

Minding your P's!

The Importance of Pacing and Planning Activities after ABI

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Acquired Brain Injury Outpatient Team

Parkwood Institute, London



Our Team:



Left brain

I am the left brain.
I am a scientist. A mathematician.
I love the familiar. I categorize. I am accurate. Linear.
Analytical. Strategic. I am practical.
Always in control. A master of words and language.
Realistic. I calculate equations and play with numbers.
I am order. I am logic.
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I am movement. Vivid colors.
I am the urge to paint on an empty canvas.
I am boundless Imagination. Art. Poetry. I sense. I feel.
I am everything I wanted to be.



Mercedes-Benz
The best or nothing.

#1 Symptoms:



Fatigue



Pain (headaches)



Pain (Pressure)

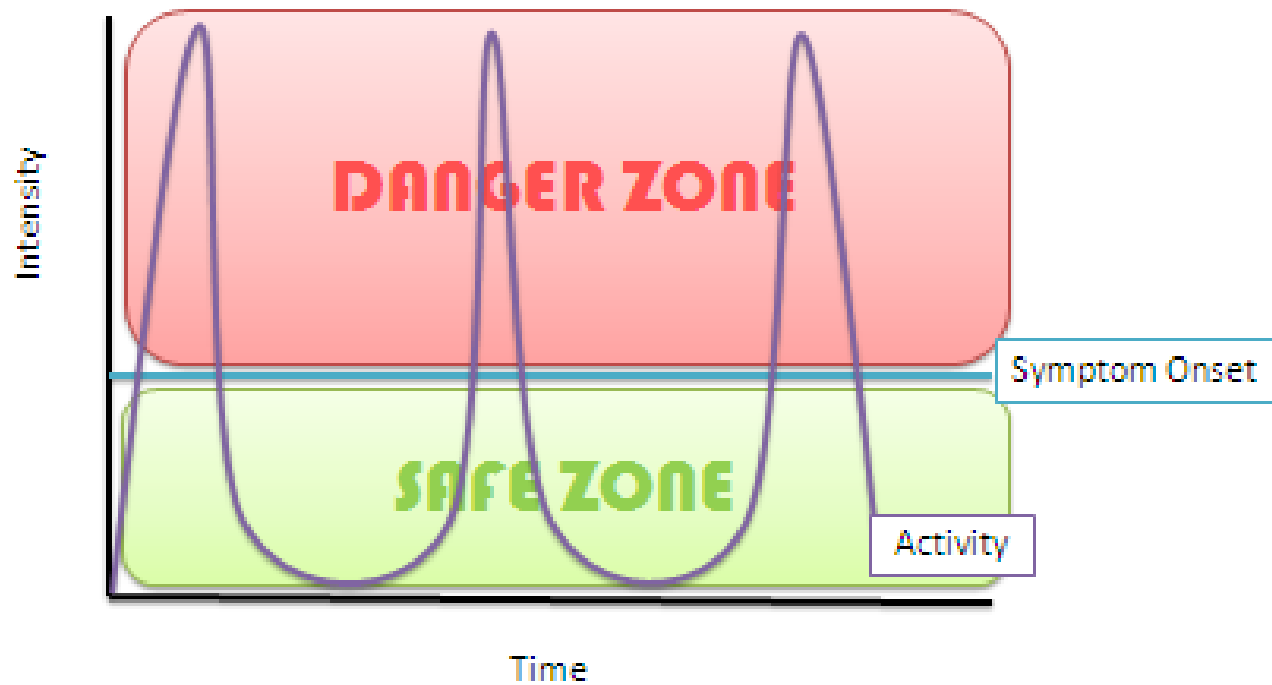
- Comes from multiple sources (i.e. overstimulation, light sensitivity, neck pain, tension, stress)
- Can have multiple triggers
- Is a huge motivating factor for getting well
- Clouds all activities

Fatigue

- Fatigue impacts everything
 - Cognitive VS physical fatigue
 - Many factors contribute to fatigue
 - Fluctuates over the day/week

Typical...

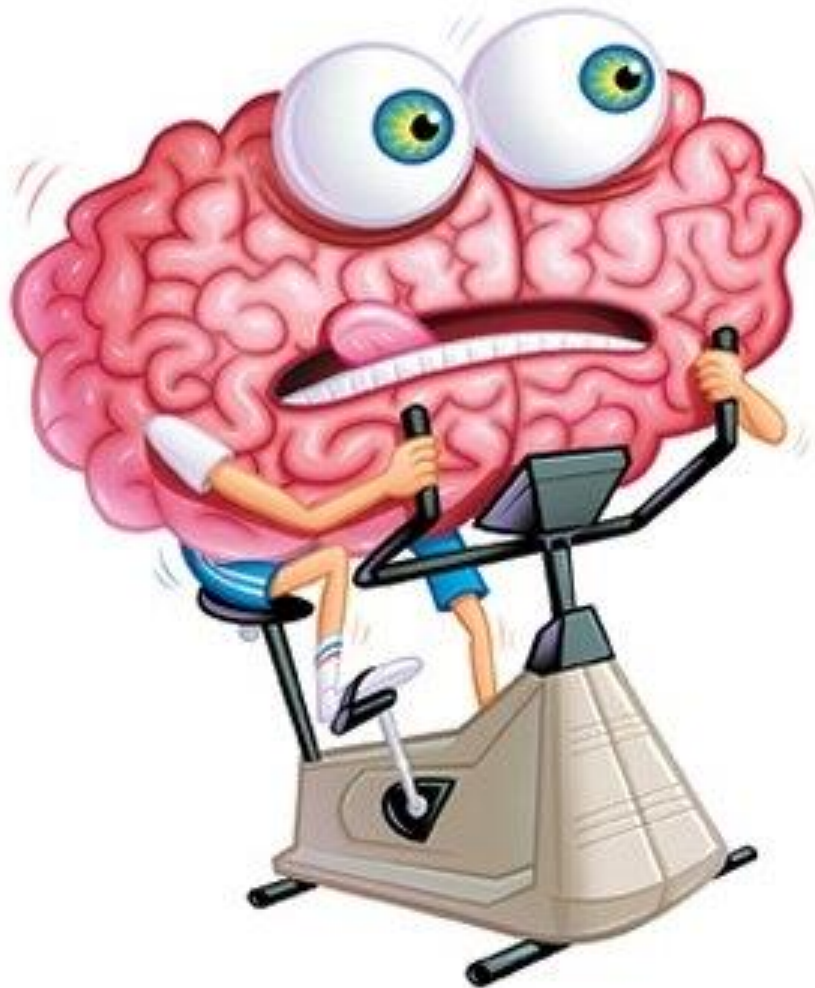
Current Activity Pattern



Common mistakes:

I am not
trying hard
enough

I need to
push through
these
symptoms



People will
think I'm lazy
(or I feel guilty)

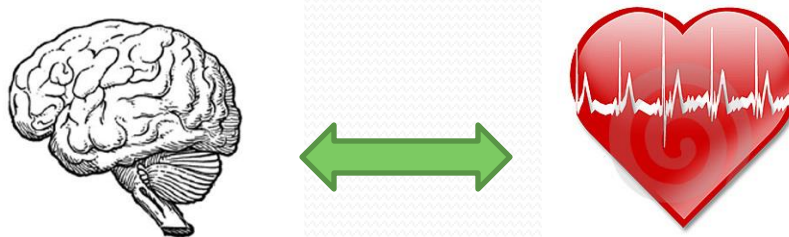
But I am
already not
doing
anything...

We Learned...

Concussion can impact heart rate variability (HRV)

Rehab is completing a sub-symptomatic exercise routine (exercise levels **BELOW** the level of symptoms). If symptoms occur, rest must happen immediately.

Philosophies of 'no pain, no gain' and 'push through' do not work with recovery of brain injury.

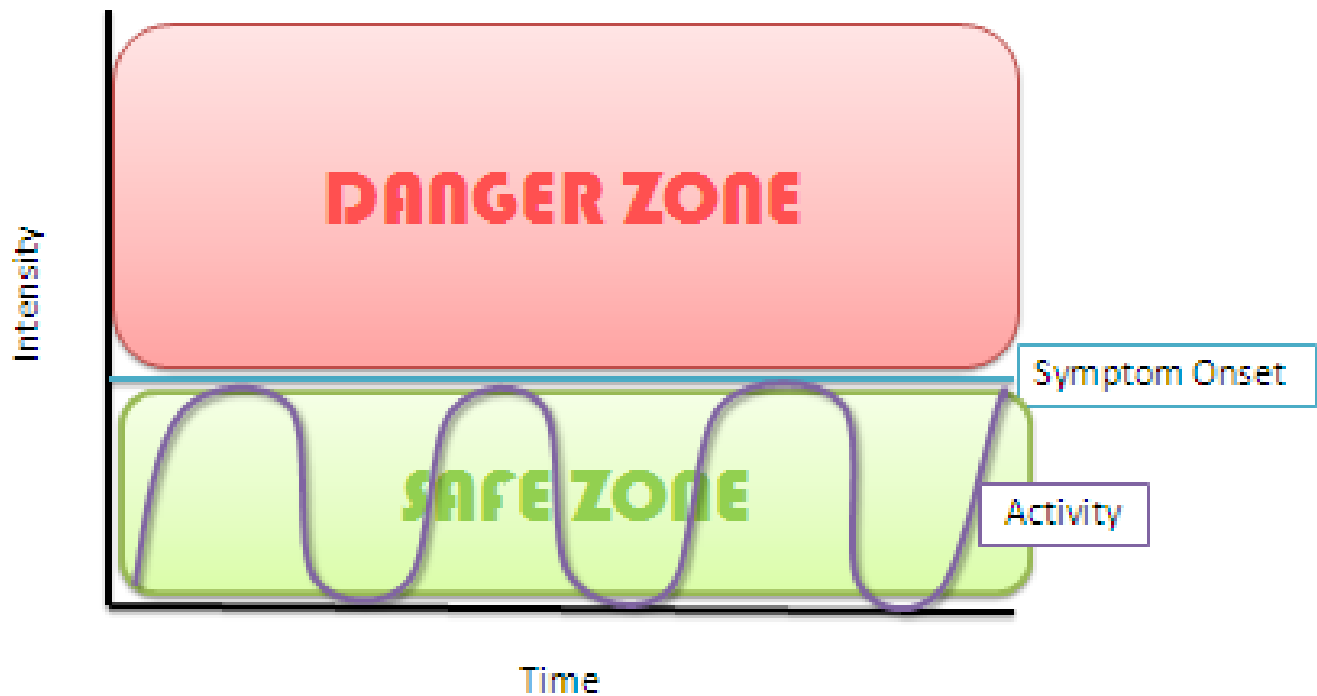


Leddy JJ, Sandhu H, Sodhi V, Baker JG, Willer B. Rehabilitation of Concussion and Postconcussion Syndrome. *Sports Health*. 2012; 4(2): 147-154.

Leddy JJ, Kozlowski K, Donnelly JP, Pendergast DR, Epstein LH, Willer B. A Preliminary Study of Subsymptom Threshold Exercise Training for Refractory Post-Concussion Syndrome. *Clinical Journal of Sports Medicine*. 2010; 20: 21-27.

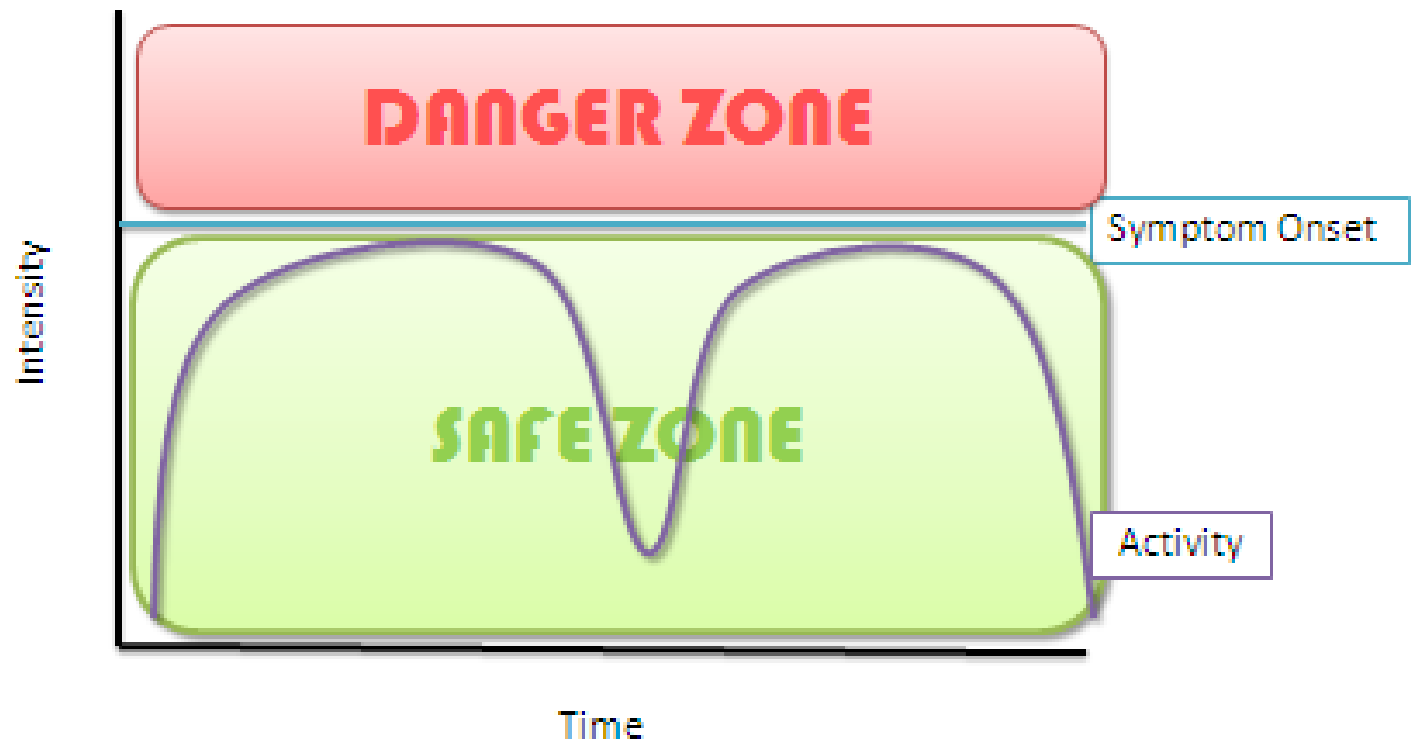
Want...

Target Activity Pattern



Goal...

Long Term Activity Goal



But, you have to do something...

- This does not mean avoid all activity; it means plan out activities so you are not doing too much
- After a concussion, it's important to rest; but **now we need to get out of rest**
- Doing nothing is not good. Total REST will not make patients better at this stage of recovery
- A lot of it is trial and error (not an exact science)

How do you get out of rest?

- Graduated return to cognitive and physical activity
- Therapists need to educate about how and when to introduce activity and monitor symptoms
- Otherwise – depression and non-compliance
- **Remember!** They are brain injured therefore their judgment and decision making is impaired

Goldilocks Philosophy of Return to Activity

- Not too much
- Not too little
- JUST RIGHT AMOUNT (different for everyone)



Occupational Therapy & Energy Conservation (Pacing)



- Trained (?) in energy conservation techniques.
- How to do this with the ABI population (especially mTBI)?
- A lot of energy conservation techniques require a huge 'lifestyle' change - our type A personality PCS patients struggle with this



Energy Conservation

- Think of your brain like a car
- And your energy level as a gas tank



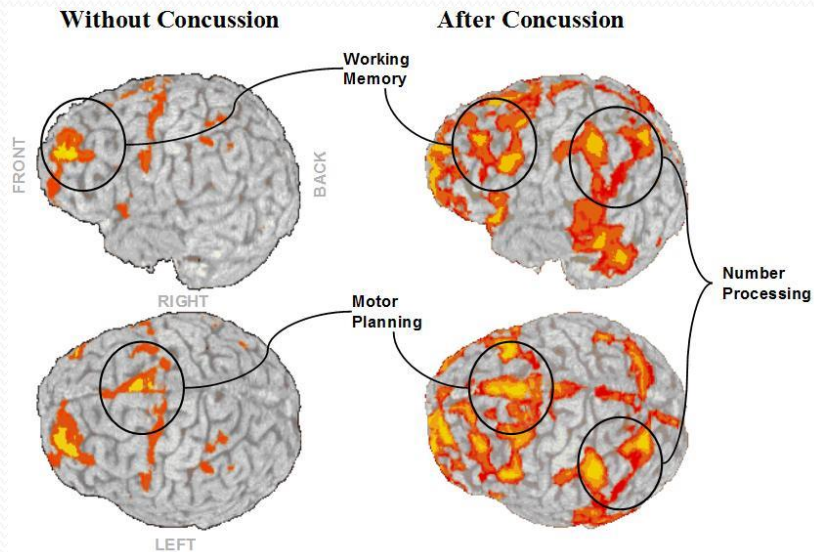
Pre-Injury



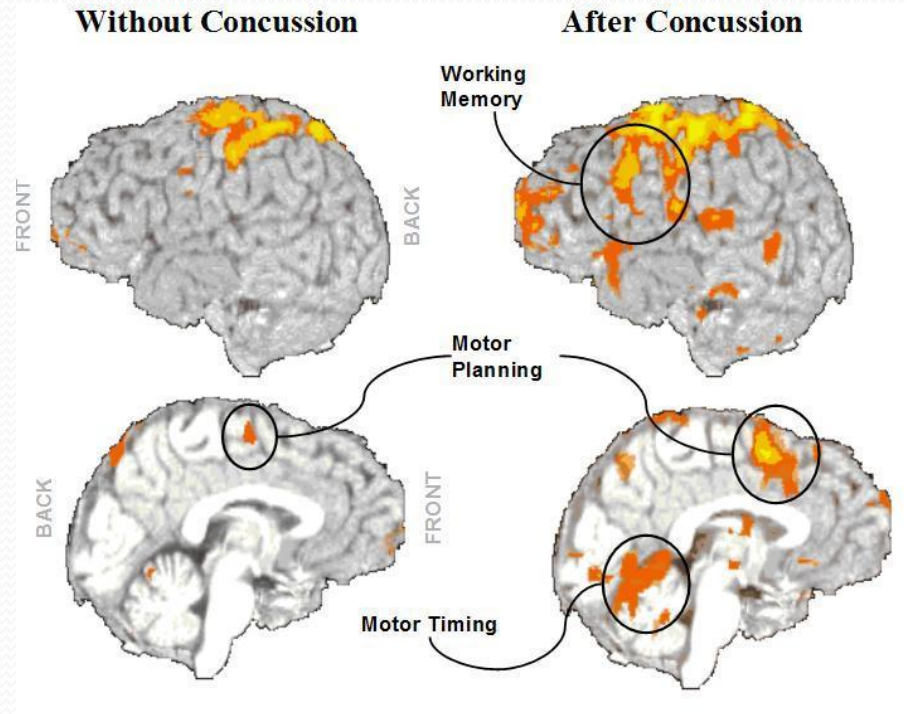
Post-Injury



Tasks are more difficult to do...



Subtraction Exercise



Right Finger Sequencing

Biggest “Gas Guzzlers”



- Talking
 - Phone, crowded environment, while others are talking
- Visually stimulating environments/activities
 - Evil triad: bright, colourful, and moving/busy (everything that you find at wal-mart!)
 - Visually stimulating tasks such as TV, computer use, reading
- Driving
 - Even as a passenger, when raining/snowing, on crowded streets
- Any activity that requires ‘filtering’
 - Any noise in the background will be distracting, and it takes a lot of energy to put up a filter
- Cognitive Tasks (increased attention and processing):
 - Reading, Sudoku/cross words, completing insurance forms, planning events
- Physical Activity
 - You are not efficient with physical activity; so simple tasks in the past may be exhausting now
 - Need to make sure your heart rate doesn’t go too high, or could bring on symptoms (HR monitor?)

Limits

- Need to limit tasks that take a lot of energy or increase symptoms
- Need to PACE activities
- Rest is still required at times



What is Pacing?

- Not doing too many activities in one day or at one period of time
- Building REST breaks into the day
 - 15 minutes per hour
 - Pomodoro technique
- Alternating types of activities
 - Thinking (banking) VS Doing (dishes)
- Reducing activities that cause symptoms (i.e. TV, computer, busy environments, etc)
- Encouraging routine, good sleep patterns, exercise and nutrition



What is (brain)REST?



KEEP
CALM
AND
REST YOUR
BRAIN

- Brain rest does **not** include reading, watching TV or using the computer (or cell phones)
- Puttering around the house is also not very restful
- Talking can be very draining, so even conversation can take energy (and cause symptoms)
- Rest COULD mean switching tasks (i.e. from a physical task to a cognitive task)
- Rest could also mean sleeping or lying down



Recommendations for Rest...

- Tasks that do NOT exacerbate symptoms

Suggestions:

- Switch tasks (usually away from a screen or cognitive task)
- Listen to something vs. watching something (music/audiobooks)
- Complete a leisure activity that is relaxing
- Sleep/nap if necessary (NOT THE WHOLE DAY)



Restful Activities

- Listening to an audiobook
- Listening to quiet music
- Meditation or relaxation activities
- Listening to radio/podcasts
- Gentle mild yoga*
- Anything leisure that 'relaxes' (i.e. knitting**, zentangle); but ensure use of a timer
- Always good to keep in mind: turn off the phone/cell phone (do not disturb mode) if trying to nap



Moser et al 2014 - Prescribed rest in Teens

(Brain Injury: early online DOI 10.3109/02699052.2014.964771)

NOT ALLOWED

- Attending school
- Taking tests or notes
- Doing homework
- Doing general household chores
- Traveling
- Driving
- Trips outside the home
- Social visits in the home
- Watching TV, video games, computer use
- Phone use
- Reading
- Playing a musical instrument
- Drawing/artwork
- Aerobic exercise & lifting weights

ALLOWED

- Listening to audiobooks or relaxing music
- Listening to low volume non-stressful TV
- Folding laundry
- Setting the table
- Taking a slow walk outdoors in the yard
- Eating lunch outside at home
- Meditating
- Sleeping
- Listening to an older family member tell stories about the family history
- Taking a relaxing bath
- Brushing the pet dog

#1 way to PACE and include REST...

USE A TIMER!



Timer

- ‘nag’ feature can be helpful, otherwise timers are shut off, and tasks continue, with the timer forgotten
- Set the timer for a sub-symptomatic amount of time (i.e. if symptoms come on after 30 minutes on the computer, set timer for 25 minutes)
- Allows for getting into a difficult task (“I only need to do this for 10 minutes, phew!”), and is also the way out of a task if patients lose track of time

Timer

- If a task is a big guzzler, set a timer and stop. Sometimes changing activity or resting can help to prevent hitting 'empty'



Strategies

- Make tasks that are big energy guzzlers not so difficult
 - Remove distractors so less filtering is required
 - Adjust screens to lower levels of brightness
 - Prepare before going to a busy store (i.e. use a list)
 - Use physical aids to help if necessary (i.e. sunglasses/hat in bright store, use a cart)
 - Only stay for a short amount of time vs. hours on end



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You cannot pace without also planning... (need a planner)

- Daily Planners are highly encouraged
 - Preferably able to see the entire week, and enter in information for months ahead
 - Tablet and Smartphone are okay too
 - Use a pencil, because changes will need to be made
 - Bring it with you! You need to refer to this multiple times in a day



November Novembre 14 - 16

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19	20	21	22	23	24
25	26	27	28	29	30
31					

17 - 20 November Novembre

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19	20	21	22	23	24
25	26	27	28	29	30
31					

20 Sunday/Dimanche 32441

Calendars

Day

Week

Month

Year

List

Q Search

April - 2013

all-day	21 Sunday	22 Monday	23 Tuesday	24 Wednesday	25 Thursday	26 Friday	27 Saturday
8 AM						OT At parkwood	
9 AM			Homework	Grocery shopping			
10 AM	Rest break	Rest break	Rest break	Rest break	Rest break	Rest break	Rest break
11 AM							
Noon	Lunch	Lunch	Lunch	Lunch	Lunch	Lunch	Lunch
1 PM	Cards at mom's house				Assignment #3		Rest
2 PM			Play guitar				Baby shower
3 PM							
4 PM		Class Scc 2032					
5 PM	Supper	Supper	Supper	Supper	Supper	Supper	Supper
6 PM							

Today

Apr 7 - 13

Apr 14 - 20

Apr 21 - 27

Apr 28 - 4

May 5 - 11

May 12 - 18

May 19 - 25

May 26 - 1

Jun 2 - 8

Jun 9 - 15

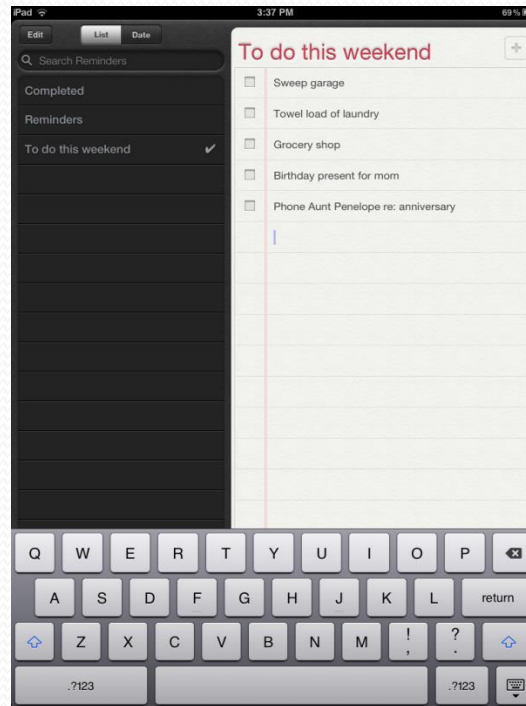


Activities:

- There are many activities that we do
 - DAILY (bathing, dressing, eating, work, get the mail)
 - WEEKLY (laundry, garbage day, dusting)
 - MONTHLY (pay taxes, give meds to dog, etc)
 - INFREQUENTLY (visit the dentist, wash the windows)
- It's important to prioritize these activities so that the most important stuff gets done first

todos		
today	thisweek	thisweekend

thescorecard	
to do	to delegate



Take your 'to do' items and put them into the schedule...

Monday		Tuesday		Wednesday		Thursday		Friday	
Time	Task	Time	Task	Time	Task	Time	Task	Time	Task
6:00 AM		6:00 AM		6:00 AM		6:00 AM		6:00 AM	
6:30 AM		6:30 AM		6:30 AM		6:30 AM		6:30 AM	
7:00 AM		7:00 AM		7:00 AM		7:00 AM		7:00 AM	
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todos

today

thisweek

thisweekend

the scorecard

to do

to delegate

Sometimes...

- You're going to find that you have too many activities in one day...
- You may see a pattern that you can group some activities together save on driving/trips out of the house
- The goal is to manage symptoms by managing activities; doing too much may bring on symptoms again
- May need to re-prioritize your activities...

Becky's Rules for Agenda Use:

- Check your agenda each morning to see what you have to do today
- Check your agenda often throughout the day
- Record activities that you do in your agenda (or symptoms that occur)
- Add new appointments as they come up
- Review yesterday's tasks and transfer any unfinished business if necessary
- Free time is okay, but write something in that spot to log what you did

The beauties of an agenda...

- You know what day it is...
- You know what you have planned for the day
- You can schedule in needed rest breaks/naps so that your brain can rest and recharge
- You can keep track of what you did that may have triggered symptoms (it's a journal or log)
- You can stay focused on the tasks that need to get completed (if you get distracted)

But I'm really not doing ANYTHING

- A lot of our patients resist the agendas/planners for various reasons:
 - I don't do anything all day b/c of my symptoms (stuck in REST), so what am I going to write in it?
 - Those things are not 'cool' and I don't want people thinking I'm disabled (I try hard to appear 'normal')
 - I don't carry a purse or a bag with me, so where am I going to put it?
 - I can keep it all in my head
- MOST patients who embrace the use of a planner/agenda begin to have less symptoms sooner

Resistance is Futile...

(consistent team messaging)





Even after all of this discussion, it
seems easy enough to plan a day
and limit activities...

But it's harder than it looks...

(especially if you're not used to doing it)



A Planning and Pacing Story...

Once upon a time...

My thoughts...



The Concept...



The Idea:
An 'Activity Diet'

The Principle:

- Every activity has a points value based on
 - How difficult a task is
 - How much it takes out of you
 - How many symptoms you get
- You get a maximum number of points per day



Why it Works:

- Provides a simple, structured way of tracking activities
- Provides a framework for limiting tasks
- Provides concrete limits to activity, rather than 'guessing'

How it works:

- Patients are given 15-20 points per day.
- Activities are given a point value, based on the level of difficulty
 - Ranging from easy tasks (1.0pts) to more difficult (5.0pts)
 - Some tasks are given a time limit and points are calculated based on time (i.e. computer use)
- Patients are to plan the day to ensure they have enough points to do the tasks they want to do within their maximum

The Change:

- As you limit the tasks, symptoms *should* improve
- Like any food diet, this is not a temporary thing, but a lifestyle change (be prepared!)
- Once you start to recover, we can increase your total points in a day, and activities will be worth less points (kind of like the maintenance portion of a diet)

No cheating...

- Like any diet, there's the temptation to 'cheat' or sneak 'junk food'... what happens if we do this?
- If you cheat yourself of points (or give a task a value that's not accurate), you will increase your symptoms
- Questioning the use of 'negative' points if a patient were to nap/sleep in the day to recharge

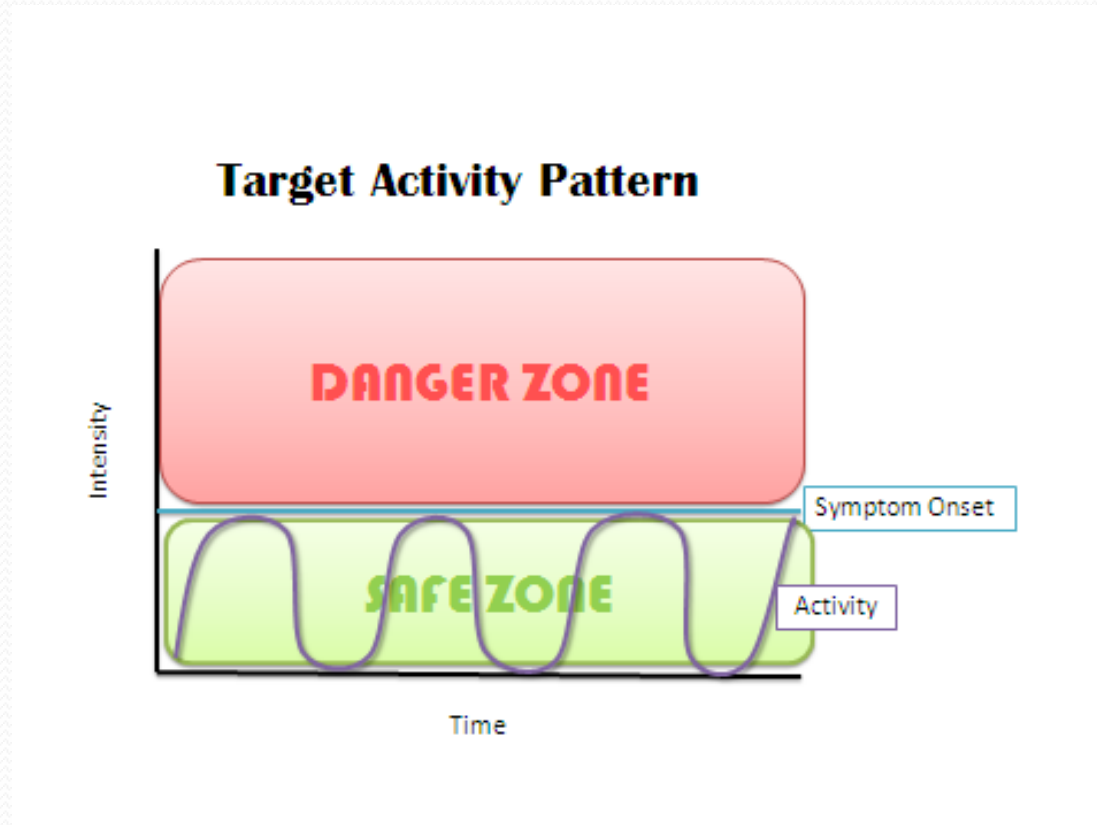
Typical point values:

Activity	Point Value	Activity	Point Value
ADLs (bathing, dressing, grooming)	0.5-2	TV use	2pts per hour
Meal Preparation	2-3 (depending on complexity)	Computer use	2pts per hour
Dishes	1-2	Reading	2pts per 1/2-1hour
Grocery shopping	5	Talking on the phone	2pts per 15 minutes
Hockey game	5	Eating out at a restaurant (2 people)	5 (+1 for each additional person)
Working	1-2pts per hour	Attending an appointment	3-5
Childcare	1-2pts per hour	Attending Group sessions	3-5

How are you getting these #'s?

- Complexity of activity (does it require a lot of thinking?)
- Stimulation (are you going to be bombarded with auditory and visual stimulation)
- The amount of talking involved
- The amount of 'filtering' involved
- Visual processing (and use of screens)
- Experience of what tasks are difficult for my patients

Use the Pacing Points to get here...



A correct tally:

- Every task needs to be accounted for (each task has a point value)
- Yes, even watching TV takes points
- Depending where you are in recovery, a nap could give negative points (i.e. -2), but you need to be cautious with this.
- It's better to plan AHEAD, rather than log after

How to use the Pacing Points:

- Start tracking the tasks you are doing in your day, and your symptoms
- Give a points value to your tasks
- Tally them up, and see if high points days are the same as high symptom days
- Start to plan your days based on your activities that are priorities.

There are other ways...

- Pacing Points are not the only way to manage activities, some use dollar amounts or 'tokens' instead
- Using a points system is not the only way either
- If you find that you can't stick to it, enlist family members to help you



Who should try using it?

1. People who are doing **too much** and having trouble managing their symptoms
2. People who are **not doing enough** and are afraid of having a setback who need to gradually reintroduce activity
3. People who have **delayed onset** of symptoms and have trouble deciding how much activity is too much

Start the journey with pacing and planning...



Finish with pacing and planning...

