

Pacing Basics 7

Adapting to a More Paced Life

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Overview of Session

Who am I?

Ground rules

Adapting to a More Paced Life

Accepting the Person You Are Today

Get Beyond the Short Term

Try To Match Your Commitments to that Person you are today

Recruiting Friends and Family

Plan a paced life

Adjust Responsibilities and Reduce the Load

Prepare for Setbacks and Relapses

Aids and Adaptations - All aspects of your life

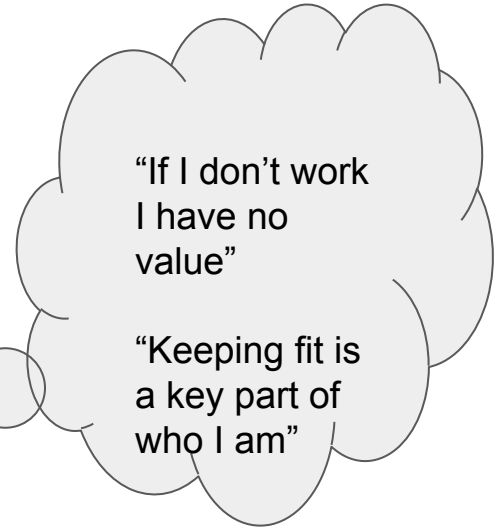
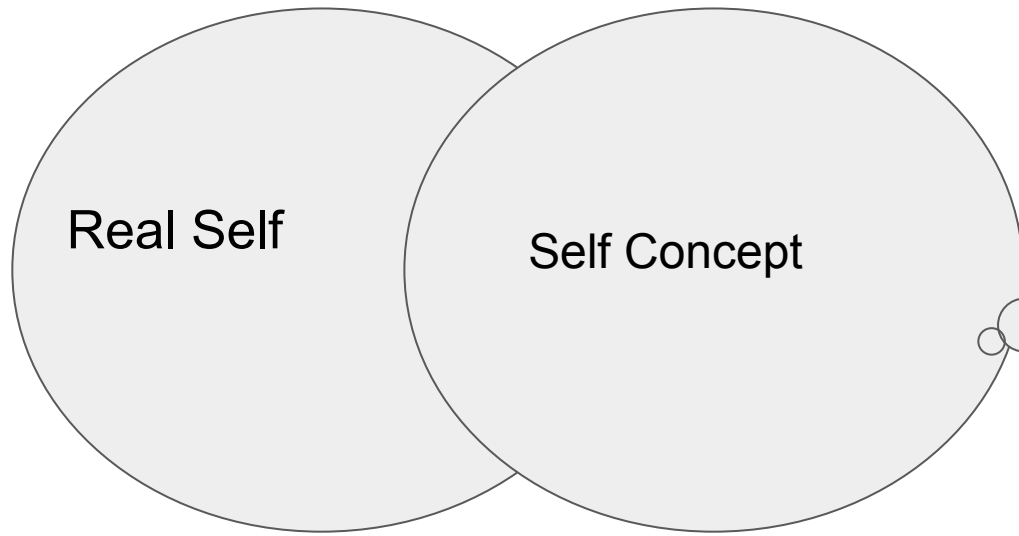
Focus on Brain Fog

Accepting (and loving) the Person you are today

Carl Rogers Personality Theory

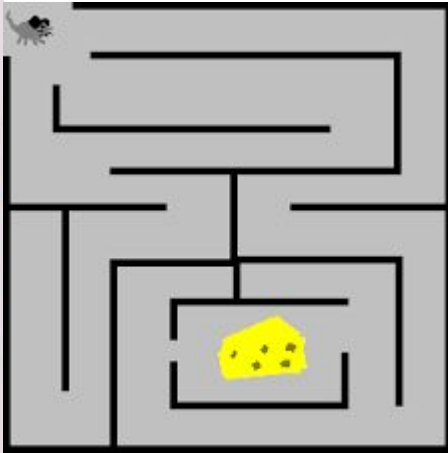
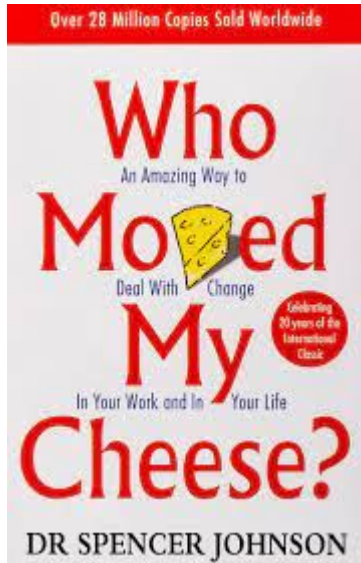


Long COVID can pull these further apart



Introjected Values

If you have PEM/PESE - You might need to learn to do things differently. The typical or habitual way you do tasks might no longer be best



What Worked Before May Not Work Now

- Try to be open to changes - you don't necessarily need to do the job you were doing before in the same way. Responsibilities you took on could possibly be reallocated
- Friendships and relationships might need to change - if not in who you are friends with then at least in what you do together so it meets your current needs

We know when something seems to be causing PEM to Stop it if we can...but sometimes that is hard

I remember when I worked as a legal trainee one of the staff would say that graveyards were full of people who thought that the world couldn't spin without them but when they die everything will usually go on just the same. It is easy to struggle to see how your responsibilities could be taken on by others but it is often more possible than you think..

Try to remove inflexible absolute words like “Can't” “must” and “Impossible” from your internal vocabulary

Getting Beyond the Short Term

When we look at trying to pace we first look to make “easy wins”. So that is adding rests to our day, reducing the amount we do and doing activities in a more paced way.

We hit roadblocks though with more challenging issues that are causing us problems such as work, Family responsibilities etc where we cannot just stop doing activities and there are limits to what we can easily do in order to reduce PEM/PESE.

Going beyond the short term is re-addressing these issues...

Try to match your activities, goals and commitments to the “you” that you are today!

Recruit and Train Friends and Family

Both to not act against what you need to do

To Understand

To Assist with Pacing

Equally - understand friends, family, room-mates might not always be the right person to share experiences with, ask for help, give support and advice etc.

Spoon Theory

HRM & HRV - objective measures can be helpful

Basic pacing info - Long Covid Kids has some simple and visual info

Lots of bad advice out there and often unfortunately that is what family grabs hold of. Just as there can be resistance to change within us there can also be that 10 times with family. Also the need to change is less pressing for them

Plan a Paced Life - with Room for Unexpected Surprises

We all have different energy levels but this is what I do:

- Plan 3 rests a day - these are not when I feel I need them but one in the morning, afternoon and evening. I also have a rest after tiring activities like dog walking, getting my daughter ready for school etc.
- I usually try to just schedule 1 out the house or otherwise tiring activity in a day
- If I have to do a day that is a bit too much then I try to shrink what I do the day before and after
- I try to balance responsibilities so I do not have too much on at any time but still take on what I feel I can manage

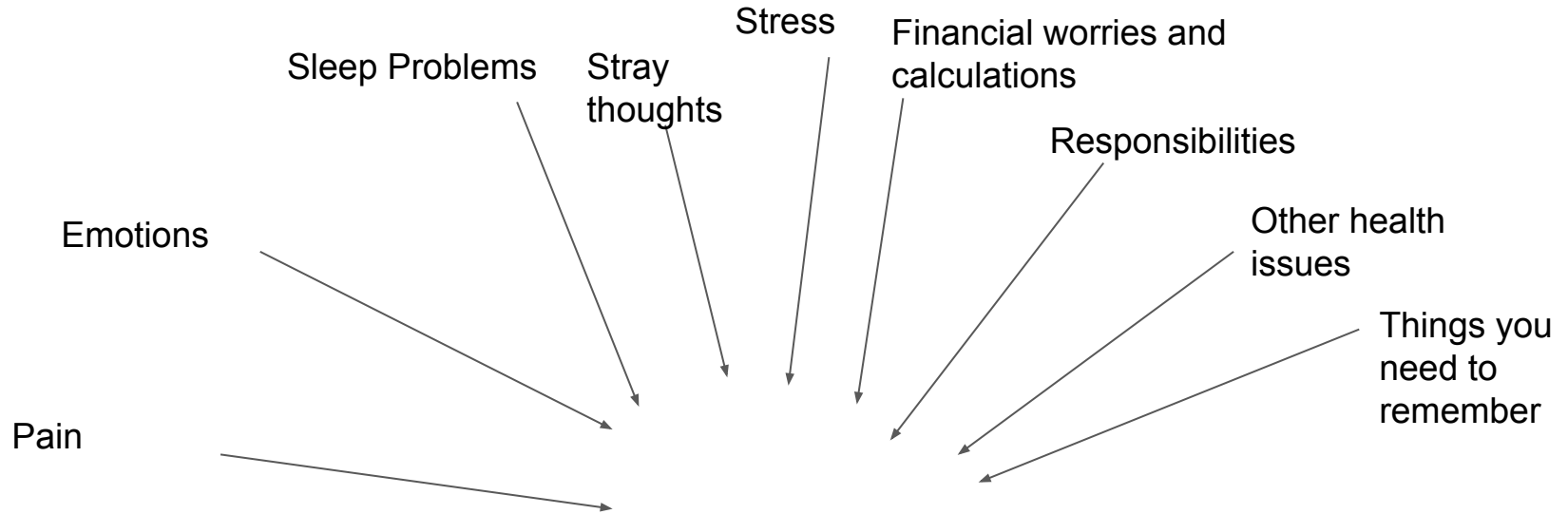
Adjust Responsibilities within family, friends, household and community

The Mental Load

Aka Invisible Labor or Emotional Labor

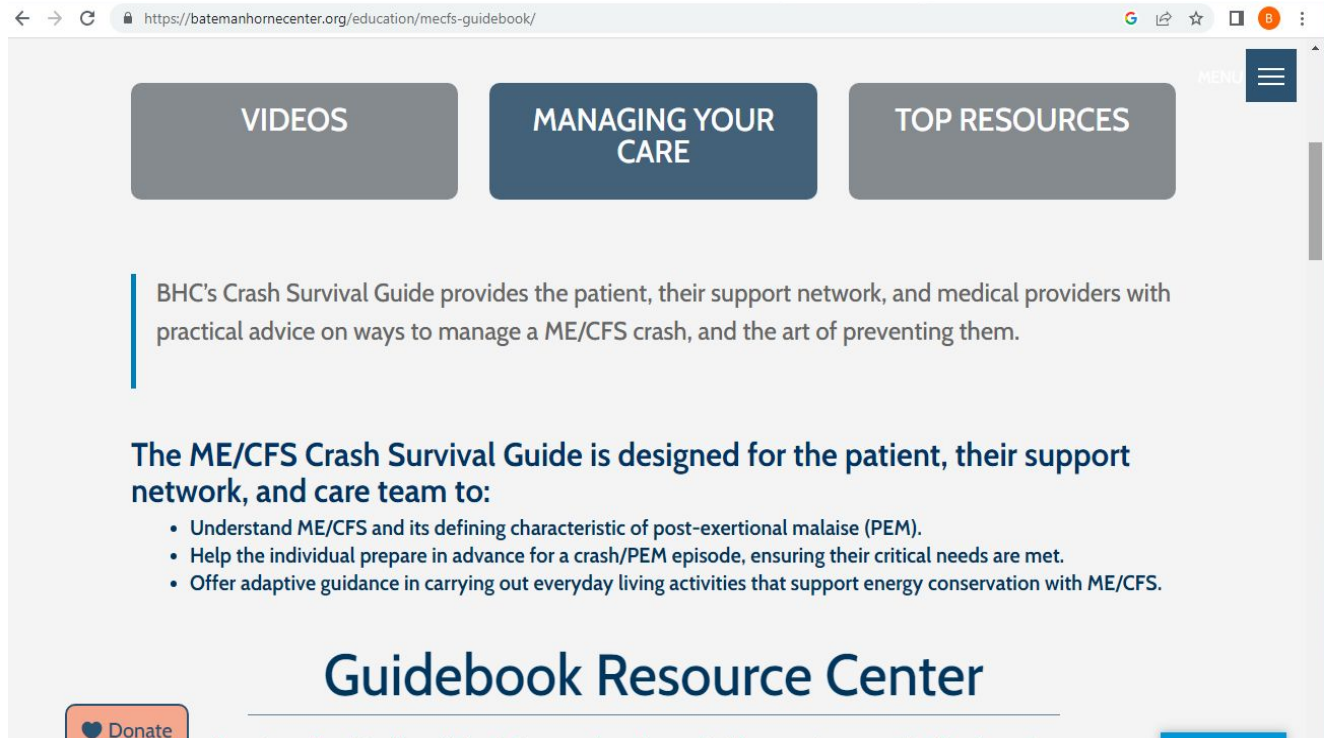


Look to Reduce the “Load”









Prepare for setbacks and relapses

Consider having some food, easy meals, supplies and if appropriate aids in for when you have very little energy



The screenshot shows a web browser window with the URL <https://batemanhomecenter.org/education/mecfs-guidebook/>. The page features three navigation buttons: "VIDEOS", "MANAGING YOUR CARE", and "TOP RESOURCES". Below these buttons, a text block states: "BHC's Crash Survival Guide provides the patient, their support network, and medical providers with practical advice on ways to manage a ME/CFS crash, and the art of preventing them." This is followed by a bolded heading: "The ME/CFS Crash Survival Guide is designed for the patient, their support network, and care team to:" and a bulleted list of three points: "Understand ME/CFS and its defining characteristic of post-exertional malaise (PEM).", "Help the individual prepare in advance for a crash/PEM episode, ensuring their critical needs are met.", and "Offer adaptive guidance in carrying out everyday living activities that support energy conservation with ME/CFS." At the bottom of the page, the text "Guidebook Resource Center" is displayed, and a "Donate" button is visible in the bottom left corner.

← → ↻ <https://batemanhomecenter.org/education/mecfs-guidebook/>      

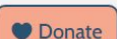
VIDEOS MANAGING YOUR CARE TOP RESOURCES

BHC's Crash Survival Guide provides the patient, their support network, and medical providers with practical advice on ways to manage a ME/CFS crash, and the art of preventing them.

The ME/CFS Crash Survival Guide is designed for the patient, their support network, and care team to:

- Understand ME/CFS and its defining characteristic of post-exertional malaise (PEM).
- Help the individual prepare in advance for a crash/PEM episode, ensuring their critical needs are met.
- Offer adaptive guidance in carrying out everyday living activities that support energy conservation with ME/CFS.

Guidebook Resource Center

 Donate

Aids and Adaptations

Memory &
pacing aids
Aids

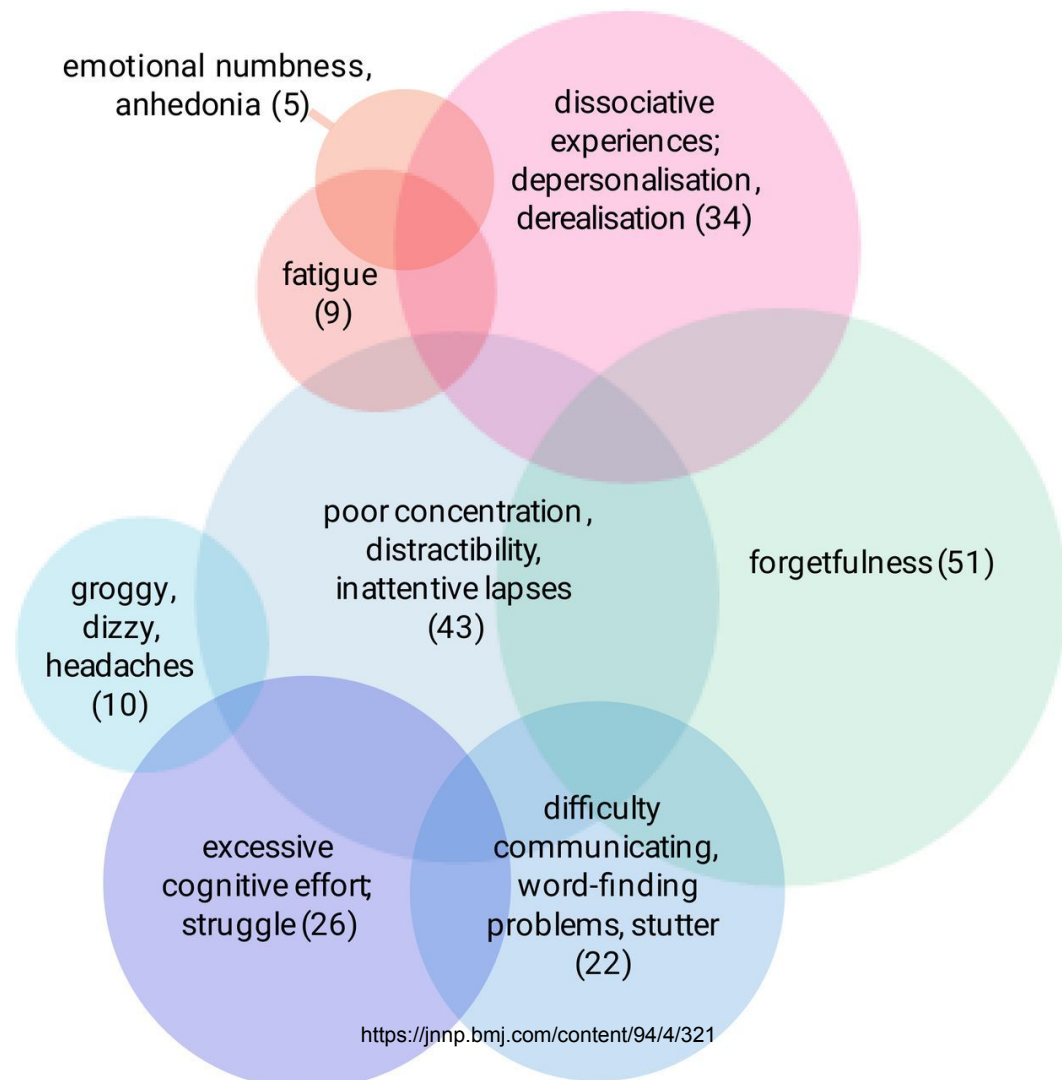


Cognitive Aids - Apps can read out loud to you, check your writing, AIs can rewrite text in ways that is easier to understand. Can ask for different fonts and sizes of writing. Aids can be people, Youtube Videos etc.

Physical aids - Note can save energy & increase safety :mobility, sensory, handrails, shower seats, laptop tables, bed wedges etc.

Brain Fog

- Can be caused by PEM/PESE
- Commonly experienced to some degree even when pacing well
- Are other causes and contributors to brain fog including sleep issues, dysautonomia, cardiac issues, PTSD and others



Adapting to Brain Fog

Reduce pressures on memory - use memory aids and supports, reduce passive memory pressures

Avoid over-stimulating activities

Adapt activities -e.g. Might be different books to read

Minimise multitasking and sensory overload

Use help and support when needed e.g. can use apps to read to you,

Can use AI to rewrite sentences etc., have someone check emails,etc.

Remember that you may need to do and approach tasks in very different ways

You might be not able to safely do some activities you did before

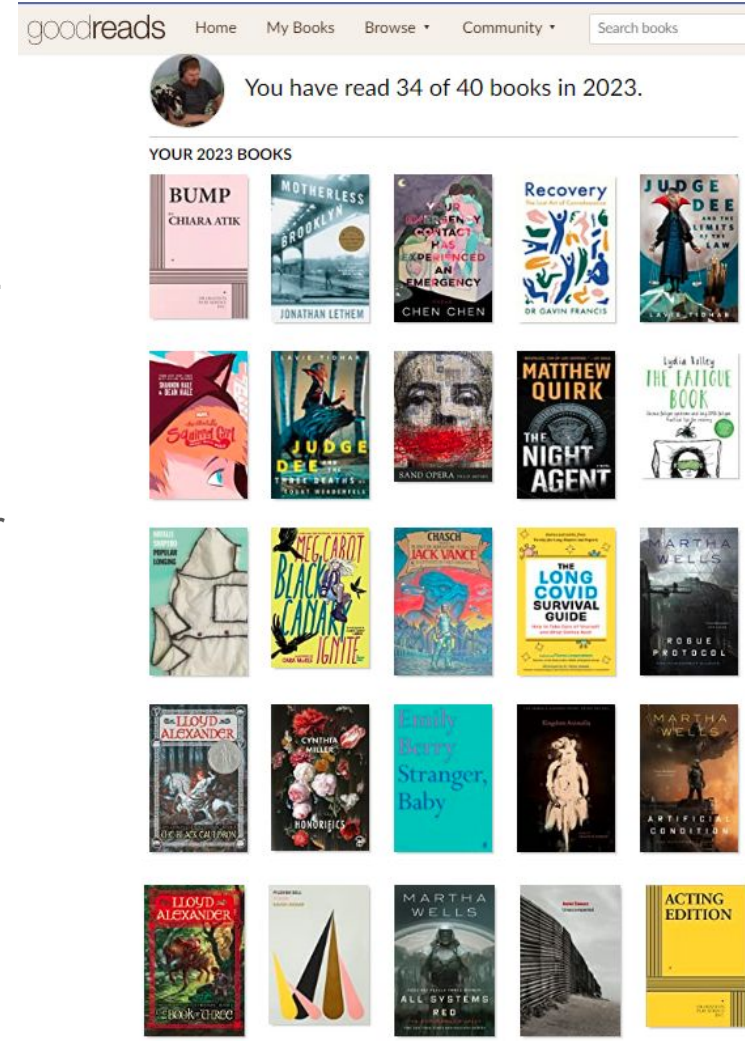
I choose to not do some things I love because they are too stimulating - so hard to switch off

Don't judge yourself on the "old" you



Example: Reading for pleasure

- I have changed what books I read - nothing too complex, nothing too stimulating, nothing too long. More likely to read short stories or poems
- I have changed when I read
- I have changed the circumstances in which I read (no distractions)
- I use Wikipedia and others sites to help remember plots and characters and reviews to help clarify or explain anything I was confused about
- I make sure to break up my reading e.g. 20 min, 5 min rest, then a longer rest after I have been reading a while.
- I cannot always read for pleasure - sometimes it takes too much out of me, sometimes I have too much brain fog



goodreads Home My Books Browse Community Search books

You have read 34 of 40 books in 2023.

YOUR 2023 BOOKS

Challenge

How much is brain fog an indication and warning you are doing too much? How much it is a problem in and of itself that you have to manage or deal with?

Other Brain Fog Challenges

- Relationships and communication with others- daughter hearing example
- Work: Reasonable Adjustments, Aids, Access to Work (UK)
- Leisure - Sometimes it's easier to do new or variations of old hobbies

The Future

Research into Brain fog is looking fairly promising:-

ADHD meds Guanfacine and NAC are being trialled with Lon COVID patients and some people are getting them outwith research too

<https://www.yalemedicine.org/news/long-covid-brain-fog-treatment>

Researchers found that damage to the brain's white matter after COVID-19 resembles that seen after cancer chemotherapy, raising hope for treatments to help both conditions

<https://med.stanford.edu/news/all-news/2022/06/brain-fog-covid-chemo-brain.html>

“toxic clumps of protein”

<https://www.latrobe.edu.au/news/articles/2022/release/possible-cause-of-long-covid-brain-fog>

Hyperbaric Oxygen Therapy - <https://pubmed.ncbi.nlm.nih.gov/35821512/>