Pacing & Planning Strategies to help after Acquired Brain Injury/Concussion

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What is an acquired brain injury, and how is it caused?

**Acquired Brain Injury**

- **Non-Traumatic Brain Injury**
  1. ↓ oxygen (anoxia/MI)
  2. Infections
  3. Strokes
  4. Tumours
  5. Metabolic Disorders
  6. Overdose

- **Traumatic Brain Injury**
  1. Assaults
  2. Falls
  3. Accidents
  4. Abuse
  5. Surgery

**Open Brain Injury**

- 1. Assaults
- 2. Falls
- 3. Accidents
- 4. Abuse
- 5. Surgery

**Closed Brain Injury**

- 1. Assaults
- 2. Falls
- 3. Accidents
- 4. Abuse
- 5. Concussions
What kind of difficulties do people have following brain injuries?

Auditory processing disorders
Emotional changes
Cognitive difficulties
Physical difficulties

“Isn’t you back to work yet?”

“You can’t remember ANYTHING!”

“He’s just not the same person”

“Headache”

“She’s always so ANGRY”

“Dizziness”

“He can’t come to the dinner AGAIN, says he’s too tired”

“Fatigue”

“Oh, she gets really car sick now”
Simple tasks are more challenging...

Subtraction Exercise

Right Finger Sequencing

http://www.ccs.fau.edu/section_links/HBBLv2/Research/MTBI.html
And you look ‘normal’

No one can see this...

What they ‘see’ is this...

You want them to know this...
Most Frequent Symptoms Reported:

Fatigue

Pain (headaches)
Fatigue

- Can have multiple triggers
- Dependent on medication, hormone levels, sleep routine, weather, mood, activity level and pre-injury energy levels
- Impacts all activities
- Cognitive vs. Physical fatigue are different
- Fluctuates over days/weeks/months
Reported to be ‘different than a usual headache’

Feels like high pressure inside the head

Can have multiple triggers:

- Light sensitivities and screen use
- Over stimulation (noise, vision)
- Neck pain/issues
- Jaw/TMJ pain/clenching teeth
- Too many activities without adequate rest breaks
- Tension/stress
Current Activity Pattern

- Significant Symptoms
- Mild-Moderate Symptoms
- Symptom Free

Developed by Parkwood Hospital
Outpatient ABI Team
Common thoughts:

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...
The **RED** zone (when you don’t rest)
Persistent Symptom Target Activity Pattern

Developed by Parkwood Hospital Outpatient ABI Team
The **GREEN** zone (when you rest...)

TIP: Think of REST as ‘ACTIVE THERAPY’, not ‘PASSIVE LAZINESS’
Long Term Activity Goal

- Significant Symptoms
- Mild-Moderate Symptoms
- Symptom Free

Intensity

Time

Symptom Onset
Activity

Developed by Parkwood Hospital
Outpatient ABI Team
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/Cognitive (banking) VS Doing/Physical (dishes)
- Reducing activities that cause symptoms (i.e. TV, computer, busy environments, etc)
- Encouraging routine, good sleep patterns, exercise and nutrition
This is NOT Pacing...

- Pacing requires a huge lifestyle change; many of our ‘type A’ personality patients struggle with limiting tasks and setting limits.
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 you out of rest.
- Doing nothing is not good either...
- A lot of it is trial and error, what you can and cannot do...
The right amount of challenge

Modelled after Vygotsky’s theory of development

All the things you used to be able to do

What you can do now

Zone of therapeutic benefit
Longer term goal

Increased ability to successfully return to activities
Goldilocks Philosophy of Activity

- Not too much
- Not too little
- JUST RIGHT
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/podcast)
- Gentle mild yoga, light walking/exercise
- Meditation/mindfulness relaxation
- Leisure activities that are not stressful (i.e. knitting, zentangle, hobbies/art)
- Sleep/nap if necessary (NOT THE WHOLE DAY)
Limited Gas in the Tank

- There is only so much usable energy per day (no ‘reserves’)
- Tasks are harder than before, so more energy is used per task
Biggest “Gas Guzzler” Tasks:

- Talking, especially in a crowded/busy environment with background noise
- Activities in a high stimulation environment (i.e. grocery stores, outdoor events, malls, school) or with high visual stimulation (movies/tv)
- Driving activities—requires a high amount of focus and multi-tasking
- Cognitive activities, especially high stakes
#1 way to pace...

USE A TIMER!
Timer

- Use a timer for those tasks that are big energy consumers (gas guzzlers)
- A ‘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 a starting point. “I will do this task for 10 minutes and see how I feel/how much I get done.” It will enable starting a difficult (long) task and doing smaller portions.
Conserve the Gas!

- Make tasks that are big energy guzzlers not so difficult
  - Remove distractors so less filtering is required (or use artificial filters for noise and visual stimulation)
  - 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
  - Break tasks into smaller chunks to allow for shorter durations of activity at one time
Daily Planner

- Preferably able to see the entire week, and enter in information for the whole year
- Tablet and Smartphone is okay too
- Use a pencil, because you will need to change things a little bit
- Bring it with you! You need to refer to this multiple times in a day
# Weekly Schedule

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April - 2013

21 Sunday
22 Monday
23 Tuesday
24 Wednesday
25 Thursday
26 Friday
27 Saturday

6 AM
9 AM
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

1 PM
Cards at mom's house
Play guitar
Assignment #3
Rest

2 PM

3 PM

Class
Sce 2032

4 PM

5 PM
Supper
Supper
Supper
Supper
Supper
Supper
Supper

6 PM

Today
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 (but this is not a way to get out of doing housework!)
To Do Items:

todos

- today
- this week
- this weekend

the scorecard

- to do
- to delegate

To do this weekend
- Sweep garage
- Towel load of laundry
- Grocery shop
- Birthday present for mom
- Phone Aunt Penelope re: anniversary
Take your ‘to do’ items and put them into the schedule...
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
- You may need to say “NO” at times
- You may need to re-prioritize your activities...
Rules for Agenda Use:

- Write down ALL activities you will do in the day (not just appointments)
- 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 heal and reduce symptom onset
- 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
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, 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 fewer symptoms sooner
Resistance is Futile...
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…
The Idea:
An ‘Activity Diet’
Every activity has a points value based on
  ◦ How difficult a task is
  ◦ How many symptoms it causes
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’
- Allows patients to say ‘no’ and stop an activity without any guilt
How it works:

- Patients are given 15–20 points per day.
- Activities are given a point value, based on the level of difficulty and symptom provocation.
- Patients are to plan the day to ensure they have enough points to do the tasks they want to do within their maximum.
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
- Experience of what tasks are difficult for my patients
The Algorithm:

How difficult is the task? (out of 10) = \( X \)

How symptom provoking is the task? (out of 10) = \( Y \)

\[
X + Y = Z
\]

\( Z \) divided by 4
The Change:

- As you limit the tasks, your symptoms will likely improve
- Like any food diet, this is not a temporary thing, but a lifestyle change (be prepared!)
- Once you start to recover, the points will change:
  - Increase total points per day (2–4)
  - Rescore the activities to a lower point value
  - STAY AT ONE LEVEL FOR APROX 1–2 WEEKS BEFORE THE NEXT INCREASE
## Typical point values:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Point Value</th>
<th>Activity</th>
<th>Point Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADLs (bathing, dressing, grooming)</td>
<td>0.5–2</td>
<td>TV use</td>
<td>2pts per hour</td>
</tr>
<tr>
<td>Meal Preparation</td>
<td>2–3 (depending on complexity)</td>
<td>Computer use</td>
<td>2pts per hour</td>
</tr>
<tr>
<td>Dishes</td>
<td>1–2</td>
<td>Reading</td>
<td>2pts per 1/2–1 hour</td>
</tr>
<tr>
<td>Grocery shopping</td>
<td>5</td>
<td>Talking on the phone</td>
<td>2pts per 15 minutes</td>
</tr>
<tr>
<td>Hockey game</td>
<td>5</td>
<td>Eating out at a restaurant (2 people)</td>
<td>5 (+1 for each additional person)</td>
</tr>
<tr>
<td>Working</td>
<td>1–2pts per hour</td>
<td>Attending an appointment</td>
<td>3–5</td>
</tr>
<tr>
<td>Childcare</td>
<td>1–2pts per hour</td>
<td>Attending Group sessions</td>
<td>3–5</td>
</tr>
</tbody>
</table>
Use the points to get here...

Persistent Symptom Target Activity Pattern

Intensity

Time

Developed by Parkwood Hospital Outpatient ABI Team
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
Now that you are points experts:

- 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.
Now you are planning and pacing

You are on the road to recovery…
You will most likely plan and pace for a long time…
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
Menu of Options (or stoplight):

1 of these
- Grocery shopping
- Family gathering
- Full day of work
- Drive for 2hrs
- School concert
- Etc.

2-3 of these
- Meal preparation
- Laundry (1 load)
- Short drives in the city
- Attending a therapy appointment
- Watching 1 hr of tv
- Reading for 30 minutes

Unlimited (5+)
- Showering
- Brushing teeth
- Making breakfast/lunch
- Going for a light walk
- Listening to an audiobook
- Meditation
- Mindfulness
- Eating a meal
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...
Questions?