CDC Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Stakeholder Engagement and Communication (MECFS-SEC) Webinar/Conference Call

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Pacing in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome & Fibromyalgia

June 3, 2019

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention

Pacing:
Learn how to stop crashing and increase your energy
in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome & Fibromyalgia

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Disclosures

None

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- My patients who continue to amaze me with their grace under pressure, who are my teachers & who inspire me to continue to learn

Goals of Pacing:
ME/CFS, FM & Chronic Physical Illness

1. Improvement of current symptoms, functioning and quality of life
2. Secondary prevention of worsening of presenting chronic complex medical condition

Judy age 52

Started after **fourth whiplash injury** after being rear-ended while driving her car

6 months later she has:

1. Pathological severe fatigue: energy 4/10 & post-exertional fatigue
2. Non-Restorative Sleep
3. **Pain in her muscles all over** & joints
4. Brain fog & poor memory
5. Dizzy when standing up

Noelle age 56

Flu at Xmas party where everyone got sick, they recovered.

6 months later she has:

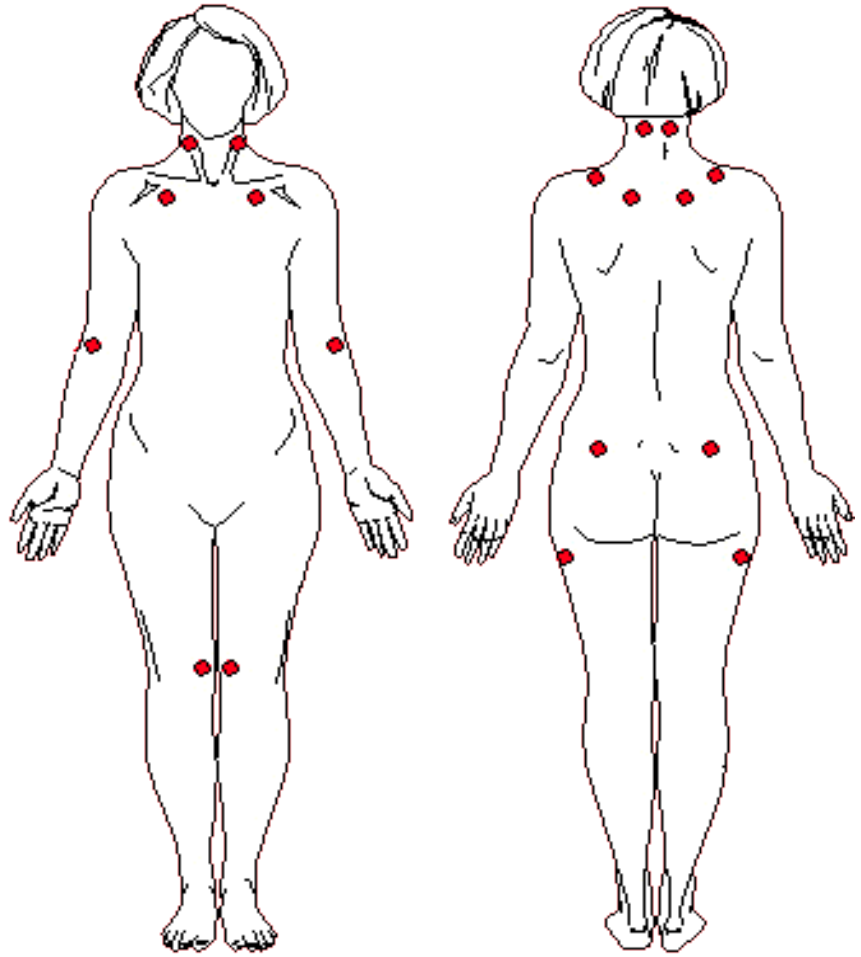
1. Pathological **severe fatigue: energy 4/10 & post-exertional malaise**
2. Non-Restorative Sleep
3. Pain in her muscles & joints
4. Brain fog & poor memory
5. Dizzy when standing up

Fibromyalgia Criteria

- Widespread Pain-11/18 +ve Tender points
- Fatigue
- Sleep Dysfunction
- Neurological Manifestations
- Autonomic/Neuroendocrine Manifestations
- Stiffness

Jain A. et al. The Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners. Journal of Musculoskeletal Pain, Volume 11, Number 4, 2003

FM Tender Points



CFS/ME Clinical Criteria

- Fatigue–severe, physical + mental; –post-exertional
- Sleep dysfunction
- Pain
- Neurological symptoms
- Autonomic, neuroendocrine & immune symptoms
- Chronic: adults >6 months, kids >3 *months*

Carruthers B. et al. Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols A Consensus Document. Journal of Chronic Fatigue Syndrome Volume 11, Number 1, 2003

SEID Definition by IOM

"Systemic Exertion Intolerance Disease"

1. Impairment in ability to maintain pre-illness levels of occupation or personal activities that lasts more than 6 months with fatigue and not improved with rest
2. Post-exertional malaise
3. Unrefreshing sleep

Plus 1 of:

1. Cognitive Impairment
2. Orthostatic Intolerance

IOM (Institute of Medicine). Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness. Washington, DC: The National Academies: 2015:282pp

Commonalities

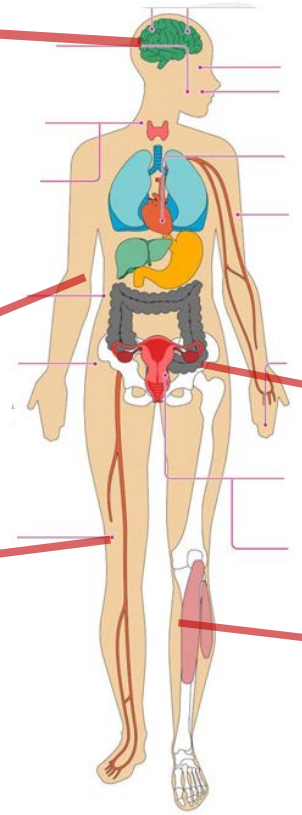
1. Fatigue-abnormal
2. Non-Restorative Sleep
3. Pain muscles/joints
4. Cognitive Dysfunction: Brain fog & poor memory
5. Parasympathetic/Sympathetic Nervous System Imbalance: dizzy when standing up

ME/CFS: CHRONIC, COMPLEX MULTISYMPTOM DISEASE

Brain Dysfunction:
- Cognitive Dysfunction
- Sleep Disorder
- Anxiety
- HPA Axis Dysregulation

Pain: new headaches, migratory muscle & joints

Autonomic Dysfunction:
- Orthostatic Intolerance
- Low Blood Volume + Mass



Immune Dysfunction:
↓ NK activity

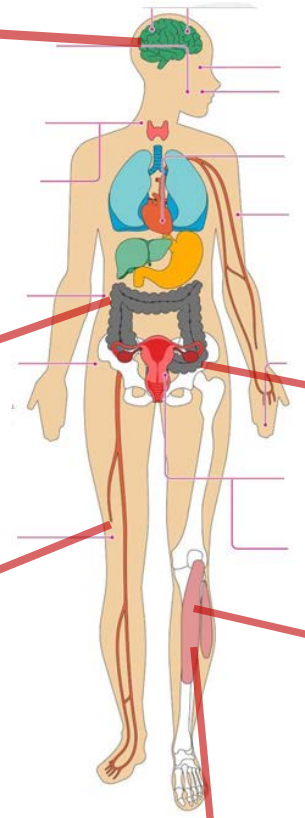
Severe Fatigue/ Post-Exertional Fatigue:
Abnormal Metabolism

FIBROMYALGIA: CHRONIC COMPLEX MULTISYMPTOM DISEASE

Brain Dysfunction:
- Cognitive Dysfunction
- Sleep Disorder
- Anxiety
- HPA Axis Dysregulation

Widespread Pain:
- Muscles
- GI Irritable Bowel Syndrome

Autonomic Dysfunction:



Immune Dysfunction:
- ?autoantibodies

Severe Fatigue/ Post-Exertional Fatigue:
- Abnormal Metabolism

Muscle Stiffness

Unrest: the Documentary: A Snippet-Jessica's Birthday

Sundance Award Winner

https://www.dropbox.com/s/00oijwxucvpprg9/Unrest_Publicity_Clip_2.mov?dl=0

https://www.dropbox.com/s/00oijwxucvpprg9/Unrest_Publicity_Clip_2.mov?dl=0

Diagnosis!

The **diagnosis is the key** for understanding your illness.

ME/CFS & FM are Physical Illnesses!

Supportive Symptomatic Care

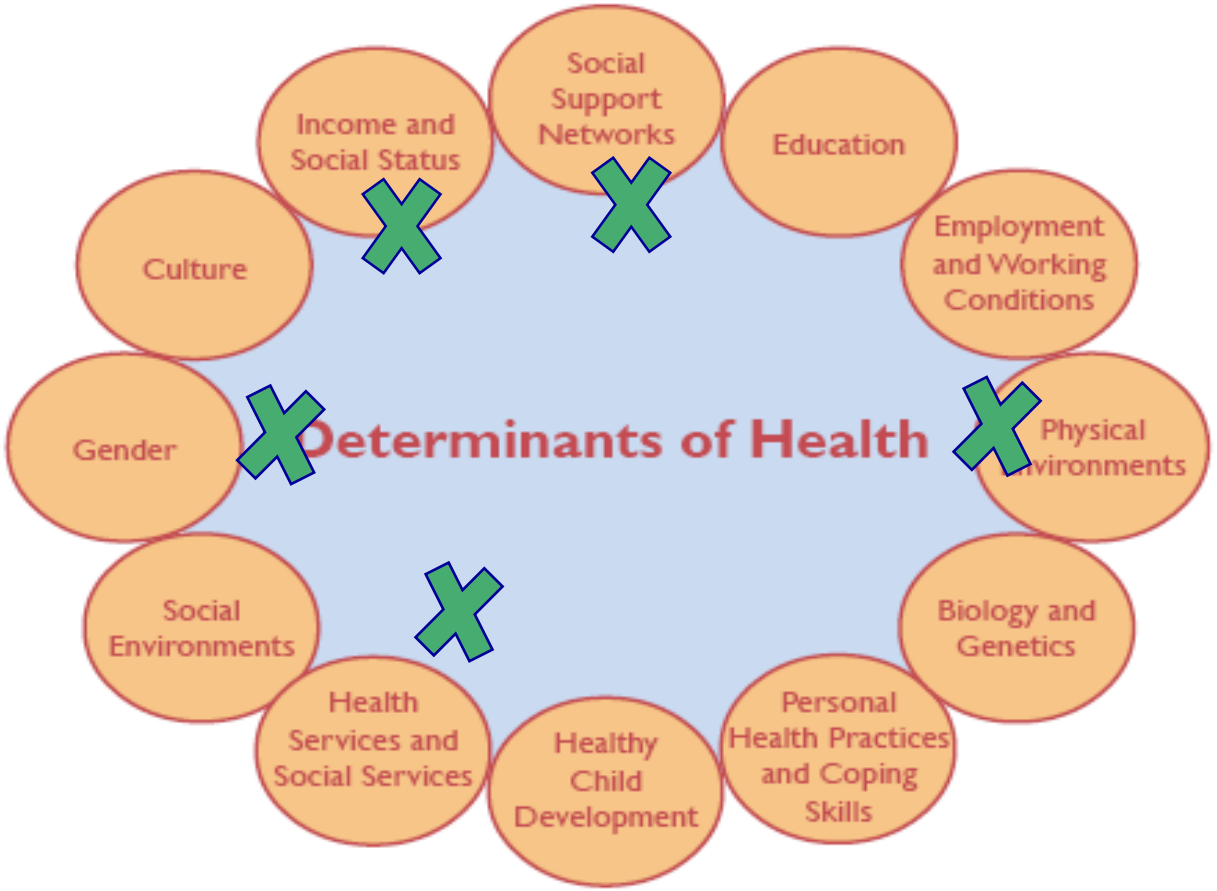
MANAGEMENT STRATEGIES

1. Improve symptoms, functioning & quality of life
2. Secondary prevention of worsening of chronic complex condition
3. Support patient & family

Multiple Determinants of Health

Source: World Health Organization, undated.
Child Health and the Environment - A Primer, CPCHE, Aug. 2005:5
www.healthyenvironmentforkids.ca

Holistic



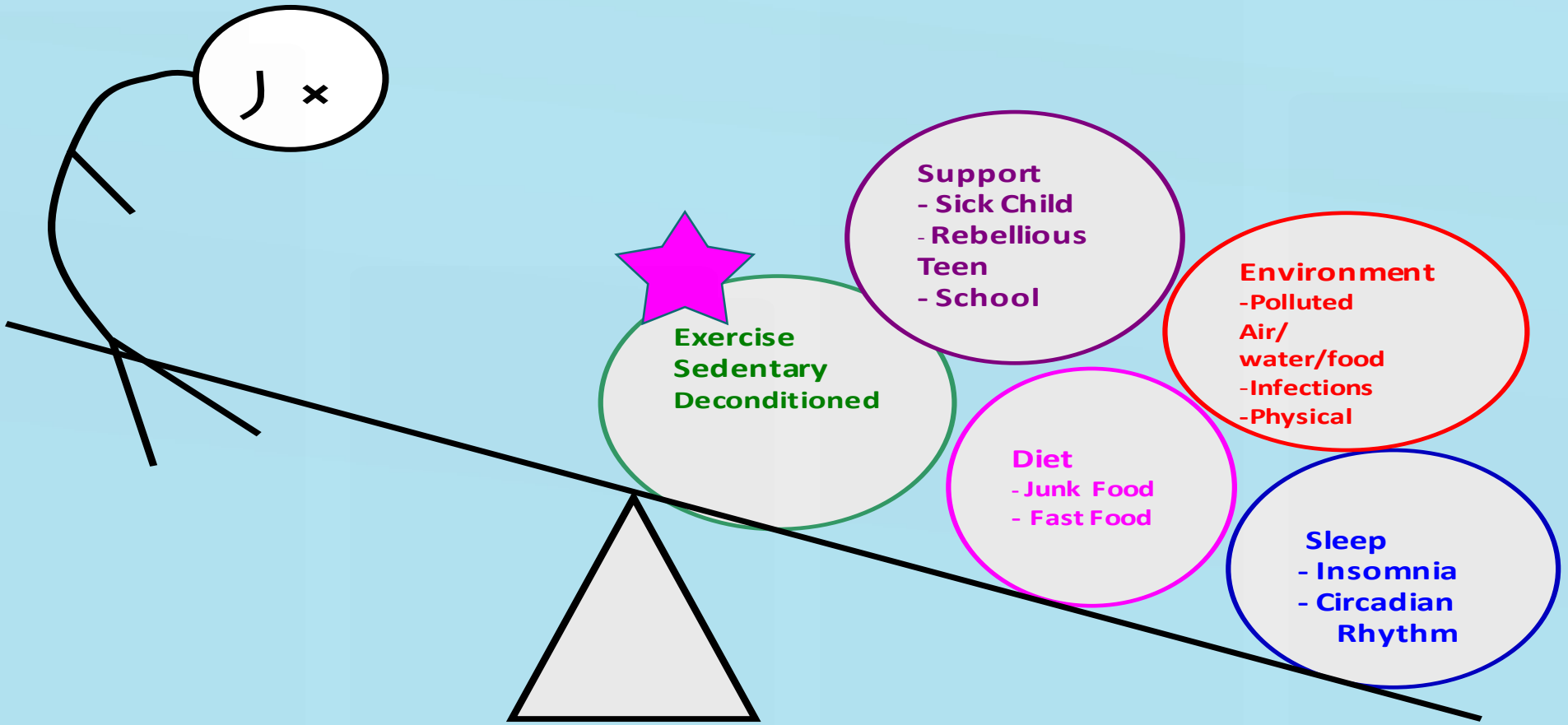
Adaptation Mechanisms

Adaptation:

- the process by which the body attempts to sustain ‘**the balance within**’

Exhaustion: SEEDS of Health

Body Systems **Stressors**



Homeostasis Imbalance

Weed, Seed, and Feed Approach

1. Weed out known aggravators/stressors
2. Plant "SEEDS" of health:

- S leep
- E xercise/pacing
- E nvironment
- D iet/Drugs
- S upport (self, family, social, medical, occupational, spiritual)

3. Feed the SEEDS (nurture whatever helps)

Pacing Treatment

Impaired Function/Fatigue/ Post-Exertional Fatigue or Malaise (PEM)

– Pacing with Activity Logs, Fitbit # steps/day. Alternate activity with rest periods.

– Stop pushing & crashing, honor body's limits and expand slowly, keep heart rate low & avoid aerobic exercise

Jason, LA, Brown, M, Brown, A, et. al, Energy Conservation/envelope theory interventions. Fatigue: Biomedicine, Health & Behavior, DOI:10.1080/21641846.2012.733602

Pathophysiology

ME/CFS –impaired aerobic metabolism

–two-day bike ergometry testing

FM –abnormal small nerve fibers discovery

–abnormal pain pathways

Activity Log and Functional Capacity Scale

Scale from 0 to 10

Incorporates:

- Energy rating
- Activities
- Symptoms/emotions on reverse side

Activity Log

Name: _____ Date Commencing: _____

DAY	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
SLEEP: Write number of hours you slept and the sleep quality: 1 = very poor 2 = poor 3 = fair 4 = good 5 = very good							
Functional Capacity Scale: Record your activity using one word and your energy rating using the scale 1-10/10 every hour in each square.							
Activities: (please specify)							
6 a.m.							
7 a.m.							
8 a.m.							
9 a.m.							
10 a.m.							
11 a.m.							
12 p.m.							
1 p.m.							
2 p.m.							
3 p.m.							
4 p.m.							
5 p.m.							
6 p.m.							
7 p.m.							
8 p.m.							
9 p.m.							
10 p.m.							
11 p.m.							
# of minutes walked							
# of usable hours / day							

Dr. Alison Bested ©
Dr. Lynn Marshall and Dr. Rosemary Underhill

We encourage you to copy this log to use with your patients.

Activity Log

Name: **NORMAL** Date: _____

DAY	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
# of Hrs Slept Btwn 11 pm & 6 am	5	5	5	5	5	5	5
SLEEP QUALITY	1 = very poor		2 = poor		3 = fair	4 = good	5 = very good
Functional Capacity Scale at the best and worst time of the day.	0 - 10						
Activities (please specify)							
6 a.m.							
7 a.m.	9	9	9	9	10	9	9
8 a.m.							
9 a.m.							
10 a.m.							
11 a.m.							
12 p.m.							
1 p.m.							
2 p.m.							
3 p.m.							
4 p.m.							
5 p.m.							
6 p.m.							
7 p.m.							
8 p.m.							
9 p.m.							
10 p.m.							
11 p.m.							
ENERGY	9	9	9	9	9	9	9
WALKED		60		60		60	60

Functional Capacity Scale

YOUR ACTIVITY LOG:

- Keep it in a handy place.
- Complete it every day.
- Take your completed logs to your doctor/other health care provider at follow-up visits.
- Your logs assist your doctor/other health care provider to adjust your treatment plan as needed.
- Completed logs may reassure your insurance company of your active ongoing participation in your treatment.

COMPLETING YOUR ACTIVITY LOG:

- You may change the times on the left hand side of the log to suit your usual schedule (e.g. if you usually get up at 10:00 a.m. and go to bed at 2:00 a.m., write 10:00 a.m. in as the first time, and adjust the other times accordingly).
- Please note your activities with one or two word(s) in the appropriate time slots (e.g. dressed, made bed, nap).
- Rest is defined as lying down, eyes shut, meditating or sleeping.

FUNCTIONAL CAPACITY SCALE:

The Functional Capacity Scale incorporates energy rating, symptom severity, and activity level. The description after each scale number should help you to rate your functional capacity at the beginning and end of each day.

0 = No energy, severe symptoms including very poor concentration; bed ridden all day; cannot do self-care (e.g. need bed bath to be given).
1 = Severe symptoms at rest, including very poor concentration; in bed most of the day; need assistance with self-care activities (bathing).
2 = Severe symptoms at rest, including poor concentration; frequent rests or naps; need some assistance with limited self-care activities.
3 = Moderate symptoms at rest, including poor concentration; need frequent rests or naps; can do independent self-care but have severe post exertion fatigue.
4 = Moderate symptoms at rest, including some difficulty concentrating; need frequent rests throughout the day; can do independent self-care and limited activities of daily living (e.g. light housework, laundry); can walk for a few minutes per day.
5 = Mild symptoms at rest with fairly good concentration for short periods (15 minutes); need a.m. and p.m. rest; can do independent self-care and moderate activities of daily living, but have slight post exertion fatigue; can walk 10-20 minutes per day.
6 = Mild or no symptoms at rest with fairly good concentration for up to 45 minutes, cannot multitask; need afternoon rest; can do most activities of daily living except vacuuming; can walk 20-30 minutes per day; can do volunteer work – maximum total time 4 hours per week, with flexible hours.
7 = Mild or no symptoms at arrest with good concentration for up to ½ day; can do more intense activities of daily living (e.g. grocery shopping, vacuuming) but may get post exertion fatigue if 'overdo': can walk 30 minutes per day; can work limited hours, less than 25 hours per week; no or minimal social life.
8 = Mild intermittent symptoms with good concentration; can do full self-care, work 40 hours per week, enjoy a social life, do moderate vigorous exercise three times per week.
9 = No symptoms with very good concentration, full work and social life; can do vigorous exercise three to five times a week.
10 = No symptoms, excellent concentration, over achiever (sometimes may require less sleep than average person).

NUMBER OF USABLE HOURS / DAY = Number of hours NOT asleep or resting/meditating with eyes closed.

Dr. Lynn Marshall, Co-Author, Director, Environmental Health Clinic, Sunnybrook & Women's College Health Services Centre
Dr. Alison Bested ©

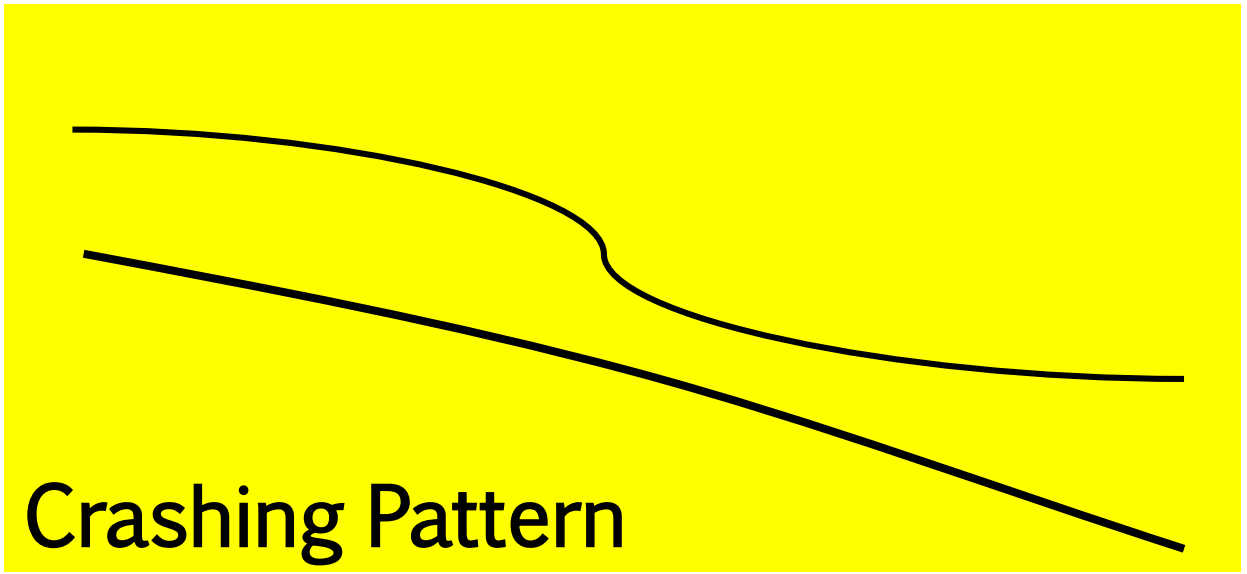
Spending your **Energy $$**

1. Physical–walk

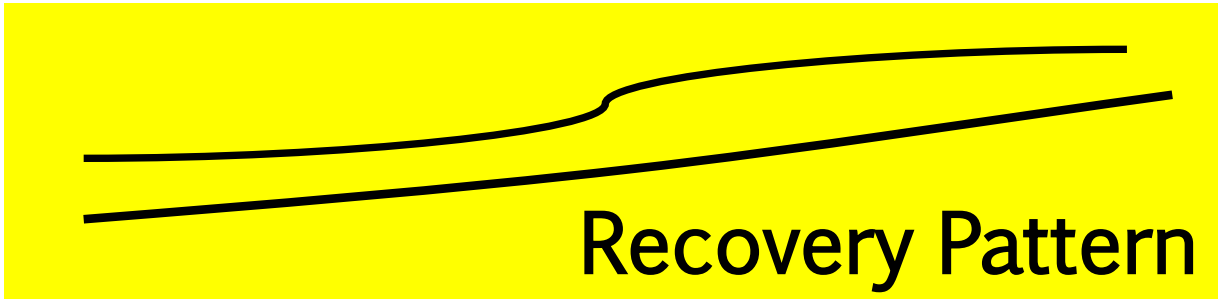
2. Mental–pay bills on computer

3. Emotional–fight with mother, husband etc.

Pushing



Pacing



Rest Definition:

- lying down, eyes shut, meditating or sleeping

Relaxation Response/Meditation

– to increase parasympathetic tone and reduce adrenal overstimulation (stop the adrenaline addiction)

Energy used:

1. Physical–walk
2. Mental–computer
3. Emotional–fight with kids

Limited energy:

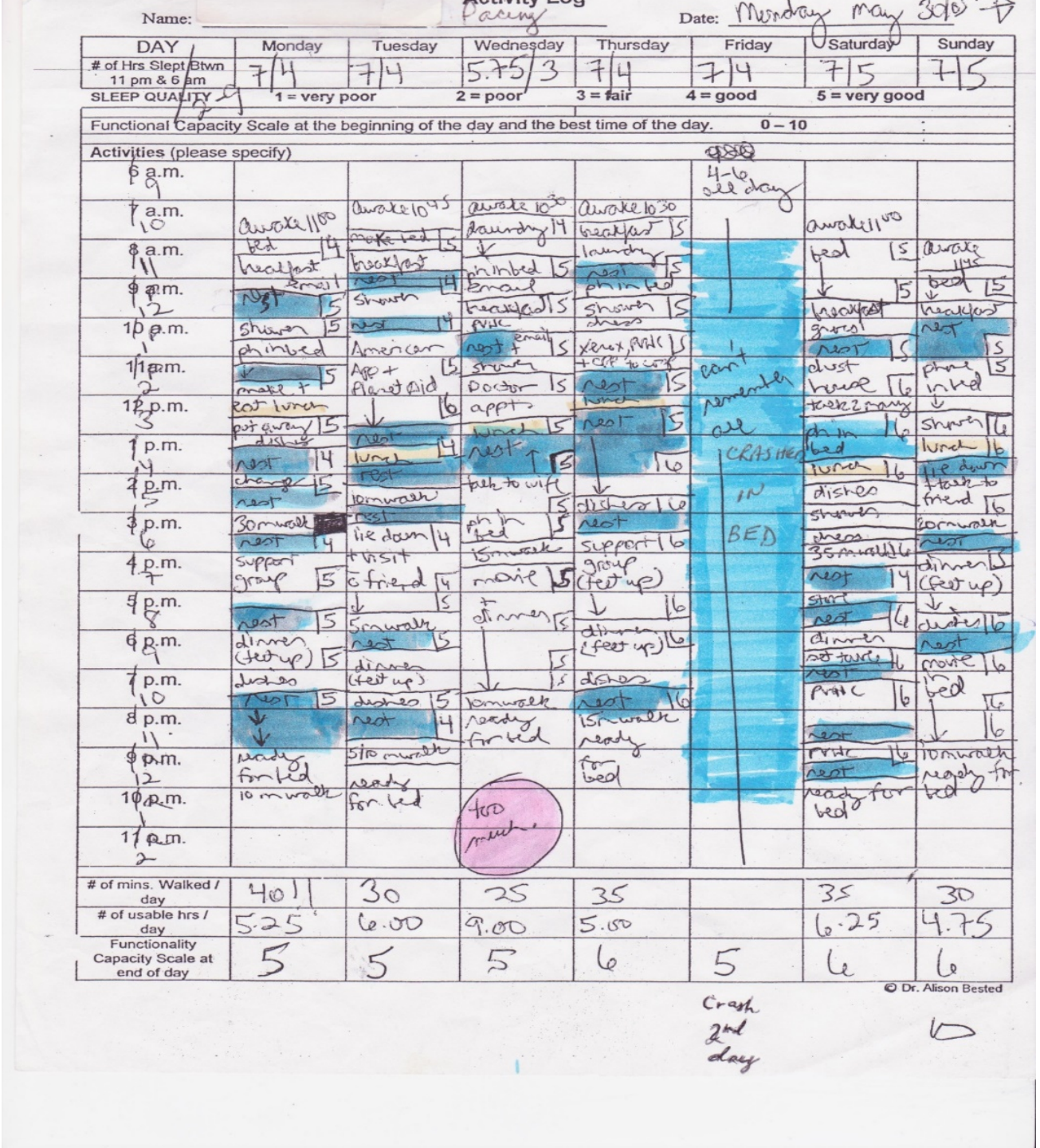
You can only use it once!

Take control! Use the tool–pace!

Activity Log

Name: **NORMAL** Date: _____

DAY	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
# of Hrs Slept Btwn 11 pm & 6 am	5	5	5	5	5	5	5
SLEEP QUALITY	1 = very poor		2 = poor		3 = fair	4 = good	5 = very good
Functional Capacity Scale at the best and worst time of the day.	0 - 10						
Activities (please specify)							
6 a.m.							
7 a.m.	9	9	9	9	10	9	9
8 a.m.							
9 a.m.							
10 a.m.							
11 a.m.							
12 p.m.							
1 p.m.							
2 p.m.							
3 p.m.							
4 p.m.							
5 p.m.							
6 p.m.							
7 p.m.							
8 p.m.							
9 p.m.							
10 p.m.							
11 p.m.							
ENERGY	9	9	9	9	9	9	9
WALKED		60		60		60	60



Activity Log
Pacing

Name:

Date: Monday May 30th

DAY	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
# of Hrs Slept Btwn 11 pm & 6 am	7/4	7/4	5.75/3	7/4	7/4	7/5	7/5

SLEEP QUALITY 1 = very poor 2 = poor 3 = fair 4 = good 5 = very good

Functional Capacity Scale at the beginning of the day and the best time of the day. 0 – 10

Activities (please specify)

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
6 a.m.					4-6 all day		
7 a.m.	awoke 11:00	awoke 10:45	awoke 10:30	awoke 10:30		awoke 11:00	
8 a.m.	bed 4	woke bed 5	laundry 4	breakfast 5		bed 5	awoke 11:45
9 a.m.	breakfast	breakfast	ph in bed	laundry			bed 5
10 a.m.	Email	rest 4	Email	ph in bed 5		breakfast	breakfast
11 a.m.	rest 5	shower	breakfast 5	shower 5		groc	rest
12 p.m.	shower 5	rest 4	pills	dress		rest 5	5
1 p.m.	ph in bed	American	rest + email 5	xerox, print + off to work	I can't remember all CRASHED IN BED	dust	phone 5
2 p.m.	make + 5	App + Plant Aid 5	shower	rest 5		house 6	in bed
3 p.m.	rest lunch	6	doctor 5	lunch		task 2 many	shower 6
4 p.m.	put away 5 dishes	rest	appt	rest 5		ph in 6	lunch 6
5 p.m.	rest 4	lunch 4	work 5	6		bed	lie down + task to friend 6
6 p.m.	change 5	rest	rest 5	dishes 6		lunch 6	20 min walk
7 p.m.	rest	10 min walk	talk to wife 5	rest		dishes	rest
8 p.m.	30 min walk	rest	ph in bed 5	support group (feet up) 6		shower	dinner 5
9 p.m.	rest 4	lie down 4	15 min walk	6		dress	(feet up)
10 p.m.	support group 5	+ visit + friend 4	movie 5	dinner (feet up) 6		35 min walk 6	dishes 6
11 p.m.	rest 5	5 min walk 5	dinner 5			rest 4	rest
12 a.m.	dinner (feet up) 5	rest 5	5	dishes		start	movie 6
1 a.m.	dishes	dinner (feet up)	dishes	rest 6		rest 6	bed
2 a.m.	rest 5	dishes 5	10 min walk	15 min walk		dinner	6
3 a.m.	ready for bed	rest 4	ready for bed	ready for bed		eat tuna 6	rest 6
4 a.m.	10 min walk	5 to 10 min walk	400 meters			PHIC 6	10 min walk
5 a.m.		ready for bed				rest	ready for bed
6 a.m.						PHIC 6	
7 a.m.						rest	
						ready for bed	
# of mins. Walked / day	40	30	25	35		35	30
# of usable hrs / day	5.25	6.00	9.00	5.00		6.25	4.75
Functionality Capacity Scale at end of day	5	5	5	6	5	6	6

Crash 2nd day

Blue = rest

Yellow = new normal energy level from Functional Capacity Scale

Orange = low energy/activity level

Activity Log

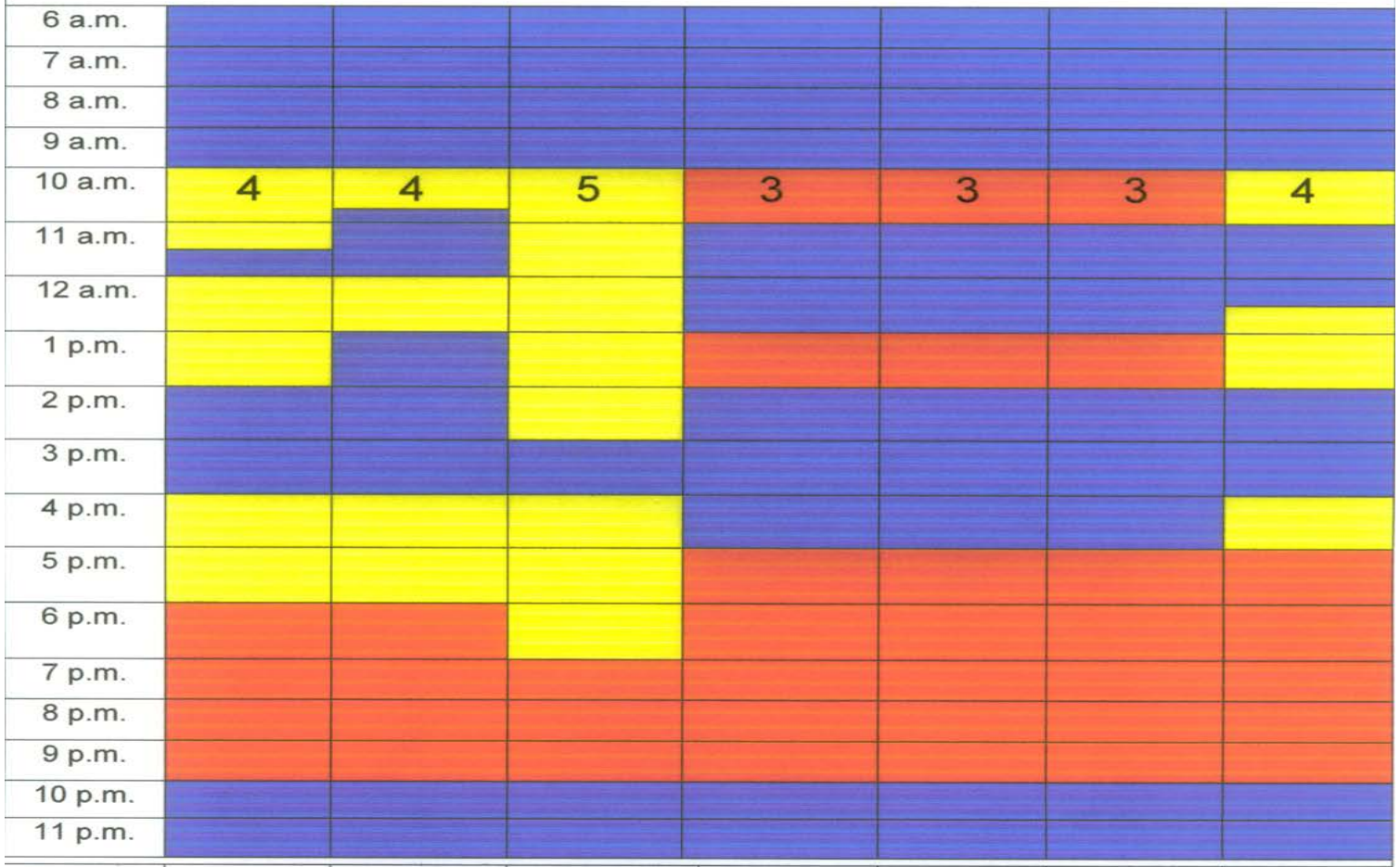
Name: **CRASHING PATTERN** Date: _____

DAY	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
# of Hrs Slept Btwn 11 pm & 6 am	4	4	4	2	2	2	3

SLEEP QUALITY 1 = very poor 2 = poor 3 = fair 4 = good 5 = very good

Functional Capacity Scale at the beginning of the day and the best time of the day. 0 - 10

Activities (please specify)



ENERGY	3	3	2	2	2	2	3
WALKED	10	10	20	0	0	0	0

Activity Log

Name: **RECOVERY PATTERN** Date: _____

DAY	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
# of Hrs Slept Btwn 11 pm & 6 am	4	4	4	4	4	4	4
SLEEP QUALITY	1 = very poor		2 = poor	3 = fair		4 = good	5 = very good
Functional Capacity Scale at the best and worst time of the day.	0 - 10						
Activities (please specify)							
6 a.m.							
7 a.m.							
8 a.m.	6	6	6	6	6	6	6
9 a.m.							
10 a.m.							
11 a.m.							
12 p.m.							
1 p.m.							
2 p.m.							
3 p.m.							
4 p.m.							
5 p.m.							
6 p.m.							
7 p.m.							
8 p.m.							
9 p.m.							
10 p.m.							
11 p.m.							
ENERGY	5	5	5	5	5	5	5
WALKED	20	20	20	20	20	20	20

Activity Log

Name: _____ Date: _____

Day	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
No. of Hrs. Sleep 11:00 pm – 6:00 am	9 plus naps	10 hours plus naps	14 hours + nap	12 hours + naps	10 hours + nap	10.5 plus naps	9.0
Sleep Quality		1 = very poor	2 = poor	3 = fair	4 = good	5 = very good	
	3	3	3	3	4	4	4
Functional Capacity Scale-at beginning of day							
0 – 10 (see reverse)	(1)	(1)	(2)	(1)	(3)	(3 1/2)	(4)
Activities (please specify)							
6:00 am	sleeping						sleeping
7:00 am							
8:00 am		woke up had breakfast		woke up ate	(Woke up no break fast)		made coffee watched
9:00 am		Drove to Dr Baxter's	lay on couch	Drove to Dr. office for Allergy Tests	Drove to chiro	woke up on couch)	snore on TV
10:00 am	woke up	Appointment	IV meds		Chiro	IV admin	9-11:30
11:00 am	& layed on couch IV admin	Drove back home for 12pm	face steam		Home for IV	Ate breakfast & walked	
12:00 pm		Ate lunch	Ate lunch had calls online		Ate lunch made by Mom	TV Went to	Had lunch
1:00 pm	lay down & slept	IV admin Drove to	watch TV	IV admin Tried to make lunch	Nap	Pharmacy/ had lunch	went outside to garden
2:00 pm		Dr. office	Nap for 2hrs	went to bed 3 slept until 6:30pm (4hrs)	went to Pharmacy & bank & grocery Store	Slept for 2.5hrs	walk Take shower
3:00 pm	Got up & made Ate lunch	waited for IV to be admin					slept 3.30pm
4:00 pm		slept in TV	Answered stressful			Took shower went out	2hours
5:00 pm	Fell asleep on couch	Drive home			Layed on couch to rest	for supper	Ate supper watched TV
6:00 pm			Ate supper				
7:00 pm	made supper & hubby & ate	went to bed with a	lay down on couch	went to room for supper	Ate for supper	6-9pm	
8:00 pm	watched TV-lying down	migraine (4)	Went to bed 5pm	slept & napped from 3 to 9:30pm			
9:00 pm							Went to bed
10:00 pm	went to bed migraine			went to bed in		drive home /	
11:00 pm			*	* navigate again		watch TV Bed time	
No. of Mins. Walked / Day	0	0	0	0	30 min	15 min	0
No. of Usable Hours / Day	2hrs	1hr	1.5hrs	0	4.0hrs	4.5hrs	5.0hrs
Functional Capacity Scale-at end of day							
0 – 10 (see reverse)	(1)	0	0	0			3

Environmental Health Clinic
Sunnybrook & Women's College Health Sciences Centre

(4) indicates migraine - 4/x this week

Name: _____ Date: AUG. 9-15 / 2010

DAY	Monday 9	Tuesday 10	Wednesday 11	Thursday 12	Friday 13	Saturday 14	Sunday 15
# of Hrs Slept Btwn 11 pm & 6 am	6	6	7	6	7	5	4
SLEEP QUALITY	1 = very poor	2 = poor	3 = fair	4 = good	5 = very good		
Functional Capacity Scale at the beginning of the day and the best time of the day. 0 – 10	6	7	7	6	6	6	5
Activities (please specify)							
6 a.m.	meditate stretch	meditate			meditate	stretch	
7 a.m.	eat / read R	stretch eat / read			stretch eat / read	meditate eat / R	
8 a.m.	wash dishes R	Sunny-brook Ontario	stretch walk / R	stretch meditate	walk / R	went to bakery	eat / read
9 a.m.	walk / R lie down	walk / R chat / read	R eat / read	eat / read water plants	cook R	R lie down	meditate shower
10 a.m.	nap	coffee / chat walk / R	prep. dinner R	R meditate	shower R	made pasta salad	R church
11a.m.	stretch	meditate	cook	nap	nap	R	
12 p.m.	meditate prep. dinner	stretch walk / R	R shower		eat / dress R	shower R / eat	
1 p.m.	R eat / read	bus / R walk / bus	meditate nap	stretch		nap	walk / R
2 p.m.	cook	R / walk R		eat / R wash dishes	chat		eat / R
3 p.m.	wash dishes R	eat / R nap		R lie down			walk / R
4 p.m.	shower watch TV		eat / R watch TV	" watch TV	chat / R meditate	stretch dress	nap
5 p.m.			" stretch		nap stretch	walk / R celebrate	
6 p.m.	stretch	stretch watch TV	dressed / R walk / R	stretch	eat / R grocery	Father's Day	
7 p.m.	R walk / R	"	watch JERSEY BOYS	take-out walk / R	w / hubby R	B-day	stretch meditate
8 p.m.	eat snack wash up	eat snack walk / R	stretch	eat / R wash dishes	lie down watch TV		eat / chat wash dishes
9 p.m.	lie down watch TV	wash up meditate	walk / R meditate	R watch TV	play cards "		walk / R
10 p.m.	sleep	" sleep	watch TV / sleep	fall asleep	R fall asleep	clean-up R sleep	watch TV " meditate
11 p.m.							
# of mins. Walked / day	45	75	60	30	60	45	45-50
# of usable hrs / day	6	6	7-8	5-6	7-8	7-8	5
Functionality Capacity Scale at end of day	5	5	5	5	5	4	4

HURRAY !!

How?

1. **Awareness:** record **hourly** activity and energy level without judgment for a week
2. Find your **best time** of the day
3. Listen to your body and **stop before you crash**
4. **Plan** for health

BESTED™ PACING METHOD
MIND-BODY MEDICINE

Body, in the moment, what do I need?

Activity or Rest.

Body, in this moment, how many minutes can I do it?

Number of minutes

Scroll through times table 5, 10, 15…until time is chosen.

Set timer and Stop when timer/alarm rings!

Airplane Symbolic Shift from

Pilot
Brain

Co-pilot
Body

Airplane Symbolic Shift to

Pilot
Body

Co-pilot
Brain

Exercise/Pacing/Mobility

Monitor via Activity Log:

- Stay as active as possible **WITHOUT CRASHING (inside your glass box)**
- Increase slowly (10% RULE)
- Warm up before, stretch after exercise (bath)
- Strength train and prevent osteoporosis
- Learn to trust your perceptions & build gradually

Strong Women Stay Young –Miriam Nelson

Examples:

1. Walking e.g. 10 minutes per day is fine

   Good day–increase walking by 10%

   –means increase walking by 1 minute

   –Total walking is 11 minutes

2. Mostly Bedridden –able walk to commode at bedside

   Good day–increase by walking to commode twice before getting back into bed

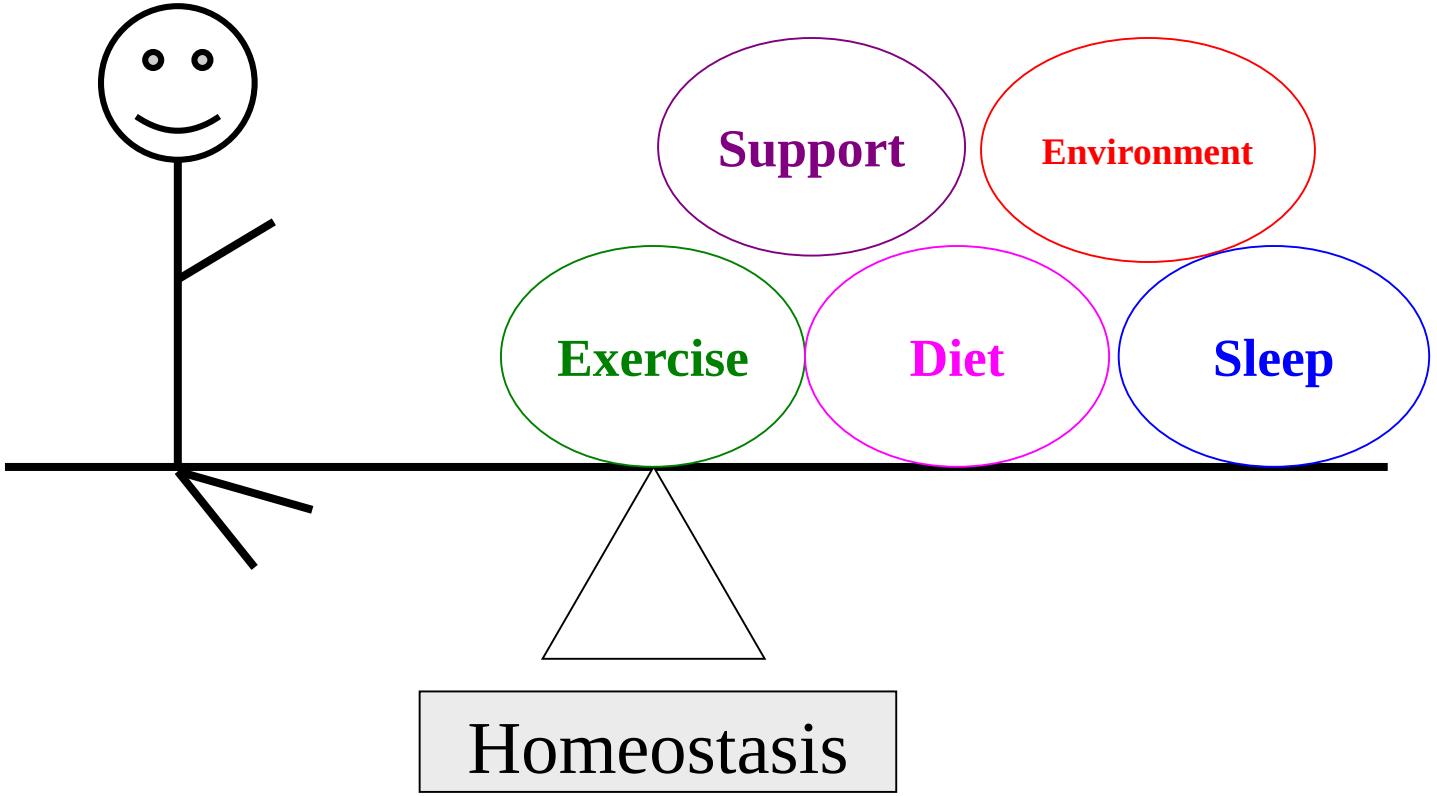
3. Bedridden–Physiotherapist assessment to begin range of motion exercises in bed passively; teach family members; then actively done by patient with ME/CFS

Results:

Adaptation

Body Systems

Seeds of Health



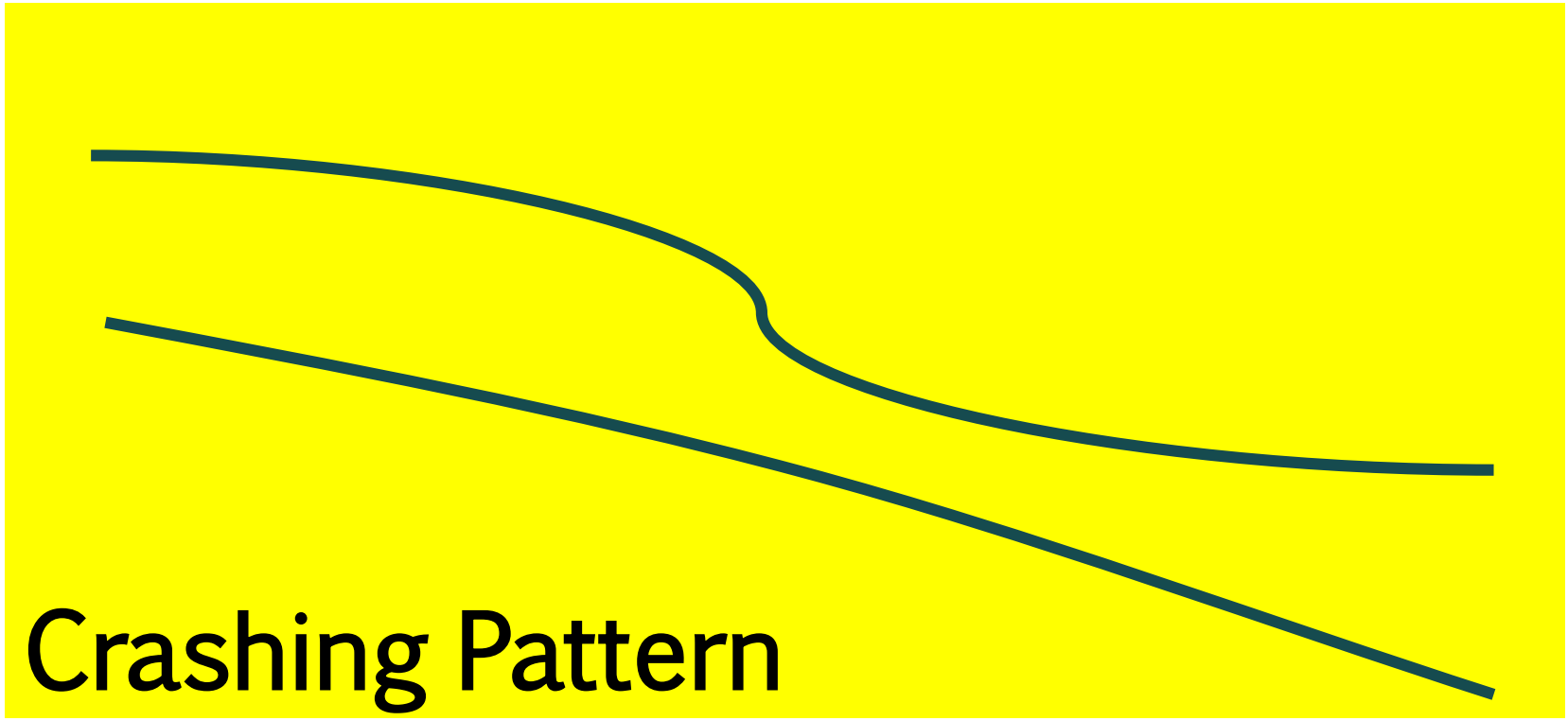
“Claire’s” Functional Status
Activity Log/Functional Capacity Scale

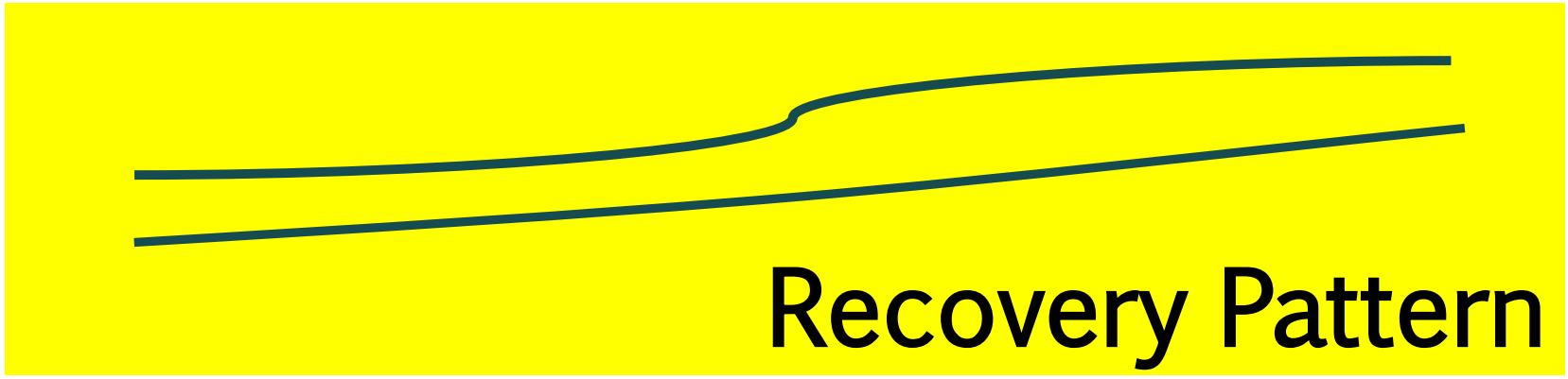
Activity Log helps physician to complete insurance reports

- Doctor could explain why she could not work e.g. fatigue was severe, energy was not reliable or sustainable (referring to activity logs)

  or

- Why she could work part time or full time


Crashing Pattern


Recovery Pattern

Energy Loan

Pay back

your energy loan **$$$**

to your body

on

Your Good Days

The Faces of ME/CFS: Dorothy

Age 55

Age 72

Never Give Up!

Boundaries/The Way to Pace

https://www.youtube.com/watch?v=N5sUkY0_wxw

Song: Boundaries-The Way To Pace

Boundaries are so wonderful to set.

When I sa-ay no-o to you, I say yes to myself.

Scattered pictures of the life I left behind.

Now I'm lying in bed crashing, from pushing myself...on my good days.

The Way To Pace part 1

Could it be that if I start to pace.
And write in my activity log.

If I persist with keeping it.
Tell me could I? Improve my energy?

The Way To Pace part 2

Boundaries are so wonderful to set.

Using my mini-timer, I can choose to stop.

When I stop before I crash, I help my body to heal.

Whenever I remember, the way to pace, the way to pace.

Melody: Marvin Hamlisch

Lyrics: Alison C. Bested

Patient Resources

Nova Southeastern University's Institute for Neuro-Immune Medicine's Website: https://www.nova.edu/nim

- Activity Log and Functional Capacity Scale

Books:

Alison C. Bested, Alan C. Logan and Russell Howe. **Hope and Help for Chronic Fatigue Syndrome and Fibromyalgia**, 2nd Edition. Cumberland House Publishing. October 1, 2008.

Louise McCrindle and Alison Bested. **The Complete Fibromyalgia Health, Diet Guide and Cookbook.** Robert Rose Publishing. Aug 23, 2013

Online Resources

Bested, A and Marshall L. **Review of ME/CFS: an evidence-based approach to diagnosis and management by clinicians.** Rev Environ Health. 2015;30(4):223-49. Doi: 10.1515/reveh-2015-0026. https://pubmed.ncbi.nlm.nih.gov/26613325/

Chronic Fatigue Syndrome/Myalgic Encephalomyelitis: **A Primer for Clinicians 2014 - IACFS/ME** https://www.iacfsme.org/assets/docs/Primer_Post_2014_conference.pdf

Carruthers B. et al. **Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols.** Journal of Chronic Fatigue Syndrome Volume 11, Number 1, 2003 and **Fibromyalgia Syndrome**: ME/FM Action Network Website: http://www.mefmaction.com

IOM (Institute of Medicine). **Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome:** Redefining an Illness. Washington, DC: The National Academies: 2015. https://www.ncbi.nlm.nih.gov/books/NBK274235/