

Communicating your pacing needs to others

Overview



Provincial Health
Services Authority

- Understanding about the disease
- Communicating your pacing strategies
- Talking about uncertainty
- Communication about crash management

Land acknowledgement

I acknowledge with gratitude, that we are gathered on the traditional, ancestral and unceded territories of the x^wməθk^wəyəm (Musqueam), Skwxwú7mesh Úxwumixw (Squamish Nation), and sə'ílwata? (Tseil-Waututh) Nations who have nurtured and cared for the lands and waters around us for all time. I give thanks for the opportunity to live, work and support care here.

Understanding about the disease and how to talk about it

“I feel seen when you take the time to learn about my disease and better understand what I am going through”

- It can be difficult to convey to others what you are living with
- In this process of sharing and boundary setting remember to be kind with yourself

Talking about the disease (sandy ADD)

What knowledge to communicate:

It's an energy limiting disease

What role does the Mitochondria play

It's about can't not won't

It's NOT a mental health diagnosis

Talking about the disease

What knowledge to communicate:

It's an energy limiting disease:

What role does the Mitochondria play

It's about can't not won't (PEM)

It's NOT a mental health diagnosis

Where to find education materials

- Friends and Family Presentation: <https://drricarseneau.ca/family-and-friends>
- Bateman Horne Center: What is ME/CFS
<https://www.youtube.com/watch?v=vQWVZdGm508>
- Long COVID Physio Video Series:
<https://www.youtube.com/playlist?list=PLzyLGd4jQxQ-zNjmOUR43ha53AjXHU3HH>
- Post-viral Fatigue Videos: <http://www.bcwomens.ca/health-info/living-with-illness/post-viral-fatigue>

Materials for others



Books for kids:

- What Happens When Someone I Love Doesn't Feel Good: A Book About Chronic or Terminal Illness That Won't Go Away - by Sara Olsher and Jenni Rogers
- How Many Marbles Do YOU Have?: Helping Children Understand The limitations of Those With Chronic Fatigue Syndrome and Fibromyalgia - Melinda Malott

Books for adults:

- Chronic Fatigue Superhero: The Hero with ME/CFS - POTS - Fibromyalgia etc. – Michael Towers
- Aches, Pains, and Love: A Guide to Dating and Relationships for Those With Chronic Pain and Illness – Kira Lynne

For providers:

- NICE guideline Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management, Published: 29 October 2021;
<https://www.nice.org.uk/guidance/ng206>
- Literature: <https://batemanhornecenter.org/providers/medical-education/literature/>

Communicating your pacing strategies - “I need extra support”



Communicating about:

- ▶ HR monitoring

Using this as an objective number, instead of a feeling. Some people respond better to that

Share app data e.g. visible

- ▶ Use of analogies (marbles, battery, gas tank etc.)

Removing comparative language (“I am tired too”)

Ask the other person if they can think of an analogy/language they can relate too

Examples:

“I need to go to my docking station” “My battery is in the red”

“I have 2 sugar packs left” “Hockey” “Me 2.0”

Explaining the energy types

Can help to understand the load of an activity and why PEM happens

Examples:

- Shared google calendar to communicate energy levels when planning to meet/do stuff
- Share access to HR data

Asking and receiving help

- This can be a big shift in the relationship dynamic as well as in self- perception
- Create a delegation list
- Use the symptom management education tool

Mild Symptoms .../10 (*adjust this to represent your mild or constant symptoms*)

Communication to family (and friends):

My symptoms feel like:

-
-
-
-

What family/friends can do:

-
-
-

Instructions for self:

-
-
-

Talking about uncertainty- symptoms being unpredictable

“I may look ok today – chances are that will change so I need to pace to stay in my energy envelope”

- ▶ Chronic illness can be like a rollercoaster

Why do good and bad days happen:

- ▶ Understanding the demands on the system, it's difficult to learn the bodies “language” and easy to miss warning signs, stressors are not always obvious

Uncertainty of Long COVID video:

<https://www.youtube.com/watch?v=KHHIYrDmby4&list=PLzyLGd4jQxQ-zNjmOUR43ha53AjXHU3HH&index=4>



Planning ahead: Identifying unusual symptoms

When the uncertainty of symptoms leads to changing plans:

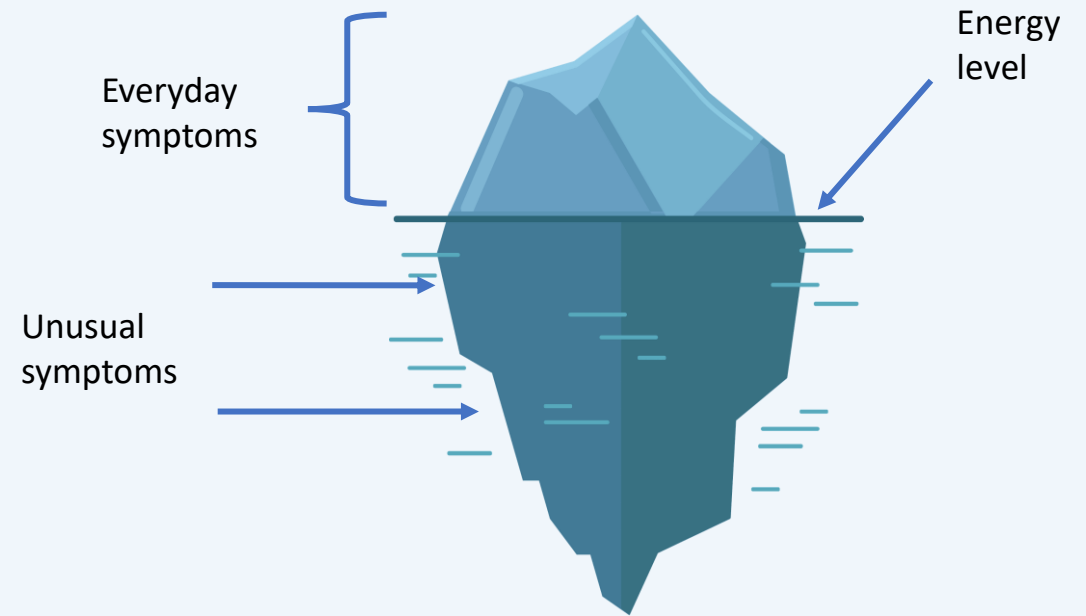
- What could a counteroffer be?

Examples:

“I can’t leave the house today can we have a video call instead of meeting up”

“Thanks for the birthday party invitation. I won’t be able to make it. I would love to celebrate you over a cup of tea just you and me”

“I need to go rest in the car during your hockey game and I will ask another parent to film it for me.”



Crash management

“I am still me”

“I did everything I could to avoid it and I am still crashing”

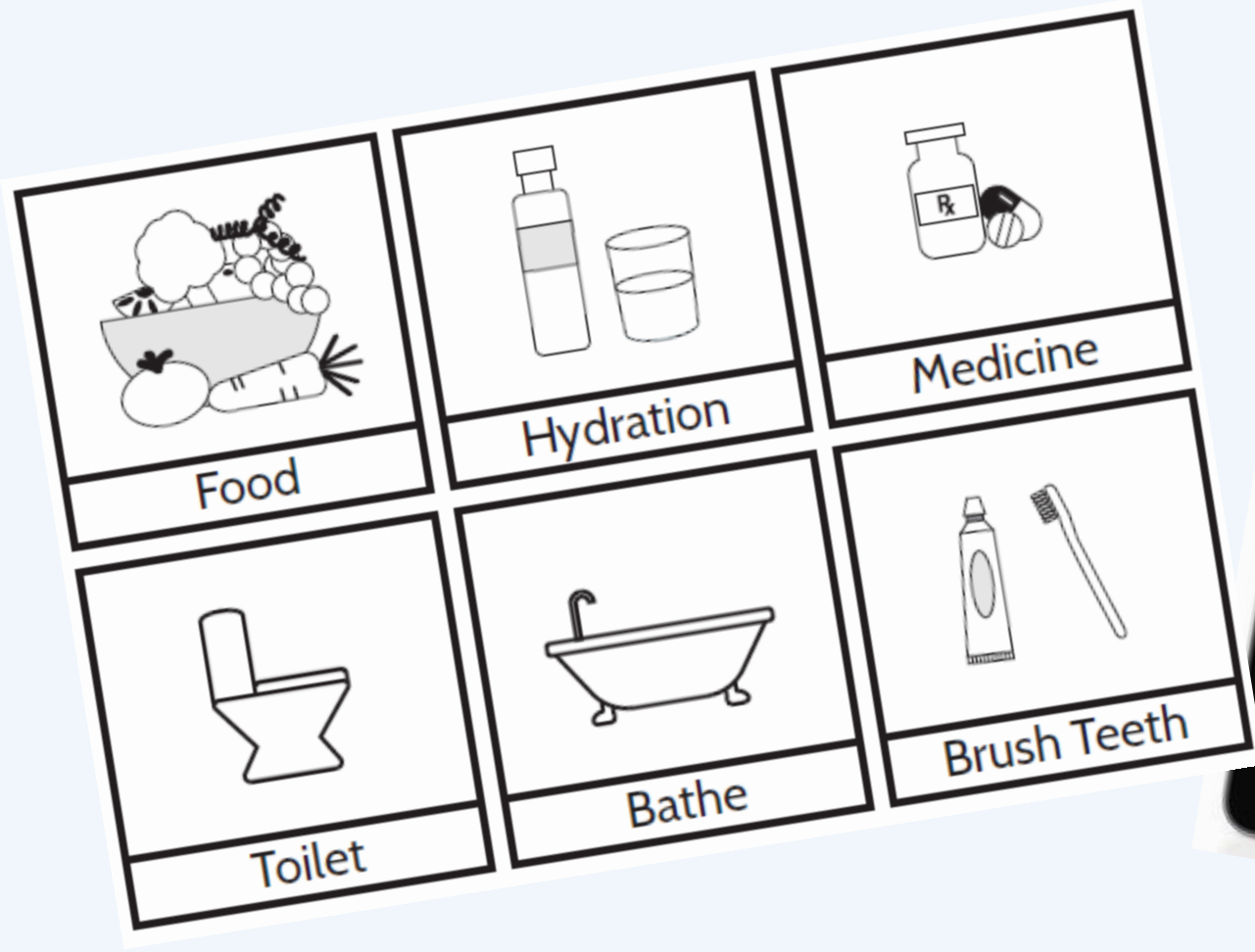
“ it just happens I need your support”

Explaining PEM:

- There is difference between deconditioning and PEM
- Can you recover after an activity?

“You went for an extra long walk and might be sore but you will be ok the next day – I will not”

Bateman Horne Center PEM video: https://www.youtube.com/playlist?list=PL-OZ_5Cqdc309Gp1hO4PpUKQIsTlyUf04



<https://batemanhornecenter.org/wp-content/uploads/2022/01/Color-Critical-Needs.pdf>

AAC is short for Augmentative and Alternative Communication. Basically, AAC can be tools, systems, devices or strategies. These tools help a person communicate, when they cannot rely on speech.

Connecting with your peers

It can be draining and defeating to not be believed or constantly explaining your needs.

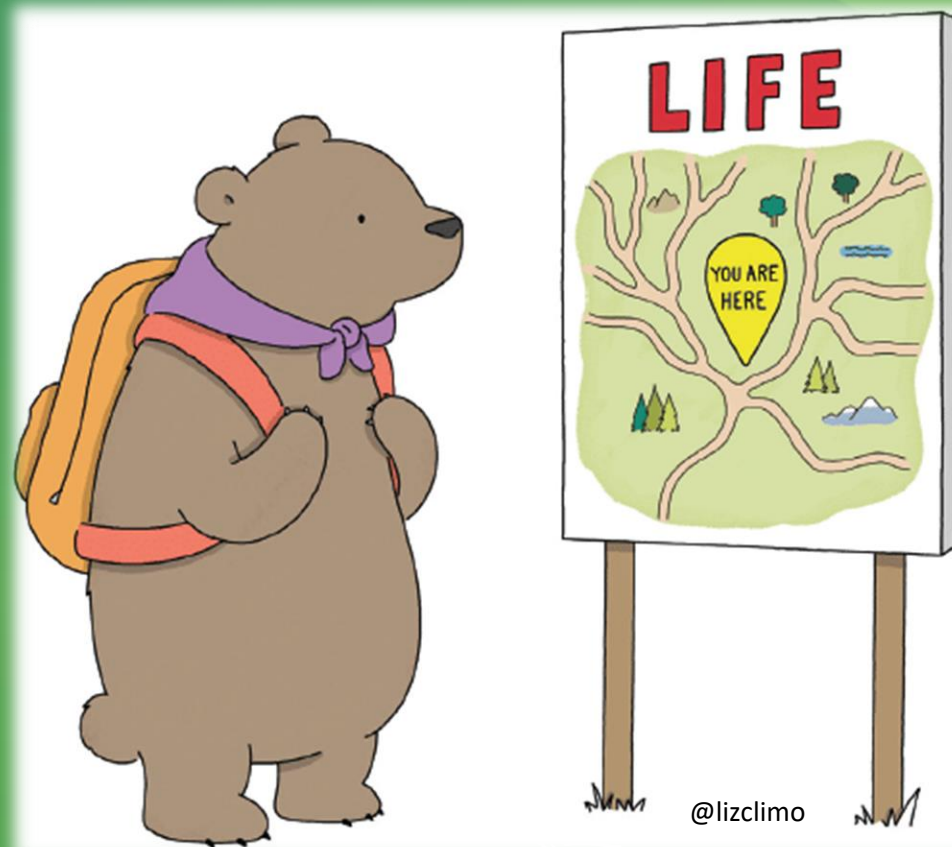
Peer support

- ME/FM Society of BC: <https://www.mefm.bc.ca/support-groups>
- Pain BC: <https://painbc.ca/find-help/support-programs>

Self-compassion Reminder

Talking to others about what you need and how you are can bring up strong emotions. Remember to be kind to yourself

<https://self-compassion.org/>



Questions?