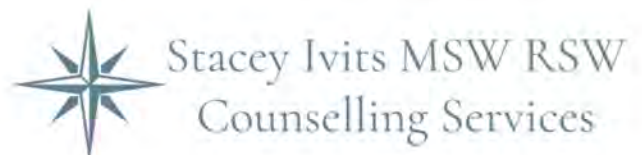


NAVIGATING YOUR VASCULITIS JOURNEY

AN INTERACTIVE
GUIDEBOOK
2024 Edition



A silhouette of a person in a yoga tree pose (Vrikshasana) on a beach at sunset. The person is standing on their right leg, with their left leg bent and foot resting on the right thigh. Their arms are raised, with hands pressed together in a prayer position above their head. The background is a soft, golden glow from the setting sun over the ocean.

WELCOME TO NAVIGATING YOUR VASCULITIS JOURNEY

Navigating Your Vasculitis Journey is an Interactive Guidebook for people with Vasculitis seeking to develop skills for managing life with this complex illness. This guidebook is not a treatment plan. It makes no promises of a cure or remedy. It is self-directed & self-paced. The materials are provided as information- for you to work through independently- to tune in and reflect on specific aspects of your own journey with vasculitis.

This interactive guidebook is provided as a tool and is intended to be a living document that you can add to and edit as needed. It can also serve as a template for you to create your own documents or journal that is unique to you, your specific diagnosis and treatment. You are invited to engage with the parts that are helpful to your journey at this time. You are also encouraged to use this to connect with your own health care providers. Nothing in this interactive guidebook is personalized medical or psychological advice. Consult with your medical team before beginning any medication, supplement, diet, or exercise regime.

3 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 1 day or 1 year (or more) to work through the guidebook - do what works for you

3

Make it YOURS

There is no right way to complete this guidebook - do what is helpful to you - no one is marking it.



NAVIGATING

UNDERSTAND, PREPARE,
PLAN AND TAKE CARE

MAIN OBJECTIVE

Identify key areas of self-care that support you in navigating your Vasculitis journey with Self-Compassion. By maintaining these areas you will be better equipped for exploring and finding your own way to live and love with Vasculitis.

LEARNING OUTCOME

- Introduction to Mindful Self-Compassion
- Importance of prioritizing your physiological needs for rest/sleep, nourishment, and movement so that you can better manage your health and wellbeing
- Learn how mindful awareness and reflection practices support you in making behaviour changes that are practical and sustainable
- Introductory understanding of nervous system regulation and its role in managing emotions, thoughts, and behaviours
- Identify behavioural goals for your Vasculitis Journey

TOPICS COVERED

- The Role of Self-Compassion
- Physiological Awareness and Meeting Your Needs
 - Sleep/Rest
 - Nourishment
 - Movement
- Window of Tolerance & Nervous System Regulation strategies
- Boundaries with Self & Others
- Behaviour Change Science

WHAT DO YOU NEED

Equipping

The key aspects of self-care

- Everyone has basic physiological needs. People living with Vasculitis are often required to pay closer attention to meeting these needs so that they can manage the many demands on their time & energy more effectively
- Assess each of these key aspects of self-care and see how you can 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 that 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 & personally

- Identify different care providers and how they can support you in Navigating Your Vasculitis Journey with compassion
- Create routines that support your needs and bring awareness to your day-to-day 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 how you are managing your self-care needs so that your loved ones better understand all that 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 goals & track them

- 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 to manage emotional and psychological distress more effectively

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USING THIS GUIDEBOOK EFFECTIVELY

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

Each chapter in the guidebook has pages labelled Orienting, Organizing, Observing, Optimizing

Orienting = Descriptive Information on a concept that may be helpful in your journey

Organizing = Understanding how the concept connects to your journey

Observing = Reflecting on your experience of using the concepts and applying them to your journey

Optimizing = Applying the information from the chapter to take action in your journey

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. Though it sounds like a simple intervention, it takes practice. Acting with self-compassion requires working with our thoughts, emotions, behaviours and relationships with kindness consistently.

Self-compassion includes:

- *changing internal self-talk to be gentle and validating of personal experiences*
- *holding space for all the feelings that occur (especially in tough moments) and using language to describe them and acknowledge their impact*
- *setting realistic expectations for behaviour based on the resources available (time, energy, current ability, money, prior experiences & skills)*
- *meeting the needs of the body*
- *interacting with others respectfully, with accountability and kindness*
- *maintaining interpersonal boundaries*
- *acknowledging and accommodating personal preferences*
- *making choices that align with individual values*
- *asking for help when needed*
- *advocating for our care needs with professionals*

Mindfulness is one type of reflection skill that can be helpful in order to act with more self-compassion. Specifically, for people living with Vasculitis, Mindful Self-Compassion brings the skills of non-judgmental awareness to our thoughts about having this illness, the emotional experience of it, the sensations—including pain, and attending to the lifestyle changes required to live with this chronic condition. Mindful self-compassion helps us to attend to all these aspects of daily life with the intention to relieve our suffering.

It is important to emphasize the two complimentary aspects of Mindful Self-Compassion: Tender & Fierce. Tender Self-Compassion is the soothing aspect such as gentle self-talk. Fierce Self-Compassion is the accountability aspect such as prioritizing rest & movement in daily life. Both Tender and Fierce Self-Compassion work together to promote wellbeing.

To learn more about Mindful Self-Compassion please check out the information and exercises presented at 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 in various forms is incorporated into many psychotherapeutic approaches and religious practices. Reflection practices, like mindful meditation and journaling, have been shown to benefit mental health independently of other interventions. Though it is often associated with Buddhist traditions, it is a secular reflective practice. If you would like to practice mindful awareness in a way that fits your beliefs, connect with a faith mentor in your community.

Throughout the Guidebook, there will be different opportunities to practice Mindful Self-Compassion alongside other invitations for reflection. Mindful Self-Compassion is part of the first chapter, because ***Mindful Awareness is an anchor that can be used whenever you may feel overwhelmed.*** It can help when living with Vasculitis to stop and notice our needs - physical, emotional, relational, or spiritual. Self-Compassion is like a compass to stay oriented to health promoting activities that relieve suffering.



Link to 20 minute Loving Kindness Meditation:
<https://self-compassion.org/wp-content/uploads/meditations/LKM.self-compassion.MP3>

In pop culture, seated meditation has been used to represent mindful awareness practices. Though this works for some, guided meditation or active practices can be more helpful when you are starting out. The skills of moment-by-moment non-judgmental 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.

When beginning a mindfulness practice, consider 5-10 minutes of guided meditation or an active practice (like yoga) every day. Build this activity into your daily routine where it fits best in your schedule. When the activity becomes a regular part of your day, consider increasing the time you spend on it or using an unguided practice. There are numerous resources available online or at your local library to learn more about the variety of awareness practices.

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

Key Points to Cultivate Self-Compassion

Mindfulness: Moment-to-moment awareness of internal & external experiences. Noticing, naming and allowing experiences to exist and change.

Self-Kindness means reliably meeting the needs of the body, brain, and nervous system. Gentle self-talk, soothing strategies, and boundaries are ways to promote wellbeing.

Common Humanity: honours the interconnectedness of people and the world, includes both joy & suffering. Understands that painful experiences are a part of being human.

Non-judgement: describe situations without assessment- many things are nuanced (including both "good & bad" qualities) and many others are neutral.
Neutral Example: Boiled rice

Non-Attachment: allowing for the natural ebbs and flows in internal & external experiences such as events, thoughts, emotions, sensations, and behaviours.

Tender Self-Compassion: gently attending to our experiences with kind self-talk. Using soothing strategies is tender self-compassion.

Fierce Self-Compassion: internal and external boundaries enacted regarding time, energy, relationships and resources.

MYTHS OR FACTS

ABOUT SELF-COMPASSION

Self-Compassion is Selfish



Truthfully, failing to meet your own needs results in more work for others-- your family, care providers or community. We all need support at times! When possible, 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 is protective.

Self-Compassion is Lazy



Self-compassion is not self-indulgent or passively accepting of difficult circumstances. Self-compassion asks us to take action to prevent and alleviate 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 & SCAN

Mindful Awareness is an anchor that can be used at various times, and is especially helpful whenever you feel overwhelmed. It can help when living with Vasculitis to stop and notice our needs-physical, emotional, relational, or spiritual. One practical application of Mindful Awareness that we will build on throughout the Guidebook is called the **Pause & Scan**. The Pause and Scan is a brief reflection on a single moment with Mindful Awareness.

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 your Heart and the feelings you are experiencing.
3. **Behavior:** Finally shift your awareness to your hands and feet and describe your actions.

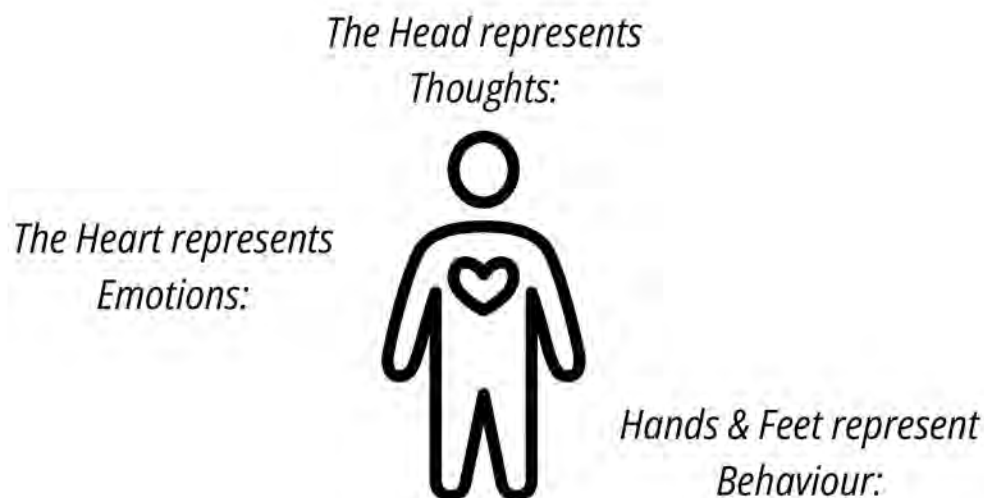
Examples

Pause & Scan while reading:

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

Pause & Scan when walking the dog:

"In this moment I am thinking about our upcoming plans. I feel anxious because there is a lot to do. I am walking quickly."



SELF-COMPASSION INVITATIONS

EXPLORE COMMON BLOCKS

Watch this video of Dr. Kristen Neff talking about this issue which stops folks from being kind to themselves.



<https://mindfulness Exercises.com/kristin-neff-overcoming-objections-to-self-compassion-video/>

LEARN ABOUT YOU

Take a self-compassion assessment.



<https://self-compassion.org/wp-content/uploads/2015/06/Self-Compassion-Scale-for-researchers.pdf>

Remember that the information you learn about yourself is one way of acknowledging the present moment with kindness.

TRY A HAND ON HEART EXERCISE

- Begin by taking 3 deep breaths and placing your hand on your chest, over your heart. If it's comfortable to you, 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 5 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.

BEHAVIOURALLY

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 am so weak! I can't even vacuum my house anymore.

COMPASSIONATE THINGS I COULD SAY

Example: I am 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 & Window of Tolerance

Chapter 4: Psychological Needs, Preferences & Values

Chapter 5: Your Health Story & Care Plan



Make the Packing List

What do you bring on your journey?



Survival
needs
must be
reliably
met in
order to
consider
thriving.

Part 2 of the Guidebook explores how to equip yourself to Navigate Your Vasculitis Journey more effectively. Please remember that each person is on a different path. The next few chapters will help you develop an understanding of your specific physiological and psychological needs, preferences, and values. You can use this understanding to work with your healthcare team to design a Vasculitis Care Plan that aligns with your needs, preferences, and values.

Physiological Needs include sleep, food, water, shelter/safety, movement, and tending to wounds/illness. These needs are common to all living beings.

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.

Please remember that the illness and treatments can impact your vulnerability in each of these aspects of self-care.

It is assumed that users of this Guidebook have access to a safe living environment. If you are underhoused or living with the threat of violence, please seek resources to meet these essential survival needs.

Needs, Preferences & Values

Self-compassion has two complementary aspects: tender and fierce. In tender self-compassion, the focus is on acknowledging and validating experiences. In fierce self-compassion, the focus is on protecting, providing and motivating oneself.

In order to practice self-compassion, it is essential to KNOW your needs, preferences and values and how they change over time, especially with vasculitis. For example, on high dose prednisone some people have trouble sleeping and have to adjust how they meet the need for rest. As the dose changes, they may have a different priority, 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 & Expression
- Meaning & Purpose

When living with chronic pain, illness, and uncertainty meeting our social-emotional and sensory needs can help to alleviate 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 are often connected to sensory experiences. Understanding our sensory experiences and preferences can be a grounding tool when we are overwhelmed. Values connect individuals to their sense of meaning and purpose. They are unique to each person.

Example of Prioritizing Specific Needs when living with Vasculitis

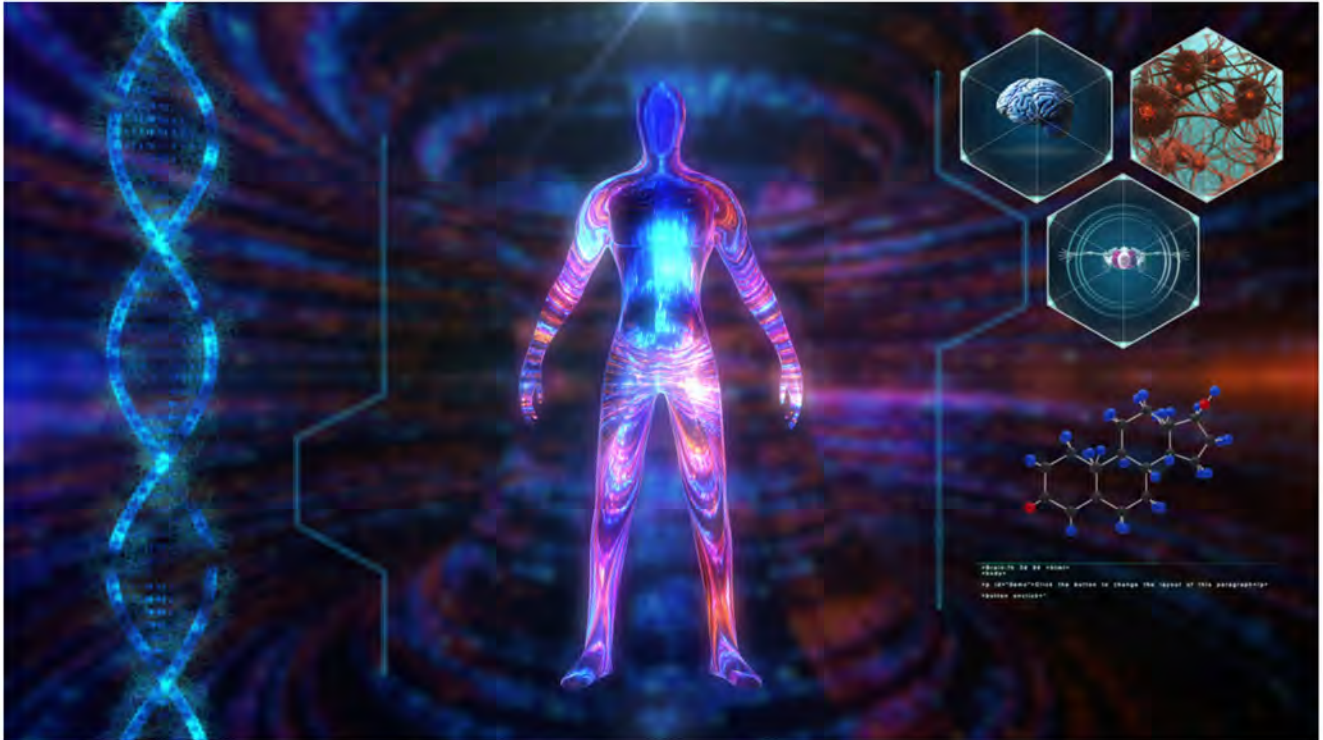
Physiological:

- Attending infusion appointments on schedule
- Having an afternoon nap every day
- Drinking more water
- Going to physiotherapy (physical therapy) every week to rebuild strength & protect bones

Psychological:

- Keeping a gratitude journal
- Attending a vasculitis support group every week
- Practicing yoga daily
- Early family dinner to connect with the people who matter most to you while alert

CHAPTER 2: IDENTIFYING & MEETING THE NEEDS OF THE BODY



This chapter provides information about meeting the physical needs for rest, nourishment, and movement that are shared amongst all people. Each person, with or without vasculitis, must find ways to effectively meet these needs for health and wellbeing. When we have vasculitis, the disease or its treatments may make it harder to meet these needs at times. Though they are presented within this chapter as part of physical wellness—they are also deeply connected to mental well-being, as explained later in the guidebook.

Sleep

Vasculitis and its treatments could be impacting your sleep and energy levels. There are some aspects of your environment and routine that you can adjust 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 all disrupt sleep. The diagnosis of vasculitis itself may be a stressor and impact your sleep, so it can be useful to learn ways to manage stress such as relaxation techniques.

There are also environmental shifts that you can make to help you to sleep better. In the next few pages some of these small adjustments are shared. Some appear so simple they can easily be overlooked, and yet they can transform your relationship with sleep.

If you had trouble sleeping prior to being diagnosed with vasculitis and you notice the effects more deeply now, it is important to address your sleep difficulties alongside your other health concerns. There are medications and interventions that are helpful for both physical and psychological co-occurring conditions that impact sleep. For ongoing sleep troubles connected to symptoms of anxiety or depression, connect with a Registered Mental Health Clinician in your region. The most effective intervention for insomnia is a type of therapy called 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) could be helpful.

If you cannot access counselling or therapy, there are some things you can do. 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

Are you setting yourself up to sleep well?

PHYSICAL & MENTAL HEALTH

Medication, pain management, stress or worry

How are you managing these important factors?



Components of Restful Sleep You can Adjust

ENVIRONMENT

Temperature: Consider how your heating and cooling system can be optimized in your home. Fans or extra blankets can also help.

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

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

Comfort: What is your bed like? Is it bumpy & lumpy? If a new mattress is out of the budget, consider a mattress topper or extra padding.

Co-Sleeping: Though sleeping alongside a loved one may have gone well in the past, is it working for you right now? If sharing a bed is adding 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 are feeling better.

DAILY ROUTINE

Movement: Moving your body during the day can help you sleep better- even if it is standing once per hour, doing arm circles and leg lifts while seated, or going for a short walk. Avoid intense exercise in the evening, though a gentle walk or stretch can promote relaxation.

Consistent Wake Up Time: Attempt 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 ensure that you are eating 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 1 hour before you hope to sleep, to avoid scrolling into the wee hours.



Sleep Reflection

How's your sleep? Consider how you can prioritize rest by making small changes to your environment, routine, or self-care practices to improve the quality of your sleep. Would it be helpful to discuss your sleep with your care team to see if there are supports available to help you sleep better?

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

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

Pain & Symptom Management: Are there any specific concerns that you could discuss with your care provider?

Preparing for a Better Sleep

3 things that could help you sleep better tonight

30-90 minutes before bedtime

1- Device Curfew: Plan to 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 when you're trying to sleep with all the things to remember for the next day or different anxieties? Schedule some time before you go to bed to jot things down. You are not trying to figure them out now- just a note to prompt you the next day.

20-30 minutes before bedtime

3- Relaxation Exercise: a guided body scan, progressive muscle relaxation, or a visualization can all help you to relax and fall asleep. Later in the guidebook you will find links to various ones to try. There are numerous apps and offerings. Below is a link to relaxing bedtime stories that are free and available across multiple platforms.



<https://www.nothingmuchhappens.com/stories>

NOURISHING THE BODY

FUELING RECOVERY AND MAINTAINING REGULATION



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

There are numerous diet trends and fads, many attributing specific health benefits to the foods that are championed and villainizing other foods. Based on the evidence to date, there is only one “evidence-based diet” that has been proven to support health for many people—the Mediterranean Diet. It is a diet that is inclusive of every food group and even sweets in moderation. It promotes fresh, plant-based foods and lean proteins from both plant and animal sources. Other approaches may claim benefits, but do not 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 are 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 region.

Two other evidence-based approaches to eating that do not list specific “good vs bad foods” or endorse a specific diet are Mindful Eating and Intuitive Eating. They are not diets and do not attempt to promote weight loss. These approaches encourage deepening awareness of the food from production to post-consumption, expressing gratitude and listening to your own body’s cues to hunger and satiety. They make space for dietary needs, preferences, and religious requirements, and can be practiced without buying an app or signing 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 do not increase risks for disordered eating, Eating Disorders, OCD, or Food Anxiety. They do not encourage fixation on the shape or size of the body, but rather on how nourishing the body attentively can improve function and wellbeing. Fad diets, carry both physical and psychological risks, and are not generally helpful to overall wellbeing.

FUELING RECOVERY AND MAINTAINING REGULATION

Ensuring 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 is less physiological stress and it is more capable of moving through environmental and emotional distress. When you live life with Vasculitis, especially when experiencing side effects from medications that change the size and shape of the body, it is 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. However, the risks of following fad diets are often amplified for folks dealing with chronic health concerns. And it makes one more stressor for your body and brain to cope with effectively, alongside all the other priorities.

Alternatively, “giving up” or the “whatever” approach to food and movement are equally unhelpful for people living with vasculitis. These tend to amplify the negative side-effects of medications, like prednisone, and can cause further long-term damage by way of steroid-induced diabetes, osteoporosis, and kidney or liver problems. It also increases the risk of meal skipping and then over-eating that is very taxing and uncomfortable.

To best support your body, including nervous system regulation, follow a regular pattern of eating that includes all food groups in moderation over 2-4 set meal times and 1-3 snacks everyday. Work with a Registered Dietician (RD) or Registered Nutritionist in your region if you are 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 your hunger cues, which are not always a grumbly tummy, and can include difficulty concentrating and fatigue, amongst many other discomforts. Respond to hunger cues compassionately by providing your body with nutrient-dense snacks-like veggies & hummus or cheese & whole-grain crackers-between meals. And similarly, respond to satiety cues-feelings of fullness-which means paying attention while eating to how your body is responding during the meal. Stop eating when you have had enough or take a few extra bites of nutrient-dense options like protein and vegetables if you are still hungry. Consider including a sweet ending after a meal-this could be a portion of chocolate, fruit, cookie, etc. On holidays and special occasions, enjoy the food that is special to you and your community without fear or self-criticism, and continue to listen to your satiety cues during these events.

If you are noticing post-meal discomfort regularly, consider food tracking and discuss this with your care provider. It is common for folks with vasculitis to have digestive difficulties. Some can be addressed through identifying the offending food and choosing to skip it. Other problems need more investigation and treatment. Working with your PCP and an RD can be an important support to help you live more comfortably, because every body needs nourishment.

Following a regular pattern of eating every day, focusing on including more nutrient-dense foods, and listening to your hunger and satiety cues are some of the most self-compassionate acts you can do to Navigate Your Vasculitis Journey. Nourishing your body promotes physical healing and supports mental health.

Foods to keep on hand

PROTEIN & DAIRY

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

VEGETABLES & FRUIT

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

COMPLEX CARBOHYDRATES

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

EASY & FUN FOODS

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

Relationship With Food

People can struggle with their relationship with food for many different reasons. Feeling conflicted or confused about what to eat or how to feed yourself is really common. Reflect on where you are at this moment in your relationship with food and nourishing your body regularly. If you notice that there is more to it, consider reaching out for support to your primary care provider or a mental health professional.

What is your current pattern of eating?

What are your hunger cues?

What are your satiety or fullness cues?

3 STEPS TO nourishment

1

Throw out food rules that are arbitrary (based on fad diets, counting calories or carbs, good vs. bad foods, etc) and begin to listen to your body and its hunger and fullness cues and how your specific body responds to different foods.



2

Keep fresh, quick, easy, and tasty foods on hand for days and weeks when pain, fatigue, or illness is overwhelming and nourishing your body feels like a chore, so that you can feed your body regularly and with more ease. It is especially important during these times to nourish your recovery.



3

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

Flare Up Menu

A 1-week meal plan that includes easy, fresh, and tasty options for you & your loved ones that uses things you keep on hand and doesn't require a lot of effort--specifically for when your symptoms flare. Include variety. Think about balancing 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 again after a Vasculitis diagnose, flare up, or setback. Please check out the Victory Over Vasculitis Physical Wellness & Movement resources. These are designed by patients with Vasculitis who 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 has been shown to reduce inflammation and improve mental health. There are two main types of physical exercise and both are important to wellbeing: Aerobic Exercise (or Cardio) & Muscle Strengthening (Strength Training). Please consult with your health care provider before beginning any new exercise regime. Additionally, a trained movement professional in your region can create a plan based on your current capacity and your 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 is gentle, accessible and fun!



<https://www.vasculitisfoundation.org/living-well/wellness-movement/>

Gentle Movement Activities

Sometimes folks have a narrow definition of exercise that is all 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 5 minutes at a time and check in with yourself regularly. If you are feeling up to it and want to do more, increase by 5 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 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. Whatever your fitness was previously, 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 that you enjoyed prior to your diagnosis that you miss? And if so, what are the barriers to engaging in them?

What do you envision as Joyful Movement?

Start Wherever You Are

It is difficult to get moving after illness. And it is equally 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! However, I can walk to the mailbox and rest on the bench then walk home, so I will do that every day until it becomes easier.*

Please do not let perfect be the enemy of good in 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 helps you to engage with your body using micro-movements and can be done while sitting or lying down. Check out this link for an example of the exercise:



<https://www.youtube.com/watch?v=ClqPtWzozXs>

Soma Yoga with Molly: Molly is a certified SomaYoga Therapist and Trainer who has vasculitis. She has provided workshops live, virtual workshops and in-person workshops for the Vasculitis Foundation.



<https://www.yoganorthduluth.com/resources/somayoga-practices/>

Seated Strength: This short video takes you through a series of strength exercises that can be done while seated. Developed by Brandon Hudgins a former long-distance runner with vasculitis who has a Master's degree in Kinesiology and Exercise Science.



<https://youtu.be/AsT1NzReLcs>

If you are able, consider incorporating a short morning stretch or walk-15 mins of movement-into your daily routine. If you are able to be more active, consider developing a daily movement practice that incorporates both aerobic and strength building exercises. Movement is an essential component for Navigating Your Vasculitis Journey.

For a glimpse ahead in the Guidebook, checkout the next activity which uses some of the goal setting strategies from later chapters.

Movement Goals

Use the following prompts to set a goal to get moving. Remember to use mindful self-compassion to guide you in choosing something that is 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 & 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 WELLBEING



Understanding a little bit about nervous system regulation is helpful for people living with Vasculitis. Your Nervous System is the threat detector for your body. Sometimes the alarm gets set off, and though that is important and helps with survival, there are times when it stays on for too long. This is chronic stress and can cause more physical and mental health problems. By meeting your physical, psychological, and nervous system needs reliably you can turn off that alarm and feel more relaxed which can help you to experience life with more calm, connection, and enjoyment.

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. Overall, it is an amazing internal communication system! It works faster than human language and works independently of conscious awareness.

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

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

The Parasympathetic System is also part for the relaxation response- Rest & 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, It has an important role in digestive function, heart rate, immune system, and mood. It has branches that connect through much of the torso.

Instinct: reactions that occur without conscious decision making and are based on survival.

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

Scripts: similar to a conditioned response, are a set of beliefs, thoughts, and behaviours that can feel automatic. Unlike instincts, scripts can be challenged and rewritten when they are unhelpful.

Routines: Like conditioned responses and scripts, these are a set of behaviours that can become automatic. To begin they are intentional and designed to support a desired outcome.

Instincts, conditioned responses, scripts and routines are different processes- but can feel the same when we are going through the motions of life and they are occurring outside of awareness.

NERVOUS SYSTEM REGULATION- THE WINDOW OF TOLERANCE

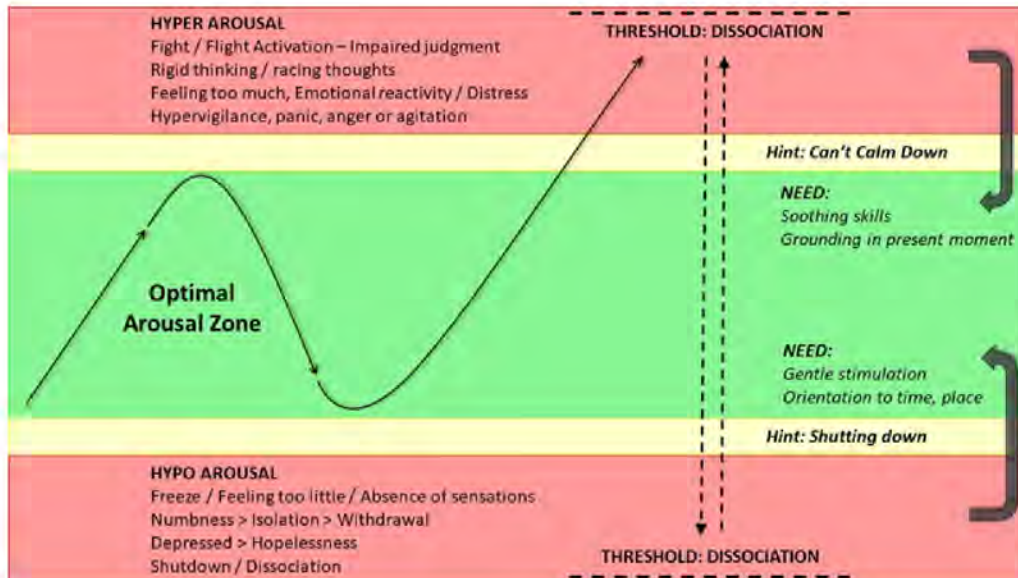


Image from: <https://mi-psych.com.au/understanding-your-window-of-tolerance/>

Optimal Arousal Zone: Calm & 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 that was first used by psychiatrist Dr. Dan Siegal. Within this model there are 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).
3. **Hypoarousal (Survival Mode):** A protective state activated by the nervous system when it perceives a threat and determines that it can't get away or fight back. 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. Activation of the fawn response when people try to befriend or please the threat in attempt to receive mercy.

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 is nicknamed the rest and digest state. This state includes all emotions and stress - it is not perpetual happiness or an absence 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 and the ability to narrow focus and notice granular distinctions and also to zoom out and see patterns or innovate. This state also allows for genuine connection with other people, animals, and even ideas. It is a true feeling of integrated presence.

When within this Optimal Arousal Zone - or “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 frustrating one) however they do not elicit a sense of hopelessness or helplessness. There is proactive energy to complete the tasks at hand. The saying “this too shall pass” reflects this state of momentary discomfort while within the window of tolerance and experiencing distress.

By becoming familiar with your personal 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).

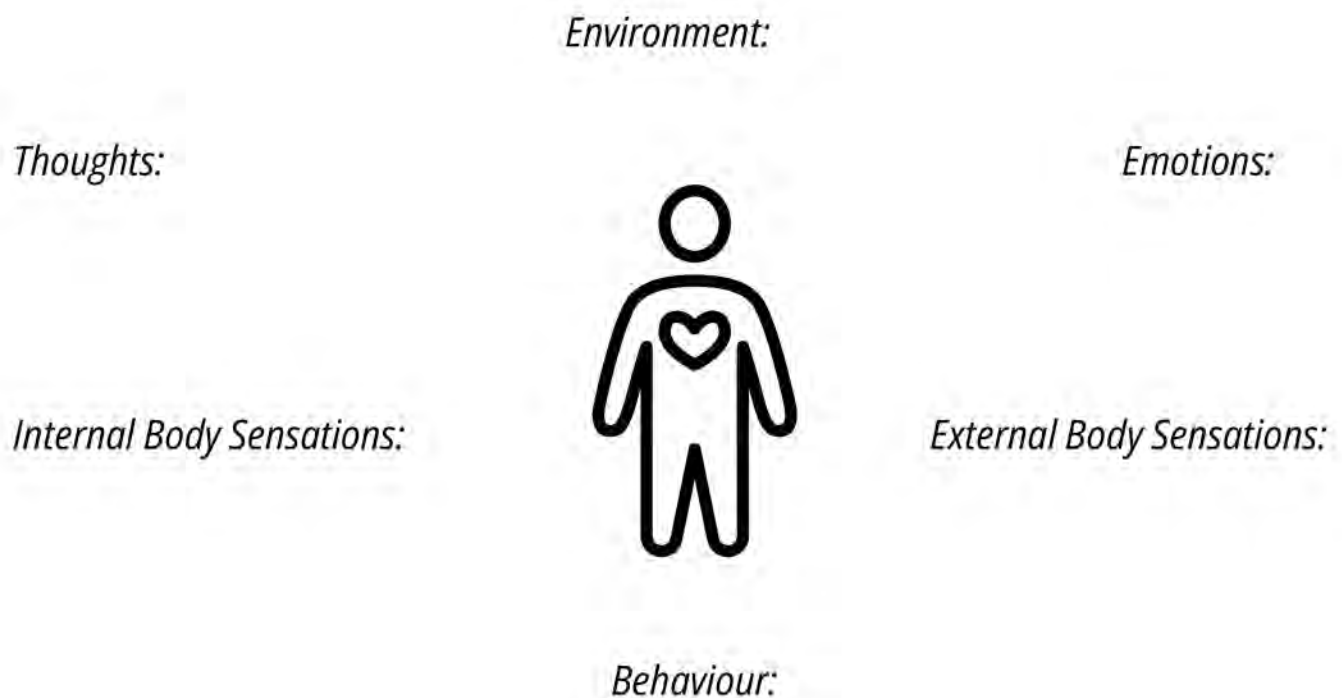
Signs of Safety or Comfort

- Environment: tidiness & order, temperature (not too hot or cold), comfort items like blankets, etc
- Thoughts: orientation to time & place, can describe experiences, ability to play logic games like Sudoku
- Emotions: capacity to observe and name emotions and choose how to express them safely
- Sensation: pleasant, enjoyable, calming or soothing
- Behaviour: understandable and connected to routines or goals

On the next page, use the Pause & Scan Image to note your personal signs of safety and nervous system regulation.

NERVOUS SYSTEM REGULATION- THE WINDOW OF TOLERANCE

Pause & Scan: Signs of Safety, Comfort & 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: Do I feel my muscles relaxing? Is my heart rate even?

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

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

THE NERVOUS SYSTEM AS THE BRIDGE BETWEEN BODY & BRAIN

The Survive State: Without conscious awareness, your nervous system senses danger - in the environment, in your body, or interpersonally and responds automatically in 4 primary ways: fight, flight, freeze, or fawn. These reactions are instinctual, conditioned, or scripted based on previous experiences. When your brain flips the switch into the Survive State you may feel alert, a surge of energy that asks to move (fight or escape), 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 the Survival Modes are 100% the most appropriate responses to situations. However, sometimes there is a glitch in the system. Like some smoke detectors - the threat detection system, can go off when you simply burn the toast. Burnt toast does not require the attention of the fire department or even a fire extinguisher. Similarly, there are many "burnt toast" situations for most people, especially if you live with a chronic illness that has previously threatened and changed your life. This means the Survival Modes for many people with Vasculitis can be over-responsive and easily activated when there is not an imminent threat. This is understandable and manageable (if you know what's happening.) Sometimes the treatments for Vasculitis (looking at you Prednisone) can contribute to this feeling of dysregulation.

Dysregulation - both hyperarousal (fight or flight responses to threat) and hypoarousal (freeze and fawn responses to a threat that cannot be escaped) hijack your thoughtful decision-making processes with the goal of survival. This is important and innate - you are not doing anything wrong when this occurs - however you can learn how to recognize when this switch from Thrive to Survive happens for you 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 & 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

THE NERVOUS SYSTEM AS THE BRIDGE

Hyperarousal: aka the fight/flight dynamic. It is the feeling of wanting to move to avoid threat- either run away or fight back. When you are in this state you may notice that you:

- feel panicky
- are hypervigilant
- feel restless
- have racing thoughts,
- are easily startled
- find it difficult to relax

You may find this happens when you are feeling intense anger or fear. Or on a boring Wednesday when you are on 60 mg of prednisone. It is quite unpleasant.

The Polyvagal Ladder is a part of polyvagal theory that proposes that under stress humans move through specific states in the following order:

1. Danger is sensed/perceived- we become more alert for risks
2. Our social system becomes limited which makes it hard to communicate deeply with others, learn new things, think critically and problem solve
3. Danger continues or intensifies and previous strategies to survive are prompted (scripts)
4. Fight or Flight energy is tapped to get a way from danger-- there can be a surge of energy
5. The danger cannot be escaped- we get tired
6. We go into hiding or shutdown mode- also called freeze/fawn- and we feel low energy. It can be hard to talk or move. We feel stuck.

For people with vasculitis, it is important to understand the other aspect of dysregulation - Hypoarousal. If you feel stuck, trapped and helpless due to your diagnosis, it's treatments, or ongoing pain then the Hypoarousal system may be activated. In this state people tend to withdraw further from people and activities- even ones they may still have the physical ability to engage in. This can lead to further physical deconditioning and more social isolation. When thinking about making changes, people stuck in freeze mode may begin by saying, "I can't..." or "I wish I could but..." or "I don't know what I like anymore..."

This **Hypoarousal state** can occur after an extended period of fight/flight energy or as a consequence of ongoing stress without any recovery. It is the brain's and body's best attempt to conserve energy to escape later. It can be understood as a wise response many 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 like vasculitis.

In hypoarousal there is a disconnection that occurs across multiple aspects of life. You can feel lethargic. It is a push to leave the house or answer a text. The apathy is debilitating. Shifting out of shutdown mode requires action- one step at a time- that is new and different that will communicate with the body that it is not stuck. Slowly you climb back up the ladder into Ventral Vagal Connection with Self & Others.

Movement helps to communicate with the body and resolve these dysregulations. For example with fight energy, pushing against a wall, running, jumping jacks, boxing or other intense movements can be cathartic. If you cannot do intense movement, consider Progressive Muscle Relaxation.

NERVOUS SYSTEM REGULATION: MAPPING YOUR DYSREGULATION

Using the diagram on this page, take note of how you experience Hyperarousal - the Fight/Flight Energy that can be activated under threat.

Environment:

Thoughts:



Emotions:

Internal Body Sensations:

External Body Sensations:

Behaviour:

NERVOUS SYSTEM REGULATION: MAPPING YOUR DYSREGULATION

Using the diagram on this page, take note of how you experience Hypoarousal - the Freeze/Fawn Energy that can be activated under threat.

Environment:

Thoughts:

Emotions:



Internal Body Sensations:

External Body Sensations:

Behaviour:

UNDERSTANDING REGULATION & 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.

Meeting the Physiological Needs of the body by eating and sleeping on a regular schedule, taking medications as prescribed, avoiding non-prescribed psychoactive substances, moving the body, practicing relaxation, and tending to physical injury or illness in a timely way helps to support nervous system regulation, allowing people to access the Thrive State more reliably. Failing to meet the needs of the body causes added stress.

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 Siegal 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 that is comprehensively trauma trained and ensure that they are certified to practice in your region.

The Thrive State: calm, curious, and compassionate. It is 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. When you are in the Thrive State you can solve complex problems and learn new information. You are able to attend to your own needs, preferences and values with care. You can connect meaningfully with the people around you.

When you are thriving, you are able to cope with typical daily demands and also respond effectively to new and challenging situations.

Survive State: Hyperarousal of Sympathetic Nervous System or Hypoarousal of Parasympathetic Nervous System in response to perceived threat.

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

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

STRATEGIES TO WIDEN YOUR WINDOW OF TOLERANCE



MYTHS OR FACTS

ABOUT FATIGUE

It is always caused by doing too much



Fatigue can be a symptom of hypoarousal, or the shut down state of the nervous system, and not an indicator of energy use. Learning more about your Nervous System and Regulation can help you to understand the difference between exhaustion, lethargy, and drowsiness.

There is nothing to do about it except sleep more



Since fatigue can be a symptom of nervous system dysregulation, sleep is not always the most helpful way to manage it. In fact, moving the body and engaging the senses gently can help to regulate the nervous system and decrease fatigue associated with nervous system hypoarousal.

Its all in my head so I just need to push through



Though “pushing through” may work for some people or in some situations, nervous system dysregulation is a systemic issue and not just “in your head” therefore a holistic approach including regular sleep & nourishment along with 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. Rather than explaining why you have specific limits, focus on stating clear boundaries about what you can and can't do when your needs change. People do not have to “get it” to respect and support you .

EXERCISES TO NURTURE THE NERVOUS SYSTEM

Self-soothing strategies are important to regulate the nervous system, recharge, and rest.



MEDITATION

- Kristen Neff PhD Loving Kindness Meditation or Self-Compassion Break
- Progressive Muscle Relaxation
- Rick Hansen PhD Relaxation Meditation 30 min meditation
- Tara Brach PhD Gathering & Arriving in Presence 4 min brief meditation
- Guided Body Scan Meditation
- Box-Breathing Exercise

Links

- <https://self-compassion.org/category/exercises/#exercises>
- <https://www.youtube.com/watch?v=1nZEdqcGVzo>
- <https://insighttimer.com/rickhanson/guided-meditations/relaxation-2>
- <https://www.tarabrach.com/brief-meditation-gathering-arriving/>
- <https://www.calm.com/blog/body-scan>
- <https://www.youtube.com/watch?v=tEmt1Znux58>

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

Links

- <https://www.healthline.com/health/sound-healing#summary>
- <https://www.ementalhealth.ca/Waterloo-Regional-Municipality/Bilateral-Music-for-Anxiety-Stress-and-Trauma/index.php?m=article&ID=84502>
- https://earth.fm/?gclid=Cj0KCQiA67CrBhC1ARIsACKAa8QPETTnwIaXgtzPdDZw15BdXwduUCdmNvWSwgSjws8ac-cav_0Nu24aAhG2EALw_wcB

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 colouring, drawing, or create mandalas to focus, relax, and quiet your worries

<https://www.art-is-fun.com/how-to-draw-a-mandala>

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 favourite movie together

VISUALIZATION

- Guided visualization from an App
- Safe place guided visualization based on previous exercise
- 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)

Links

- <https://www.tenpercent.com/meditations/freeguidedmeditations>
- <https://www.youtube.com/watch?v=rliAH9ewHEU&t=9s>
- <https://www.nothingmuchhappens.com/>
- <https://www.youtube.com/watch?v=UfgoKNejOBs>

NERVOUS SYSTEM REGULATION

CALM & PEACEFUL STATE REFLECTION

What are your signs of safety? How does your body feel when you are 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 bringing up the sensations when you are safe and secure can be a tool to turn to when you are overwhelmed or feeling anxious or worried.

DESCRIBE WHERE YOU FEEL THE
MOST COZY AND AT HOME

NAME THE PEOPLE WHO YOU
FEEL MOST AT EASE AROUND

DESCRIBE AN ACTIVITY YOU
FIND RELAXING

WHEN YOU ARE SAFE, AT EASE,
AND RELAXED DESCRIBE THE
SENSATIONS IN YOUR BODY

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

Try this Calm, Peaceful Place Guided Imagery
<https://www.youtube.com/watch?v=rliAH9ewHEU>



CHAPTER 4: EMOTIONAL AWARENESS, PREFERENCES, AND VALUES



Humans don't come with an operating manual, however, developing emotional awareness is like reading the operating manual for your Self. In previous chapters, physiological and psychological needs have been discussed. In this chapter, we review how emotions help us to identify our unique preferences and values. Noticing what experiences and activities are pleasurable and meaningful to you is another step in Navigating your Vasculitis Journey with more self-compassion. Both preferences and values can be anchors during times of difficulty - such as life transitions, illness flares, and relationship troubles - directing each person to what matters most to them so that they can make decisions that will work best for them.

EMOTIONS AS UNIQUE DATA

DEVELOPING EMOTIONAL AWARENESS & AGILITY



Every emotion provides information about a need, preference or value

Susan David, a psychologist at Harvard Medical School writes in her book, *Emotional Agility*, that emotions are data points not directives. Meaning that emotions provide information about your unique needs, preferences and values without indicating WHAT you should do. Throughout her book, she discusses how disconnecting from emotions, by ignoring, minimizing, bottling or brewing impairs the ability to make decisions effectively. Additionally, feeling a certain way does not provide an excuse for behaviours that are hurtful to yourself or others. Harnessing this ability to notice the emotion, name it, and work to understand the information is building emotional agility. Simply knowing emotional states is not enough - being able to process and respond effectively is key.

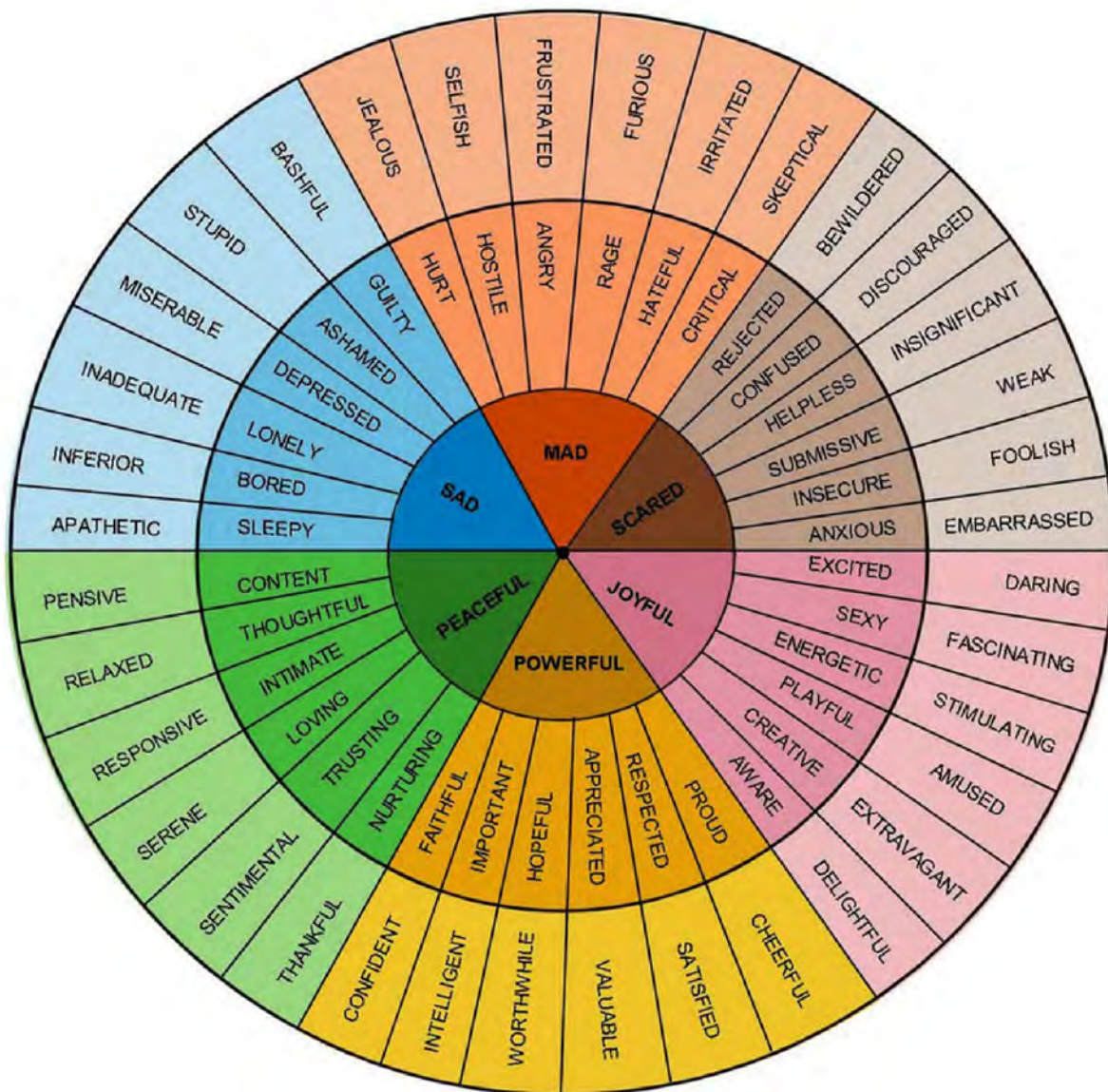
While living with Vasculitis, emotional agility skills can help you manage the impact of diagnosis and treatment on the aspects of your life that matter most. Emotions provide clues on how to build a self-care plan that works for your needs, preferences, and values.

In order to notice, name, and respond to emotion cues it is important to understand emotions in general and how they show up for you specifically - in your thoughts, behaviours and body sensations. On the next page is an emotion wheel. Like many concepts, this emotion wheel 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 - consider adding to the wheel so that it is 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 "core" human emotions are represented by the characters Joy, Sadness, Fear, Disgust and Anger. Watching this movie can be a fun way to learn about emotions. There are many ways to get to know emotions better, so that you can use the information that they provide.

EMOTIONS AS UNIQUE DATA

DEVELOPING EMOTIONAL AWARENESS & 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 & AGILITY

Self-validation is a skill from Dialectic Behavior Therapy (DBT) and is the part of Mindful Self-Compassion that encourages understanding the context when uncomfortable emotions occur. It requires non-judgemental awareness and avoids classifying emotions as “good or bad.” Self-validation specifically separates the emotional experience from the urges or behaviours 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 & name the emotion(s) without judging them

Step 2: Allow Let yourself feel the emotion even if it is uncomfortable. In 1-3 sentences, describe the events and environment occurring alongside the emotion using neutral language - just the fact.

Step 3: Understand Use “because statements” to connect events and situations that are contributing to the emotion.

Example: “I am feeling frustrated because I am exhausted from a day of medical tests. I need to rest. I notice anger rising, and have an urge to shout at them. I asked for quiet and my family continues to play loud music and this makes it difficult to nap. I feel unheard and disrespected.”

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

Key Note: *Self-validation does not suggest any specific action in response to the emotion. By taking time to pause, avoid judgment, and understand yourself in the moment you are responding with self-kindness.*

EMOTIONS AS UNIQUE DATA

RESPONDING TO EMOTION: SOOTHE THEN CHOOSE

In Dialectic Behavior Therapy (DBT), Self-validation is followed by soothing and then choosing. There are many different strategies that promote Emotion Regulation, just a few are reviewed below. If this interests you, consider working with a Mental Health Clinician who is trained to provide DBT.

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

Step 5: Choose: In DBT and Mindful Self-Compassion, using emotions as data points means going beyond naming the emotion - to using that data to learn about what you need, prefer or value - and making decisions based on this information. Some ways to do this from DBT include:

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

In the example from the previous page with family members not respecting the person's request for quiet to rest, choosing problem solving might be to use earplugs to block the noise. Choosing coping ahead might look like having a heart-to-heart conversation with the family about the importance of respecting rest and planning quiet activities that they can do instead of playing loud music when rest is needed.

Emotional Awareness and Agility Skills can also help you to notice the things that are delightful to you. Responding effectively might mean prioritizing these enjoyable experiences in your daily life (where it is possible).

COPE AHEAD

USE EMOTIONAL REGULATION SKILLS TO IMPROVE TOUGH MOMENTS

Is there a tough moment you experience regularly in your vasculitis Journey? How can you improve it with your self-knowledge? Self-knowledge includes your understanding of nervous system regulation, emotions, behaviours, and preferences. When we travel there are items we bring for comfort, not simply out of necessity. These can vastly improve our experiences. Considering 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 and they are impacted by sensory sensitivity and cultural contexts. These are the things you LIKE and DISLIKE. Generally, preferences are connected to a feeling of pleasure and delight. In order to notice delight, individuals must develop some emotional and sensory self-awareness. Preferences do not impact basic survival so they are negotiable with others. There is no hierarchy of preferences or aesthetic (despite what marketing agencies would have you believe), and people can share some preferences while disagreeing on others. Preferences are unique to each person. For example, I like roller coasters; the faster and higher, the better! My partner does not like roller coasters. Neither of us are “right or wrong” based on this preference, even 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 can be especially important to individuals facing pain, disability and disruption to their daily life due to vasculitis. Noticing your preferences allows you to prioritize the daily experiences that you enjoy and express your individuality. Preferences can also be used to anchor you in times of distress.

Since each person is unique, what is comforting to one may be intolerable to another, and 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 bags” to Navigate Your Vasculitis Journey. This is helpful in daily life, but even more so when you encounter a flare. By preparing ahead of time, you can tell loved ones about the practical supports that would be helpful to you or prepare to make a hospital stay more comfortable.

Noticing the Senses

Mindful awareness helps us to notice the aspects of an experience that we find pleasant. 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 flavours
- Sweet flavours
- Bitter flavours
- Tart/sour flavours

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 principles of Mindful Awareness, choose a daily activity you often enjoy and engage with it intentionally. This expands on the Pause & Scan Strategy. Notice the sensory information (see, hear, touch, smell, taste, texture); emotions (anger, sadness, joy, surprise, disgust); and thoughts (questions, assumptions, beliefs, patterns) that you experience. Some activities to consider: dance to your favourite 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

By tapping into your preferences, you can transform your experiences. Brainstorm items to include in a Superpowered Senses Kit that you can use to improve a moment. Make it portable so that you can take it with you to medical appointments to provide distraction, soothing, or enjoyment through sight, sound, smell, taste and proprioception (sense of movement through space- think of rocking a baby). These items can be things you can use to pass time, provide comfort, decrease sensory activation, or to 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 mendela
- Eye mask
- _____
- _____
- _____



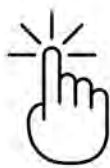
Proprioception - Sense of Movement

- 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 had never traveled to explore lands they had never experienced. Similarly, your values constellation can guide you to new ways of living with vasculitis that are meaningful and fulfilling. Your values may not protect you from adversity, just like reading the stars did not protect sailors from storms, but they can help you to get back on track to living well with vasculitis.

Personal values are connected to an individual's culture, the family that they were raised in, and to their own unique 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 can be helpful to think of your personal values constellation as your own Mission Statement. (You will be invited 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.

UNDERSTANDING VALUES



OPERATIONALIZING VALUES

Dr. Brene Brown discusses Living Into Values on her Podcast Unlocking Us in the episode below.



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

FEELING INTO YOUR VALUES

Dr. Steve Hickman, author of *Self-Compassion for Dummies*, provides the following guided meditation that leads you to 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.”

LEARN ABOUT YOU

Complete a Values Card Sort - a tool from Motivational Interviewing - a form of counselling that can be helpful for making meaningful changes in life.



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

Remember that the information you learn about yourself is one way of acknowledging the present moment with self-compassion, and that values can change as you learn more about yourself & the world.



IDENTIFYING YOUR VALUES

Since values are formed based on individual characteristics, history, and community; identifying your specific constellation of values - your why - is important for navigating. Sometimes it can be difficult for people to identify their specific values but they can completely understand NOT THAT or NOT FOR ME. It is 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. You can also use a Gratitude Journal to track the things you appreciate in the day-to-day. A gratitude journal template is provided on the next page.

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:

GRATITUDE JOURNAL TEMPLATE

Use this template to take note of the parts of your day that bring you joy, connection, or satisfaction. Use it for one week to understand your values better or consider making copies of this page or buying a notebook to continue this practice. Alternatively, you can find gratitude journals with unique daily prompts in your favorite bookstore.

S	
M	
T	
W	
TH	
F	
S	

ALIGNING WITH YOUR VALUES

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

Your primary (core) values will be the qualities that are most important when making decisions in your life. Primary values inform and underpin who we are and what we do. It is very rare for someone's primary values to change. For example, if someone has a primary value of generosity, they will choose options in daily life that allow them to give kindness, share resources, and provide support to others regularly. 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 do not contribute meaningfully.

Secondary values are qualities that are important to you, but they may change over time or be areas in which you are open to compromise. While it is rare for primary values to change, secondary values may be influenced by your environment, interactions with others, or societal changes.

Primary Values

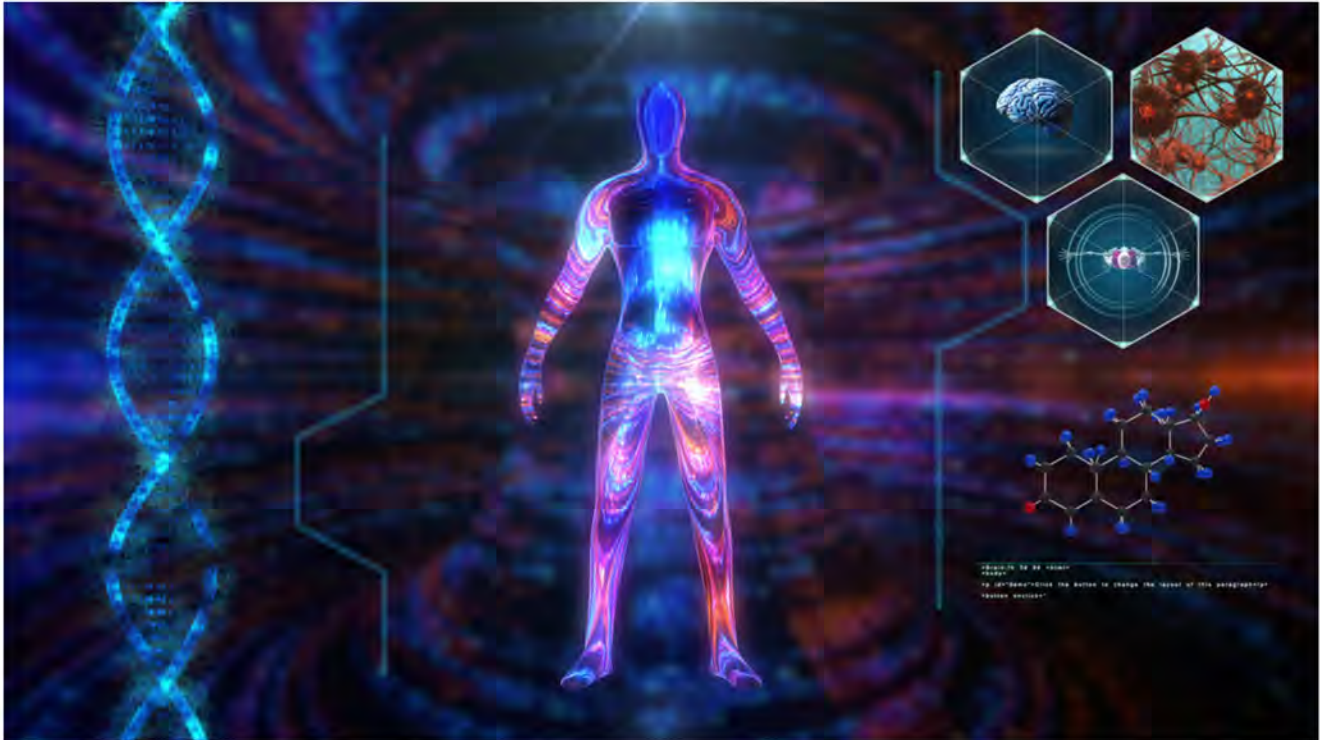
Secondary Values

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 is helpful to have your medical history and the contact information for your vasculitis specialist on hand when you meet new care providers or follow up with an existing provider after diagnosis. This information aids you in self-advocating effectively. In this chapter of the Guidebook, the activities will help you to organize your health information in a way that you can look back on and share with treatment providers (if you so choose).

This information can also help you to understand your vasculitis journey so far, and how that has impacted you. Grief is part of the process of adapting to diagnosis. Adaptation does not mean surrender. It means changing to flourish in a new environment.

YOUR HEALTH STORY

Before deciding where to go, it is important to consider where you have been and where you are right now. This type of reflection allows you to orient to the events, emotions, thoughts, beliefs, and people that have been important in your journey with vasculitis. One way to do this is through writing or telling your health story. Like any story, your health story has both a long and a short version.

There are many ways to organize your story. You can write it as a long-form narrative; writing prompts are provided on the next page. You can make bullet points. You can voice record. You can draw a cartoon. Some people prefer a photo collage. The important thing is to reflect back and consider how your health story has impacted you on the path of your life.

Activity 1: Major Health Events List

Using either your long form recollection or the medical documents you have, compile the list of major health events connected to your vasculitis diagnosis and treatment. Include hospitalizations, surgeries, flares, symptoms. Include dates (if known) and where tests or treatments took place, and if possible name the care provider. Make a note of any complications or side effects to 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 & pen) write your health story using the prompts on the following page. You can share this writing, but it is your own and there is no obligation to share this work with anyone. Capture what you remember thinking, feeling and experiencing.

You do not 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 choose to use labels or diagnoses if that is helpful to you.

If the writing process is overwhelming at any point, allow your self time and space to recharge. After you finish writing your health story, consider putting this 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 people will find this process cathartic and energizing. If you are energized and want to continue on to the next part, go for it! If you need a break, take it.

MAJOR HEALTH EVENTS

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

NAME	
DIAGNOSES	
ONGOING TREATMENT	

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

DATE & HEALTH EVENT

**TREATMENT PROVIDED
(TYPE, BY WHO, WHERE)**

**OUTCOME (RECOVERY,
COMPLICATIONS,
CURRENT IMPACT)**

DATE & 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 & 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 day-to-day life.

WHEN

State the date (as close as possible) that 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 day-to-day life right now.

Include how it impacts different aspects of life such as family, work, school, relationships, and recreation.

WHY

Describe your reasons for engaging with the Guidebook.

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

What other skills could help you ?

PRACTICE REGULATION SKILLS: EMOTION TENDING

Recollecting all that has happened in your health story can be an emotional process. For most folks it brings up a sense of tenderness that can be uncomfortable. Rather than pushing away the emotions that bring up this discomfort, distracting yourself from them, or sinking into them in a ruminative cycle; consider trying an emotional regulation skill. I invite you to try Emotion Tending.

Emotion Tending is a practice that brings together concepts from Emotional Agility, Mindful Self-Compassion and Dialectical Behaviour Therapy (as reviewed in the previous chapter). This tool is another way to build on the *Pause & 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 are feeling tender in this moment**
- 2- Name the emotions that you are experiencing**
- 3- Self-Validate the impact of the experiences leading to this moment (the reasons you are feeling tender)**
- 4- Radically accept the emotion and discomfort of this moment, just as they are without judgement or blame**
- 5- Respond to yourself kindly by taking a moment to soothe, distract, connect or rest based on your needs in that moment**


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

"I am feeling sad after writing my health story because I experienced a lot of suffering related to 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 for me. I am 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 & current care providers and a trusted family member or friend.
 - 2- Connect with a person you trust to share what it was like to recall your Health Story and Major Health Events. Tell them about working with this guidebook and how you hope it will support you in your journey with vasculitis.
 - 3- Consider joining a Vasculitis Foundation Support Group to feel seen, heard, and understood in this journey.
<https://www.vasculitisfoundation.org/living-well/find-support/>
- 
- 4- Consider sharing your unique story with the vasculitis community when opportunities to do so arise.
 - 5- Learn more about working with your emotions and meeting your psychosocial needs by connecting with a mental health clinician in your region.

KNOW YOUR CARE TEAM

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

Use the provided template to record this information quickly and easily. You can then make copies to share with each of your care providers. Ask if they are willing and able to collaborate with each other for your care. It is especially important that all your prescribers are aware of all the medications, supplements and substances that are prescribed to you and that you use.

Consider if it would be helpful to you for the professionals involved in your care to communicate and collaborate with your primary medical specialists.

Your **Vasculitis Specialist:** is the expert physician who looks after all things related to your vasculitis diagnosis. In some locations, it will 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 your life with Vasculitis.

Your **Primary Care Provider (PCP)** is the physician or nurse practitioner who attends to your typical health care needs such as regular check ups and routine exams. You would connect with them first for any new symptoms and ongoing care.

Other Medical Specialists: Depending on the type of vasculitis you have you may have multiple organs and body systems involved in the disease process 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 within 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; social workers who can help you adapt psychologically and socially to the changes that a vasculitis diagnosis can bring. There are many other Allied Health Professional who may be involved in your care.

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

Holistic Treatment Providers: These professionals use complimentary protocols and therapies to support their patients. For example, chiropractors, massage therapists, and naturopathic doctors.

YOUR TREATMENTS

Use the provided worksheets on the next page to record all current medications, supplements, treatments, and therapies that have been prescribed and you are currently taking.

How well are you currently following your treatment plan? Many people are able to take the medications as prescribed and others struggle for a variety of reasons. What about any physiotherapy/physical therapy exercises? Attending appointments with your care providers are important, however, many treatment plans have activities you are to complete independently between sessions. How does that work for you? On the next page, is a treatment tracker you can use to note your adherence and your day-to-day functioning. Consider whether this would be helpful for you to track for two weeks (or longer - make copies).

Many people seek additional treatments and/or work with multiple allied and complimentary treatment providers hoping that someone has the magic wand to make everything better. Wanting to improve your day-to-day functioning is understandable and important. However, before seeking out more intensive or expensive options, consider the ways that you could optimize your current treatment plan (by taking your medication regularly, doing assigned home exercises, or engaging 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, and as the person with vasculitis it is your job is to put them together in a way that works for you.

Don't forget to communicate with your all of your care providers about the treatments, therapies, supplements, or protocols that are prescribed or recommended by other clinicians.

Care Team Contact Info

PERSONAL CONTACT INFORMATION

EMERGENCY CONTACT INFORMATION

DIAGNOSES

PRIMARY CARE PROVIDER

ADDITIONAL CARE PROVIDERS

NAME & LOCATION

ROLE

CONTACT

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

PRESCRIBED TREATMENTS/THERAPIES

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

CURRENT TREATMENTS & FUNCTIONING TRACKER

Use the chart below to track your current adherence to prescribed treatments and your level of functioning over a two-week period.

To track your adherence, note each dose of medication, each supplement, or daily therapy using a scale of 1-5. A five on adherence means that you adhered to all prescribed treatments. A five on functioning means that you were able to complete your planned activities with no pain, fatigue, or health-related difficulty.

See if there is a relationship between Adherence & Function for you at this time.

WEEK 1

Adherence

Functioning

Monday

Tuesday

Wednesday

Thursday

Friday

Saturday

Sunday

Week Overall

WEEK 2

Adherence

Functioning

Monday

Tuesday

Wednesday

Thursday

Friday

Saturday

Sunday

Week 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 have done so far, consider where you are in your vasculitis journey at this moment. List potential adjustments you could make to your current lifestyle or treatment plan (after talking with your doctor) to better support your health needs at this time. You can also sketch how you are making sense of the process so far.



Part 2: Packing Your Bags

Your Packing List

State what you have identified as helpful for each of these physiological & psychological aspects of your journey. Remember that these can change over time and it is helpful to check in regularly and adjust based on current circumstances. Don't forget your comfort items that can help you to soothe intense emotions or help you to cope with pain or sensory overwhelm. Noticing and meeting your needs, preferences, and values helps you become better equipped to navigate your on-going 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 & Resources

Chapter 7: Relationships & Roles

Chapter 8: Pacing & Assessing



Chart Your Course

Using mindful self-Compassion principles to assess your resources and invest wisely.



Building awareness of your resources allows you to make informed choices about where to go next.

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

Chapter 6 Time & Resources is about accounting for these variables in order to meet the needs, preferences & values you identified in Part 2 of the Guidebook.

Chapter 7 Relationships & Responsibilities provides information about how roles often change after a vasculitis diagnosis. This can lead to disconnection from activities and people who are important to you. This contributes to loneliness and dissatisfaction. Developing new ways to connect with your people and passions can be key to Navigating Your Vasculitis Journey more meaningfully.

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

It is important to remember that these reflections are about the current moment, just one snapshot in time, and that 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 & RESOURCES



At first glance taking time to assess may seem boring or unnecessary, however, it is essential to understand how your time, energy and resources impact your journey. A solid understanding of these parameters means that you can use them more wisely. Planning effectively is a tool that allows you to reconnect to the parts of life that are meaningful and enjoyable.

When you have vasculitis there are more things 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 that you can take care of your health and do what you love!

Resources



In addition to time and energy, it is important to consider the financial and material resources that you can access to support your vasculitis journey. People reading this guide may be living in various regions with vastly different medical and social security systems. Below are some questions to consider when thinking about 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 my eligible expenses through my insurance providers?
- Are there support programs in my area to help me 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 at this time?
- How does Vasculitis impact my job security, future earnings, or savings?

Talking about money can be really uncomfortable, however, it is vital to have these hard conversations with loved ones and care providers so that you can meet your current needs and plan for your future with vasculitis.

UNDERSTAND YOUR TIME

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

Every person has 10,080 minutes in a week. Approximately 3,500 minutes are spent sleeping (ideally). If you work full time (5 days/week for 8 hours/day) 2,400 minutes are spent working. That leaves 4,180 minutes for everything else. How is that adding up for you?

This does not account for basics of daily living such as food preparation & eating, hygiene, movement/exercise, or commuting. It also doesn't account for connecting with loved ones, tending a garden, or watching tv. So how much time do you actually have to take care of your complex chronic health needs?

Time accounting may seem boring. However, it can validate that sense of never having enough time to do it all.

Time accounting can also provide perspective so that you can choose how to spend your valuable time on the things that are most important to you. If you have a severe time deficit, consider how that may be contributing to your well-being, especially your mental health. Chronic stress and burnout are impacting many people, and this impact may be amplified for people with vasculitis.

Time accounting works alongside energy awareness. Christine Miserandino, a woman living with chronic illness, uses a spoon analogy to describe the changing energy reserves that are impacted by pain, fatigue, and symptoms. Consider how your time commitments and changing energy impact your day-to-day living with vasculitis. Using the spoon analogy can be helpful when communicating your limits to others.

Learn About Spoon Theory



<https://www.goodrx.com/health-topic/mental-health/spoon-theory>



TIME ACCOUNTING PART 1

Add up the amount of time that you spend taking care of your health & wellness. Include activities directly related to your treatment AND include all the other health maintenance activities such as tending to your body, nervous system, and psychological wellbeing as reviewed in Part 2 of the guidebook.

At the bottom, find the total time you spend on Health Management

	MORNING	AFTERNOON	EVENING	TOTALS
MONDAY				Morning: Afternoon: Evening: Total Minutes:
TUESDAY				Morning: Afternoon: Evening: Total Minutes
WEDNESDAY				Morning: Afternoon: Evening: Total Minutes:
THURSDAY				Morning: Afternoon: Evening: Total Minutes:
FRIDAY				Morning: Afternoon: Evening: Total Minutes:
WEEKENDS				Morning: Afternoon: Evening: Total Minutes:

TOTAL WEEKLY MINUTES

TIME ACCOUNTING PART 2

In this chart, account for all your other responsibilities & interests such as work, childcare, household management, sport, creativity, leisure, community engagement, participation in your faith, connecting with family & friends. These are things you need to do to provide for yourself as well as activities that you enjoy.

At the bottom, find the total time you spend on Personal Commitments

	MORNING	AFTERNOON	EVENING	TOTALS
MONDAY				Morning: Afternoon: Evening: Total Minutes:
TUESDAY				Morning: Afternoon: Evening: Total Minutes
WEDNESDAY				Morning: Afternoon: Evening: Total Minutes:
THURSDAY				Morning: Afternoon: Evening: Total Minutes:
FRIDAY				Morning: Afternoon: Evening: Total Minutes:
WEEKENDS				Morning: Afternoon: Evening: Total Minutes:

TOTAL WEEKLY MINUTES

REFLECT ON YOUR TIME

Remembering that there are only 10,080 minutes in a week, what do you notice? Does anything surprise you? Do you feel satisfied with how you are spending 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 & CONS OF HOW I SPEND MY TIME

BENEFITS OF HOW I SPEND MY TIME
NOW

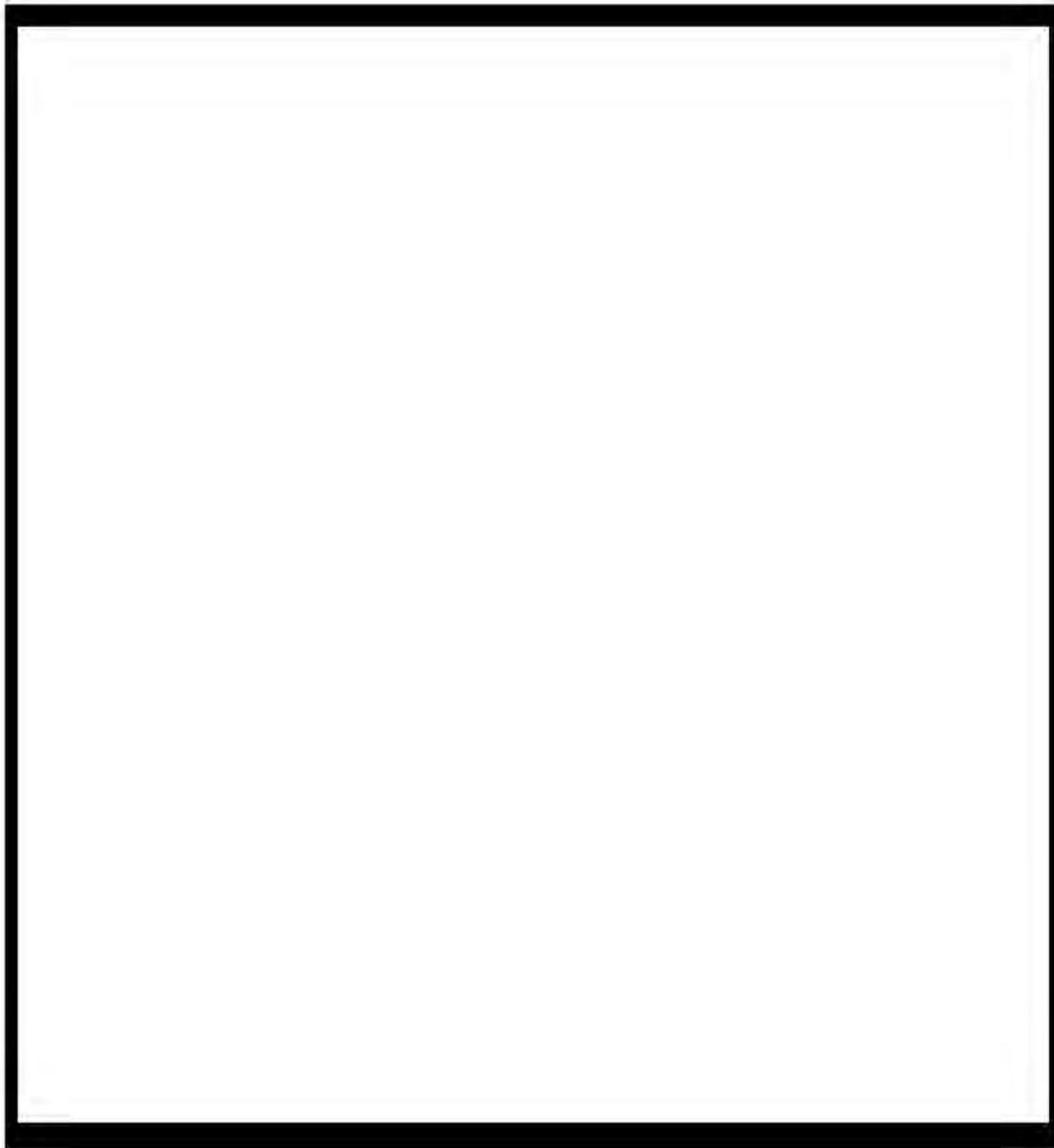
COSTS OF HOW I SPEND MY TIME
NOW

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 have done so far regarding time and energy, doodle or draw how you are making sense of your relationship with time & energy. Does this activity provide any new insights into your current relationship with time and energy? Does this help you determine where you want to go next in your vasculitis journey? 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 & ROLES



Each individual with vasculitis is connected to a network of people - family, friends, peers and/or colleagues, neighbours and social groups. In this way, the impact of vasculitis ripples through communities. Understanding how vasculitis effects you requires thinking about your roles in each of these networks and especially within 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 that this has on the people we love or the work that we do. Ignoring the shifts does not make it easier on anyone. How you acknowledge these changes within your social network will be different depending on the closeness of the relationship, the level of trust you share, your care needs, and your preferences.

VALUING HEALTHY RELATIONSHIPS

Healthy relationships are nourishing and sustaining to the people within them. Nurturing relationships are a vital resource for people living with vasculitis. However, the importance of these relationships to health and healing can be overlooked within the medical system.

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. Reciprocity means both asking for and accepting help. **Trust** can be harder to define, however in her work on leadership, Brene Brown PhD breaks it down into 7 elements using the acronym BRAVING.

BRAVING Formula for Trust in Relationships

B- boundaries: what is okay, not okay, and why
 R- reliability: following through with what you say you'll do
 A- accountability: acknowledging mistakes, apologizing, and taking steps to do better in the future
 V- vault: keeping private information safe (not gossiping)
 I- integrity: authenticity across contexts which means upholding your values even when its tough
 N- non-judgment: creating space to share emotions and experiences vulnerably
 G- generosity: assuming the kindest interpretation of intentions, words, and actions

When folks are in a healthy relationship there is space for hard truths, including setting boundaries. Both individuals are able to have unique thoughts, emotions, preferences, needs, and values. Healthy relationships value assertive communication which is kind, clear, and direct. It upholds the dignity of self & others when setting boundaries.

In healthy relationships, boundaries are welcomed even though they create changes in the dynamic and require adjustments to return to flow. Using assertive communication when setting boundaries upholds the dignity of self & others. The boundary may be stated firmly, but it is respectful of individual autonomy. You can not determine another's response to your boundary (ie: emotions or actions). In healthy relationships, each person takes responsibility for managing their own responses and how they behave. A loved one expressing disappointment regarding a boundary is not disrespect nor a reflection of detrimental relationship patterns. Disagreement and expressing emotions safely are two signs of healthy relationship dynamics, even though it is uncomfortable. As a caring person you can validate your loved one's feelings about the boundary without backtracking on it or compromising your needs. Remember that negotiation can be a healthy part of assertive communication and boundary setting when you are open to alternative solutions to meet the need or you are discussing preferences and the mutual enjoyment of a shared experience.

Boundary Setting Guide:

- 1-Determine the need that is 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 and your plan to meet it more consistently (the boundary) and how this impacts them and your relationship
- 4-Explain how you will be protecting this boundary (consequences for violating the boundary)
- 5-Assert & Protect the boundary
- 6-Continue to assess- needs change so boundaries may change

DETRIMENTAL RELATIONSHIP DYNAMICS

Unfortunately, healthy relationship dynamics are not taught explicitly in our culture. Parents, educators and community leaders do the best that they can with the tools that 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 are not nurtured. Many families and communities have had unhelpful patterns passed down through generations and it is difficult to teach what we've not experienced ourselves.

Some relationship patterns are annoying but harmless. In caring and 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): In some situations relationships are built on uneven ground, where one person in it has more power or authority than the other person (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 and other times 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 would enjoy.

Passive-Aggressive Communication or Aggressive Communication Styles: In these relationship patterns, boundaries are set as an extreme reaction to discomfort or as a way to intimidate or guilt-trip another person. These are 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 can impact many different social relationships; even between trustworthy people. These patterns can be resolved with communication, support, and respectful intentions. To foster improved social connection, it can be useful to learn more about Assertive Communication and Boundary Setting.

CHANGING RELATIONSHIP DYNAMICS

Prior unhealthy relationship experiences can make it difficult to trust people, especially when you are feeling vulnerable - like during a vasculitis flare. It can make it harder to use assertive communication skills that center your health needs. In the next pages of this chapter, you will learn tools for kind communication and boundary setting.

Remember that 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 can interrupt the previous flow in the relationship. In healthy & trusting relationships, there will be a period of adjustment and then flow will be restored. However, it is important to keep the following in mind when setting interpersonal boundaries:

Safety first Assertive Communication and Boundary Setting Skills rely on safety. If you are concerned that you are living in an unsafe relationship, please know that no one deserves to be disrespected or abused and it is not your fault. You are not alone. For more information and support, connect with the National Domestic Violence Hotline: [thehotline.org](https://www.thehotline.org). Choose the communication style that keeps you the safest, especially when vulnerable.

Clear is Kind Be direct when stating 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 Not Control Others Responses or Their 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 are allowed to express care without changing your stance.

Value the Circle Back Take a break if the interaction is becoming heated, soothe your nervous system and work on perspective taking. When you're feeling 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.

SETTING BOUNDARIES

Setting boundaries is an ongoing process that is necessary in all relationships. It is common to be unfamiliar with the boundary setting process and there are many resources to help you learn more about them. Check out Nedra Tawaab on Instagram or her book *Set Boundaries, Find Peace* if more info on this process would be helpful to you.

Below is a boundary setting strategies from Dialectical Behaviour Therapy referred to by its acronym DEARMAN. Use this formula to practice setting a boundary that is 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 are 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 types of relationships and levels of connection based on many factors. How frequently you see someone does not necessarily 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 who you do not see socially - like a boss, a doctor or 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 do not trust to share your personal thoughts, feelings, and opinions. In the two rings closest to the centre, it is important to include only those whom you trust. It can be helpful to visualize your social connections. You may not have space to list everyone - take note of 1-5 individuals for each ring.

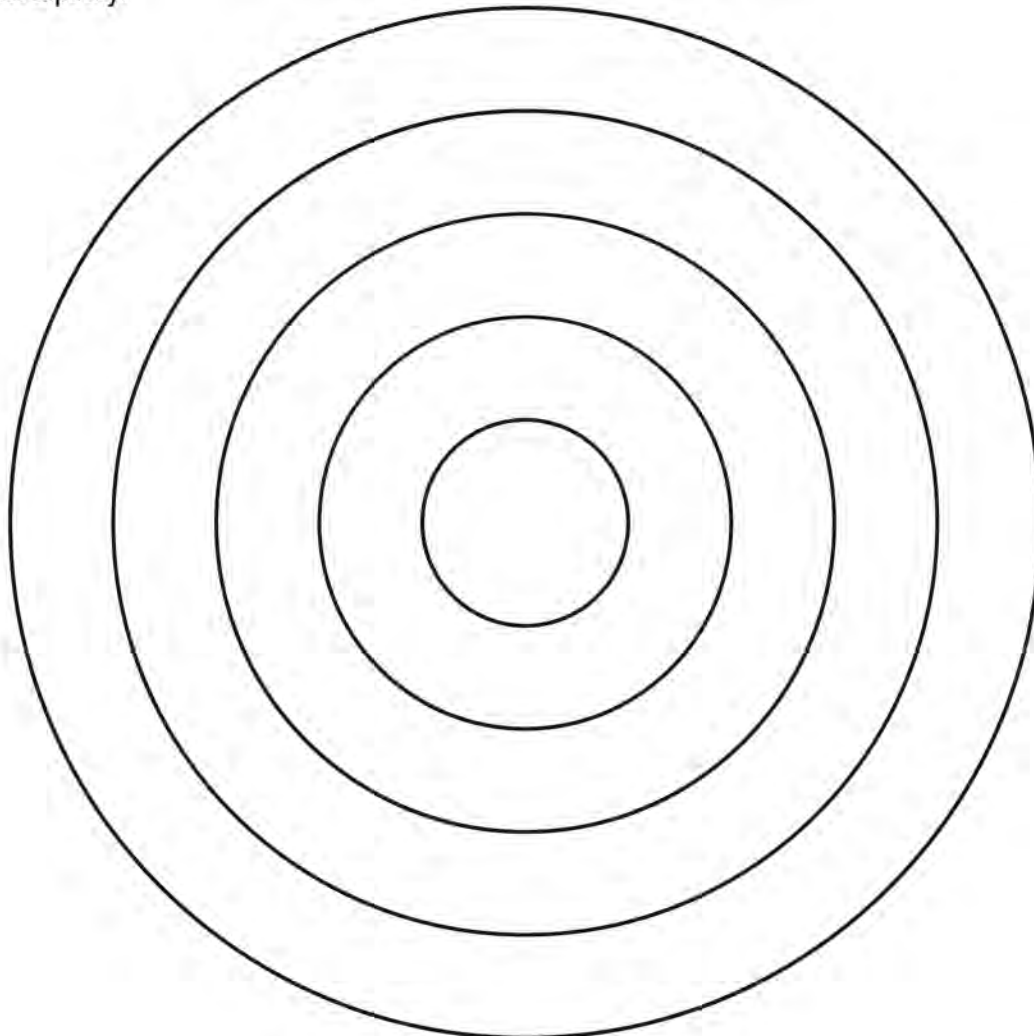
The Inner circle Highly trusted people with whom you share a deep reciprocal relationship.

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

Ring 3 People you may see frequently at work, participating in hobbies, or in the neighbourhood. Acquaintances.

Ring 4 People who you have recently met, or with whom you share a common interest, or someone with whom you had a deeper level but you are not able to see as frequently or there has been a relationship rupture.

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



CONNECTION REFLECTION

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

In the boxes below take note of the most important relationship in each category listed, and 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 catchp-up? For instance, if you met playing a sport could you suggest watching a game together? Is there another way to engage now that respects your current level of ability and energy?

THE INNER CIRCLE

CLOSE FAMILY MEMBER (PARENT, CHILD, SIBLING)

FRIEND

NEIGHBOUR

COLLEAGUE/ACTIVITY PARTNER

OTHER

YOUR CIRCLE OF CARE

A circle of care includes treatment providers and professional supports, but it can also include your trusted loved ones and extended community network. Each person's relationship with you will be different and will be influenced by their role in your care. The circle is a helpful visual because it is 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 and this can change how you relate when you are feeling better. It is helpful if this "Point Person" learns about vasculitis, your treatment plan, and the roles of different treatment providers. The previous chapters in the guidebook could be helpful to share with them. Your Point Person may also benefit from Mindful Self-Compassion skills and support.

Sometimes it can be beneficial to have a Logistics Point Person to manage the details of your care and a separate Emotional Point Person with whom you discuss your inner experiences. Trust is an essential component in your relationships with your Circle of Care.

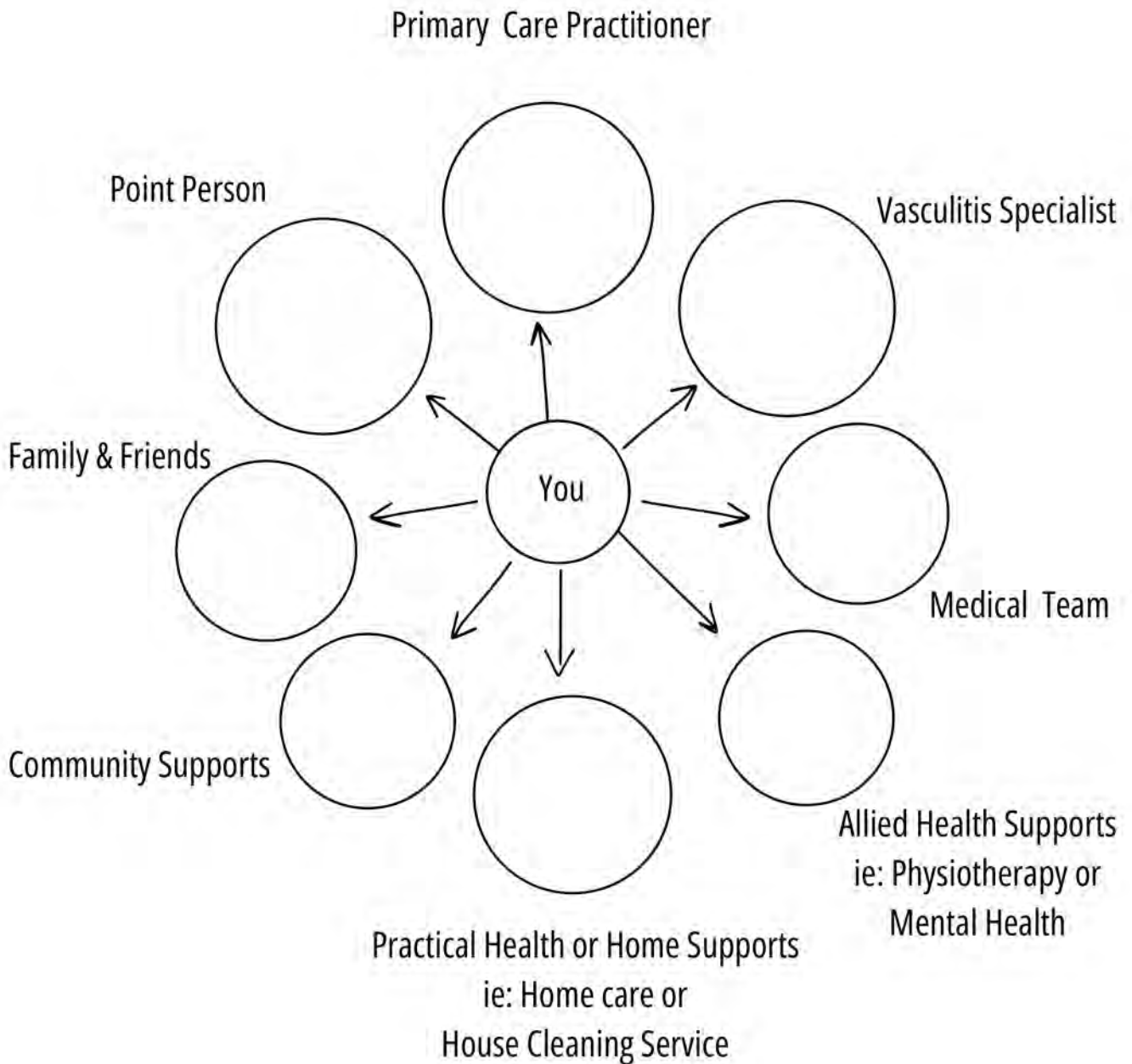
In addition to your Point Person, other members of your community can provide necessary assistance. Some folks who live nearby may be able to help with practical tasks - like mowing the lawn or bringing a dinner on your tough days. Others, who you trust but are at distance, may be a source of comfort, creativity or connection. Some folks can relieve your Point Person so that they can take some time to nurture themselves. Clear communication is an essential part of building and maintaining your Circle of Care.

For many people with vasculitis, the feeling of being a burden can come up, especially during flares when you need more help. Noticing and naming that worry with your loved ones can be helpful. Additionally, reminding yourself that you are worthy of care and practicing self-compassion is important. Fostering a culture of responsible self-care within your Circle of Care, so that your loved ones are also encouraged to tend to their needs regularly, can help maintain your relationships.

It can be 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 regarding your Circle of Care. What does each person do to support you on your Vasculitis Journey?



FLYING SOLO

Due to a myriad of circumstances, you may be navigating your vasculitis journey solo, without that key Point Person by your side for logistic & emotional support. Intentionally creating a safety net of professional and volunteer services can help you get through it.

Looking back in the guidebook can assist you in enhancing your Circle of Care while flying solo. A Point Person does not need to be a parent, partner or adult child. A Point Person is a trusted associate. It can be a colleague, a neighbour, or friend whom you invite into this role in your life and care circle. Clear communication outlining what you are asking from this person, especially when it is not a traditional Point Person, is essential so that they are clear on the role and your expectations. You may invite someone who is unable to take on the full responsibility of Point Person, so consider if you have a few people who you can invite to 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 get navigate your vasculitis journey independently. Using a digital planner and reminders is likely important, along with taking notes or voice memos when at medical appointments. In addition, 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 self are impacted.

In Chapter 2, Physiological Needs were reviewed. When you think about your home, consider what logistic supports you require now or in the future. For example household management tasks that help you to maintain a safe and comfortable living space can be physically demanding. At different points in your journey, handling these tasks may be too taxing for you physically or mentally. Depending on where you live, different home care services may be available. This is one subject where the resources available to you can be vastly different based on where you live. Connect with your primary care provider or your local social services agency for the most accurate information for your situation.

If you can afford a professional care navigator, they can be a valuable support to connect you with the resources in your region. Other professionals can also be helpful, such as psychotherapist or counselor, clinical or registered social worker, or nurse case manager. Having a variety of allied health professionals to check in with periodically can also provide social connection. For example, physiotherapists/physical therapists, massage therapists, and chiropodists/podiatrist can provide both allied health care and an ongoing professional relationship.

There may also be volunteer networks in your community that can assist you with meal delivery or transportation to medical appointments. As a patient flying solo in this journey, 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 to 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 simultaneously 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 in the Guidebook: 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

Similarly to how 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 the relationship you have with your Point Person - whether that is your partner, parent, adult child, or trusted neighbour.

Step 1: Intentionally & Collaboratively **Protect Time to Connect**

Step 2: **Express Gratitude** for their role in your life before diagnosis and also the extra care they give you in their role as your Point Person in your Vasculitis Journey. 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 may find it more practical to express vulnerable emotions in a card or with a gift. If that's your style, go for it. Maybe you recognize that your Point Person needs a bit of a break, so you ask another person in your community to support you so that they have the time to go and take care of themselves. If you have the means, consider gifting them a spa day, trip to a museum, or round of golf etc based on their preferences. But remember, gifts are not required to express appreciation!

Part 4: Taking Steps

Chapter 8: The Change Process

Chapter 9: Pacing, Reflecting & Celebrating

Chapter 10: Evolving



The Science of Change

Connecting the process of change with principles of Mindful Self-Compassion to take the next important steps on your Journey with Vasculitis



Bringing all of the practices together to traverse the next phase of your Journey with Vasculitis

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

Oftentimes, 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 review strategies for managing the storms. Important factors to keep in mind on this part of the journey 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 that are sustained over time, requires a skill set. Fortunately, like many other skills, behaviour 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 needs to be meaningful to you. The following activities are designed to help you connect your preferences and values to any goal and set you up for success!

Please 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 feel overwhelming before you even begin. This does not mean you are 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 like vasculitis, one shift can flow into multiple spheres. This can be amazing for building momentum! For this reason, 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 of the journey 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 be used to help you adhere to your currently prescribed treatments and therapies or to try an adjunctive treatment that may help you to better navigate your vasculitis journey. 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 to protect your precious time and limited energy for the people and activities that matter most to you.

Pace yourself - choose one overall goal. Break that down into small steps, and then take the first step. As that step becomes 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 own values and priorities. There is no "right" way to use these activities - do what works for you.

CHOICE POINTS MENU

Looking for ideas for small changes you can make that support your health? Everyone using this guidebook will have different priorities based on their needs, preferences and values. This is not a complete list of changes, but a small sample based on topics covered in previous chapters. Consider which topics were most interesting to you or seemed most impactful. This is not 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 & Rest
- Practice Mindful Eating
- Add Daily Movement
- -----
- -----
- -----



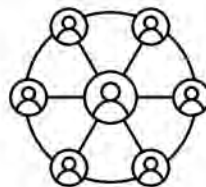
Gentle Self-Compassion

- Respond to Distress with Kind Self-Talk
- Understand & Embrace Preferences
- Practice Daily Relaxation Exercises
- -----
- -----
- -----



Adherence

- Track Your Medication and Symptoms
- Do Home Activities from Allied Therapies
- Attend Lab Tests & Appointments as Scheduled
- -----
- -----
- -----



Tend Your Resources

- Budget your Money, Time, and Energy
- Prioritize your Self-Care & Schedule Effectively
- Cultivate your Circle of Care & Communicate Needs
- -----
- -----
- -----



Nurture Relationships

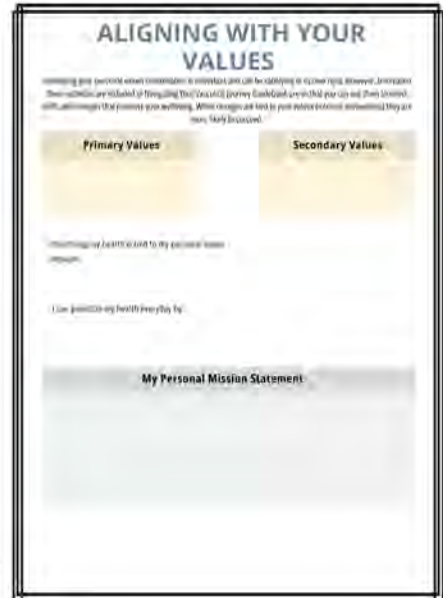
- Develop Assertive Communication Skills and Boundaries
- Connect with a Support Groups
- Reconnect with Your Point Person
- -----
- -----
- -----

SELECTING A FOCUS

Do you remember the Aligning With Your Values activity from Part 2?

Using that information, reflect on any changes you are considering to better manage your health. Is there one specific area of life that you are 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 better Navigate Your Vasculitis Journey.



TAKING THE FIRST STEP

Since making changes can be overwhelming, breaking the goal into smaller, actionable steps is helpful. To Navigate Your Vasculitis Journey, 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 towards achieving your goal. The key thing is to create a step you can complete daily in as little as 5 minutes and taking no more than 30 minutes. You can build it beyond those parameters eventually if it makes sense to 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 towards your goal.

EASY Step

Every day

Anchored in Values

Simple

Yours

EASY Steps are about building a path towards your goal into your daily life.

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

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

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

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

Goal

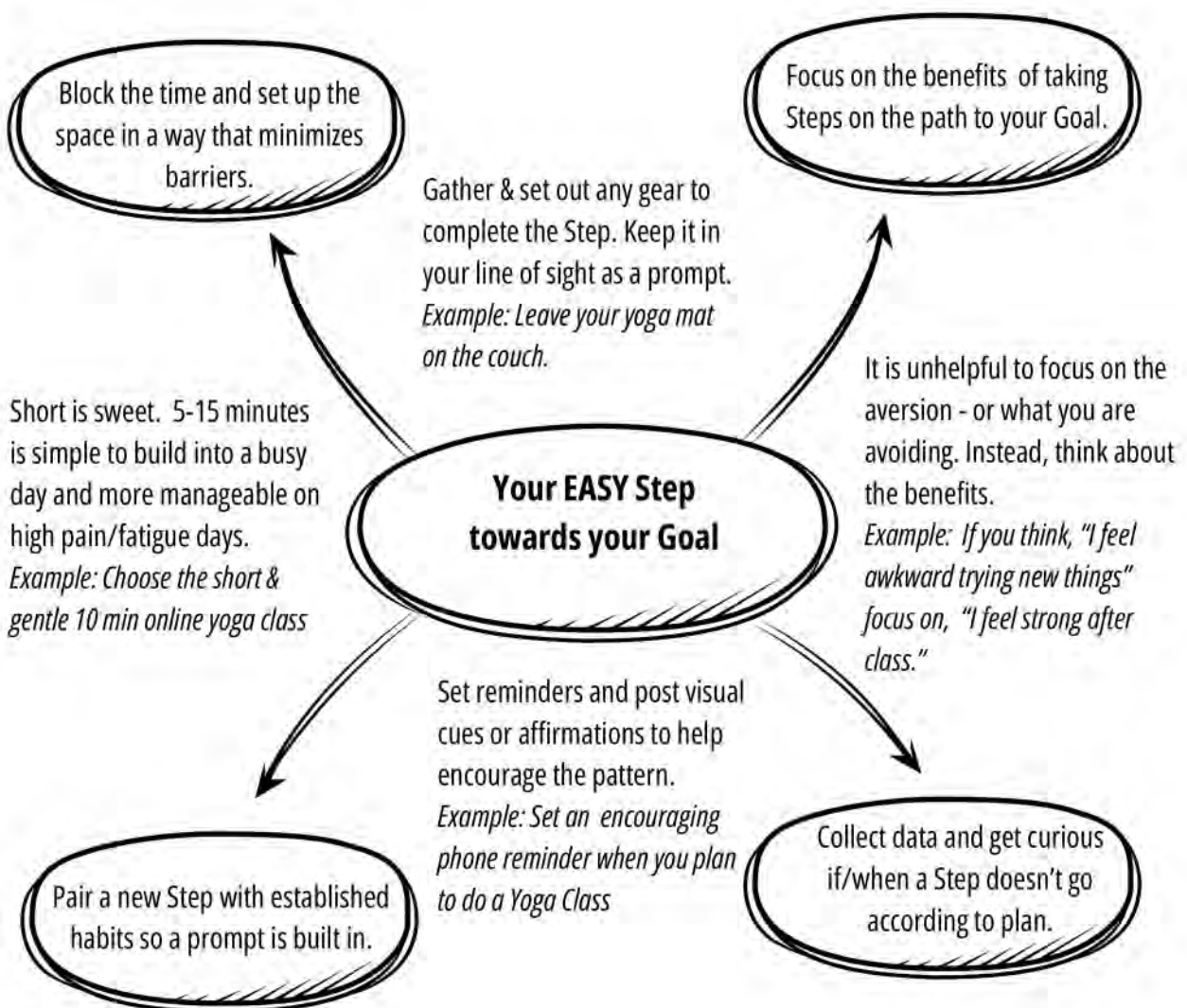
EASY Step

When, What & How Long

What do you like about it

HOW TO SIMPLIFY THE STEP

Scaffolding is a tool that provides support to help you to take your first Steps towards your Goal. Scaffolding includes: gathering any materials you need to take the Step, scheduling the time to complete the Step, thinking about what you are doing 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 times people will attempt to make a change because they think they “should” based on external pressures. It is key that the goals you set in Navigating Your Vasculitis Journey are ones you desire 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 are working on it? • Are you tracking? • How will you know you are achieving 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 & 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 & adapt if needed? • When will you celebrate success? 	

MYTHS OR FACTS

ABOUT MOTIVATION

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



Motivation is not a personality trait. Rather, it is impacted by the context, the support available, and the individual's interests and confidence. Research shows that people have more motivation when there is less judgement, they feel more prepared, and they are connected to 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. Additionally, people 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 in the face of challenge.

If something really matters, all you need is motivation



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

UNDERSTANDING MOTIVATION

Motivation is made up of multiple factors. Connection to the goal is key, whether it is from external sources (rewards and/or punishment) or internal alignment (it is enjoyable and/or meaningful). In addition, you must have capacity - the resources, time and energy to take the steps required to reach your goal. Finally, it is 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 in the face of challenge. 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 the following scales to see if the goal you have set for yourself is aligned to your values, 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

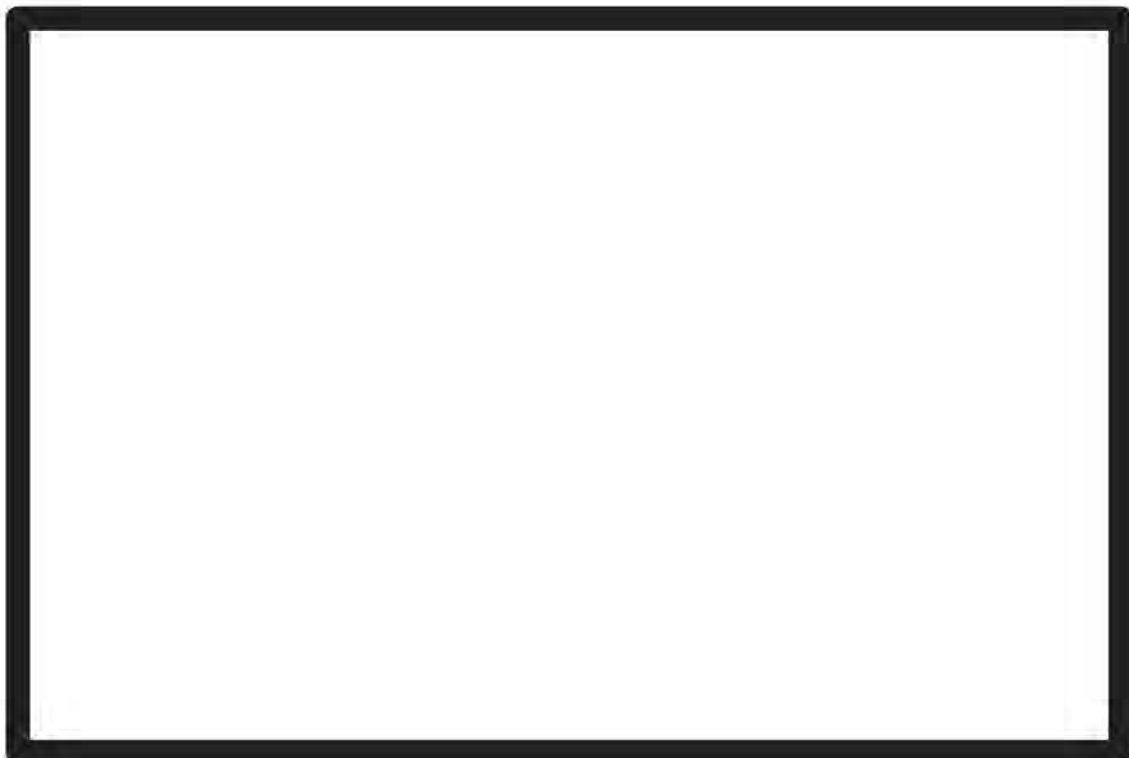
1 2 3 4 5

Reflecting on your scores above, what would it take to score higher on each of these measures?

PICTURING THE BENEFITS

Visualization can be a powerful part of planning for the future. Athletes use visualization to rehearse the technical aspects of their sport and prepare for competition. In your vasculitis journey, it is helpful 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 towards your goal into your routine. What happens before, during, and immediately after this behaviour 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 you. Alternatively 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 - PACING, REFLECTING & CELEBRATING



A lot of energy is invested in the preparation for change (it is important) and a lot of attention is given to “successful completion of 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 the reason 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 towards your Goal.

THE VALUE OF PACING & PAUSING

Timing is an essential component to taking any journey. There are seasons, tides, lunar phases, daylight & darkness, circadian rhythms, and healing cycles that effect each of us in different ways. When Navigating your Vasculitis Journey, it is important to consider pacing and pausing. These two factors can easily be overlooked. Both pacing and pausing allow us to more mindfully experience the journey - which means we can notice when we are experiencing joy, satisfaction and pleasure. They also help us to stay attuned to our needs - which is essential to prevent overwhelm and burnout.

If you think of travel, when you take 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 may want to plan buffer time in between to account for any delays or complications with your flight. This is pacing. It's similar in your Vasculitis Journey. You never know when an appointment will run late, or a nap is needed. Slowing down and staying connected to the present moment can decrease pressure and prevent overwhelm. It can also help you check in with yourself regarding your preferences and values.

It's important to ask yourself along the way:

Are these Steps still serving my Goal? Is my Goal still relevant & important? Am I on the path that works best for me?



NOTICING & REFLECTING

In Chapter 1, mindful awareness was introduced as an essential component to use your self-compassion compass. Throughout the guidebook, mindful awareness practices have been highlighted to help you understand your needs, preferences and values.

As you take steps towards your goal, these reflection skills continue to be important. They orient you to what is working and what you want to tweak along your journey.

Effective Reflection Practices:

- Intention setting, which provides focus.
- Using descriptive words, which avoids judgement.
- Observing through the five senses and noticing emotions, which allows thorough consideration.
- Language - writing out or talking through observations, allows for meaningful connections to be made.
- Allow yourself to have more than one perspective. *(Example: On one hand taking a walk in the morning is enjoyable and helping me move more & on the other hand I feel more rushed to get out the door on time in the morning.)*

Taking time to reflect during the change process allows you to make adjustments. It also connects you to the present moment which can help you to enjoy the process more. Consider how taking photos during travel serves to highlight moments in the midst of the journey. Reflective journaling can capture these key moments during the change process.

Reflection can get an unfair reputation as being the opposite of taking action, when in fact, it facilitates decision making.

Some unhelpful thinking patterns can be mistaken for reflection. These include making assumptions about situations you have not experienced or making harsh judgements about yourself or others. These thinking short cuts disconnect you from present moment awareness, curiosity, and discernment. Rumination, or 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 is a sense of dread and disgust.

Differentiate Between Thinking Traps & Reflection Practices

- **Write or talk it out (get it out of your head)**
 - **Notice how you feel when you are reflecting**
 - 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 thought traps like *Catastrophizing* or *Fortune Telling***
 - **Plan an activity afterwards**
 - go for a walk
 - do a puzzle
 - phone a friend
 - **Choose prompts that elicit helpful data for decision making**
-

REFLECTING ON YOUR CURRENT STEP

Use any of the following prompts, along with a journal of your choice, to reflect regularly in the midst of your Journey. You can create your own prompts. Choose 2-3 prompts and set a timer each time you take a moment to reflect.

SPECIFIC

Describe the step in your process that you are currently taking.

Using mindful awareness, note the thoughts, feelings and sensations that you are experiencing

Is it fun or satisfying?

ATTAINABLE

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

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

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

TIMELY

How is this step fitting in your schedule?

Is it taking longer or shorter time to complete the step each day than you thought? Can you modify the duration?

Are you struggling with the frequency?

MEASURABLE

Use a rating scale, like 0-5, to measure how this step is going for you. Attempt to use the same scale consistently if this is a prompt you choose.

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 towards your goal.

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

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

ACKNOWLEDGING PROGRESS

Setting SMART(R) Goals means knowing how and when to measure progress. A regular reflection practice can help you to understand how the change process is going. There are also some “thresholds” that can be used to measure progress, however these are estimates because every person is unique.

As a guideline, assess how things are going every 3 days, every 3 weeks, and every 3 months. A single day or even a week can be a fluke. Whereas 3 weeks of data gives you something to work with effectively.

Notice what an **improvement** feels like for you. It can be more calm, more connection, more creativity, more capacity... it depends 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 towards your Goal can create a change cascade.

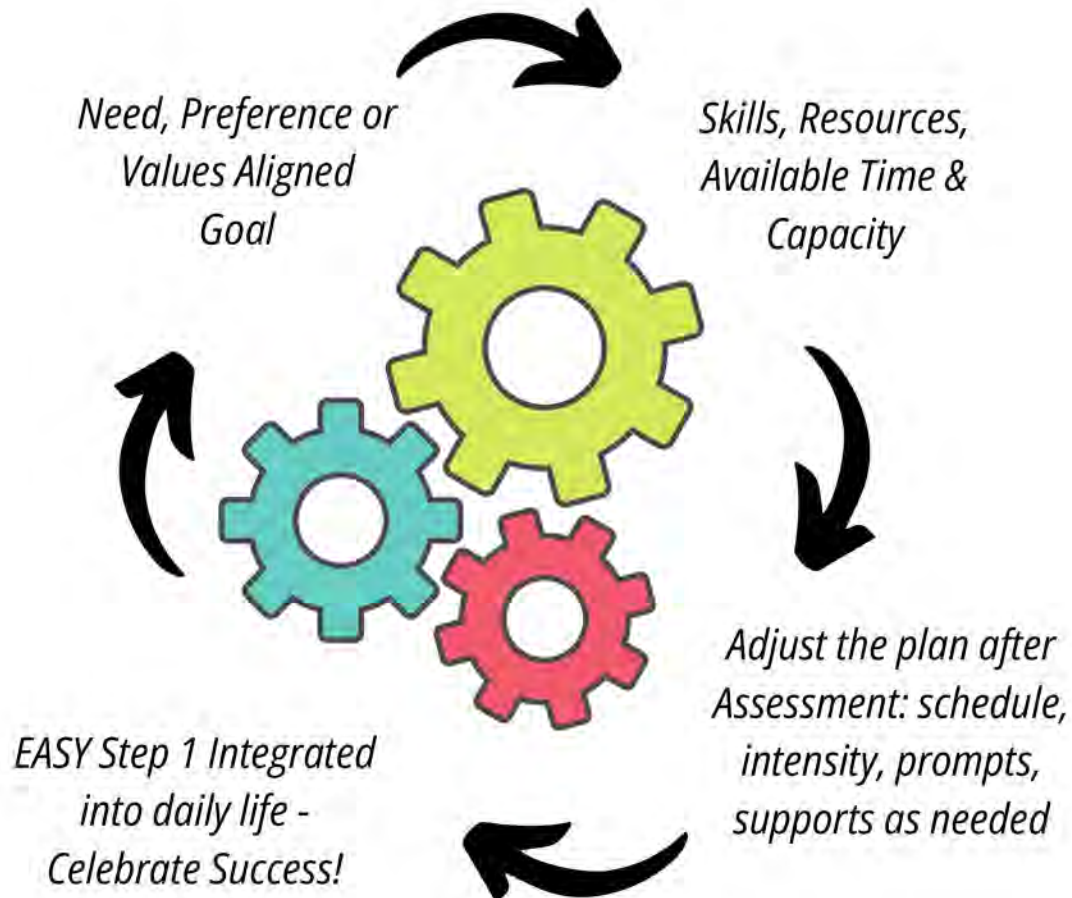
Even if you are doing *the thing*, if you are not enjoying yourself, no amount of discipline is going to help you succeed. The goal and the steps to reach it must be attractive to you- which is why understanding your nervous systems, your emotions and your preferences are vital. And also why there is no specific regiment for Navigating Your Vasculitis Journey. It is a process so that you can discover what works best for you.

Assess Progress

Focusing on Improvement + Enjoyment



REFINE & ALIGN



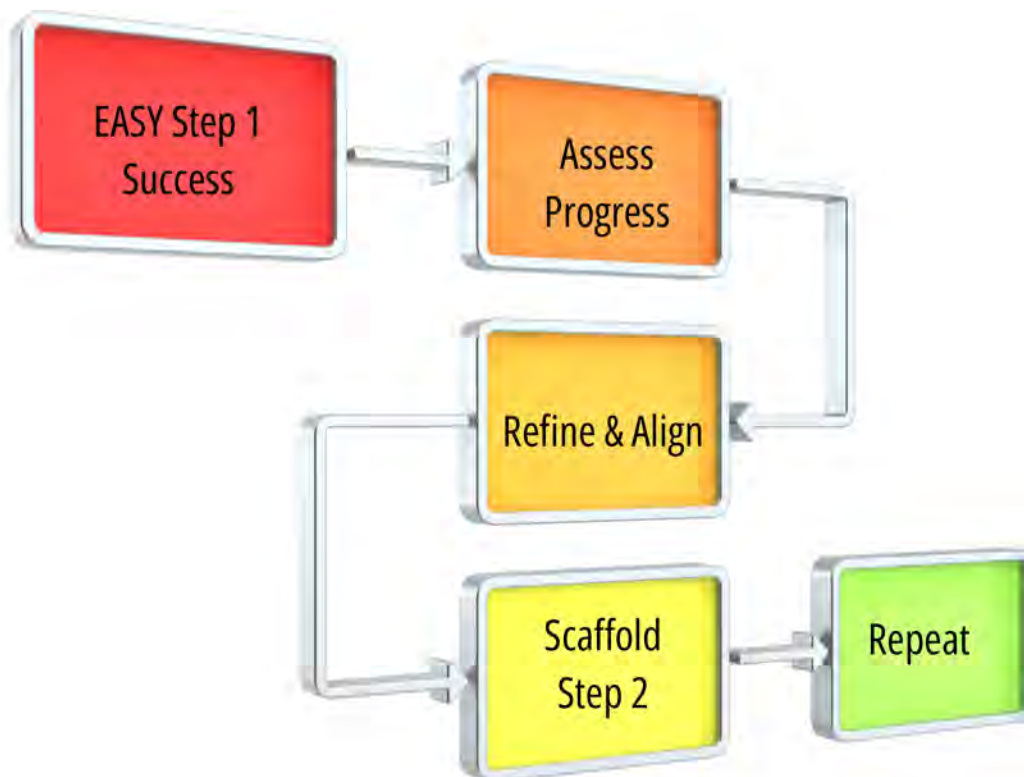
Making adjustments to your EASY Step is an important part of the change process. It is normal to notice things that need to be refined. Consider how the Step is fitting into your schedule, if the intensity is too much to begin or if it is not challenging enough (making it boring). Notice if you need 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. Consider if the challenges are because you are getting used to it and you are in the awkward learning phase. If so, do you have the desire to stick with it a little longer before choosing whether or not to adopt it in your day? If you decide that this specific step is not 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).

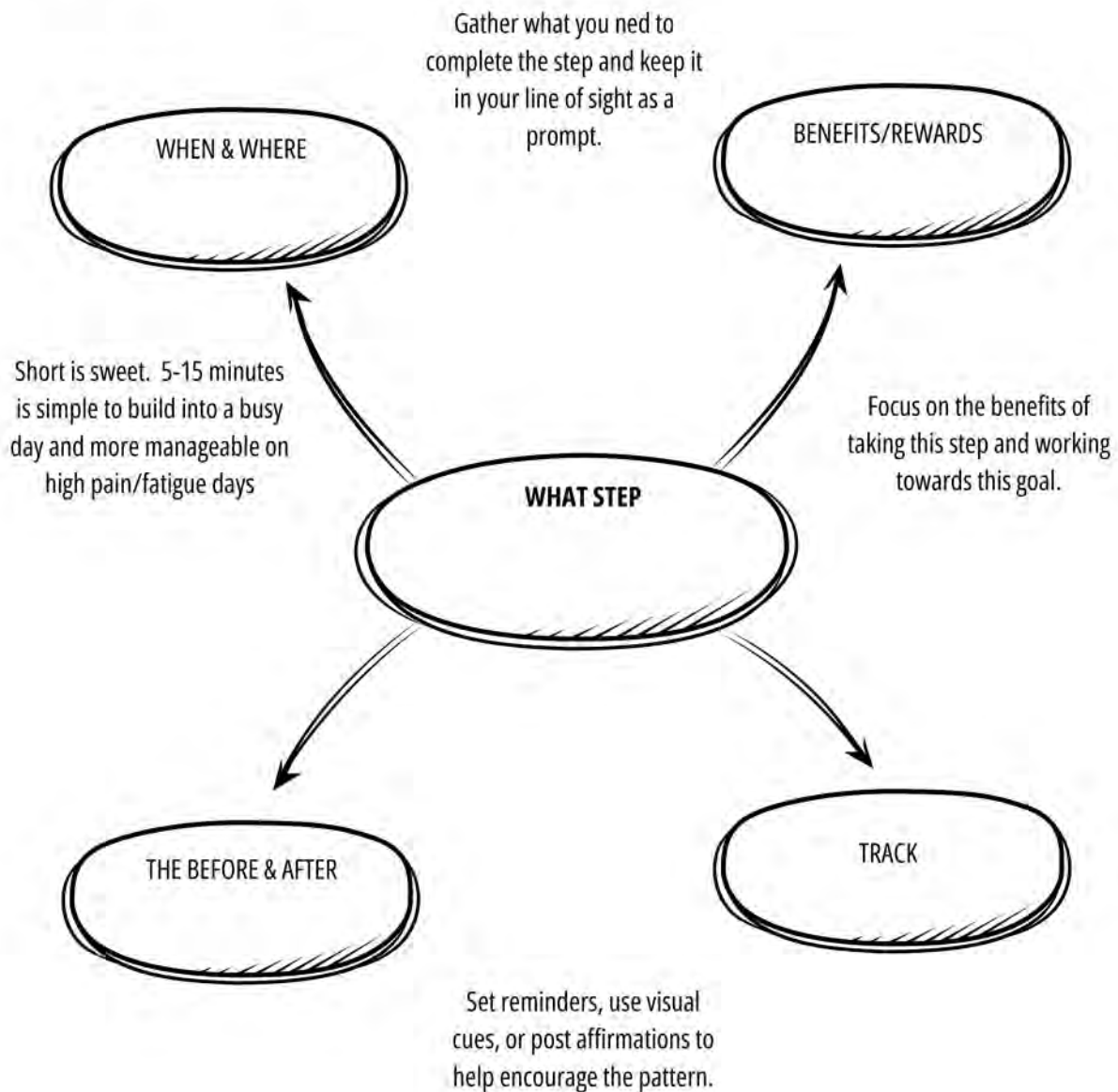
TAKING THE NEXT STEP TOWARDS YOUR GOAL

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 that it works with your resources and demands, it will become a habit. When you notice that a Step takes less effort and it 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 have made (maintenance) OR you can plan to take another Step towards your Goal (new Action). When taking the next Step, take time to prepare and plan as reviewed in Chapter 8.



SCAFFOLDING YOUR STEPS

Use the EASY step formula to consolidate the progress you have made so far towards 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 that 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



REFLECTING ON PROGRESS

Sketch or write how you are making sense of the progress towards your Goal using EASY Steps.

Have you noticed impatience or self-judgment come up? If so, are you able to 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 is typically used to mark important milestones in the environment, across individual lifespan and personal achievements, and to recognize specific relationships. It is 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.

Within this process of Navigating Your Vasculitis Journey with more self-compassion you are embarking on a new chapter. You are mindfully meeting your needs, finding new ways to channel your interests, and connecting with your values. Surviving and finding ways to thrive with vasculitis are milestones that you can be proud of and celebrate with your family & friends.

Within the process of making health promoting changes, you are celebrating YOUR creativity, effort, and commitment to living & loving with Vasculitis along for the journey.

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 does not have to mean a party - though it could if you like. Celebration means planning a 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 - a 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 prompts on the following page to plan the gathering that you would most enjoy to celebrate the steps you have taken so far in Navigating Your Vasculitis Journey.

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



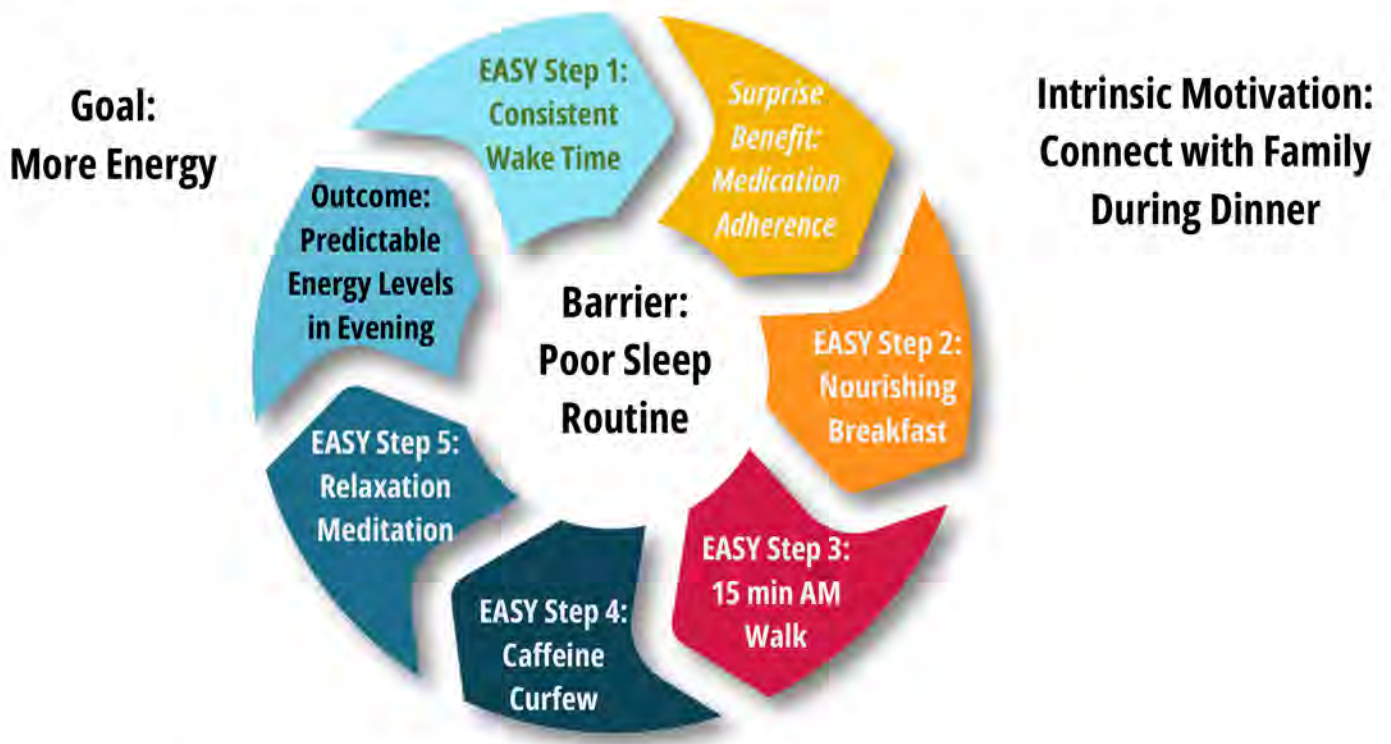
Continuing to prioritize your needs, preferences and values as your vasculitis journey evolves is an ongoing commitment to yourself and to your loved ones. It allows you to show up in your life in the ways that matter most to you. Maintaining this way of being in the world requires a growth mindset, 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 Vasculitis Journey with more self-compassion is not a secret healing recipe that makes everything better. You will likely still experience flares since vasculitis is a relapsing and remitting chronic condition. Also, life demands change over time and you will have to re-evaluate your priorities during these times. Medications can have side-effects, even when you are in remission. Some days will suck. Instead of providing certainty, mindful self-compassion provides a framework that you can apply to each new challenge. You are equipped with a skillset to navigate vasculitis with more integrity, self-kindness, and resilience.

CHANGE CASCADE

Throughout the guidebook, steps & goals have been presented as ways to improve living life 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 is 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 to it 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 every day, 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). Altogether these led to more predictable energy levels; which then resulted in more energy at dinner time to connect with loved ones.



Your goals & motivations will change as you evolve & grow. You can return to the Change Process anytime you notice that your day-to-day routine needs a refresh, so that it supports you.

ACKNOWLEDGING

Throughout the guidebook, various aspects that impact well-being were reviewed. Take a minute to check-in with each area and consider how you are managing it at the moment. This is to acknowledge, without any expectation or pressure, what is working well and which areas you may consider focusing 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 that this is just one snapshot of time in your journey.

Mindful Self-Compassionate Approach (Pause & 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

CONSOLIDATING

In addition to growing and striving, it is 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 are allowed to let it be exactly as it is with self-compassion. You are 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 can drift off course. There can be intense emotion when this occurs along with self-judgement. Though drifting off course is disappointing, it is quite common and only indicates one thing - you're human. Using your nervous system and emotion regulation skills, 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 is not the same as toxic positivity because it does not 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 & 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 behaviour change is a product of creating a habit. He maintains that there are 4 interconnected parts that form a self-reinforcing **Habit Loop**.

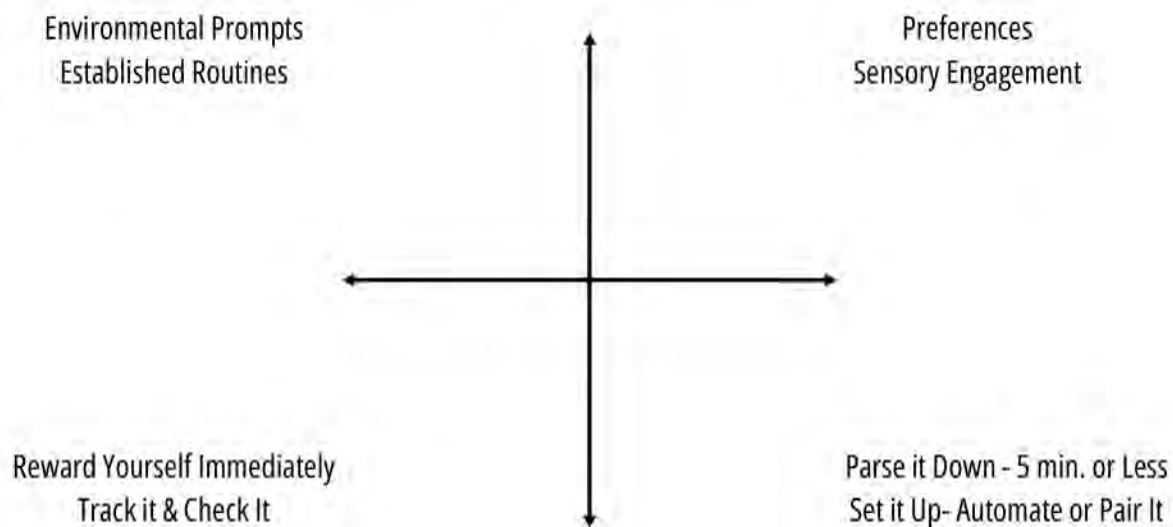
Cue Use your environment to prompt you to take the step by making it obvious and on your mind.

Craving It is 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 have noticed yourself drifting away from your EASY Steps and SMART(R) Goal, you can 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 that 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 are just looking for the chance to move on and forget about it. Anchor your vasculitis 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, also strengthens your commitment to the process.

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

How can you make each step more interesting or fun?

Who can you tell about the steps that you are taking and your success?

Maintaining



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

- Continue to use mindful awareness in daily life
- Reflect & 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?
- Consider how your Circle of Care can 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 the improvements on a “check in” schedule. Maybe once per month?
- Celebrate maintenance with monthly anniversary acknowledgments such as eating your favourite meal, treating yourself to a new book, or a gathering 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.) consider the habit you have 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 & 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 & 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 have been on your journey, validate the challenges you have encountered, and help you to connect with your priorities, so that 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 is up to the people living with vasculitis to take on the added responsibilities involved in managing it along with all the other life demands. Some days are a grind. Finding moments of gratitude within it is essential.

The idea for this course 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 & loving with chronic pain & illness along for the ride.

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

With care,
Stacey