

EXTERNALLY LED PATIENT-FOCUSED DRUG DEVELOPMENT MEETING

31 OCTOBER 2023

PRESENTATION

**Accessing Comprehensive
Integrative Care for Hypermobility**

SPEAKER

Maggie Buckley, MBA, BCPA
Independent Health & Patient Advocate



Nothing to Disclose



What We Will Cover



- Growing up with Hypermobility
- Balancing Building Blocks of Care
- Obstacles to Care
- Hope & Solutions
- Example of Comprehensive Integrative Care



Journey to Coping With Hypermobility

- ❖ 1973 Hypermobility Diagnosis
- ❖ Orthopedist listed things to limit or avoid doing
- ❖ First gift: disclosing his own diagnosis hypermobile joints
- ❖ Second gift: sharing lived experience of how to cope with hypermobility
- ❖ Third gift: Facilitation and guidance

The To Do List



- ✓ Learn anatomy and medical terms
- ✓ Communicate Concisely
- ✓ Listen to my body
- ✓ Take notes
- ✓ Try everything
- ✓ Be willing to stop/fail
- ✓ Pacing
- ✓ Set personalized limits



Healthcare Provider Support

Set up a referrals to learn the skills needed to succeed:

- Physical Therapy – strengthening key muscle groups to compensate for loose joints
- Yoga – build a mind body connection
- Meditation – breathing, pacing, calming
- Mental Health support

Follow-up appointments to monitor progress, adjust recommendations, advise other HCPs



Patient Engagement

- Different Methods; acupuncture, massage, Pilates, Feldenkrais, Alexander Technique
- Different sports/exercise options; aerobics to yoga
- Assistive devices; needle-nose pliers to wheelchairs
- Build a network of people with chronic health conditions to learn tips and tricks to cope

Evolution of Access



- Teenage years: many things were available through the HMO, local university research studies and school
- Young Adult in the workforce, things were not as easily accessible due to geographic, financial and insurance coverage limitations/denials
- Maturing Adult: maintaining medical coverage, appealing coverage denials, age bias

Other Obstacles

- Denial of insurance coverage
- HCPs disbelieving the diagnosis
- HCPs not understanding the multi-systemic nature of hEDS, HSD or Hypermobility diagnoses
- HCPs saying “This doesn’t mean you are going to die or be cured so figure out how to accept the symptoms that cannot be resolved.”
- Under-treated Pain
- Under-recognized Fatigue

Hope & Solutions

- Listen to those with lived experience
- Envision Comprehensive Integrative Healthcare
- In your sphere of control facilitate change to support Comprehensive Integrative Healthcare



CIPM TOOLBOX

IMPORTANT FACTORS

Trauma-Informed Care
Education
Risk Assessment
Stigma

SOCIAL FACTORS

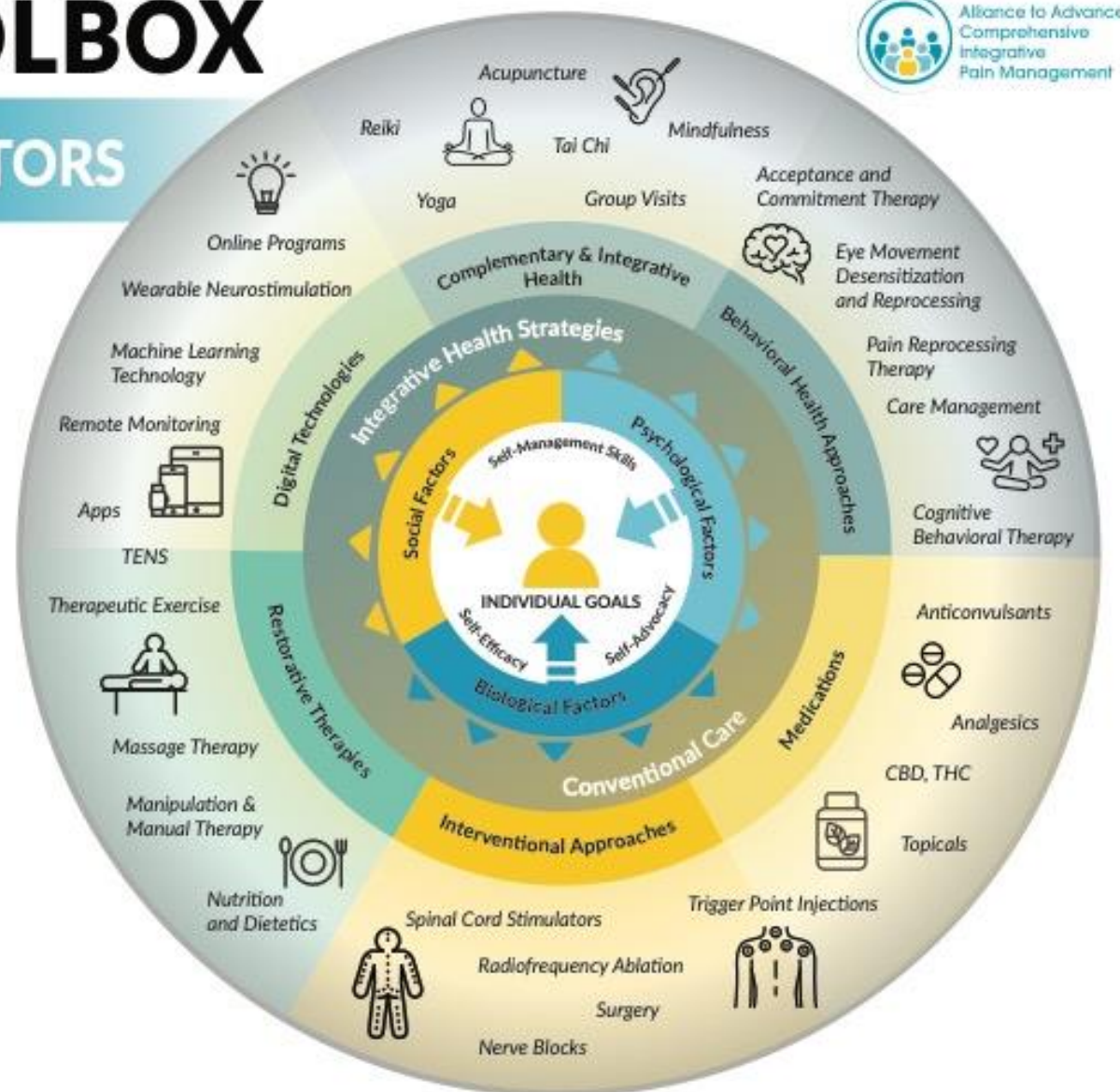
Environmental
Stigma
Cultural
Racism
Discrimination
Housing
Transportation
Food Security

PSYCHOLOGICAL FACTORS

Mood
Stress
Coping
Trauma
Isolation

BIOLOGICAL FACTORS

Age
Injury/Past Injury
Illness/Diagnosis
Neurologic
Genetic
Hormones
Nutrition
Metabolic Health



AACIPM offers this visual tool to illustrate and increase awareness of the various therapies that may be a part of whole person, multidisciplinary, multi-modal, evidence-informed, integrative pain management. This does not represent an exhaustive list of interventions, and not all interventions will be covered, covered without limits and/or without patient out-of-pocket cost.* Most services must be provided by a licensed or credentialed health care provider or community-based service provider.





**Thank you for
your attention**