

Newly Diagnosed

MEETUP

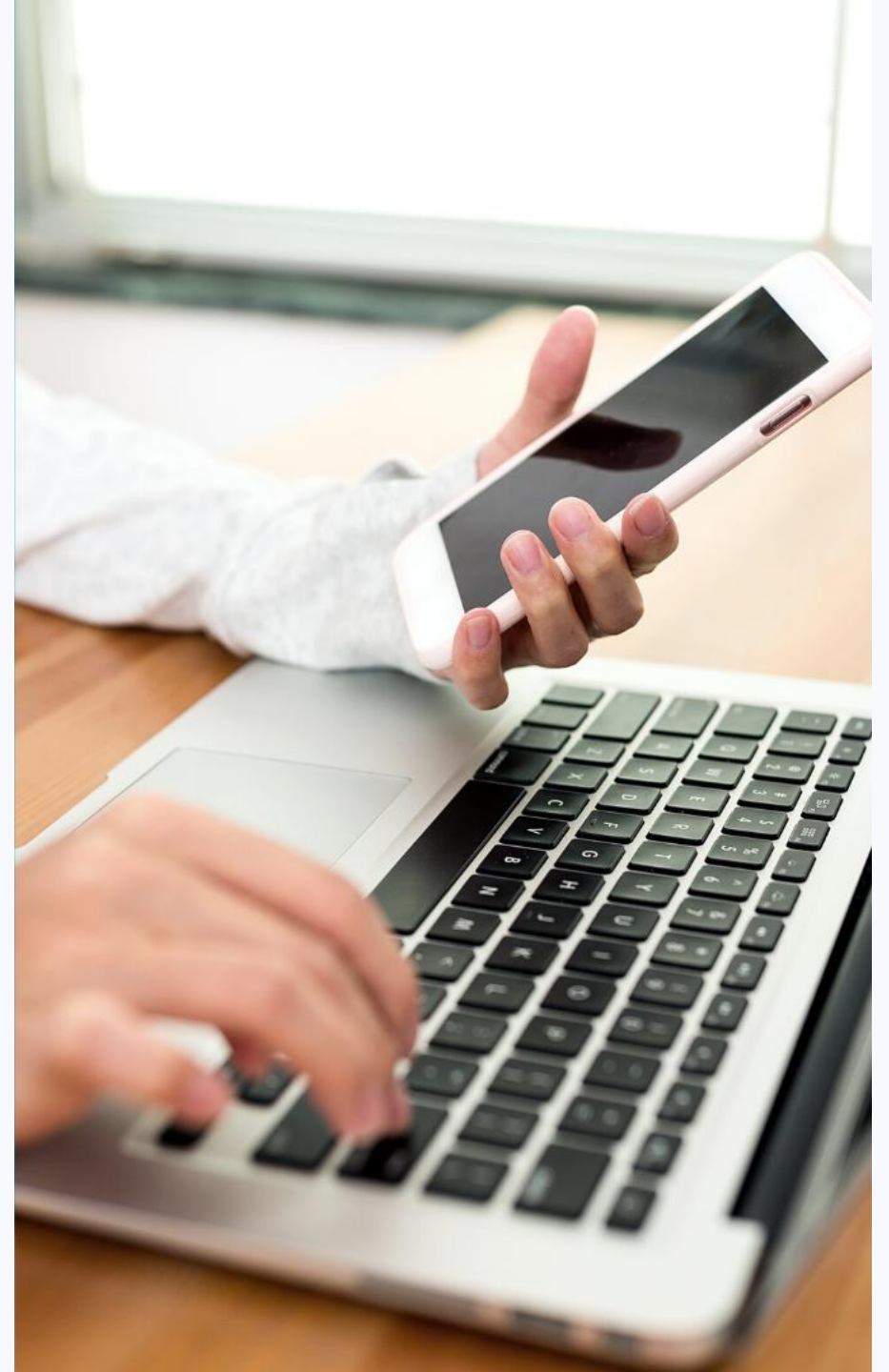
Managing Your MS in Real Life

CAN DO
MULTIPLE SCLEROSIS

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YOUR COACHES



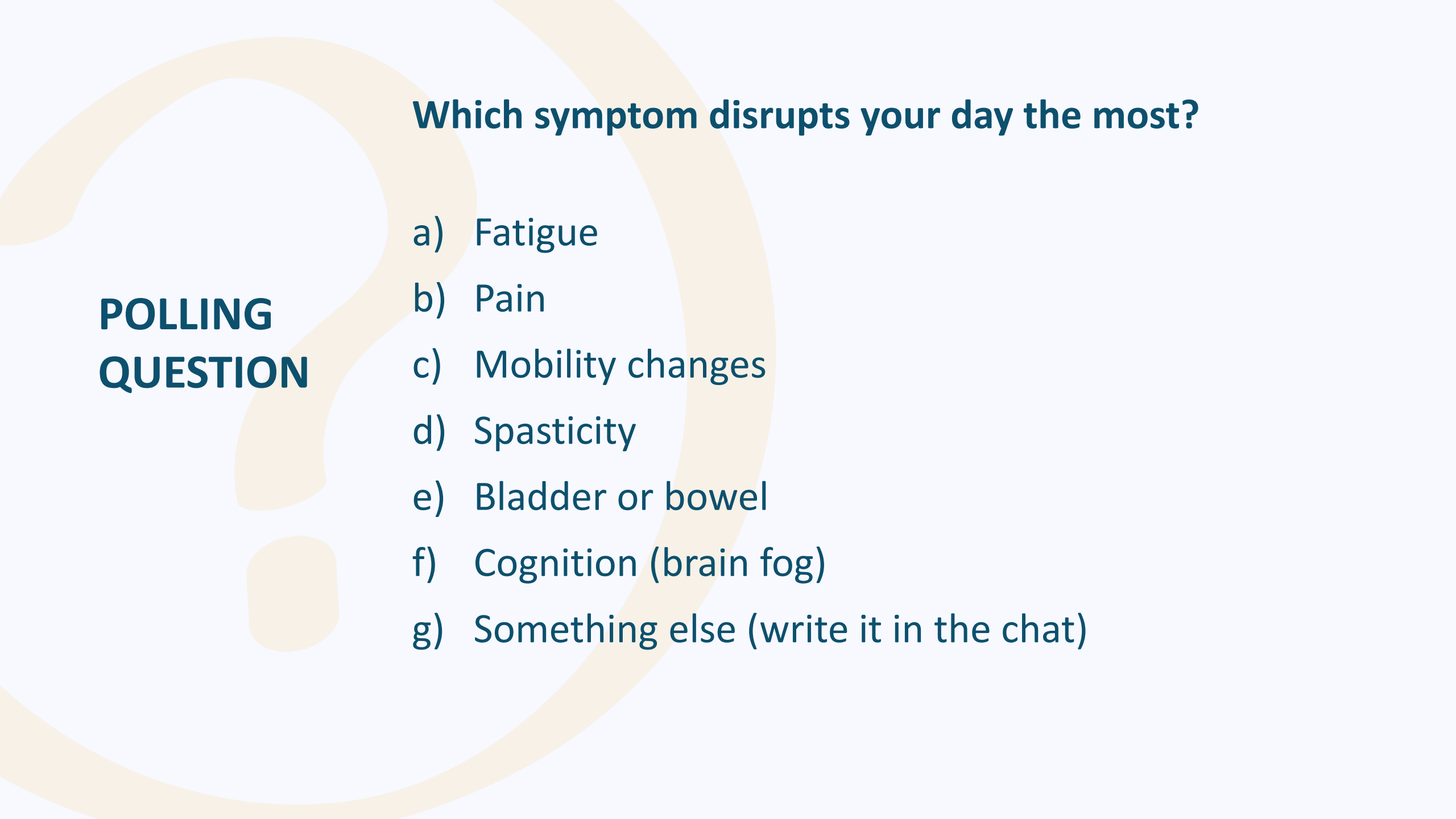
Meghan Beier

Neuropsychologist



Brandyn Geist

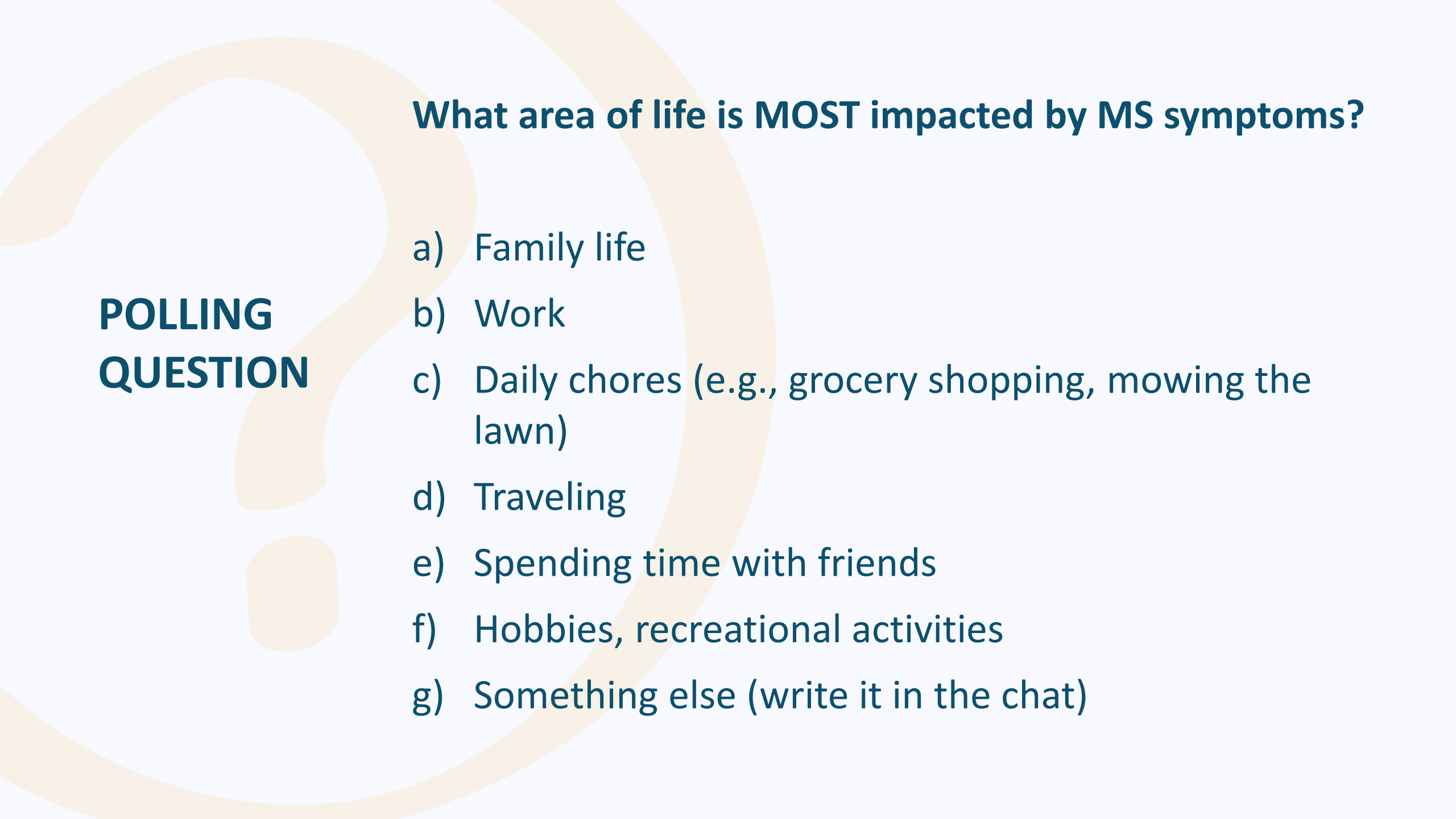
Occupational Therapist



POLLING QUESTION

Which symptom disrupts your day the most?

- a) Fatigue
- b) Pain
- c) Mobility changes
- d) Spasticity
- e) Bladder or bowel
- f) Cognition (brain fog)
- g) Something else (write it in the chat)



POLLING QUESTION

What area of life is MOST impacted by MS symptoms?

- a) Family life
- b) Work
- c) Daily chores (e.g., grocery shopping, mowing the lawn)
- d) Traveling
- e) Spending time with friends
- f) Hobbies, recreational activities
- g) Something else (write it in the chat)

Daily Management of MS Symptoms

What we will cover today:

1. Medical Management
2. Behavioral Strategies
3. Tools and Environmental Strategies
4. Managing Disruptions

We want you to learn from each other as much as from us!



Share ideas that have worked for you in the chat, during discussions

Working with Your Medical Team



Start by Getting It Checked Out



- **New or persistent symptom? The first step is to have your neurologist or medical team evaluate it.**
- **They can sort out what's going on: an MS symptom, a possible relapse, a medication side effect, or something unrelated.**
- **From there they might recommend a medication or procedure, suggest a therapy or strategy, or refer you to a specialist.**



What Medical Management Can Look Like



Fatigue:

- check for treatable contributors such as sleep, mood, medications, or thyroid, then discuss options.

Spasticity or stiffness:

- stretching and PT
- medication
- targeted injections

Bladder changes:

- medication
- pelvic floor PT
- referral to urology

Walking or balance:

- PT and OT
- assistive tools
- rehab referral

Write it in the chat



How has your medical team
been helpful in addressing
MS symptoms?

Building Your Medical Team



- **Neurologist:** MS symptoms
- **Primary care:** whole-health, treating comorbidities (e.g., diabetes, heart disease, etc.), ruling out other causes such as infections.
- **Rehab team (PT, OT, SLP):** movement, assistive devices, energy management, daily tasks, communication, and cognition
- **Urologist, Urogynecologist, Pelvic Floor PT, GI:** bladder, bowel, sexual dysfunction
- **Psychologist, Social Worker, LPC:** mood, coping, adjustment, communication, relationships, and cognition

Addressing Symptoms in Medical Appointments

- Track symptoms and patterns between visits.
- Prioritize your top two or three, then keep the rest for any remaining time in the appointment
- State the impact: “This is stopping me from ____.”
- Ask: “What are my options?”



Group Discussion

Who is on your medical team?
Do you see a specialist that was not listed?



Behavioral Strategies



What Are Behavioral Strategies?

Mindset

- Setting realistic expectations
- Learning to address or work with unhelpful thoughts
- Education



Behavior

- Developing predictable routines
- Helpful and healthy habits
- Scheduling activities that bring joy or contentment



Addressing How Your Body Feels

- Relaxation strategies
- Massage, Acupuncture

Mindset

1. It's ok to feel frustrated, anger, grief, and more
 - Name the emotions
 - Comfort yourself
 - Continue engaging in activities and relationships that are meaningful
2. Set realistic expectations without giving up on goals or dreams
3. Adapting routine rather than abandon them
4. Set the bar for the day you're having, not your best day
5. "Good enough" still counts
6. MS symptoms are hard AND you can still build a meaningful life

Write it in the chat



**Are there any mindset strategies you
use?**

Managing Fatigue: The 4 P's

Planning

Schedule hard tasks during your best hours.

Prioritizing

Decide what truly has to happen today. Let the rest wait.

Pacing

Break big tasks into pieces. Schedule rest breaks.

Positioning

Set up your space and body to use less energy.

Relaxation Exercises

Good for:

- Anxiety, stress, mood
- Pain
- Cognitive challenges

Examples:

- Mindfulness: 5 senses, mindful eating
- Pursed-lip breathing: in through the nose, out slowly through pursed lips. Especially good for people with COPD or shortness of breath
- Box breathing: in 4, hold 4, out 4, hold 4.
- Body scan: move your attention slowly from head to toe.
- Autogenic training



Mini Body Scan

Let's Practice



Group Discussion

What was your experience like doing this relaxation exercise?



Group Discussion

What is one way you've successfully adapted your daily routine to incorporate those disruptive symptoms?



Tools and Environmental Strategies



Environment

- ★ **The environment shapes wellbeing as powerfully as the coping you do.**
- ★ **Depending on your environment, you may have a very different day.**
- ★ **MS research shows supportive environments help people stay engaged even as symptoms change.**

Examples:

- **heat and weather**
- **financial resources**
- **busy or chaotic store**
- **accessibility**
- **distance from the store to parking space**
- **the people around you (helpful or critical)**
- **public attitude or stigma**

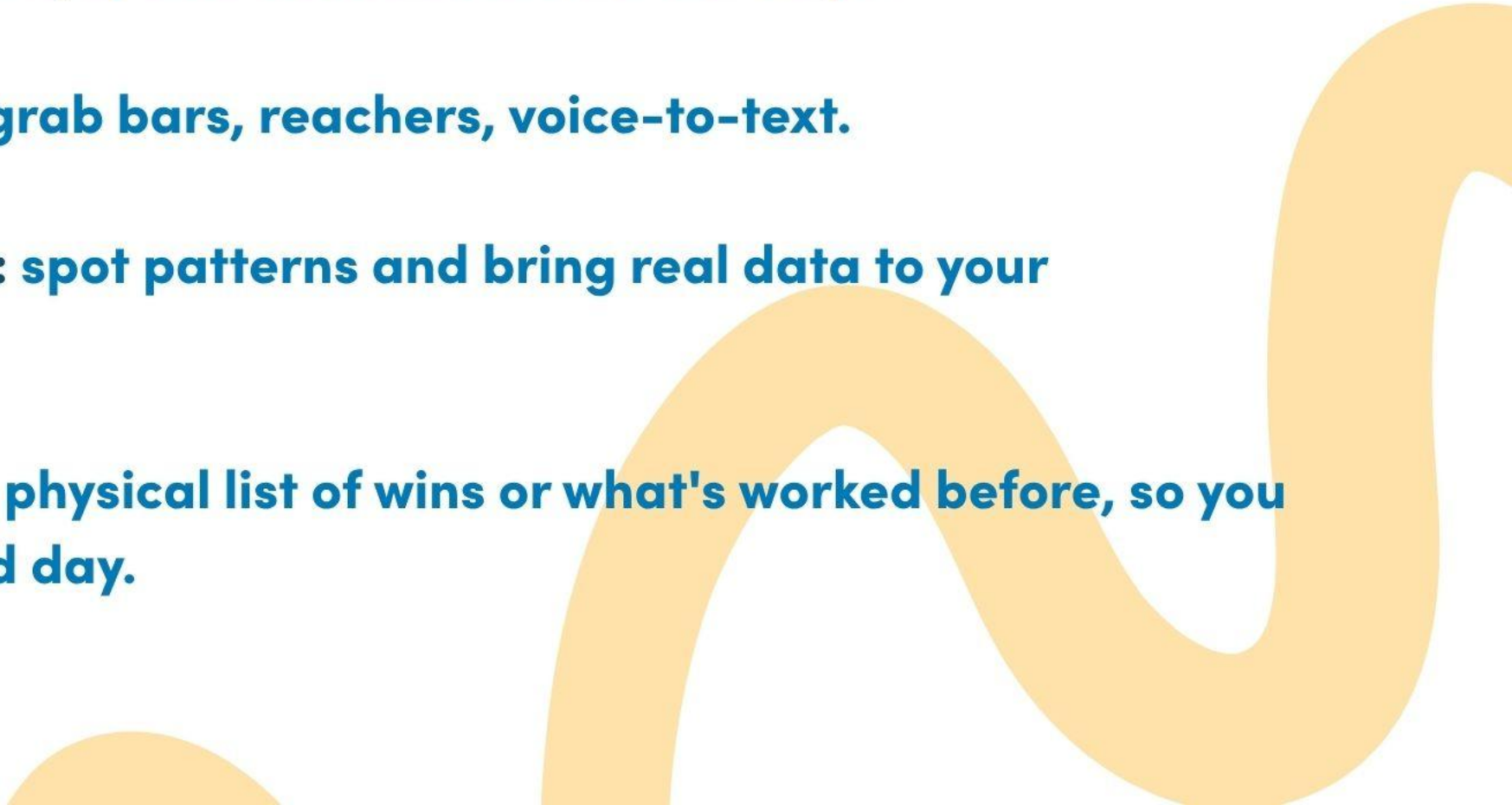
Tools & Assistive Devices

Cooling devices: vests, wraps, and neck coolers for hot days.

Assistive tech and aids: grab bars, reachers, voice-to-text.

Symptom-tracking apps: spot patterns and bring real data to your appointments.

List of successes: keep a physical list of wins or what's worked before, so you can reach for it on a hard day.

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You Are Not Alone

Find your people: support groups exist online and in person. A few good starting points are Can Do MS, the National MS Society, and My MSAA Community.

Online Connection: reading an online forum, a one-on-one peer match, an on-demand webinar, or a helpline.



Group Discussion

**What practical tool, strategy, or workaround
has made the biggest difference in your day-to-
day life?**



Managing Disruptions



Write it in the chat



How do you prepare for situations you know might be harder (travel, long days, heat, busy weeks)?

Getting Started Is an Experiment

Starting a new habit or routine starts with experimenting if it will work for you.

- ★ Can I stick with this?
- ★ If not, what got in the way?
- ★ How can I adjust?
- ★ Do I need to pick something else?

Start tiny: A 2-minute version you do every day solidifies the habit

- Good for bad fatigue days

Anchor a new habit into something you already do

Celebrate wins!

Habits: What Helps Or Interrupts

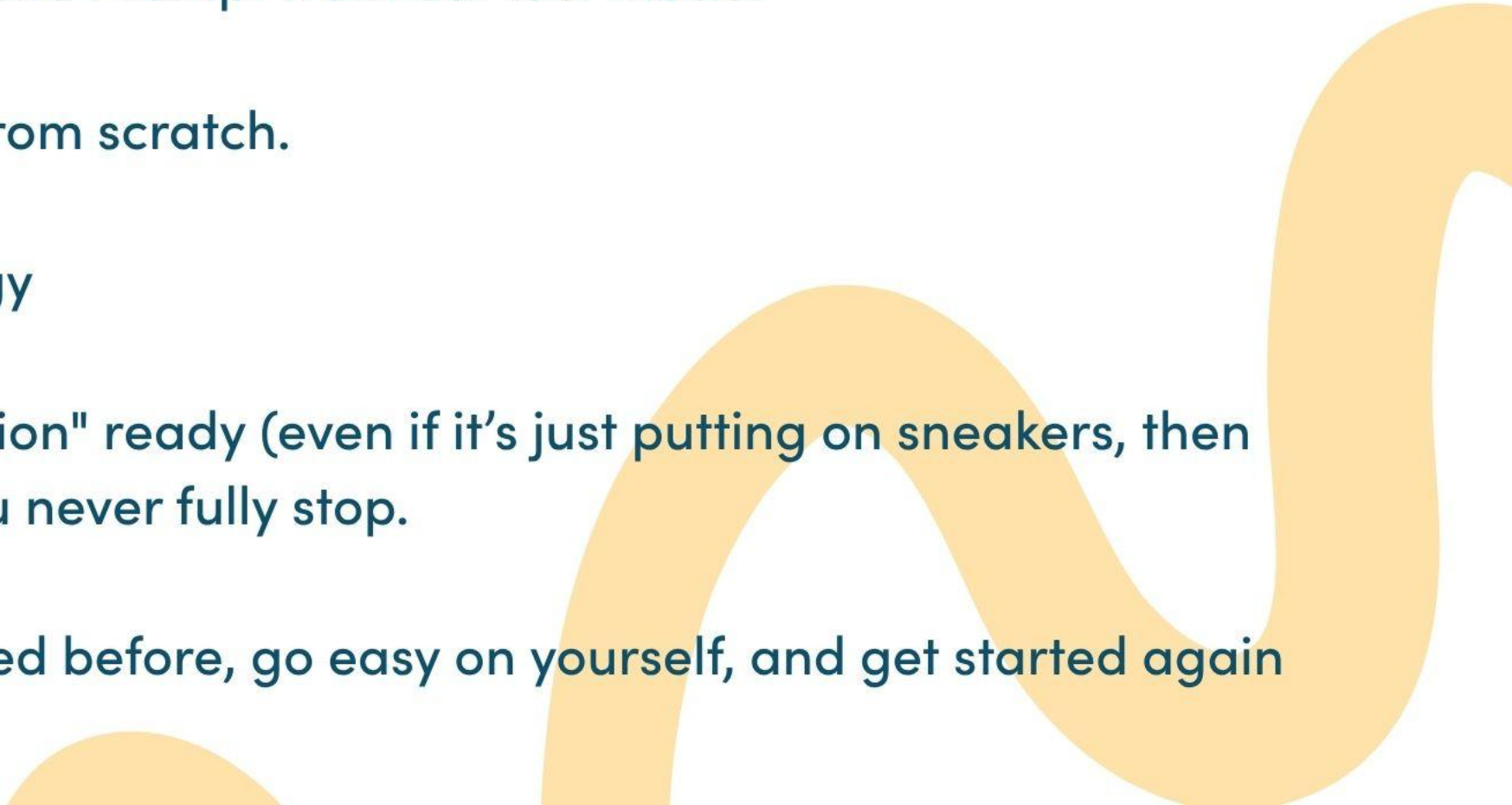
Why It Works (or doesn't)

- **M: Motivation** – do I want to do it?
- **A: Ability** – how easy it is to do
- **P: Prompt** – Cue that tells you to do it right now
- Often one of these is missing
- Lean on ability – make the behavior so small, easy, and tiny you don't need much motivation to do it

How to Start

- Emotions solidify habits
 - After I [existing routine],
 - I will [new tiny behavior].
 - Then [celebrate] immediately
- While I wait for my morning tea to steep, I will do one stretch. Then smile and say “good job” to myself.

Restarting After a Disruption

- Travel, illness, a sick kid, a rough fatigue stretch: disruption is expected, will happen to all of us, not a failure.
 - These often knock out the Prompt from our last model
 - You're never starting from scratch.
 - Flexibility is the strategy
 - Keep a "minimum version" ready (even if it's just putting on sneakers, then taking them off) so you never fully stop.
 - Remember what worked before, go easy on yourself, and get started again when you are able.
- 
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Group Discussion

**How do you celebrate your wins (big or small)
or validate the success you've earned?**





**Please Take
Today's Survey**

**Thank you!
We Appreciate Your Feedback!**



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