



Rainbow Pacing Program

Pacing activity to promote recovery

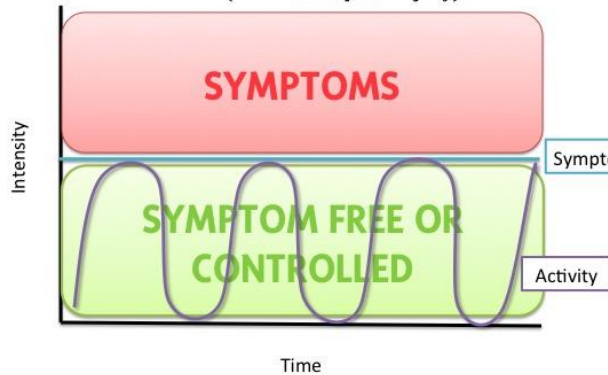
A photograph of the Parkwood Institute building, a large, multi-story brick structure with many windows. In the foreground, there is a lush garden with tall green reeds and a wooden walkway with a metal railing. The sky is clear and blue.

At Parkwood Institute we are
known for strategies to teach
patients how to plan and pace
their activities

The Evolution of Pacing Education at Parkwood



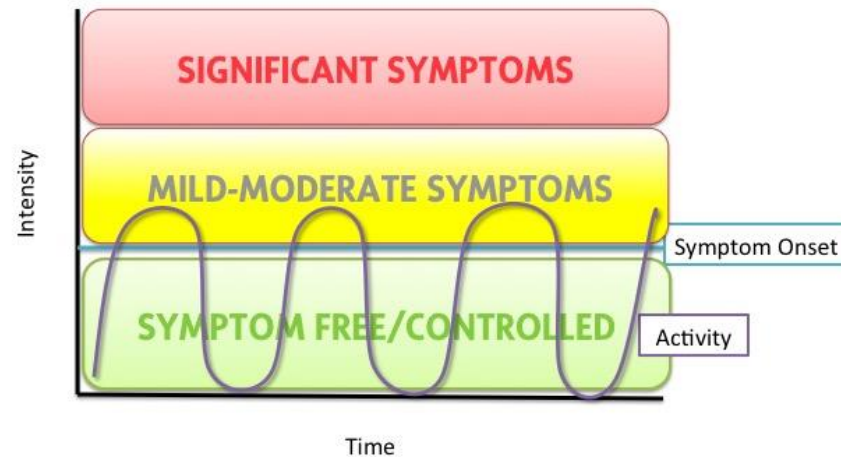
Early Target Activity Pattern (1-4 Weeks post injury)



Developed by Parkwood Hospital
Outpatient ABI Team



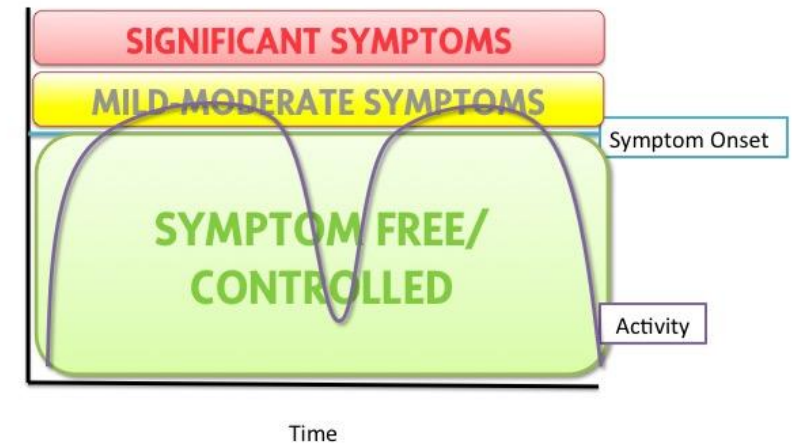
Persistent Symptom Target Activity Pattern



Developed by Parkwood Hospital
Outpatient ABI Team



Long Term Activity Goal



Developed by Parkwood Hospital
Outpatient ABI Team

First...our pacing graphs!

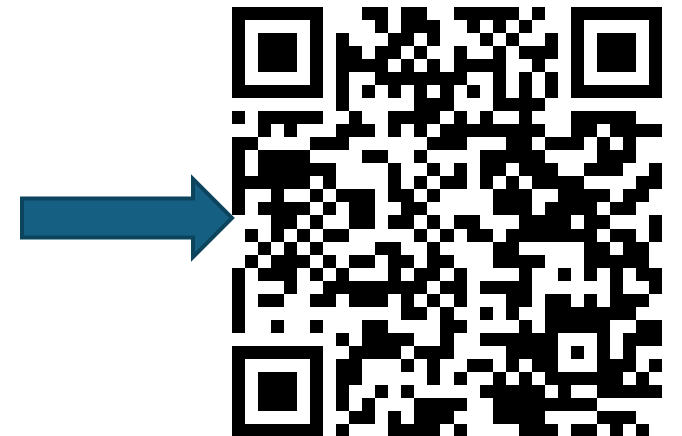
Next...Parkwood Pacing Points

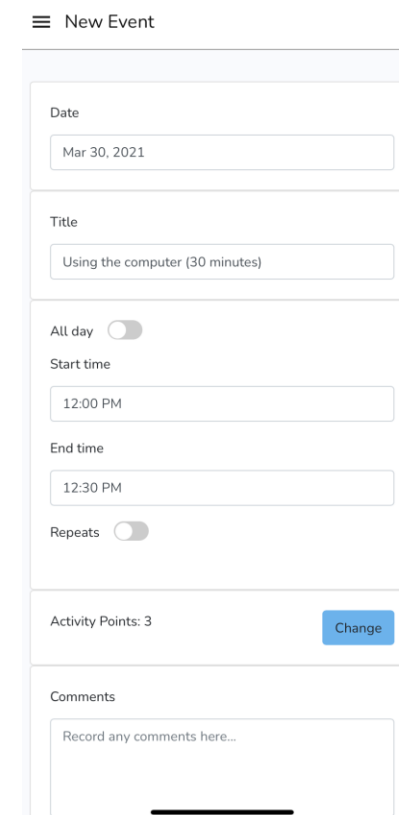
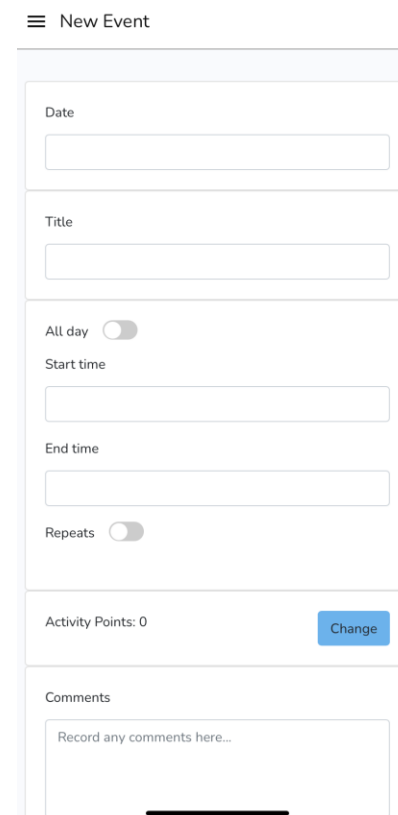
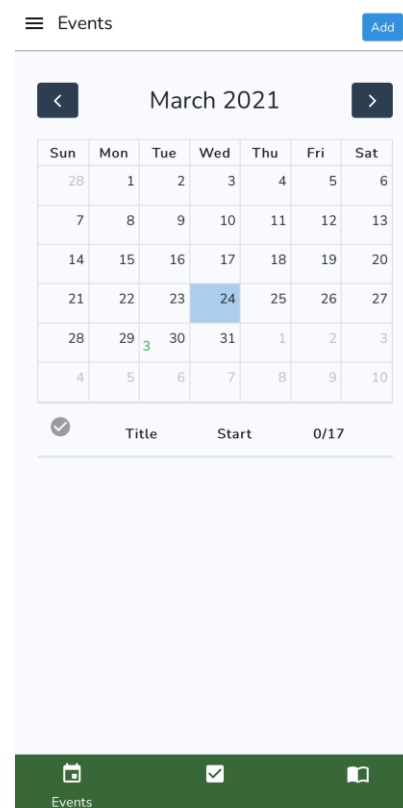
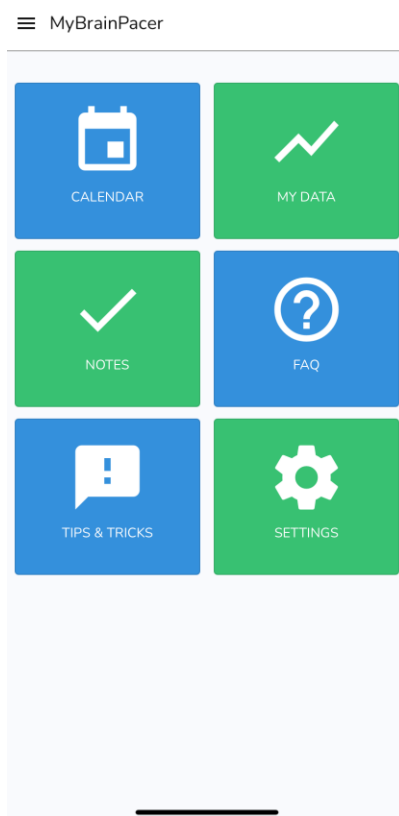


MyBrainPacer
CONCUSSION RECOVERY POINTS PLANNER

TM

- Web based app now available!!
- www.mybrainpacer.ca
- Video to demonstrate how app works
- Collecting data for research purposes





Edit Event

Date: Mar 30, 2021

Title: []

Us: []

All d: []

Start: 12:00 PM

End time: 12:30 PM

Repeats:

Activity Points: 3 Change

Comments: Record any comments here...

Activity Points: 3

Difficulty 4

Symptom Aggravation 8

Save

Edit Event

Complete

Symptoms

- Headaches
- Dizziness
- Nausea
- Noise Sensitivity
- Sleep Disturbance
- Fatigue
- Irritability
- Depression
- Frustration
- Forgetfulness
- Poor Concentration
- Slowed Thinking
- Blurred Vision

Edit Event

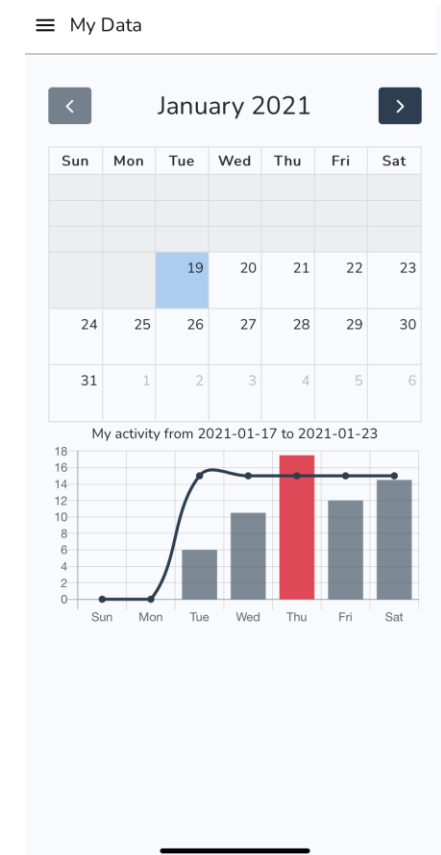
Complete

Symptoms

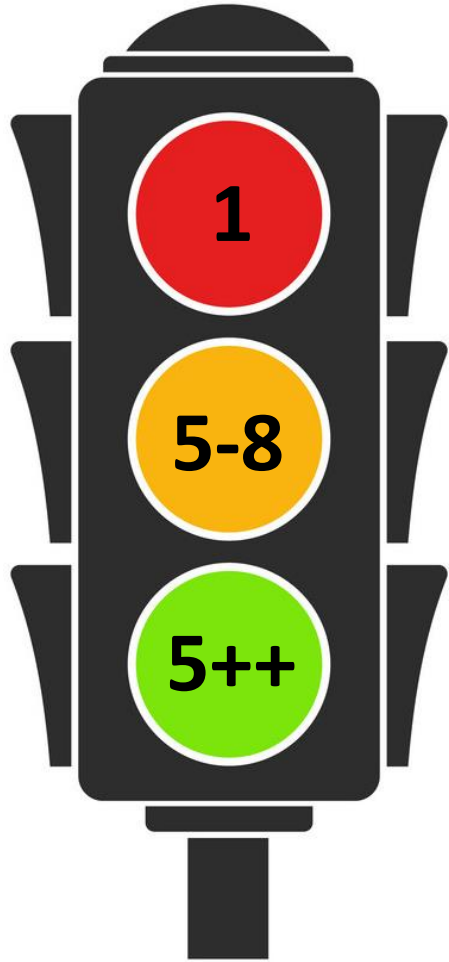
- Headaches

Intensity: 0

Duration: - Please Select -
- Dizziness
- Nausea
- Noise Sensitivity
- Sleep Disturbance
- Fatigue
- Irritability
- Depression
- Frustration
- Forgetfulness
- Poor Concentration



A Simplified Option: The Stoplight Activity Menu



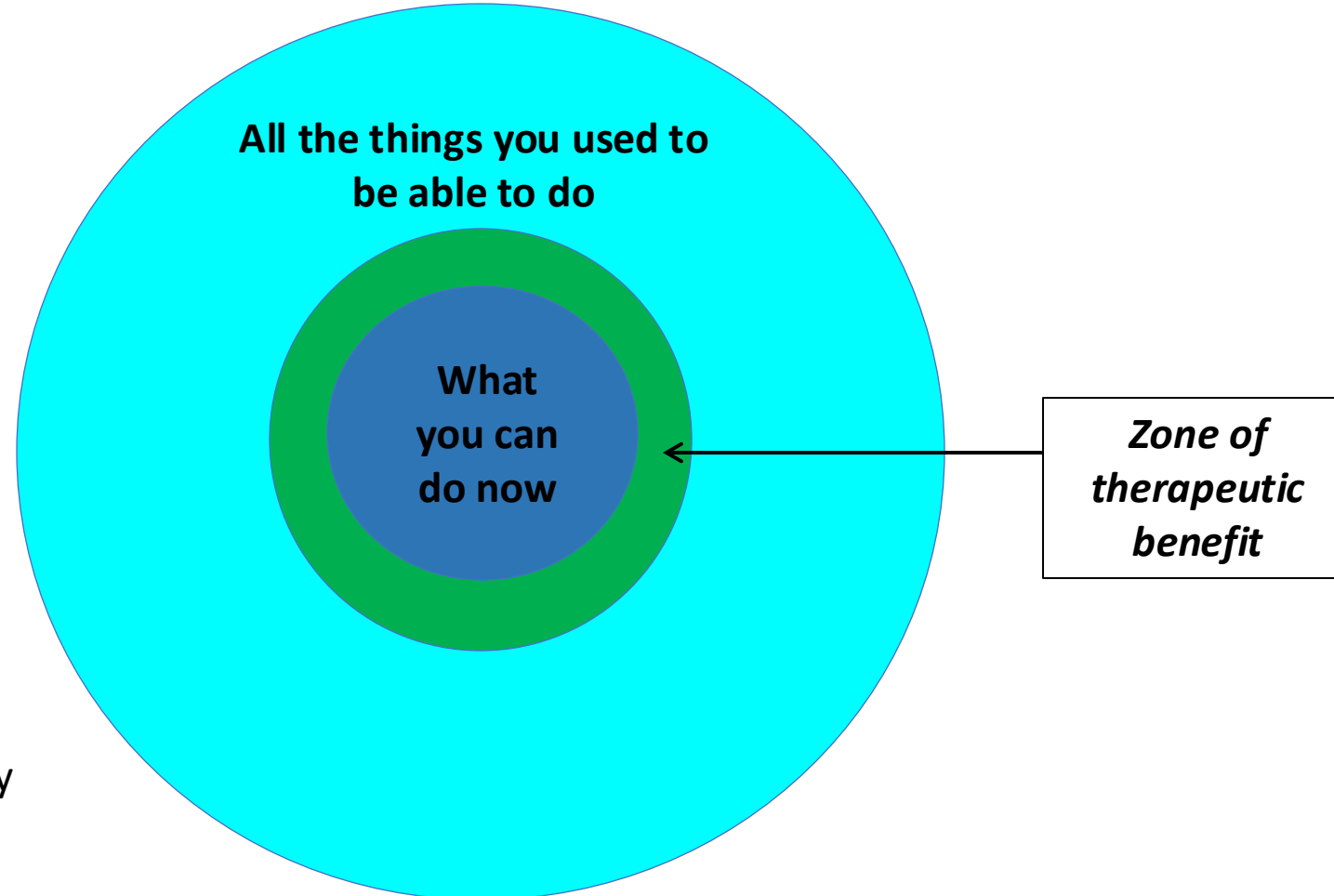
Grocery shopping, Family gathering, Full day of work, drive for 2 hrs, school concert, sporting event, etc

Meal preparation, laundry, short drives, therapy appointments, watching 30-60 min of TV, reading for 15-30 min

Showering, grooming, making breakfast/lunch, light walk, listening to an audiobook or music, meditation, eating

Another graphic - The right amount of challenge

Modeled after Vygotsky's theory of development



Patients need to work slightly harder than is easy – this can be a moving target

Longer term goal



Then I started working with Long Covid patients



Mental Health

- Anxiety
- Depression
- Sleep problems
- Substance abuse



Respiratory System

- Cough
- Low blood oxygen
- Shortness of breath



Kidney

- Acute kidney injury
- Chronic kidney disease



Gastrointestinal

- Diarrhea
- Acid reflux
- Constipation



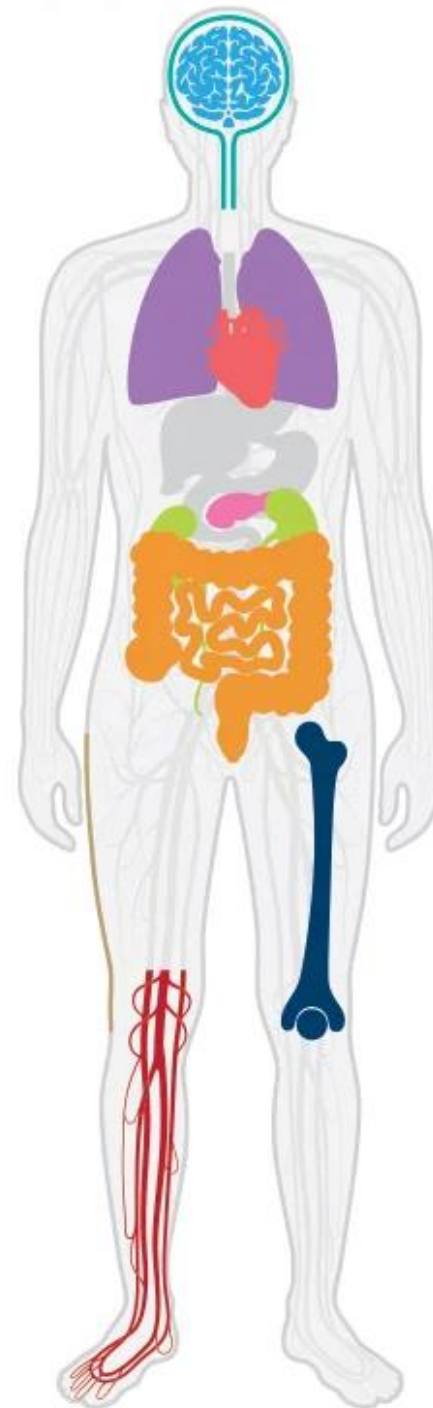
Skin Disorders

- Rash
- Hair loss



Blood Disorders

- Anemia
- Blood clots



Nervous System

- Stroke
- Headaches
- Memory problems
- Loss of smell and taste



Cardiovascular

- Arrhythmia
- Palpitations
- Heart failure
- Acute coronary disease



Metabolic/Endocrine

- Obesity
- Diabetes
- High cholesterol



Musculoskeletal

- Joint pain
- Muscle weakness



General

- Fatigue
- Malaise
- Mitochondrial dysfunction

Dimensions of post-exertional malaise



Source: DSQ-PEM, 2018

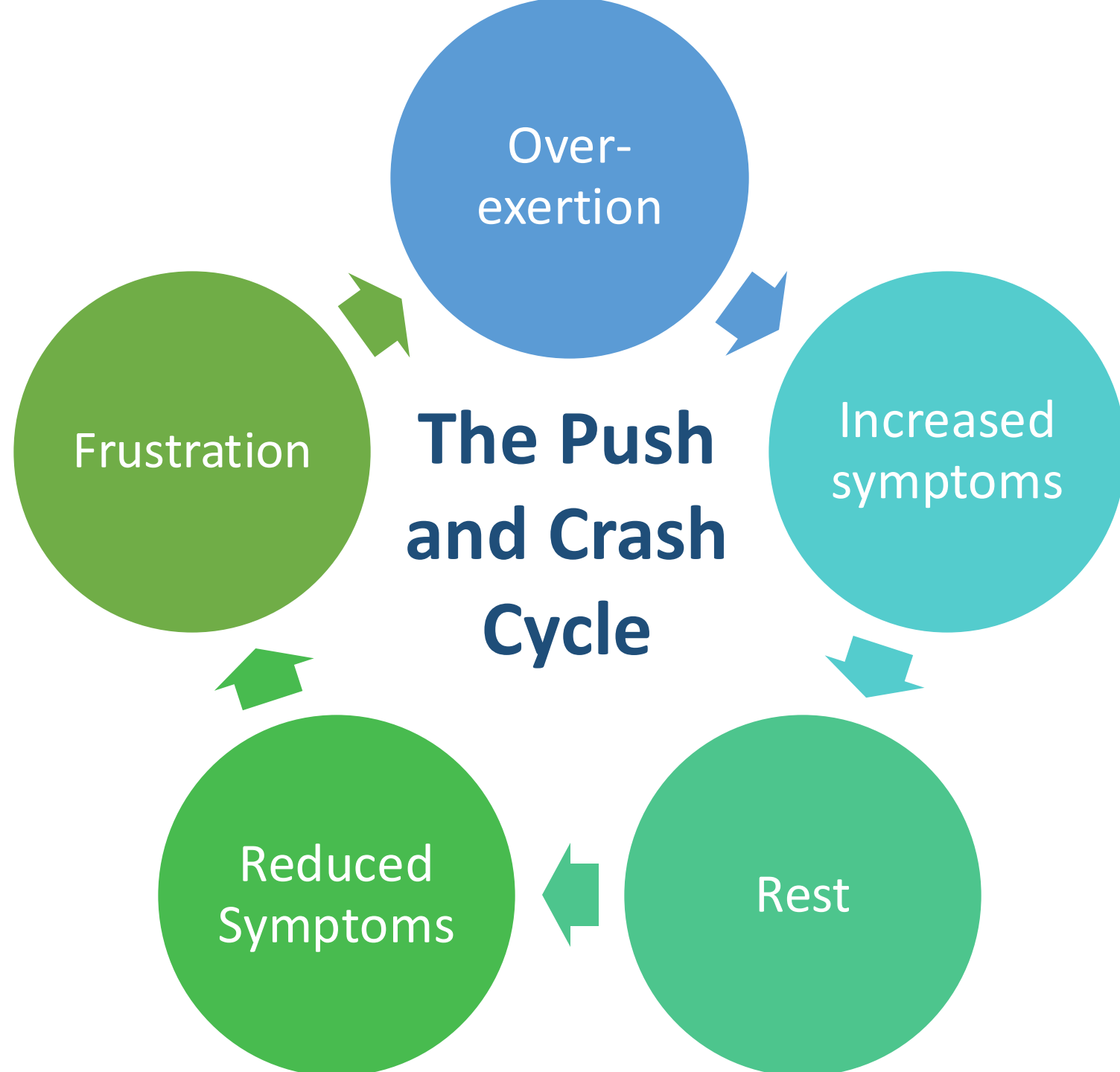
ME-pedia.org

ABI

- Constellation of symptoms
- Benefit from exercise
- Can have delayed response to activity
- Need to systematically challenge system to improve
- Usually recover from activity < 24-48 hours
- Benefit from pacing

Long Covid

- Bigger constellation of symptoms
- Exercise can be harmful
- Frequently have 24-48 delayed response to activity
- Need to be very careful about doing too much activity
- May require several days of complete rest to recover from activity
- Pacing is essential to management





**Out of frustration came a
Rainbow...**

Flare

Push

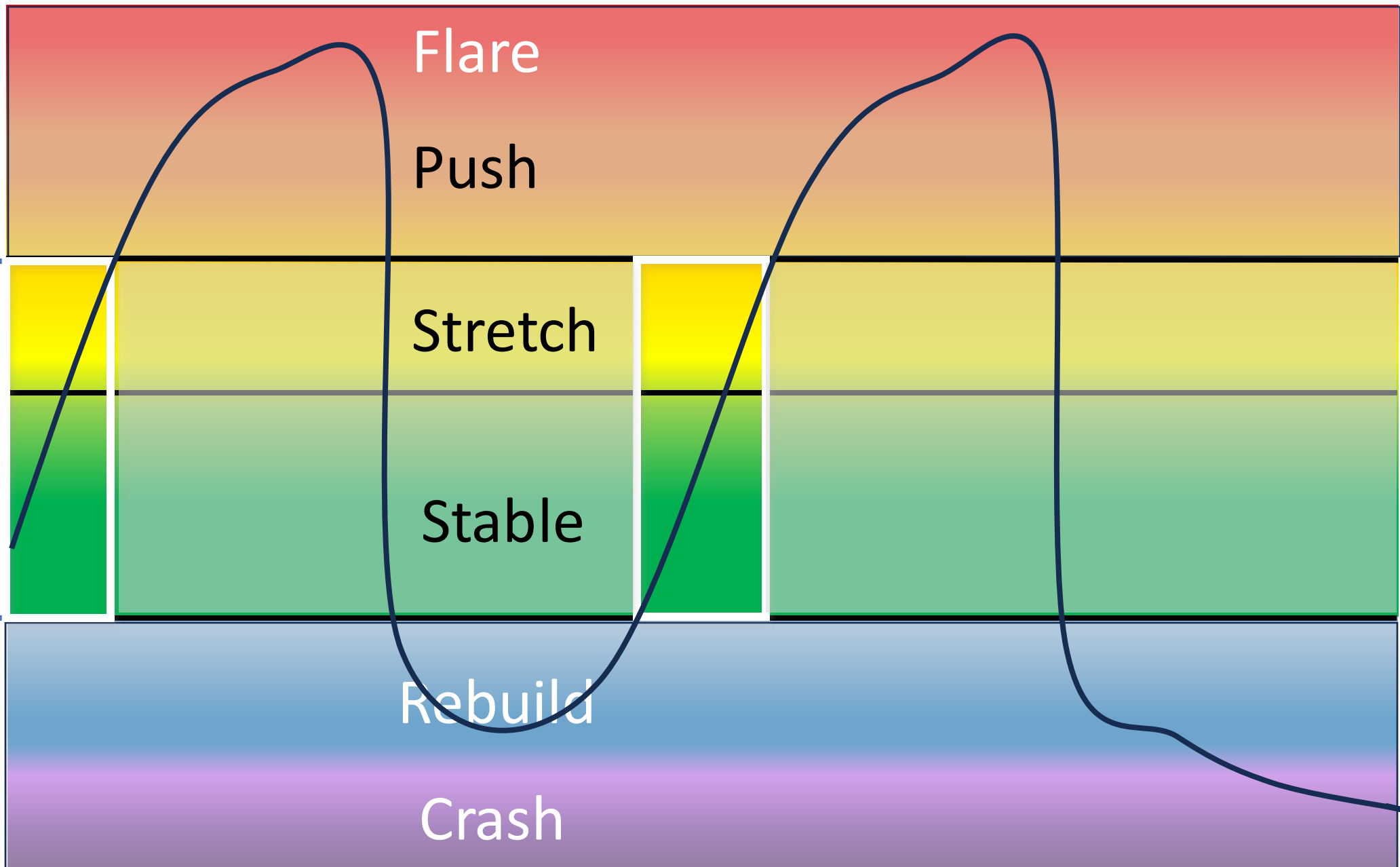
Stretch

Stable

Rebuild

Crash

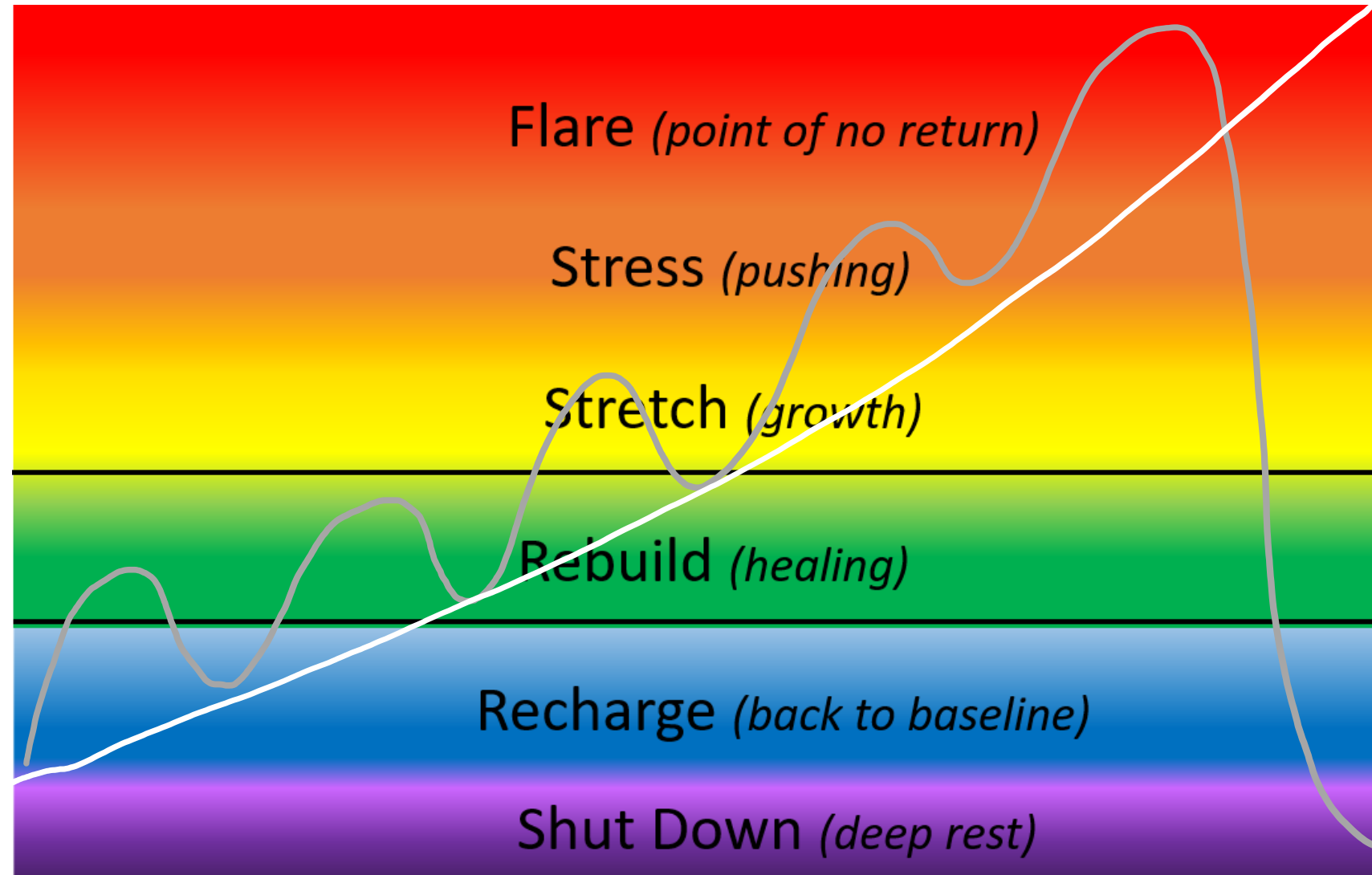
Target
Activity
Zone

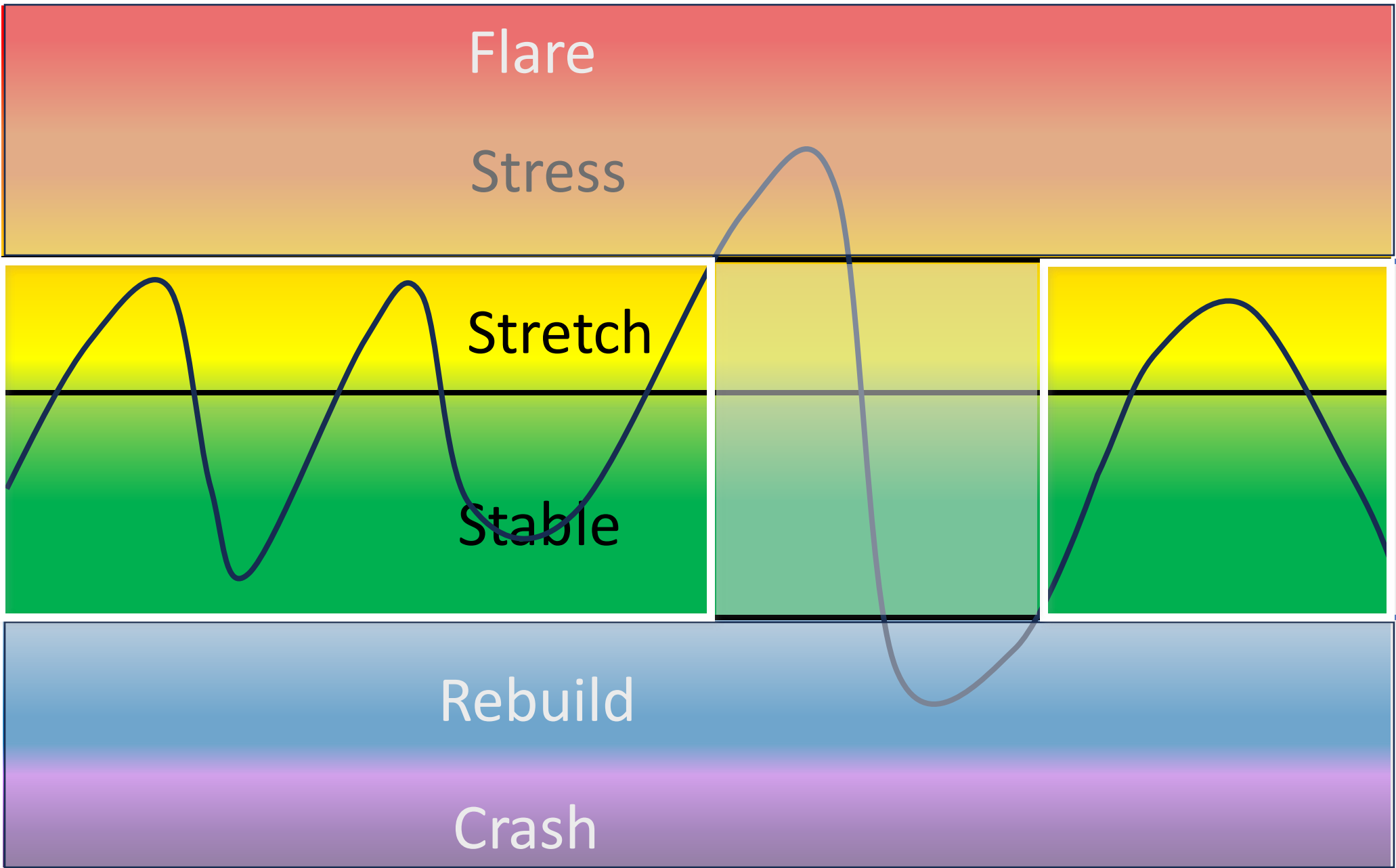


Target
Activity
Zone

Time

Common Post
Covid Pattern:
Cumulative
Activity





Target
Activity
Zone

← Time →

So what happened
when I took it to
my patients...



Flare → Flare (*point of no return*)

Push → Stress (*pushing*)

Stretch → Stretch (*growth*)

Stable → Rebuild (*healing*)

Rebuild → Recharge (*back to baseline*)

Crash → Shut Down (*deep rest*)

Words Mattered

They wanted the name of the zones to match their perception of what was happening

They wanted more descriptors so it was easier to remember and understand

Then they
took the
concept and
ran with it...

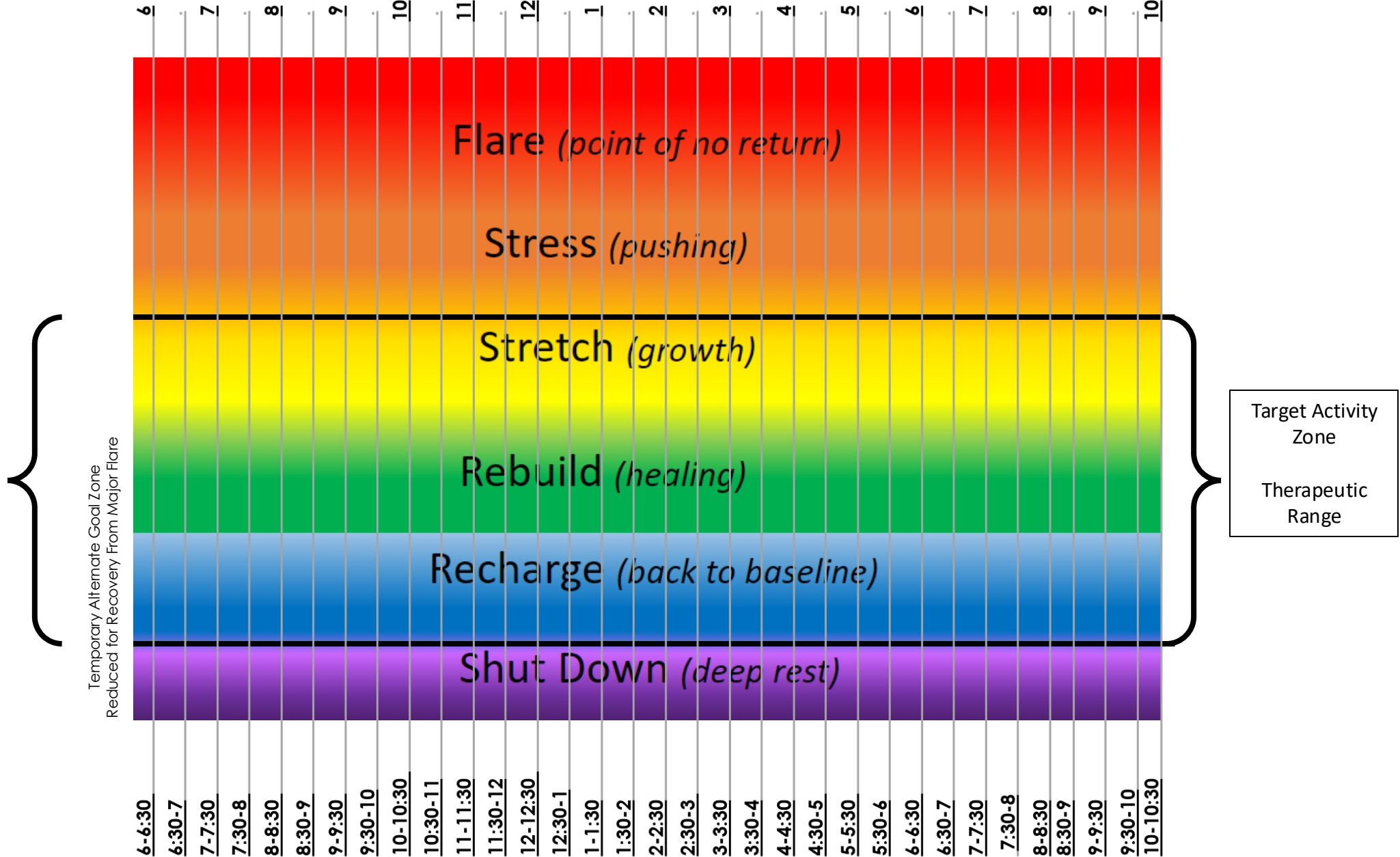


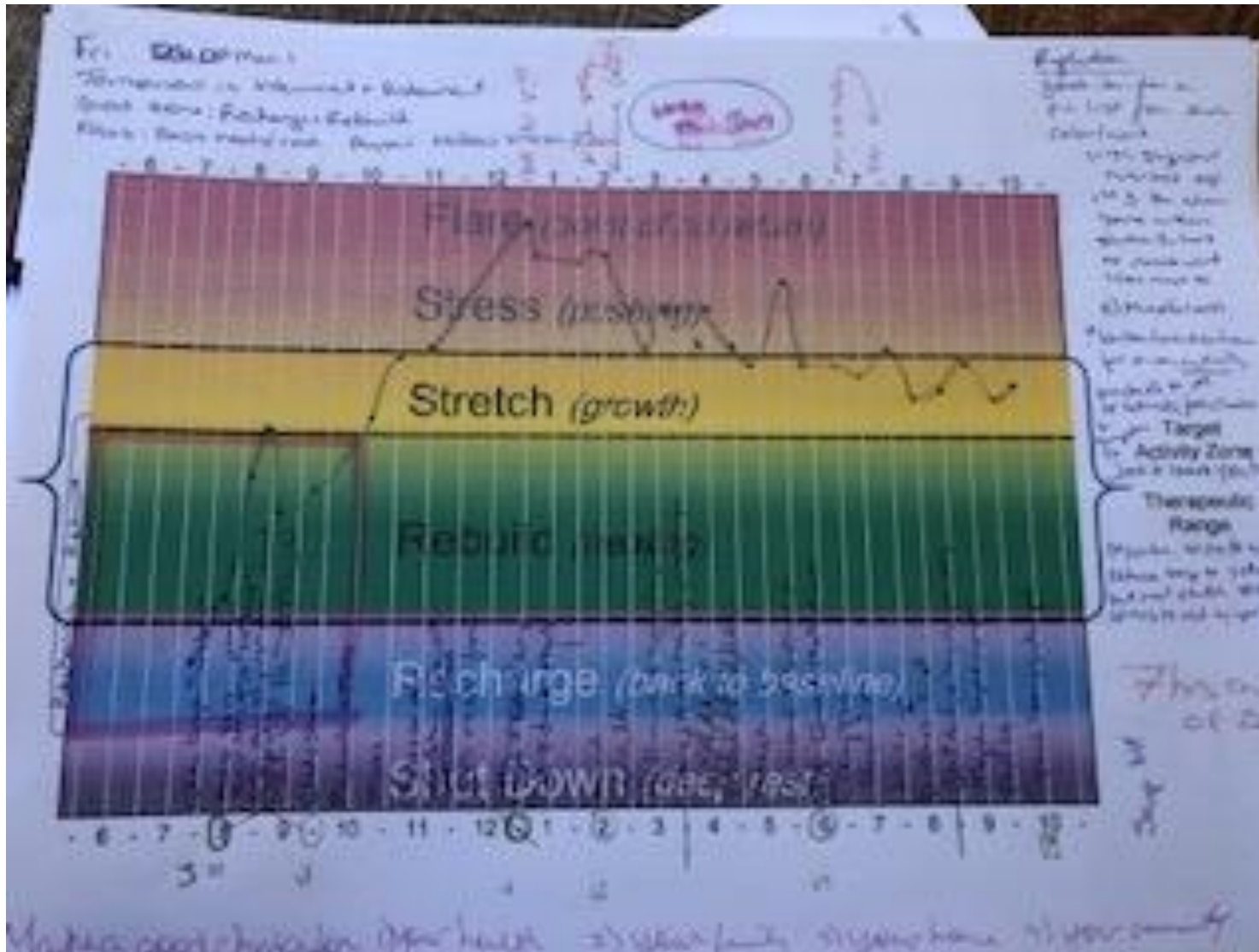
Date: _____ Focus: _____ Today's Goal Zone: _____ Total Hours in GZ: _____ / _____

Yesterday: Light / Mod / Heavy Tomorrow: Light / Mod / Heavy

Sleep Last Night: X Weather: H / L Pressure _____

Reflections



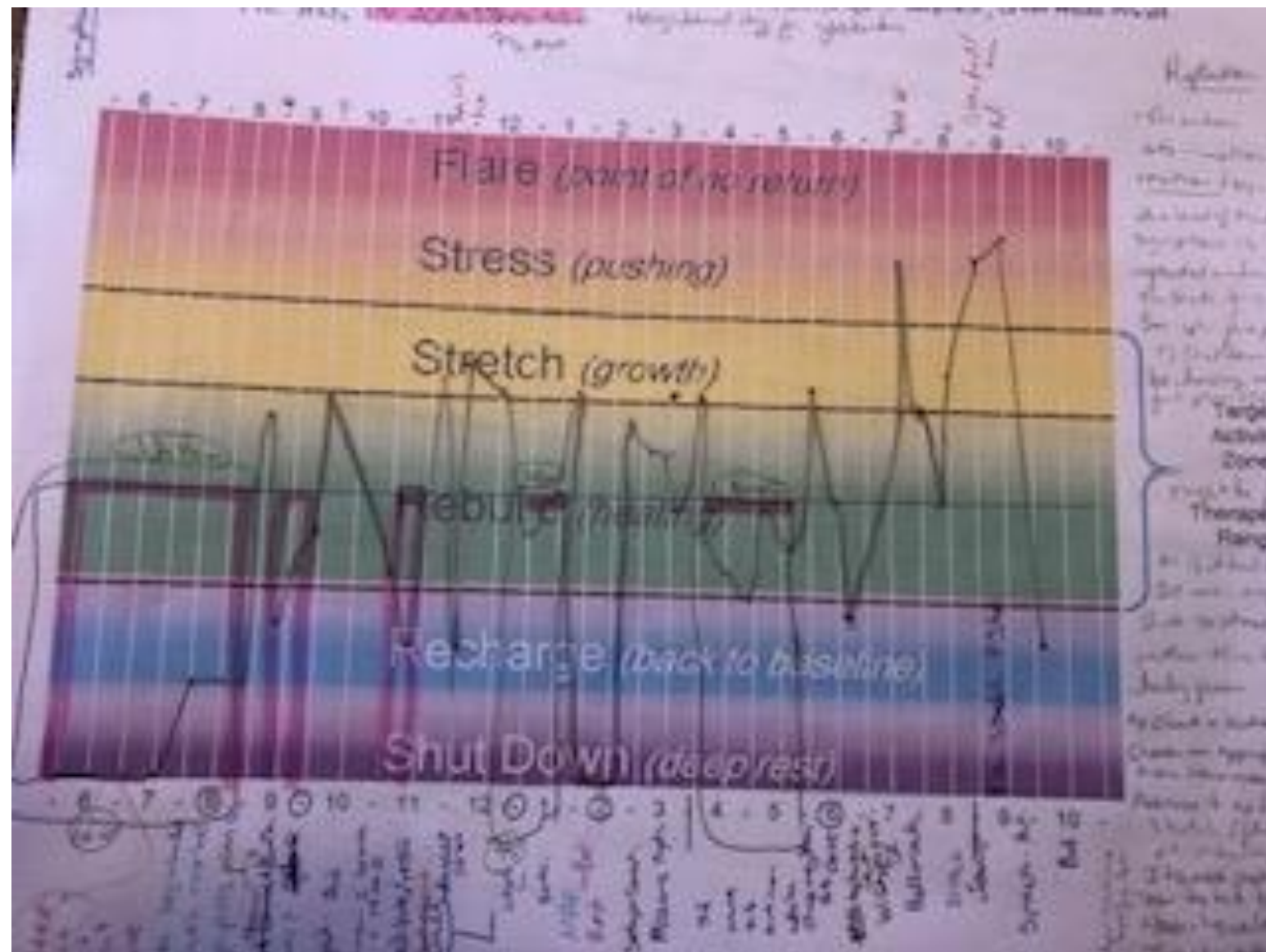


“First... permission to go into the **shutdown** and **recharge** zones to recover from major flares was huge. Going into that zone for a few days was also revealing because the activities I would do were from that zone but my body would still react way up into the **Stretch** and **Stress** zones.”

“I had to wrestle with the understanding and differentiate how I could be doing a **purple** task but feeling **Stress/Orange**.”

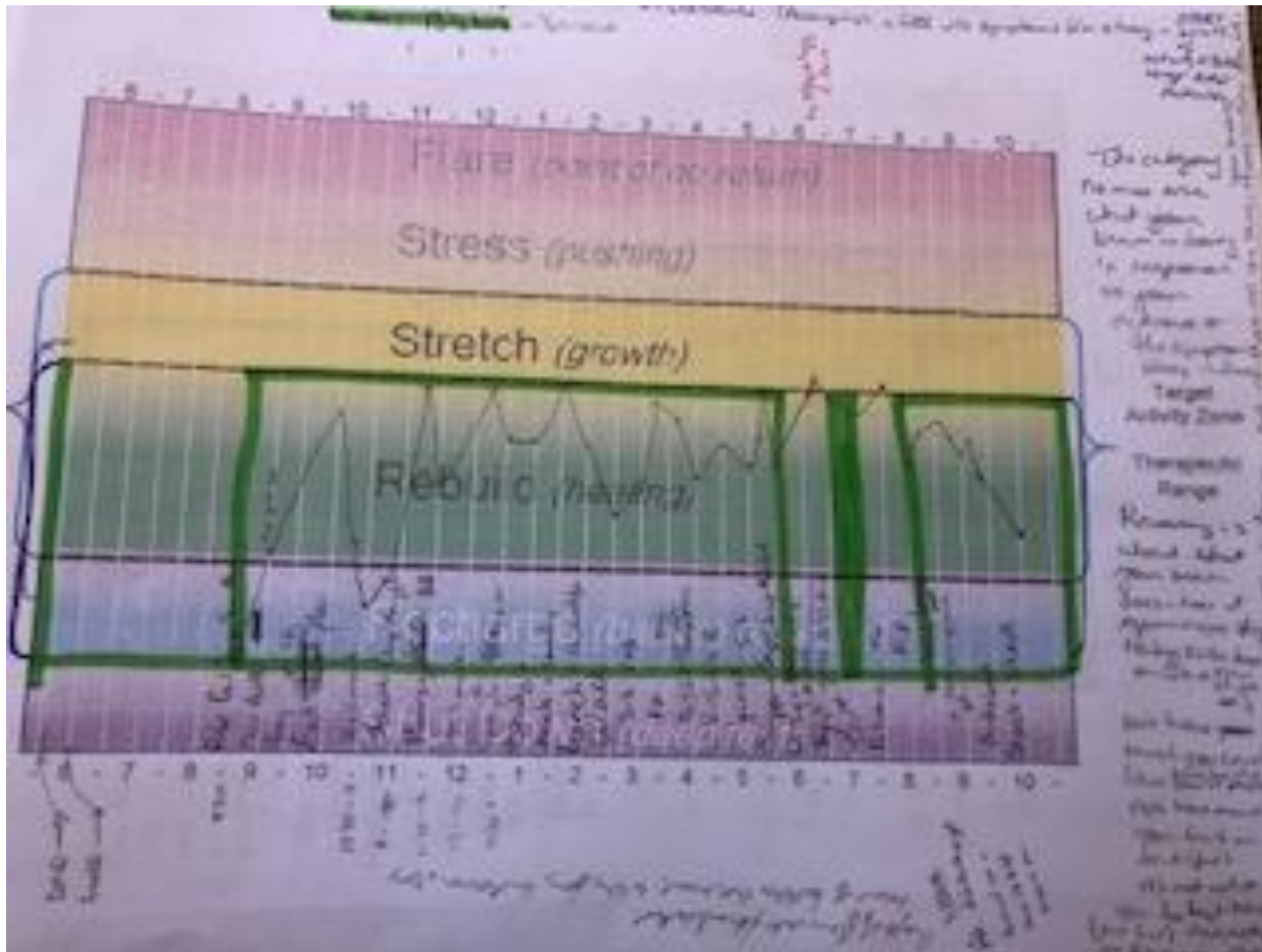
“Eventually I came to recognize that, that is **actually the whole point** and that eventually what I'm doing and what I'm feeling can line up”

I got there by graphing feeling but doing low zones.



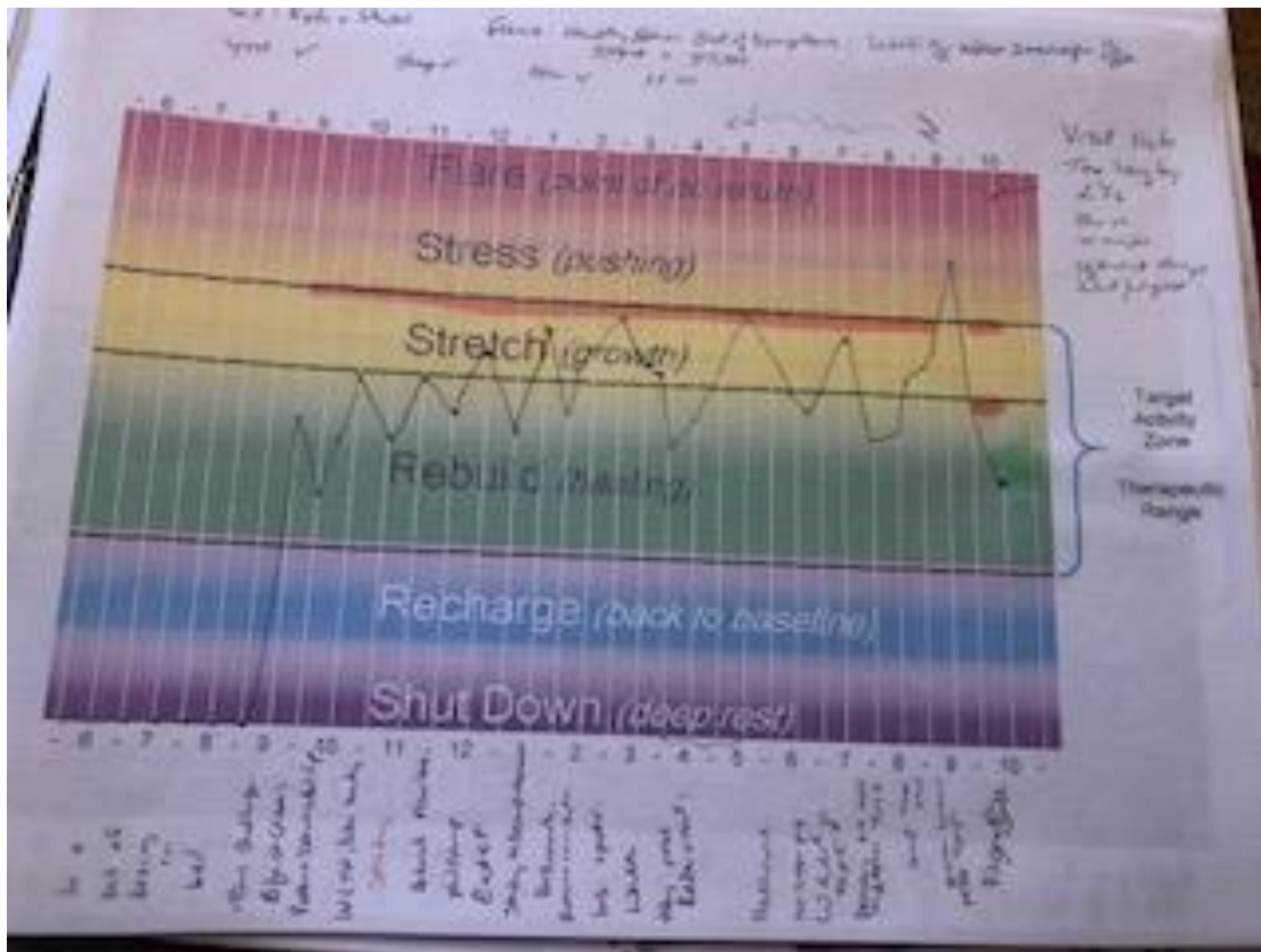
“Seeing in graphic form what the shape of my graph looks like makes it real. It's not just an abstract idea.”

“It really revealed that a poor decision in the morning can blow the symptoms of the whole day.”



”It showed me that a busy day in which I feel great and stay in the zone can result in a delayed spike/flare of several days”

“And it doesn't have to happen too many times to realize its more efficient & more pleasant **to control it before hand than play catch up after.**”



“It becomes obvious that you don't actually feel like crap all the time... you feel crap in very specific times and ways for specific reasons and ***you can start to make the connections in a way that can't be denied.***”

“You've been telling me all along that if I can just get in the zone and stay there things will be, feel and get better. This chart helped me wiggle my way there and finally *understand* internalize* it for myself in a way that changes things.”

Target Recovery Zone

Flare (*point of no return*)

Stress (*pushing*)

Stretch (*growth*) Where neuroplasticity happens – need to challenge to change

Rebuild (*healing*)

Need to spend time here to allow brain space and time to heal

Recharge (*back to baseline*)

Shut Down (*deep rest*)

Goal is to spend majority of the day in the Target Activity Zone

Life will take them into **Stress** & **Flare** but use **Shut Down** & **Recharge** to return to **Target Recovery Zone** as fast as possible

SLEEP: A B E G -H5

EXERTION: yesterday L/M/H
Today L/M/H
tomorrow L/M/H

MORNING ROUTINE: ✓ ± ✗

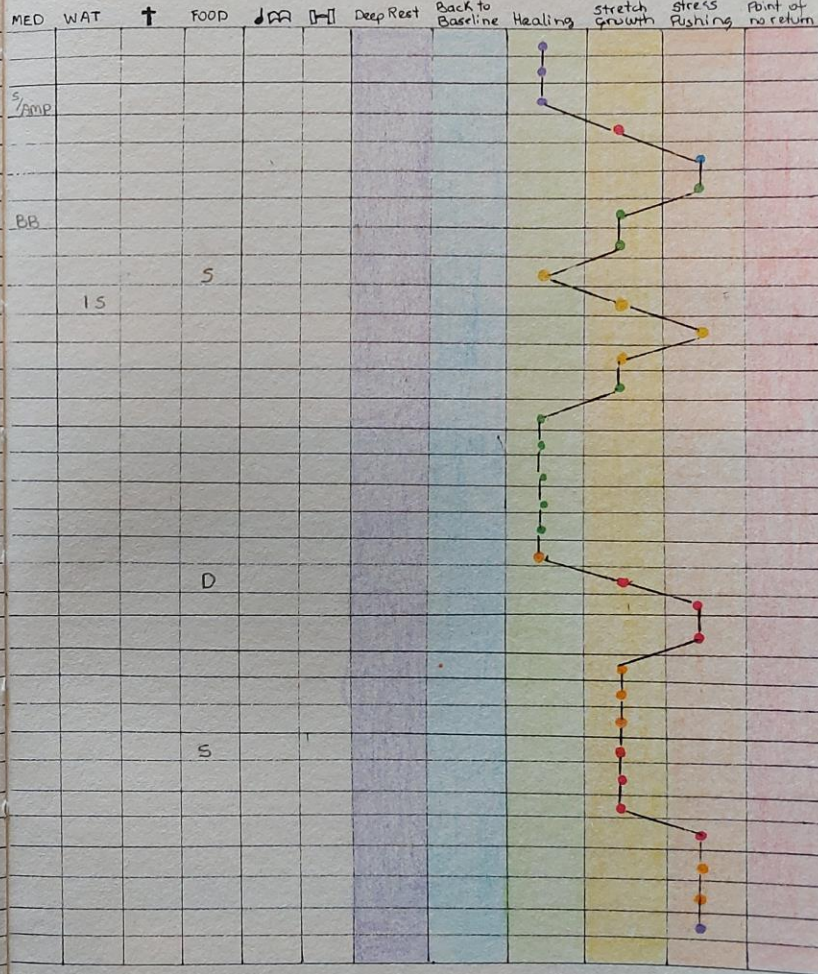
NIGHT ROUTINE: ✓ ± ✗

THU 28th, MAR 2024

1 - bad 5 - good

	Mood	Symptoms
7:00 Wake up	•	
7:30 lay down	•	anxious 1
8:00 meds / rest	•	1
8:30 downstairs / food prep	•	1
9:00 planner	•	1
9:30 social media	•	1
10:00 Social media	•	2
10:30 Guitar lesson	•	3
11:00 organizing food / planning	•	1
11:30 Planning	•	overwhelmed dizziness / hungry
12:00 Planning	•	1
12:30 texting	•	1
13:00 resting / phone?	•	1
13:30 resting / phone?	•	2
14:00 resting / phone?	•	2
14:30 resting / phone?	•	2
15:00 resting / phone?	•	2
15:30 resting / phone?	•	3
16:00 Preparing for going	•	3
16:30 chatting Catherine / food	•	3
17:00 shower	•	3
17:30 Dressing up	•	3
18:00 Drive Cinema	•	5 ²
18:30 Drive Cinema	•	5
19:00 Popcorn shopping	•	2
19:30 Movie	•	3
20:00 Movie	•	3
20:30 Movie	•	2 ³
21:00 Movie	•	3
21:30 Drive back	•	3 ⁴
22:00 Drive back	•	3
22:30 Sleep	•	2
23:00		

1. not wanting to go down for food for not wanting to meet Sean's parents
2. The drive was beautiful and recharging, some stress but enjoyable
3. The body was complaining during the movie, but it was okay
4. Hard drive back



“Thanks for sharing the visual graphs and ideas with me. It is making it all a lot easier for me to assimilate the information and to stick with it.”

“Graphing my symptoms/mood/activities vs how I'm feeling at the moment, made me see a direct connection of my anxiety to seeing people.”

Identifying Rainbow Zones for Symptoms

- Notice if there is a predictable progression of symptoms
- Are there early warning signs? A symptom that consistently appears first?
- When are they getting to a point where it will take time and rest to recover to baseline?
- When are they past the point of no return? What are the symptoms and what is their intensity?
- When do they feel good? When are tasks easier?
- Try to consider what zone the symptoms correspond to so they can be graphed accurately throughout the day

Rainbow Pacing Symptom List

Shutdown <i>(deep rest)</i>	Recharge <i>(back to baseline)</i>	Rebuild <i>(healing)</i>	Stretch <i>(growth)</i>	Stress <i>(pushing)</i>	Flare <i>(point of no return)</i>
<ul style="list-style-type: none"> • symptoms still elevated – feel unable to complete activities. Can't push through – sleeping or laying down most of the day. • brain fog (8-9/10) • body feels heavy (8/10) • fatigue (9-10/10) • nausea comes and goes • dizzy (6/10) • ringing in ears (5/10) 	<ul style="list-style-type: none"> • fatigue (6/10) - tasks are effortful • brain fog (5-7/10) – not performing activities as well as usual • crash symptoms lingering so can't do harder tasks • starting to feel some symptoms are lessening 	<ul style="list-style-type: none"> • body weakness present but minimal (1-2/10) • fatigue (2-4/10) • brain fog minimal (1-2/10) • mind feels calm • doing simple tasks is easy • ringing in ears, nausea, dizziness <u>not</u> present or mild • Can settle symptoms quick with recharge task 	<ul style="list-style-type: none"> • body weakness (4/10) • fatigue (4-6/10) • dizzy (4/10) • brain fog (5-6/10) – things feel harder • ringing in ears, nausea not present or mild • feel able to use strategies to manage symptoms but need a slightly longer recovery time • Tasks starting to be effortful 	<ul style="list-style-type: none"> • body weakness (5-7/10) • fatigue (6-8/10) • ringing in ears starts (4/10) • dizzy (5-6/10) • brain fog (6-8/10) – slower with responses and mixing up words. • Headache • Temperature hot/cold • Irritable, noise sensitive, overwhelmed • Family/friends may notice you are struggling 	<ul style="list-style-type: none"> • brain fog (8-9/10) – feel confused • body feels heavy/shaky (8/10) • debilitating fatigue (10/10) • start to feel nauseous • dizzy (7/10) • ringing in ears (6/10) • worsening headache • temperature hot/cold • More irritable, noise sensitive, overwhelmed • Strangers would notice you are struggling

Next Step – Identifying Rainbow Tasks

- Reflect on the things they need and want to do and consider their ability to complete them and how they make them feel
- Place the activity in the colour that matches what the task difficulty level.
- When putting tasks into the colour categories, think about time – eg. reading for 30 min might be an orange task but for 10 min a green task.
- Plan out their day using the colours – minimize or eliminate the amount of red & oranges tasks they do and increase the amount of blue and green tasks they have in their day.

Expanded the Stoplight Activity Menu to a Rainbow

Red	<ul style="list-style-type: none">• Groceries, heavier household chores, more intensive physical tasks (exercise, lifting, bending)• Longer, busier social events, computer or paperwork, reading > 30 min, travel/driving, louder environments, medical appointments, intense emotional experiences
Orange	<ul style="list-style-type: none">• Walking outdoors, standing yoga, moderate household chores, showering, > 1 errand• Paying bills, meal planning, watching TV, smaller social events
Yellow	<ul style="list-style-type: none">• Shorter walk, meal prep, light to moderate household chores, gentle yoga or tai chi, 1 short errand• Phone conversation, checking emails, hosting a short social visit, board game, cognitive app, scheduling your day/week
Green	<ul style="list-style-type: none">• Walking in your house, seated yoga or tai chi, light chores (seated meal prep, folding laundry, tidying), gentle strength exercises• Listening to audiobook or podcast, leisure task, short duration cognitive task (meal planning, scheduling)
Blue	<ul style="list-style-type: none">• Breathing, mindfulness, gentle stretching, listening to music, audiobook, podcast• Cuddling a pet, sitting outside, easy leisure task, colouring, snack/drink, cold therapy
Purple	<ul style="list-style-type: none">• Nap, lying horizontal, breathing, sitting quietly, drink/snack

Purple <i>(Shutdown)</i>	Blue <i>(Recharge)</i>	Green <i>(Rebuild)</i>	Yellow <i>(Stretch)</i>	Orange <i>(Stress)</i>	Red <i>(Flare)</i>

Based on
Patient
Feedback:

Changed the list to vertical

Tasks named by colour but kept the words from the symptom list

Using tracking to help make connections

Time	Activity	Rating	Symptom Tracker					Date:
7:00				Exertion:				
7:30				Yesterday	Light	Med	Heavy	
8:00				Tomorrow	Light	Med	Heavy	
8:30				Sleep				
9:00				Good	Med	Poor	___ Hrs	
9:30				Reflections				
10:00								
10:30								
11:00								
11:30								
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How to use the Rainbow Tracking Graph

- Each morning – consider if yesterday was light/moderate/heavy and what the plans are for tomorrow.
- Try to plan out a day that they can handle
- Write down activities & then rate what colour they are
- Every 30-60 min place a dot on the symptom tracker for the zone of your symptoms
- At the end of the day or the next morning try to reflect on what the graph shows to see if they notice patterns between activity and symptoms
- Start to build a daily schedule in ways that keep them in the target activity zone

Time	Activity	Rating	Symptom Tracker					Date:
7:00			<p>Shut Down (Deep Rest)</p> <p>Recharge (Back to baseline)</p> <p>Rebuild (Healing)</p> <p>Stretch (Growth)</p> <p>Stress (Pushing)</p> <p>Flare (Past the point of no return)</p>	Exertion:				
7:30	Wake up/Breakfast			Yesterday	Light	Med	Heavy	
8:00	Shower/Dressed/Blow dry hair			Tomorrow	Light	Med	Heavy	
8:30	Walk kids to school/home			Sleep				
9:00	Check email/vision & balance exs			Good	Med	Poor	___7_ Hrs	
9:30	Mediation/tea/stretching			Reflections				
	Clean kitchen/make			More symptomatic in the morning after dropping kids off than I expected, My afternoon nap really helps me bring my symptoms from the morning activities down, I don't have any blue tasks from when I pick up the kids until they go to bed. I need to find a way to build in some restorative blue tasks otherwise I have a hard time falling asleep.				
10:00	beds/laundry							
10:30	Reading/TV/make grocery list							
11:00	Sit outside/breathing/cuddle dog							
11:30	Lunch & dinner prep							
12:00	Eat lunch							
12:30	clean up kitchen							
13:00	Nap							
13:30	Nap							
14:00	Facetime Mom							
14:30	Restorative Yoga/Balance exercises							
15:00	Listen to audiobook							
15:30	Pick up kids from school							
16:00	Dinner prep							
16:30	Homework help							
17:00	finish dinner & eat							
17:30	clean up kitchen							
18:00	Walk to playground							
18:30	Sit & watch kids on playground							
19:00	Play board game							
19:30	Bedtime routine/Kids in bed							
20:00	Finish bedtime/Meditation							
20:30	Listen to audiobook							
21:00	Make lunches/Get ready for bed							
21:30	Sleep meditation/go to sleep							
22:00	Trouble falling asleep - headache							
22:30	Finally fell asleep							

Feedback from Patients:

Keep the colours in the symptom tracker

It is important to connect the dots as you go along in the day

Added the Exertion and Sleep tracker

The section for Reflections is helpful

Time		Schedule		Charity's Rainbow Activity List				
Today's 3 Things	1.	Deep Rest	Recharge	Healing	Stretch	Stress	Flare	
	2.	Sleep/Lay Nap	Sit Quietly Sit in Window	Sunlamp Stretch	Scheduling Computer (10 min.)	Appoint (20+)	Ments (30+)	
	3.							
7:00		Heat Pad	Heat Pad	Tai Chi	Iphone (10)	Bills (5)	(15)	
7:30		Autogenic Trn	Mindfulness	Garden		Wk(25+)	Wk(40+)	
8:00	Eat	Stroll <5	Stroll <10	Walk (15)	Walk (20)	Insurance		
8:30				Swim / Stat. Bike	Meal Plan <10	20	20+	
9:00		Hot Bath	Bath	Shower(fast) (<10)	Shower Long (<15)	w Hair		
9:30		Hot Tea or	Ravn Roast	Cool Drink	Bake or	Grocery	Shopping	
10:00	Eat	Snack (Ready to eat)	Snack (Ready to eat)	Snack (Ready to eat)	Meal Prep In Stages:	-Full Meal prep all at once	-Full Meal prep all at once	
10:30				Simple Meal (re-heat & dish out)	-Chop Veg			
11:00					-Measure Ingredients			
11:30	Prep Lunches				-Monitor stove/oven			
12:00	Eat	Breathe	Fresh Air			rest b/f eating	just b/f eating	
12:30			Animals					
1:00		Eat Alone	Eat Alone	Eat with Paul	w 2 ppl	w group	Eat Out	
1:30		Sit Quiet	Sit Outside	Convo <10	<20	30+	45+	
2:00		Shade	Sun	Camera w glasses	Camera w/o glasses	(15+min)	(20+min)	
2:30	Early Meal Prep	Home	Home	Outing (<20) in Neighbourhood	<30 beyond Neighborhood	<45 BN req car	60+ BN Spontaneous	
3:00	Eat	Alone	Quiet	Physio 8-5-8-5-8	Cardio (<10)	(>10)	Outing	
3:30							Past 7:30	
4:00		Recliner	Music	BrainEx's 5-5-5				
4:30	Meal Prep	Hammock	Simple solo Game	Kobo Rd <15	Journal & Bble	>15	Church	
5:00	Table Set	Lay on Swing	Audiobook	Aud Msg List <5	L 6+ / Rec >5	L10R>15	Show/	
5:30	Eat	Lay on outdoor chair	(simple/low emot)	Podcast (lgt ent)	->Learning		Concert	
6:00			Comedian	Youtube (lgt ent)	-> Learning			
6:30		Lay in a different room	(quiet/short)	TV (<20)	(20)	(45)	(60+)	
7:00			Colour	-familiar/calm/quiet/hallmark/seen before	-new	-movie	-flashy	
7:30	Dishes	*change environment and body	sudoku		-sitcom/docu	-news	-accents	
8:00			Word		- low intensity	-h. int.	-subtlls	
8:30			scramble	Light Chores	H. Chores	Project	Shopping	
9:00	Eat	positions for health (phys & mental over time)		-tidy/putter	-bathroom (1 rm/prt)	(1+)		
9:30				-sweep	-vacuum (1 rm/prt)	(1+)		
10:00				-fold laundry	-dust (1 rm/prt)			
10:30				-L: wash/dry (1 ld)	(2 loads)	(2+ lds)	+ Fulls	
Bliss, Leisure & Spice of Life List:		Visualization Memories Dreams	Knit Guitar Sing Snorkel	Dance Piano Game Garden	Sew Paint Bake Visual Game Dehydrt	Beach Photogr	WdBurn Edit pics	

The Rainbow Zones – A Refined Definition

Flare (*point of no return*)

Very symptomatic, difficult to continue any tasks

Stress (*pushing*)

Symptoms more noticeable and start to interfere with performance, can still continue but there is a cost

Stretch (*growth*)

Some symptoms starting but can still perform tasks and recover in a reasonable time period

Rebuild (*healing*)

Feeling good, things are easy to do without too much effort, symptoms are minimal or brief and easy to settle

Recharge (*back to baseline*)

Recovering from doing too much, may have symptoms, fatigued, tasks that are normally easy are harder than usual

Shut Down (*deep rest*)

Exhausted, unable to do much, retreating from people and activities

What started to happen

- Patients started to notice there might a predictable progression in their symptoms
- There could be early warning signs they had been missing before so they were better able to switch tasks to manage their symptoms.
- They started to identify what tasks made them feel better
- They made their own connections and insights without their therapy team needing to point it out to them
- They felt more in control of symptom management and were more motivated to continue strategies that were helpful.

Progressing to the next
level...



Flare (*point of no return*)

Stress (*pushing*)

Stretch (*growth*)

Rebuild (*healing*)

Recharge (*back to baseline*)

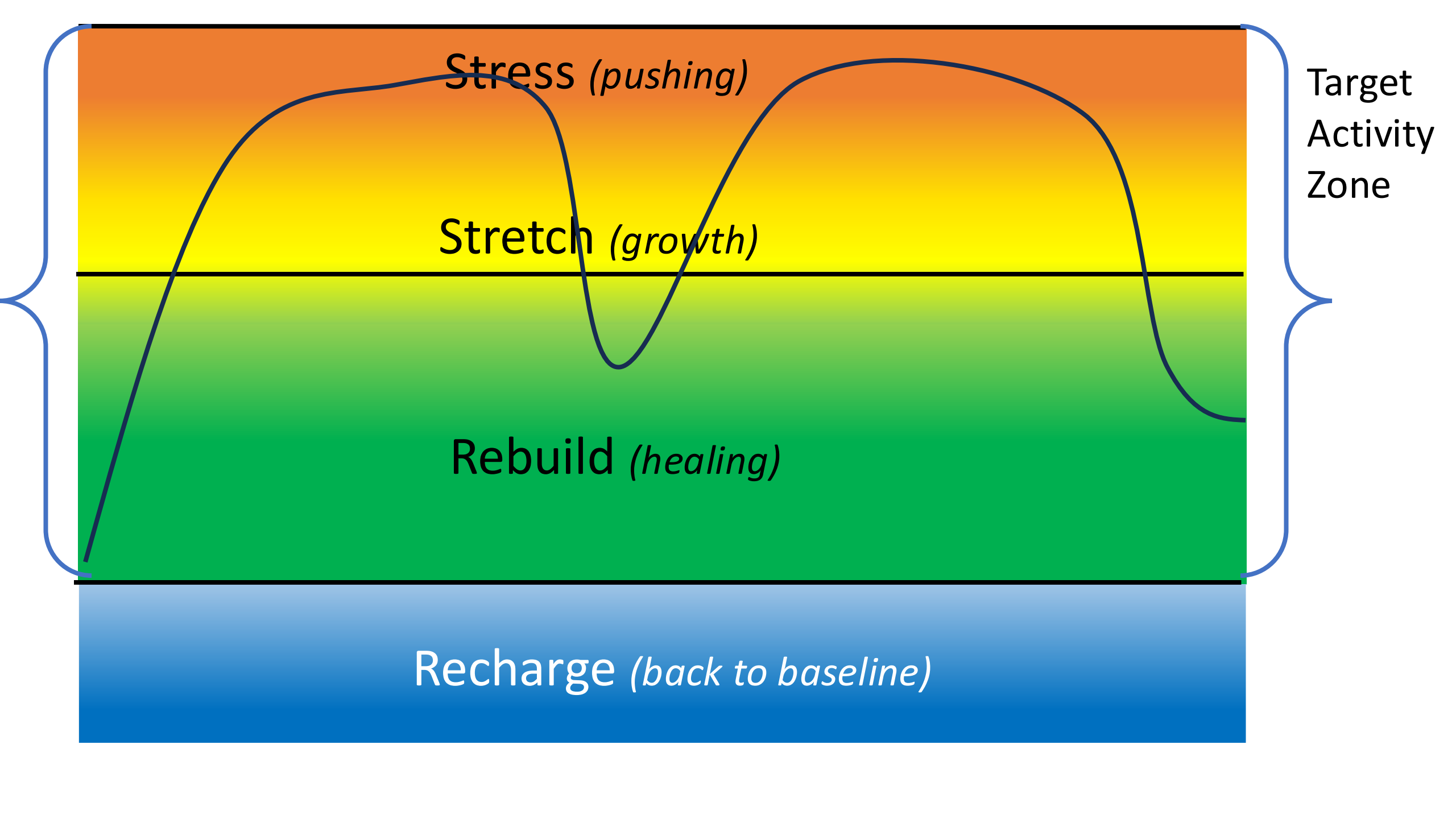
Shut Down (*deep rest*)

Target
Activity
Zone

Time

Ultimate goal...





Rethinking **Blue** and **Purple** tasks

- Try to notice if you have an early symptom that is signaling you to change tasks or try to settle your nervous system
- How can you use restorative blue tasks to ‘power up’?
- Don’t do reluctant or resentful rest!



More patient wisdom ...

- Permission for the purple zone was important (when you're someone inclined to blow your limits... you need this to reset your foundation).
- Valuing what is accomplished in that zone, for the base of healing, even more important.
- And the ***permission***, led to the ***valuing*** which led to actually being able to *do* the purple zone ***well***.
- Being in the zone isn't what helps... ***relaxing into it*** does. It's like you say... it's not what you do but how you do it.

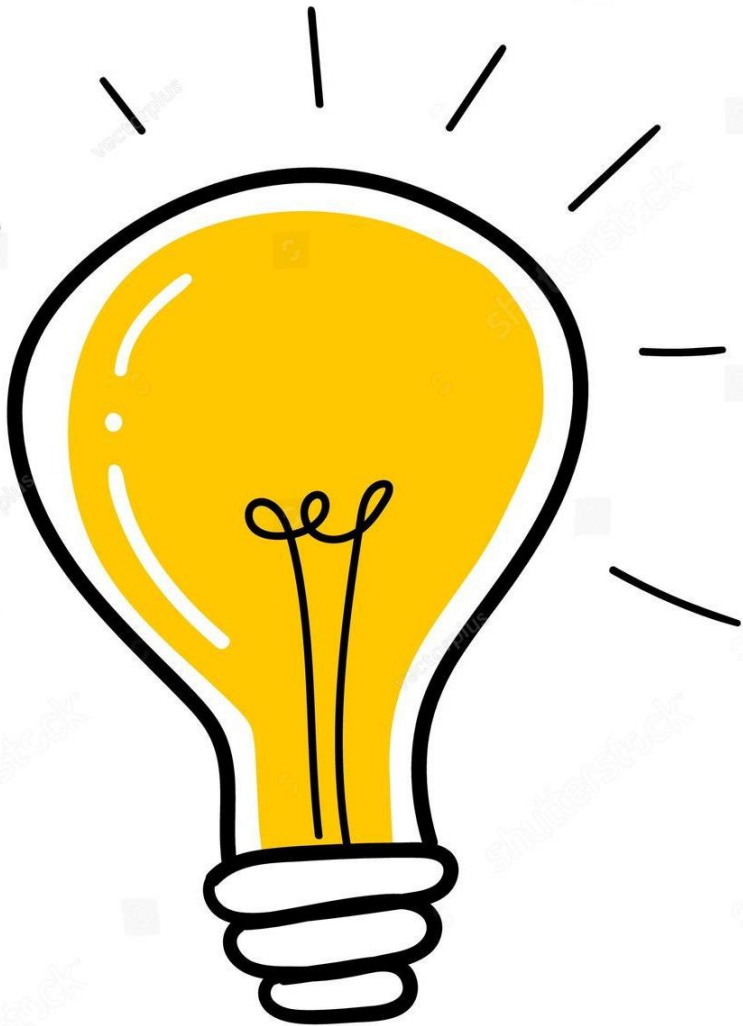
- I can't tell you how much time I've spent over my concussion recovery years doing purple zone activities... sitting in a chair, staring at the wall, lying in bed, having a cup of tea, sitting alone on a park bench... ***but wasn't really giving myself over to the rest.*** Stressing over being there/over the limitations, holding the tension in my body, feeling guilty that I wasn't doing other things with/for other people/myself... sure it took me out of the expenditures of the other zones... but not until I started to learn and practice relaxing into it, easing into it like a hot bath and letting it ***soothe me, *enjoying**** it - could I effectively use that time and those activities to really give myself a ***solid*** base for deeper and more lasting healing.
- Learning to relax my face, breathe, soften my body and give myself permission to ****enjoy**** the quiet moments has been pivotal.

- Now, I can't believe I wasted all that time resisting the feeling, the enjoyment offered by the things I was forced into... (the things that stressed and busy working-long-hard-hours people long for)... out of guilt that I wasn't one of them anymore.
- So, I've painted the purple Shutdown (Deep Rest) zone in the most positive light in my mind and practice. It is **not** being locked out of the activities I long to be engaging in, it is the **key** that opens the door to the path leading to them.



Considerations for use with your patients...

- Who needs to tune into their body and who needs to focus less on symptoms?
- Filling in the sheets, graphing and reflecting takes time and cognitive abilities – not every patient can manage this
- This is not designed for long term use – it is a way for patients to gain insights and build good habits
- They can always come back to it if they have a set back
- It can be a tool to communicate with family/friends
- It can give patients confidence to experiment with activity and test their limits



My insights...



- Talk to your patients about your ideas and solicit feedback
- Talk to your patients about your other patient's ideas & insights
- Language and labeling is really important
- Visuals matter and graphing makes it easier to see patterns
- How we talk about restful activities is critical
- We can always do better
- I think this is a system that gives patients tools so they can develop their own insights and connections

A special **thank you** to all of the patients who helped in the development and took their time and energy to send their feedback and videos

*Charity, Jenn, Sarah,
Stephanie, Diane, Chris,
Lorie..and more*

*And to my ABI & Covid
Rehab Teams*

