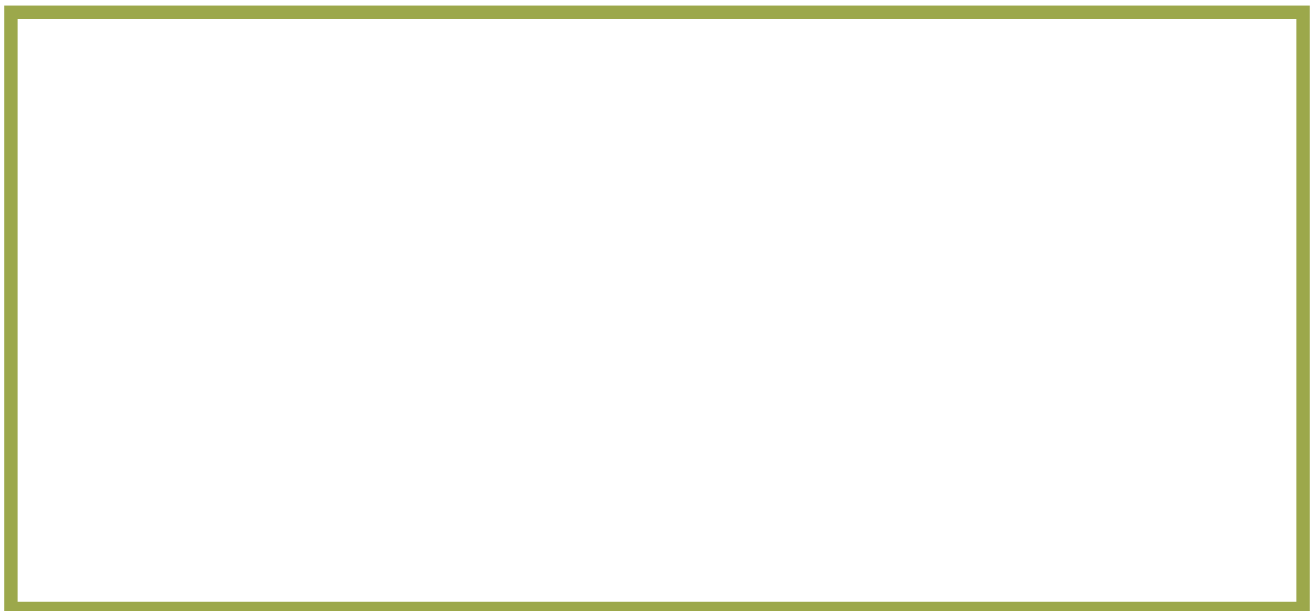
SCAFFOLD YOUR STEPS

Use the EASY step formula to consolidate the progress you've made so far toward your goal and set up the next step. Remember the importance of your using your resources wisely: Time, energy, equipment, etc. EASY steps are those you can take daily, are short (5-30 minutes), and accessible to you. Use mindful self-awareness to check in often and adjust based on needs, preferences, and values.



REFLECT ON PROGRESS

Sketch or write how you make sense of the progress toward your goal using EASY steps. Do you notice impatience or self-judgment coming up? If so, can you tap into self-compassion? What's that like? Are the steps and the goal still meeting your needs? Is it still interesting, fun, and meaningful to you?



WHY CELEBRATE?

Celebration is an important part of all human cultures because it has individual psychological benefits and social significance. Celebrating with our group of family, friends, or peers enhances our connections and typically marks important milestones in the environment, across individual lifespan and personal achievements, and recognizes specific relationships. It's a collective expression of gratitude.

In your vasculitis journey, it may be difficult to think of things to celebrate with your loved ones. Generally, we don't feel appreciation for illness, disability, increased stress, and financial burden. Totally understandable.

When navigating your journey with more self-compassion, you embark on a new chapter. You mindfully meet your needs, find new ways to channel your interests, and connect with your values. Surviving and finding ways to thrive with vasculitis are milestones you can be proud of and celebrate with your family and friends.

Within the process of making health-promoting changes, you celebrate YOUR creativity, effort, and commitment to living and loving with vasculitis.

If you need a scientific reason to celebrate, the dopamine and endorphins released during milestone social celebrations promote brain health and are natural antidepressants.

A celebration doesn't have to mean a party (though it can if you like). Celebration means planning time with the people that you care about to express gratitude together. A celebration can look however you want. It usually begins with an acknowledgement of the purpose of gathering (toast, speech, or prayer), followed by whatever makes your heart happy. It could be a picnic at the beach or a board game around the dining table on a snowy day.

Use the following prompts to plan the gathering that you'd most enjoy to celebrate the steps you've taken so far.

Celebration PLANNER

EASY Step

Goal

What will you celebrate?

When will you celebrate?

How will you celebrate?

Taking Delight in the Journey

What parts of taking this step did you enjoy in the moment?

CHAPTER 10: EVOLVING



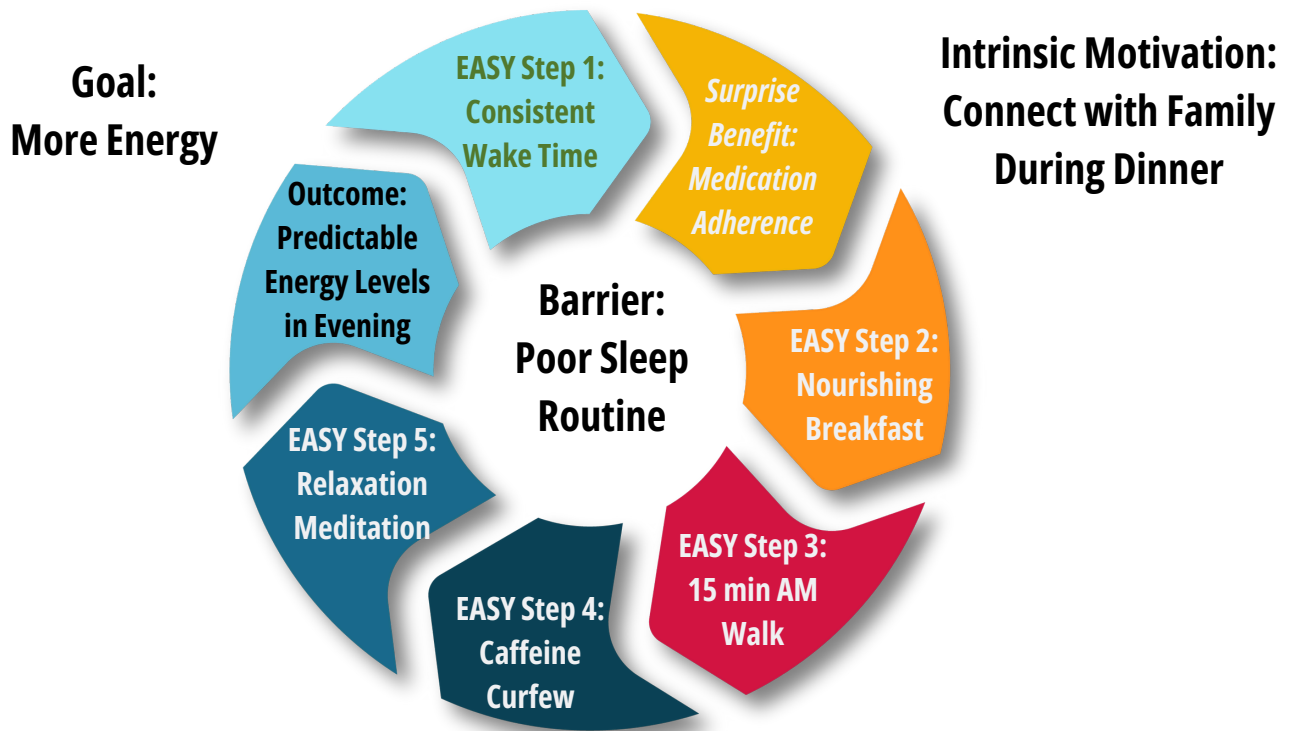
Continuing to prioritize your needs, preferences, and values as your vasculitis journey evolves is an ongoing commitment to yourself and your loved ones. It allows you to show up in your life in ways that matter most to you. Maintaining this way of being in the world requires a growth mindset, social support, and collaboration with your care providers. In turn, it allows you to flexibly adopt new goals in service to your well-being as your capacity changes across your lifespan.

Navigating your journey with more self-compassion isn't a secret healing recipe that makes everything better. You'll likely still experience flares since vasculitis is a relapsing and remitting chronic condition. Also, life demands change over time; you'll have to re-evaluate your priorities at times. Medications can have side-effects, even when you're in remission. Some days will suck. Instead of providing certainty, mindful self-compassion provides a framework you can apply to each new challenge. You're equipped with a skillset to navigate vasculitis with more integrity, self-kindness, and resilience.

CHANGE CASCADE

Throughout the guidebook, steps and goals are presented as ways to improve living with vasculitis. Small steps build toward larger, impactful change. Significant attention has been given to planning and scaffolding these individual steps. Each of them are important. However, it's also important to zoom out and consider the change cascade — how the daily health-promoting steps, these small shifts, work together to promote well-being.

In this example the primary goal was more energy. The identified barrier was not following a sleep routine. The first EASY step to develop a sleep routine was to follow a consistent wake-up time each day. This then allowed medications to be taken at the same time daily, which led to improved adherence (no missed doses), and eventually to other health-promoting activities that improve sleep (having a nourishing breakfast every day, going for a short morning walk, decreasing reliance on caffeine, using relaxation exercise before bed). All of these led to more predictable energy levels, which then resulted in more energy at dinnertime to connect with loved ones.



Your goals and motivations change as you evolve and grow. Return to the change process anytime you notice your daily routine needs a refresh, so it supports you.

ACKNOWLEDGE

Throughout the guidebook, various aspects that impact well-being were reviewed. Take a minute to check in with each area and how you're managing it in this moment. This acknowledges, without any expectation or pressure, what works well and which areas you may should focus on in the future to navigate your vasculitis journey with holistic well-being. Some folks like to describe it with words. Others like to give it a rating, from 0-5. Either way, remember this is just one snapshot of time.

Mindful Self-Compassionate Approach (Pause and Scan Anchor)

Fierce Self-Compassion (Tending the Needs of the Body)

Gentle Self-Compassion (Tending the Nervous System and Psychological Needs)

Vasculitis Treatment Adherence

Mindfully Budgeting Your Resources (Time, Energy, Finances)

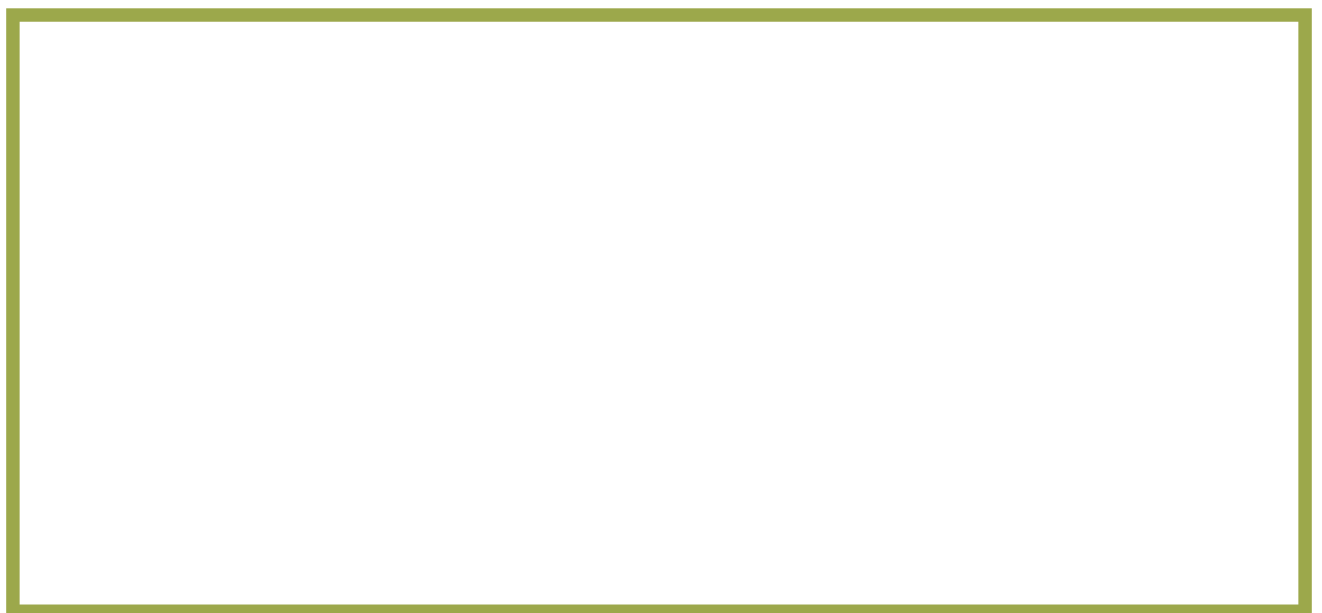
Cultivating Your Circle of Care and Community Connections

Nurturing Supportive Relationships

CONSOLIDATE

In addition to growing and striving, it's important to take time and allow new practices to take root in your life. Even if not every aspect of well-being reviewed on the previous page is at 5/5, you can let it be exactly as it is with self-compassion. You're doing enough. You are enough. You are worthy. One aspect of maintaining change is allowing yourself to be at ease in the middle of the journey. These moments encourage deepening into a practice or routine and are vital for flourishing.

Describe or draw what this moment of maintenance — the good enough — is like for you.



DRIFTING

Sometimes, even with careful planning, a newly established habit drifts off course. Intense emotion and self-judgement may rise when this occurs. Drifting off course is disappointing, but it's quite common and only indicates one thing: You're human. Use your nervous system and emotion regulation skills to soothe the distress, and then use growth mindset to reframe this situation. Can you tap into curiosity and observe any factors contributing to drifting off course?

Growth mindset is all about learning. Setbacks are viewed as opportunities in disguise. It's not the same as toxic positivity because it doesn't offer platitudes without substance. Instead, growth mindset allows for the acceptance of complexity and emphasizes creativity, critical thinking, and effort. Drifting is an opportunity to reflect and refine your steps with the most helpful information. What isn't working?

In the book *Atomic Habits*, James Clear writes that people don't fail, systems fail. Using his approach, all behavior change is a product of creating a habit. He maintains that there are 4 interconnected parts that form a self-reinforcing **habit loop**.

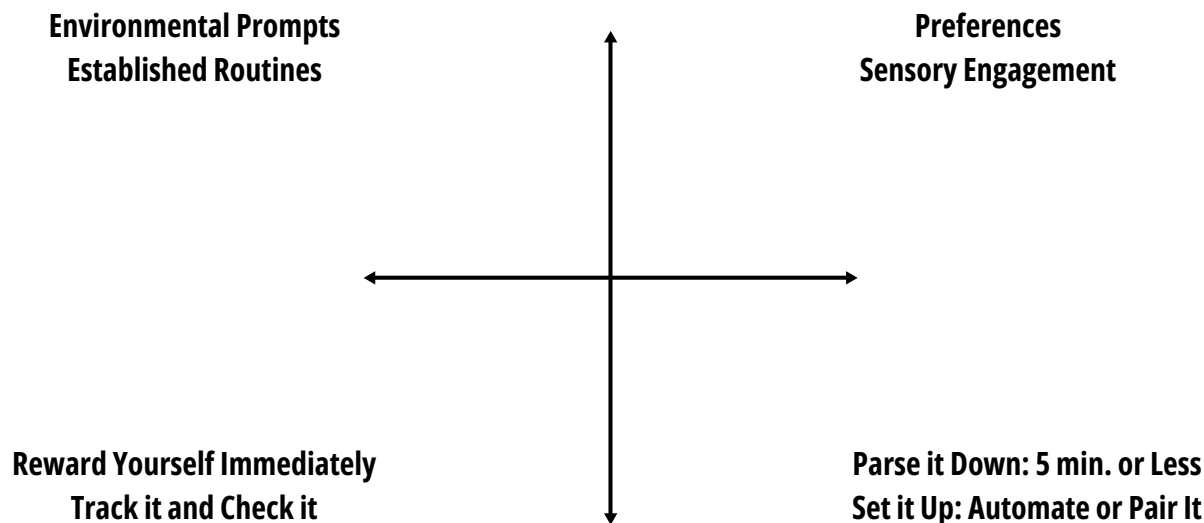
Cue: Use your environment to prompt you to take the step by making it obvious and on your mind.

Craving: It's vital that you enjoy some aspect of the step or pair it with something you like.

Response: Reduce interference between you and completing the step by parsing it or automating it.

Reward: If needed, bribe yourself to complete the step and focus on the benefits

If you notice yourself drifting away from your EASY Steps and SMART(R) goal, use this formula to understand how to get back on track and make your system more resilient (which actually makes it more likely to be sustained). Use the chart to brainstorm simple ways to make your EASY step easier and more rewarding.



ANCHORING

Humans don't keep doing things they find unpleasant, boring, difficult, or meaningless. The steps towards your goal must hit the mark on these factors most of the time, otherwise you'll just look for the chance to move on and forget about it. Anchor your journey in habits that are health-promoting and grounded in mindful self-compassion by making each step enjoyable, interesting, fun, and meaningful. Sharing these experiences with loved ones or a community of like-minded peers strengthens your commitment to the process.

What do you enjoy most about the steps toward your goal?

How can you make each step more interesting or fun?

Who can you tell about the steps you're taking and your success?

Maintaining



Self-compassionate daily habits require ongoing nurturing. Using intentional maintenance strategies helps you consolidate your progress.

- Keep using mindful awareness in daily life.
- Reflect and assess at regular intervals. Do your daily activities continue to align with needs, preferences, and values?
- Your vasculitis symptoms or treatments can change over time. How can you respond to these changes with mindful self-compassion?
- When you anticipate challenging circumstances, can you use strategies like cope ahead? How can your circle of care support you in maintaining the habits?
- Connect with a community that shares a similar commitment to self-care. Is it beneficial to keep working with a professional to maintain improvements on a check-in basis, maybe once a month?
- Celebrate maintenance with monthly anniversary acknowledgments: Eat your favorite meal, treat yourself to a new book, or gather with loved ones to reinforce and celebrate the change.
- If/when you encounter a major life transition (new life stage, work or school change, relocation, change in health status, etc.), look at the habit you formed and how you can build it into the next chapter of your life, transform it, or let it go with gratitude.

10 TIPS FOR NAVIGATING WITH CHRONIC PAIN AND ILLNESS

- 1 CONNECT WITH YOUR VALUES
- 2 KNOW YOUR STORY
- 3 CONNECT WITH YOUR CARE PROVIDERS
- 4 ATTEND TO YOUR NEEDS
- 5 CONNECT WITH FRIENDS AND FAMILY
- 6 MAKE CHANGES THAT WORK FOR YOU
- 7 SLEEP, EAT, AND MOVE JOYFULLY
- 8 REFLECT REGULARLY
- 9 CELEBRATE OFTEN
- 10 LIVE YOUR VALUES BY PRIORITIZING YOUR HEALTH NEEDS

“

When we deny our stories, they define us. When we own our stories, we get to write a brave new ending.”

– Brené Brown in *Rising Strong*



In the beginning of this guidebook, I invited you to engage with your needs, preferences, and values along with your experience of vasculitis so far. My hope was that the skills, strategies, tools, and processes shared would aid you in understanding where you've been on your journey, validate the challenges you encountered, and help you connect with your priorities, so you can define where you would like to go next.

I believe that each person navigating vasculitis — either as a patient or care partner — can be equipped for the journey. Professionals are important, but ultimately, it's up to the people living with vasculitis to take on the added responsibilities of managing it along with all the other life demands. Some days are a grind. Finding moments of gratitude is essential.

The idea for this project came from the numerous guidebooks I reviewed planning my travels. I realized that like planning an epic adventure, navigating vasculitis requires knowledge, preparation, skills, support from professionals, and devoted travel companions. I find it satisfying to tie my everyday moments and daily actions to my values and preferences, rather than focusing on a specific destination. To me, this is what the journey is all about, and I was frustrated that there were no guidebooks for folks like me living and loving with chronic pain and illness along for the ride.

I hope you'll use what's compiled here and make it your own so you can choose the next steps in your own journey and write your own brave new ending.

*With care,
Stacey*

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