

Pacing through the summer

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Overview

- Environment
- Attending and Hosting Events
- Travel car/plane
- Crash planning

It's a new way of being and doing

- It can be hard to change the way to approach life and activity
- Frustrating when you don't have the energy to do things, and when you need to stop/rest
- Be kind to yourself as you learn about pacing and learn new tools to support your health

It's an investment in your long-term health and function!

PACE

Plan	Plan your energy
Adapt	Adapt your activities and environment
Cope	Coping and Resilience
Engage	Engage with the community

Plan your Energy: Environment

Does weather impact your symptoms?

- Check weather report ahead of time
- Is there places you can get relief (Access to A/C, air purifier etc.)
- Plan for more time, more rests

Adapt activities: Environment

Air:

- Air purifier (HEPA filter for smoke particles)
- Respirator (Example: Disposable 3M 8511 and 3M 8210 or reusable 3M 6501QL)

Adapt activities: Environment

Heat:

- Foot bath with ice packs
- Handheld fan
- Spray bottle
- Cooling garments
- Cooling mats or seat cushions

Cooling Vests

1. Phase Change Cooling Vests:

releases the stored cooling energy more slowly and they do not overcool the skin

2. Cold Pack Cooling Vests:

immediately cool down the skin

3. Evaporative Cooling Vests:

fabric generates a cooling sensation as the water evaporates

<https://www.mscoolingvest.ca/>

<https://www.thermapparel.com/>

Plan your Energy: Events

General tips:

- Pre-emptive rest
- spread out tasks
- look for energy savers
- set expectations for yourself and the host/guests

Plan your Energy: Events

Attending:

- Consider emotional energy expenditure
- Is there a space to recharge?
- Have an exit strategy

Hosting

- Plan the party type around your needs
- Delegate tasks to others (must do, nice to do, not to do, who else can do).

Adapt activities: Events

While attending:

- Follow your activity tolerance – use Microbreaks
- Manage emotional energy – can you have a point person
- Environment – Where is it quieter/possibility to sit etc.

While hosting:

- Switch between energy types (socializing, food prep etc.)
- Delegate responsibilities during the event (collecting cans to put in recycle, check on food etc.)
- Easy cleanup – use paper plates/cups, station garbage bins
- Have a set time when the event will end

Cope: Events

Plan for recovery rest after the event

Reflect on the event – What strategies worked?

What will you try next time?



Success stories

Use the “raise hand function” if you have a success story to share



Plan your Energy: Travel

- use to-do lists (save and reuse them)
- spread out tasks such as preparing packing and tidying over a few days/weeks prior. Same with unpacking on return.
- Pre-emptive rest: clear your schedule the day before/day off travel to ensure you are staying within your energy envelope.
- Bring your own snacks to make sure you have food that is agreeable for you. Airports/ rest stops do not always have a lot of options.



Adapt activities: Travel

Air travel:

- Use gate assistance service (<https://www.yvr.ca/en/passengers/accessibility-at-yvr>)
- Sunflower lanyard
- Plan for layovers (<https://www.sleepinginairports.net/>)
- Adapt your position: foot hammock, seat support, noise cancelling headphones, neck support
- Think about where to sit on the plane. If you like to get up frequently or lean on the window? How much legroom do you need? (Seat Guru or similar)

Prioritize what are the most important things to you when you get to your destination

Adapt activities: Travel

Car:

- Map out rest stops and set driving times
- How do you rest? Stretching, relaxation?
- Adapt your position (stool, car bed, blind spot mirrors),

Ferries:

free reservations and travel for patients travelling to and from medical specialist appointments as part of the BC Government's Travel Assistance Program (TAP)

<https://www.bcferries.com/book-sailings/medical-assured-loading>

Adapt activities: When you get to your destination

- Use Komoot or similar app to plan any walking (elevation and grade)
- Are e-bike/e-scooters available where you are going. Make an account or get the app before you get there.
- Tours
- Bookmark places/restaurants (brainfog and decision making)

Cope: After Travel

- Plan for recovery, what is your travel crash kit?
- Set expectations for yourself based on your energy level e.g. useable hours.
- When visiting friends and family, discuss expectations and adjustments

Success stories

Use the “raise hand function” if you have a success story to share



Crash Kit when travelling

- What do you need to bring from your at home crash kit?
- List of doctors' names, specialty, and phone number(s), printed recent patient visit note
- List of emergency contacts
- High protein snacks such as protein or breakfast bars, nuts, dried fruit
- Protection for sensory overload (eye mask, earplugs etc)
- Ice or heat packs
- Written crash care instructions
- Rescue medications

<https://batemanhornecenter.org/crash-care-kit-essentials/>

Engage: Community Resources

- Cooling Stations
- Water parks
- Beaches – water quality
- 211

Questions?