

NAVIGATING YOUR VASCULITIS JOURNEY

AN INTERACTIVE GUIDEBOOK

PART 1 - Orienting and Organizing
2022



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VOV

VICTORY OVER VASCULITIS
MENTAL HEALTH & MINDFULNESS



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 and 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 to work through the course—do what works for you.

3

Make it YOURS

There is no right way to complete this course. Do what is helpful to you—no one is marking it.



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NAVIGATING YOUR VASCULITIS JOURNEY

WORKSHEETS

MODULE 1- GETTING ORGANIZED

KNOW YOUR STORY

KNOW YOUR TIME

KNOW YOUR TEAM

BEHAVIOUR CHANGE-
KNOW YOUR WHY

KNOW YOUR
TREATMENTS

BEHAVIOUR CHANGE-
KNOW YOUR HOW

MODULE 2- PHYSIOLOGICAL AWARENESS &
ATTENTIVENESS (COMING IN 2023!)

ATTEND TO YOUR
TREATMENTS

ATTEND TO YOUR
MOVEMENT

ATTEND TO YOUR
SLEEP

ATTEND TO YOUR MIND

ATTEND TO YOUR
NOURISHMENT

BEHAVIOUR CHANGE-
MAKE THE CHANGES
YOU CHOOSE



MODULE 1

GET ORIENTED & ORGANIZED

MAIN OBJECTIVE

Know where you have been in the past on your journey with vasculitis, where you are currently, and consider where you want to go next and how you can get there.

LEARNING OUTCOME

- Understand your journey with vasculitis.
- Know who does what on your care team.
- Understand how the different parts of your treatment plan work together.
- Organize the information to make it easier to connect with the support you need, when you need it.
- Identify why you are seeking skills to better navigate your journey with vasculitis.

TOPICS COVERED

- Know your Health Story (long & short version)
- Know your care providers
- Know your treatments
- Know your time
- Know your WHY (values)
- Know your HOW (change process)

www.vasculitisfoundation.org
www.staceyivits.com

WHERE ARE YOU?

Orienting

Where have you been on your journey with vasculitis so far?

- Everyone has a Health Story. Those with vasculitis often have more plot points on the storyboard and these may have started long before diagnosis.
- Know and tell your Health Story effectively with care providers and with your friends and family.
- Consider your reasons for using this Interactive Guidebook.

Organizing

Record the information to keep & share

- Use the provided worksheets to record the information.
- Alternatively, use the worksheets as prompts to record it in your own journal or records.
- There is no one way to do this but finding the system for you is a start. Maintaining your information is important so that you can communicate effectively with care providers and your own social supports.

ENLIST SUPPORT

Reflecting

Who can support you professionally & personally?

- Identify different care providers and how they can support your journey with vasculitis.
- Look for ways to include your loved ones that are respectful to you and your needs, and also to them and their own journey.

Sharing

Providing information with intention

- Own your Health Story without apology.
- Determine who, how, and what you share based on relationships, needs, preferences and boundaries.

SETTING GOALS

Preparing

Get clear on your purpose for taking this course

- Connect to your values to get ready to take the next steps on your health journey.
- Understand WHY you want to make behavior changes, which can help you set SMART goals and maintain motivation.

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 who 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.

In the first activity you are invited to write the long version of your Health Story. In the second part of the activity, you have the opportunity to notice the key points and organize it so that you can share it with care providers more effectively.

Activity 1:

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.

Most importantly, it should capture what you remember thinking, feeling, and experiencing.

If writing it doesn't work for you, consider telling your story to someone you trust.

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 it away for the day; emotionally and physically writing your story may be a big step. You may want or need to connect with a friend, family member, counsellor or faith mentor to get support or comfort. 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.

Activity 2:

After you have written your Health Story in long form, you can highlight specific events to make a point form list of Major Health Events and then include them in the following template. In your list of Major Health Events include hospitalizations, surgeries, and when and how symptoms started. Provide the date(s) they occurred and duration, care provider, location, and any treatment provided along with any complications.

This is designed to be a way to share information concisely with your care providers.

YOUR HEALTH STORY

ACTIVITY 1: OWN YOUR STORY

WHO

Describe yourself. Include your preferences, work, recreation, and leisure pursuits. Think about 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? Describe any changes.

WHAT

Describe your health challenges 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 in regards to pain, fatigue, and impairment.

WHEN

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

If you started treatments, describe the impact they have had on your day-to-day life.

Describe the activities you do every day that help you manage your vasculitis.

WHERE

Describe your health right now.

What things are going well, which are not, and how do the good and bad impact you?

What is most difficult for you living with vasculitis?

HOW

Describe how you have adjusted to your vasculitis diagnosis in your day-to-day life right now.

What kind of impact has vasculitis had on your key aspects of life such as family, work, school, relationships, and recreation?

WHY

Describe your reasons for engaging with this Interactive Guidebook.

Think about the strengths and abilities that have helped you on your journey with vasculitis so far.

What other strengths and skills could help you navigate your health journey going forward?

YOUR HEALTH STORY

ACTIVITY 2: MAJOR HEALTH EVENTS LIST

For the Major Health Events use point form notes. Include hospitalizations, surgeries, flares, and when and how symptoms started. Provide the date(s) they occurred and duration, care provider, location, and any treatment provided along with any complications.

NAME	
PHYSICAL & MENTAL HEALTH DIAGNOSES	
ONGOING TREATMENT	

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

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

YOUR HEALTH STORY

1- Write or tell your Health Story by using the prompts.

2- Organize your Health Story by Major Health Event to share it more effectively with care providers.

3- Observe and reflect on the process of writing your Health Story and summarize the key points.

ACTIVITY 3: 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. However, 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 a new way of being with yourself in these moments. I invite you to try Emotion Tending.

Emotion Tending is a practice that brings together concepts from Emotion-Focused therapies, Emotional Agility, Mindful Self-Compassion and Dialectical Behavior Therapy.

Steps to Emotion Tending

- 1- Notice that you are feeling tender in this moment.**
- 2- Name the emotions that you are experiencing.**
- 3- Validate the impact of the experiences leading to this moment (the reasons you're feeling tender).**
- 4- Radically accept the emotion and discomfort of this moment just as they are, without judgment or blame.**
- 5- Respond to yourself kindly by taking a moment to soothe, distract, connect or rest, based on your needs 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. It is stressful for me to remember all of these things at once even though I know they are in the past and that I am not alone in experiencing suffering. These events really 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 before continuing the activities."

This is one way of working with emotional agility, radical acceptance and mindful self-compassion. If this feels new and interesting, consider learning more about these ways of interacting with suffering and emotion by working with a psychotherapist or counsellor. Some people also find that they can learn and grow through reading about these concepts. Check out the resources section at the back of this Guidebook for links.

YOUR HEALTH STORY

ACTIVITY 4: CONNECTING WITH CARE PARTNERS

Next Steps on Your Vasculitis Journey

Stories are meant to be shared; you are not alone.

- 1- Share your Major Health Events list with new and current care providers.
- 2- Connect with a person you trust and share what it was like to recall your Health Story and Major Health Events.
- 3- Consider joining a Vasculitis Foundation support group to feel seen, heard, and understood in this journey.
- 4- Learn more about working with your emotions by connecting with a psychotherapist, reading more, or following key experts on social media so that you can know and own your Health Story.

YOUR CARE PLAN

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 of this page to share with each of your care providers and you can 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 rheumatologist is the specialist physician who usually looks after things related to your vasculitis diagnosis. They monitor the symptoms and treatments and work with your primary care provider (PCP) and other specialists to provide you with the best care possible to live your life with vasculitis.

Your PCP is the physician or nurse practitioner who attends to your typical health care needs - like regular checkups 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 different organs and body systems involved in the vasculitis disease process that must be monitored and treated. These specialists monitor each specific part of you and work with your rheumatologist and/or PCP for your care and treatment planning. The involvement of these other specialists may change over time depending on disease activity or other life stages.

Allied Health Professionals: These are regulated professionals who work with your medical care team, often within hospitals or medical settings, to support other aspects of your health care. For example: 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 professionals who may be involved in your care.

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

Holistic Treatment Providers: These professionals often work outside the medical system to support folks with complementary protocols and therapies. For example: chiropractors, massage therapists, naturopathic doctors.

Dentists, Optometrists, Podiatrists: Professional specialists who provide regular assessment and care for specific health care needs that are common for all people but are provided outside of a medical setting.

YOUR CARE PLAN

Care Team Contact Info

ACTIVITY 1: CONNECT & COLLABORATE

PERSONAL CONTACT INFORMATION

EMERGENCY CONTACT INFORMATION

DIAGNOSES

PRIMARY CARE PROVIDER

CARE PROVIDERS

CARE PROVIDER	ROLE	CONTACT

CURRENTLY PRESCRIBED TREATMENTS/THERAPIES

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

YOUR CARE PLAN

KNOW YOUR TREATMENTS

Use the provided worksheet on the next page to record all current medications, supplements, treatments, and therapies that have been prescribed and you are currently taking. Also indicate the symptoms they are treating. Use the page to share your treatment information with your care providers. Communication between providers can allow you to optimize your care. When considering any changes, communicate clearly with all prescribers. By using one pharmacy to fill your prescribed medications you can work with the pharmacist and your doctors to ensure your safety.

How are you currently following your treatment plan? Many folks can take the medications as prescribed and many others struggle for a variety of reasons. What about any physiotherapy exercises? Attending appointments with your allied and holistic care providers are important; however, many treatment plans have activities you are to complete independently between sessions. How does that work for you? Included is a worksheet to track your adherence to prescribed treatments and your day-to-day functioning. Consider whether this would be helpful for you to do for the two week period (or longer - make copies).

Many people seek additional treatments and/or work with multiple allied and complementary treatment providers hoping that someone has the magic wand to make everything better. Wanting to improve your 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, or nourishing your body adequately, taking up a hobby).

1-TAKE YOUR MEDS

2- DO YOUR EXERCISES (MOVEMENT/MENTAL)

3- NOURISH YOUR BODY- ENOUGH SLEEP, FOOD, WATER

4- CONNECT WITH PEOPLE WHO UNDERSTAND YOU

5- DO SOMETHING FUN

**IF YOU'RE DOING ALL OF THE ABOVE CONSISTENTLY AND
STILL STRUGGLING, TALK TO YOUR DOCTOR**

YOUR CARE PLAN

CURRENT TREATMENTS

ACTIVITY 2: ASPECTS OF YOUR CARE

DIAGNOSES

PRIOR SURGERIES/PROCEDURES

PREVIOUS TREATMENTS

ADVERSE REACTIONS/EVENTS

CURRENT MEDICATIONS

NAME OF MEDICATION

DOSE

DATE STARTED

ADDITIONAL SUPPLEMENTS & THERAPIES

YOUR CARE PLAN

ACTIVITY 3: FOLLOWING YOUR CURRENT CARE PLAN

CURRENT TREATMENTS & FUNCTIONING TRACKER

Use the following chart to track your current adherence to prescribed treatments and your current level of functioning over a two-week period. Reflect on any relationship between level of functioning and adherence to the prescribed treatments.

To track your adherence, each dose of medication, each supplement, or daily therapy is worth 1 point. Give yourself a total for each day based on your unique treatment plan.

To track your functioning you can give yourself a score from 0-10 with 10 that you had no pain, fatigue nor symptoms and functioned at your best - a 10/10.

Use the scoring system so that it makes sense to you and reflects your day-to-day experience and ability.

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		

YOUR CARE PLAN

ACTIVITY 4: CONSIDERING CHANGE

The Range of Possibilities



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.

UNDERSTAND YOUR TIME

One aspect of living with vasculitis that can be overwhelming and elusive is your time. Attending to your health takes time and energy — a precious commodity. Not only is it harder to do your regular day-to-day tasks when you have vasculitis, but now there are also appointments, tests, or therapies to fit in to your life.

An activity that can help capture the impact of vasculitis on your life is time accounting.

Every person only 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. There are 4,180 minutes left for everything else you do in life. How is that adding up for you? If you follow a 5-day work week, the majority of that time is found on 2 days (1,920 awake minutes). This does not account for basics of daily living such as food preparation and eating, hygiene, movement/exercise, or commuting. Those are the typical adult responsibilities that a person has with or without vasculitis. 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. It can also provide perspective so that you can choose how to spend your valuable time on the things that are most important to your well-being and aligned with your values. If you have a severe time deficit, consider how that may be contributing to your well-being.

Time accounting also works with energy awareness. Another person who lives with chronic illness, Christine Miserandino, wrote about Spoon Theory to describe the changing energy reserves that are impacted by pain, fatigue, and symptoms. If this is something that you think could be helpful, look it up and consider how your time commitments and changing energy impact your day-to-day living with vasculitis.

By making the effort to account for your time and energy expenditures in day-to-day life, you can make informed choices about how to spend both your time and energy on things that are most important to you!

UNDERSTAND YOUR TIME

ACTIVITY 1: DAILY COMMITMENT LOG

LIST YOUR DAILY, WEEKLY & MONTHLY HEALTH COMMITMENTS:
APPOINTMENTS, THERAPY, EXERCISES, TESTS

MONDAY

TUESDAY

WEDNESDAY

THURSDAY

FRIDAY

SATURDAY

SUNDAY

WEEKLY

MONTHLY

UNDERSTAND YOUR TIME

ACTIVITY 2: ACCOUNT FOR YOUR TIME PART 1

Add up the amount of time that you spend taking care of your health and wellness. Include all the different activities from the previous page that are directly related to your treatment AND include all the other health maintenance activities like getting groceries, preparing food, and eating; taking much-needed naps, doing movement activities, preparing for health and wellness appointments. 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:

UNDERSTAND YOUR TIME

ACTIVITY 2: ACCOUNT FOR YOUR TIME PART 2

List all the other commitments that you have each day, aside from your health and wellness. Everything from household management, work, family/friends to other social engagements and responsibilities. Include things like cleaning the house, doing lawn maintenance, paying bills, getting ready for work, commuting, coaching your kids soccer, meeting up with friends.

At the bottom you will have your weekly total for 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:

UNDERSTAND YOUR TIME

ACTIVITY 3: REFLECT ON YOUR TIME

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?

UNDERSTAND YOUR TIME

ACTIVITY 4: SPEND YOUR TIME



Prioritize & Schedule

M T W Th F

M T W Th F

M T W Th F

M T W Th F

UNDERSTAND CHANGE

KNOW YOUR WHY

Mariners used the stars and constellations to guide them across oceans they had never travelled 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.

Values are defined as the importance, worth or usefulness of a thing. A person's values are connected to their 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.

**Why does the WHY matter for behaviour change?
Because it helps to motivate and sustain behaviour changes over time.**

KNOW YOUR HOW

Making changes effectively that are sustained over time, requires a skill set. Fortunately, like many other skills, the ability to make behaviour change can be taught and practiced. A commonly used strategy for teaching behaviour change 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 (especially when a change isn't maintained) is RELEVANCE; the goal must be meaningful to you.

Part of the process of making changes is clarifying individual values so that they can be directly connected to the individual steps of achieving the goal. The following activities are designed to walk you through the process so that your values are clearly connected to each step of making a change.

Please remember that this resource is not individualized medical nor psychological advice. No specific change is being advocated nor 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.

UNDERSTAND CHANGE

ACTIVITY 1: IDENTIFYING YOUR VALUES

KNOW YOUR WHY

Values are formed individually and in community so that each person's constellation of values - their why - is specific and unique to them. Sometimes it is difficult for people to identify their WHY but they completely understand their NOT THAT or NOT FOR ME. Reflection activities - such as meditating, journaling, talking to a counsellor or faith mentor - can help people to connect to their own values constellation. The following prompts can help you identify and clarify your values.

If your values constellation continues to be unclear, take time to practice gratitude for a week or a month and then revisit these prompts.

GROWING UP, THE QUALITIES THAT WERE EMPHASIZED BY MY FAMILY, FAITH, OR COMMUNITY:

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:

UNDERSTAND CHANGE

ACTIVITY 3: GRATITUDE JOURNAL

KNOW YOUR WHY

S	
M	
T	
W	
TH	
F	
S	

UNDERSTAND CHANGE

KNOW YOUR WHY

ACTIVITY 2: ALIGNING YOUR VALUES

Primary Values	Secondary Values

Prioritizing my health is tied to my personal values because:

I can prioritize my health every day by:

How I want to Navigate My Health Journey

UNDERSTAND CHANGE

KNOW YOUR HOW

The second step in the behaviour change process is the HOW of taking steps to reach your goal. Connect each practical step on the journey to your individual needs and reasons that reflect your values back to you. You can use SMART goals to help you maintain the suggested treatments and therapies that are already prescribed or to embrace lifestyle modifications that help you navigate your vasculitis journey by focusing on sleep, nourishment, and movement.

It is important to pace yourself. You may have identified changes that you hope to make in multiple areas of your life to improve your wellness. Try to choose one area to start. As you develop skills in making changes in your life, you can apply the same practice to each area that you hope to improve.

Important factors to keep in mind are curiosity, compassion, and consistency.

When things don't go exactly to plan the first time, because life happens, bring curiosity to the table. Consider how to adapt your plan. Gently acknowledge the difficulty of making changes in your life, even the smallest steps, and recognize your efforts with compassion.

Pick small things that you can do even on the worst days so that you can build consistency into your routine and harness that momentum.

In the next few pages you will find activities emphasizing the choice points in your care plan, connecting behavioral change through SMART goals to your values, assessing the plan, maintaining your momentum by crafting your day to focus on your priorities, and finally celebrating!

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

UNDERSTAND CHANGE

KNOW YOUR HOW

ACTIVITY 4: NOTICE YOUR CHOICE POINTS

Aspects of Well-being

Treatments	Mental Health
Mindful Awareness	Nourishment
Movement	Sleep

Consider the various aspects of your care plan and how a small shift in one area can you help you align with your personal values constellation so that you are better equipped to navigate your vasculitis journey.

UNDERSTAND CHANGE

KNOW YOUR HOW

ACTIVITY 5: GOAL SETTING

Setting goals can help improve your vasculitis journey.

SPECIFIC	<ul style="list-style-type: none"> • What is your goal? • Tie in your WHY. • When are you doing it (Schedule it?) 	
MEASURABLE	<ul style="list-style-type: none"> • How do you know you are working on it? • Are you tracking? • What will you celebrate? 	
ATTAINABLE	<ul style="list-style-type: none"> • How are you prepared? • What materials do you need? • Do you need support? From whom? 	
REASONABLE	<ul style="list-style-type: none"> • Do you have the time and resources to meet your goal? • Do you need to consult a professional? 	
TIMELY	<ul style="list-style-type: none"> • When will you begin? • When will you reflect and adapt if needed? • When will you celebrate? 	

UNDERSTAND CHANGE

KNOW YOUR HOW

ACTIVITY 6: ASSESS YOUR MOTIVATION

Use the following scales to see if the goal you have set for yourself is aligned to your values and reasonable, given your time and ability, and appropriate based on where you are right now in life. If you notice that any part of your motivation is lower than 3/5, consider any adjustments to increase and maintain your motivation.

MOTIVATION MEASURE

Importance of the change 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

UNDERSTAND CHANGE

ACTIVITY 7: CRAFT YOUR DAY

KNOW YOUR HOW

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...

UNDERSTAND CHANGE

KNOW YOUR HOW

ACTIVITY 8: ENVISION SUCCESS

CELEBRATION PLANNER

Goal(s)	Strategy

What will you celebrate?

When will you celebrate?

How will you celebrate?

After the celebration reflection

10

TIPS TO 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



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“

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*



Dear Traveller,

As a patient with Vasculitis I know that there can be an overwhelming number of things to do, information to learn, and appointments to keep to manage health and wellness effectively. As I've been living with vasculitis for the past twenty years, I have often wished for a guidebook to help me make my way through all of it. So here I bring together many strategies to help you get organized and plan the next steps in your health journey. This guidebook may not make everything better, and it won't change your diagnosis. However, my hope is that it helps you to find your own way to embrace life, with Vasculitis along for the ride.

At the beginning of this guidebook, I suggested writing your own health story: to understand where you have been on your journey, to acknowledge the challenges you have encountered, to contemplate your preferences and values. In the subsequent chapters various tools were presented

because I believe that each person navigating life with Vasculitis needs to be well equipped. I hope that you were able to use what's helpful (and leave the rest). If you find yourself feeling stuck sometime down the road, I created this Guidebook to be something that you can look back at to find a new way through.

Overall, I hope you can take the next steps on your health journey with courage, confidence, and compassion. Sometimes you may have to adjust course and that's understandable. Remember to reach out to your family, friends, community and medical professionals to enlist their support. Connect with other travellers to share your highlights and lowlights along the way. Curiously seek out new resources so that you can keep going and write your own brave new ending to your health story.

With care,

- Stacey

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