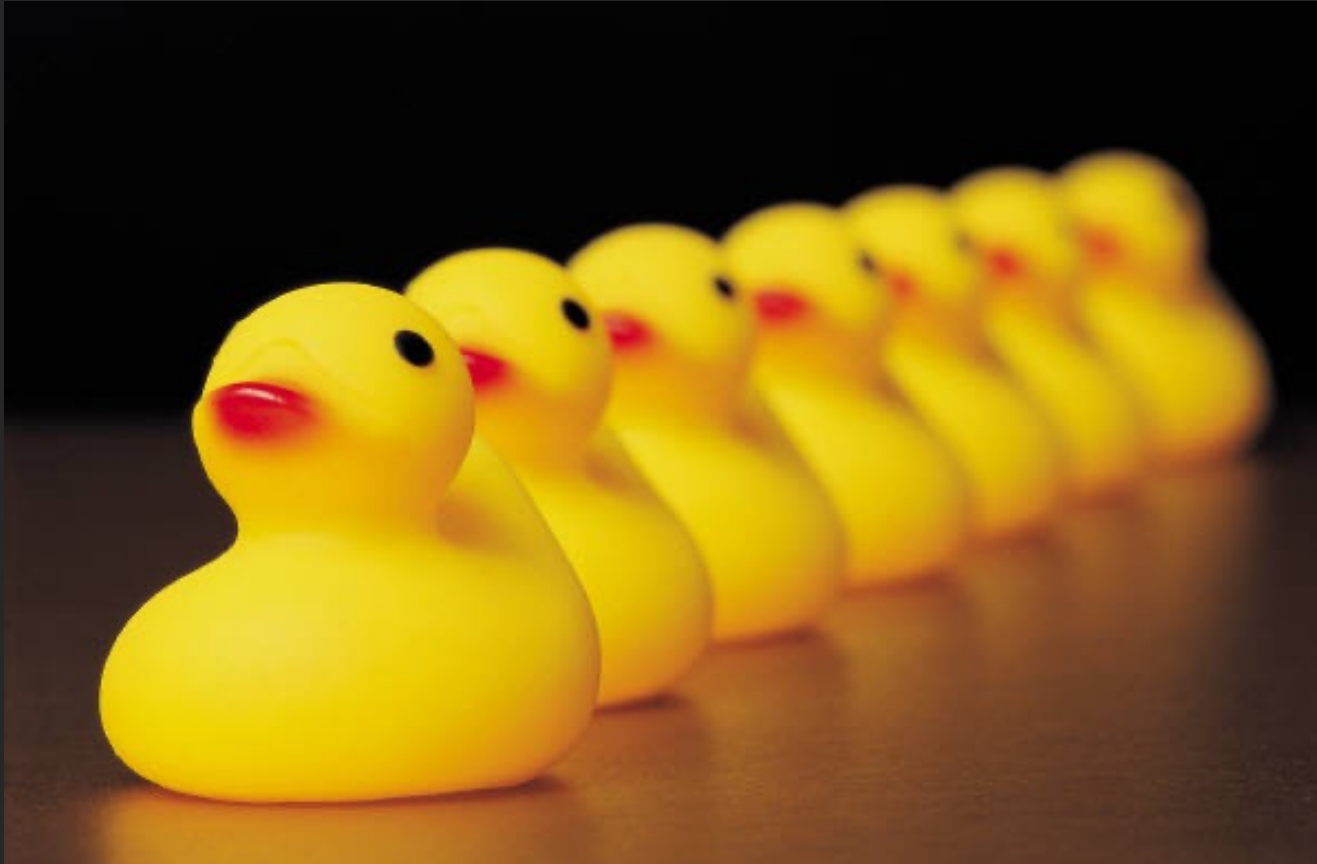


What is a Psychiatrist?

*Dr. Stephanie Plamondon
MD, FRCPC
Clinical Associate Professor
Department of Clinical Neurosciences
University of Calgary*



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FSHD 360 Conference



Objectives

- What is a Physiatrist?
- What role do Physiatrists have in treating patients with FSHD?
- What role can the interdisciplinary team play in treating symptoms of FSHD?

What is a Psychiatrist?

NOT





NOT



Medical doctors (MDs) who have completed training in the medical specialty of Physical Medicine and Rehabilitation

PM&R is one of 30 medical and surgical specialties recognized in Canada at the Royal College of Physicians and Surgeons



Physical Medicine and Rehabilitation specialists (PMR or
PM&R)

aka

Rehabilitation medicine specialists

aka

Physiatrists

American
US

Canadian, eh?

fi-zē- 'a-trist

fizz-EYE-a-trist

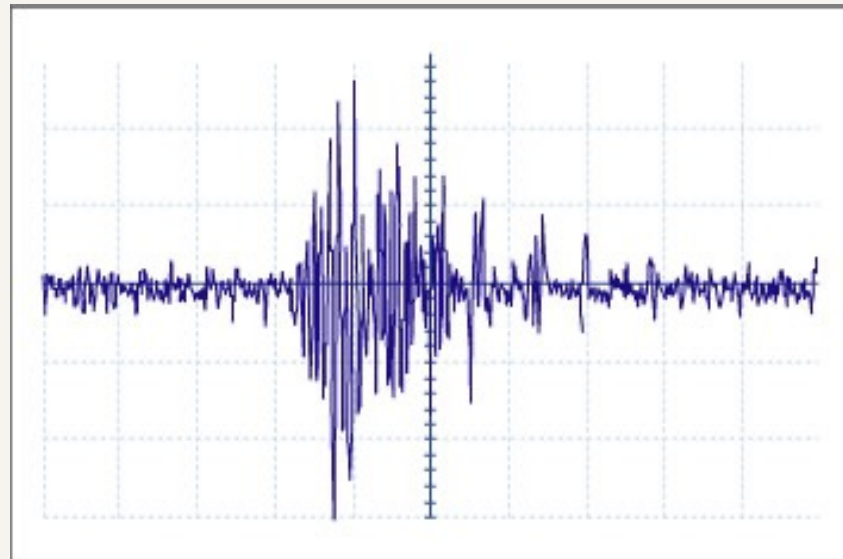


Physiatrists, or rehabilitation physicians, are nerve, muscle, brain and bone experts who treat injury or illness non-surgically to decrease pain and restore maximum function



How do rehabilitation physicians diagnose?

Using diagnostic processes and tools that are the same as those used by other physicians (medical histories, physical examinations, imaging, EMG and laboratory tests)



- **What procedures do PM&R specialists do?**
- Botulinum toxin injections (not cosmetic)
- Pain management interventions such as nerve blocks, soft tissue, joint and spine injections (with or without ultrasound or fluoroscopic guidance)
- Nerve conduction studies and electromyography (EMGs)



What is the rehabilitation physician's role in treatment?

Once a diagnosis is made, PMR physicians design a treatment plan that can be carried out by the patients themselves **or** with the help of **a team**



This interdisciplinary medical team may include physicians and non-physician health professionals

- Physiatrists, neurologists, respirologists, cardiologists, orthopedics, ophthalmologist, ENT/audiologist, family doctor
- Nursing, physical therapists, occupational therapists, speech pathologists, dieticians, orthotist, psychologists, social workers



Common SMART Functional Goals

Our Aim is...Wellness

To Improve and maintain QOL in Neuromuscular disease patients

IS	IS NOT
To Educate Patients about their NM condition	To Replace the family doctor and primary care
To Monitor The disease and how people are functioning day to day	To Diagnose neuromuscular diseases If new or unexpected neurological symptoms develop, a clinic neurologist is asked to see the patient
To Intervene when necessary with rehabilitation and medical treatments	
To Connect Patients and families to local resources	

Core Values of PMR

World Health Organization

International Classification of Functioning, Disability and Health (ICF):

Impairments

Activity Limitations

Restrictions in participation

Contextual factors

- Environmental
- Personal

*Neuromuscular
Rehabilitation
Teams in
Calgary Zone*

<http://www.calgarygi.com/>



*Community Accessible
Rehabilitation
3 locations – South,
North, Central*



*South Health
Campus
Neuromuscular
Clinic*

JMacPherson image - wikipedia



Symptoms and QoL in FSHD

*J Hamel, et al
Neurology 2019*
**Patient Reported
Symptoms in FSHD
(PRISM-FSHD)**

Surveys sent to 514 adults with FSHD in US

328 participants from 47 states responded to the survey, answering >48,000 individual questions

Age 23-86, average age when symptoms started: 23.1y

- Problems with shoulders or arms (96.9%)
- Activity Limitation (94.7%)
- Core weakness (93.8%)
- Fatigue (93.8%)
- Limitations with mobility and walking (93.6%)
- Changed body image due to the disease (91.6%)
- Pain (87.7%)

Problems with Shoulders and arms, and limitations with mobility and walking had the greatest effect on participants lives

PMR works with PT and OT to.....

Prescribe exercise programs safely

Treat painful conditions

- Identify the most likely pain generators
- Provide physical, medical treatments, or injection therapies

Prevent complications of immobility

Prescribe braces, gait and mobility aids,
advocacy for funding

Education on fatigue management and
pacing

Adaptations for personal care,
participation in work, leisure, social roles

What Physiotherapists do:

In the neuromuscular clinic the PT performs a detailed assessment in order to develop a treatment plan and to track function over time.

The PT focus on the following:

- Joint and muscle pain
- Changes to posture
- Problems walking and balance
- Safe lifts and transfers education for family and/or caregivers
- Exercise and recreation.
- Orthoses and walking aids.
- Among others...

Pain Management

Prevalence and Types: 56-89% of pwFSHD

N=821, 8 studies

Most mild to moderate, 20% severe

Commonly low back, neck, shoulders, legs

Musculoskeletal - muscle weakness, imbalance, overuse, trauma, posture, cramping, movement compensations

Less often *Neuropathic pain* - nerve

Psychological factors

- beliefs, coping skills, depression, anxiety

Social factors

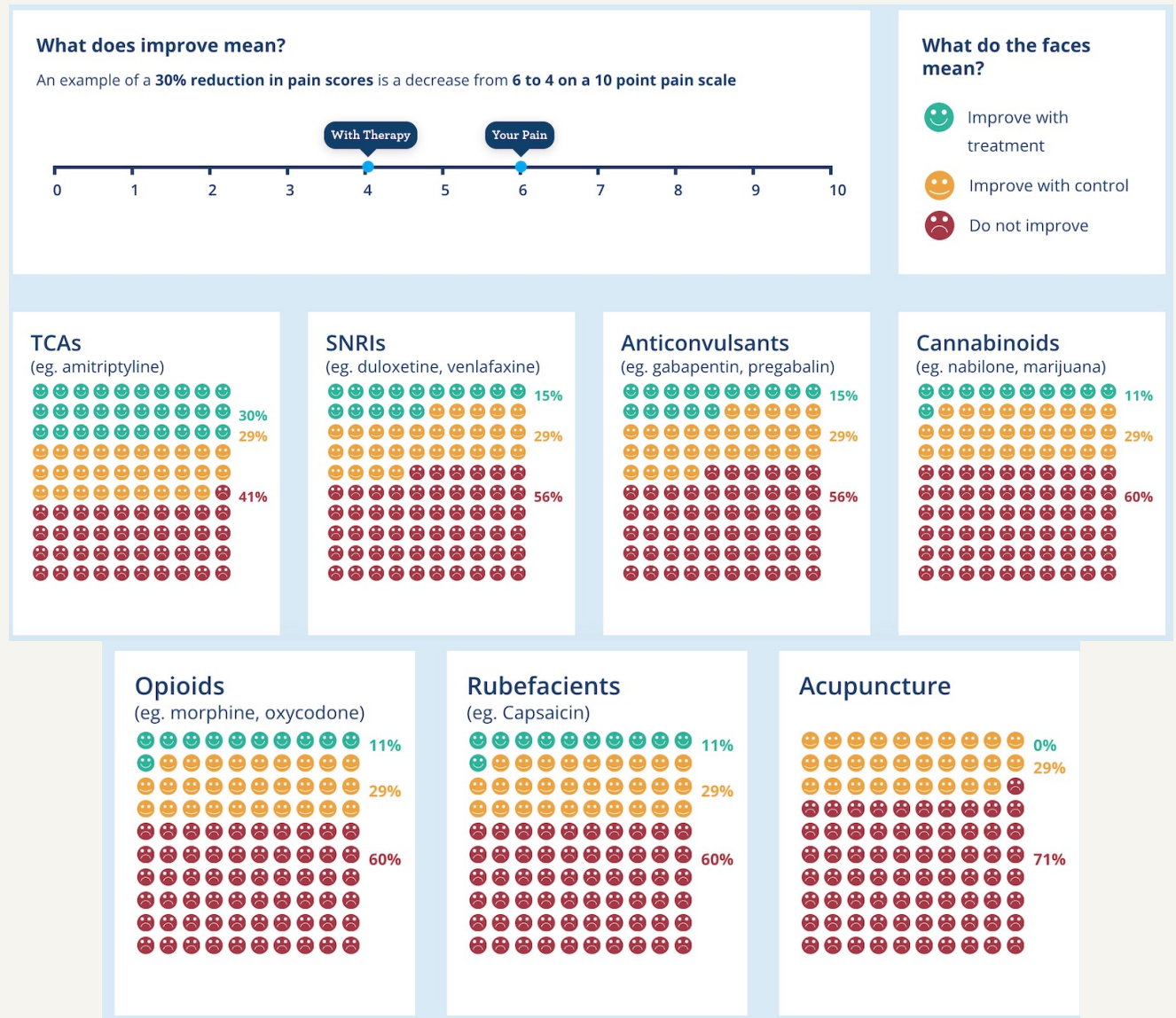
- Culture, social supports

Treatments:

Nonpharmacological - physical, cognitive, adaptations

Pharmacological

Surgical



Huang et al. The Prevalence, Characteristics and Impact of Chronic Pain in People With Muscular Dystrophies: A Systematic Review and Meta-Analysis. **Journal of Pain 2021**

Therapeutic Exercise

Aerobic, resistance, flexibility, balance

What makes you Move?

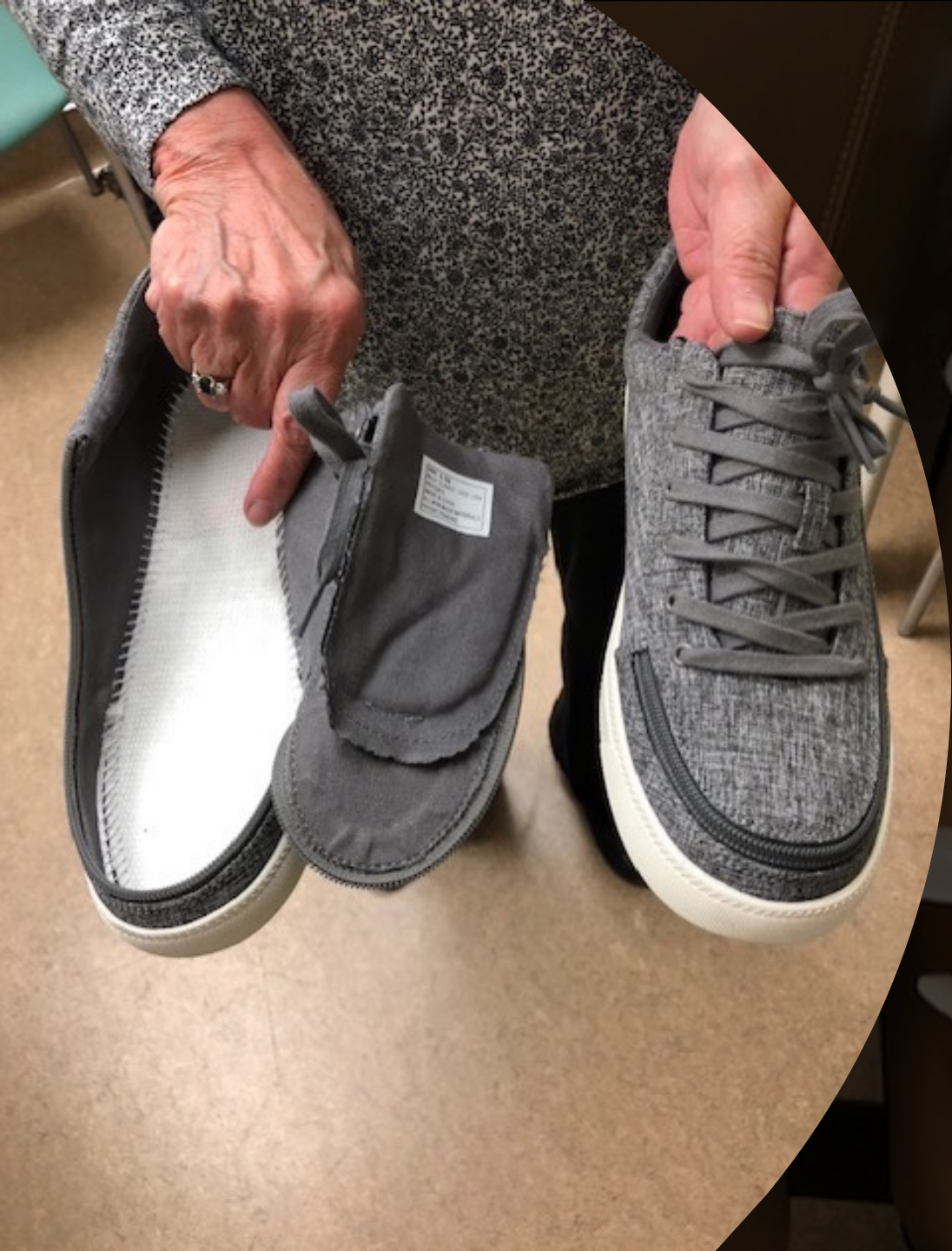
Physical Activity

<https://www.flickr.com/photos/queensucanada/9615275189/>



Functional Mobility





Custom Thermoplastic AFOs

Heavy

Bulky

Cosmesis

Comfort

Extra Size shoes



Carbon Fiber AFOs custom and External AFOs

www.cmtausa.org

Ultra-light weight
Fiberglass, Kevlar
Carbon fiber



“Occupational therapy is the art and science of enabling engagement in everyday living, through occupation; of enabling people to perform the occupations that foster health and well-being; and of enabling a just and inclusive society so that all people may participate to their potential in the daily occupations of life.”

Occupational Therapy Defined

(Townsend& Polatajko, 2007, p. 372).

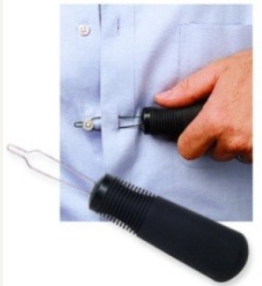


Basic Activities of Daily Living



Use adaptive devices (i.e. button hooks, elastic shoelaces, dressing sticks, universal cuffs, built-up utensils)

Teach client compensatory strategies for dressing, bathing



Acquire bathroom equipment to ensure safe transfers

Practice safe transfers (tub, toilet, car, bed, etc...)



Prescribe appropriate mobility devices - Wheelchairs, scooters



Education on energy conservation strategies, planning daily schedules



*Home and
Community
Accessibility*



Environmental

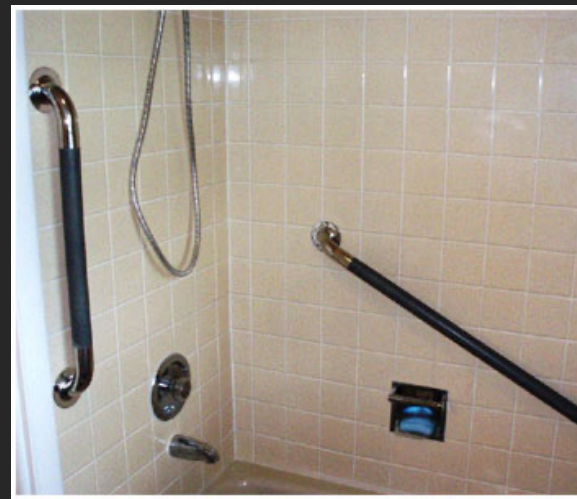


Equipment

- Transfer lifts
- Bathroom and bedroom
- Wheelchairs (manual/power)
- Adaptive devices

Home modifications

- Ramps
- Doorways
- Zero threshold showers
- Organization



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Instrumental Activities of Daily Living

- Example interventions: (IADLs)
 - Screen for ability to safely drive*
 - Apply for "Access Calgary" for client use*
 - Develop/practice strategies for household management*
 - Work or leisure accommodation or modification*



Swallowing Communication Nutrition



- **Swallowing** difficulties 2-25%, cheek compression strength correlates, generally mild

longer eating duration and fear of choking (only 5-7% reported actually choking on solids/liquids)

- **Communication** difficulties related to speech articulation 35%

"say something quickly" and "getting your turn in a fast-moving conversation"

- **Nutrition** for muscle and bone health
- Protein intake, Vitamin D, Calcium
- Creatine, antioxidants

Psychosocial functioning

R Murray *et al.* The lived experience of facioscapulohumeral muscular dystrophy: A systematic review and synthesis of the qualitative literature. **Muscle Nerve Jan 2024**



NB Rasing *et al.* Psychosocial functioning in patients with altered facial expression: a scoping review in five neurological diseases. **Disabil Rehab 2023**